

A thesis submitted to the University of Birmingham for the degree of

DOCTOR OF CLINICAL PSYCHOLOGY (DClinPsy)

VOLUME I

Research Component

**How do adults with a learning disability experience and value the residential and
inpatient services they receive? - A systematic qualitative review**

And

**How do psychologists experience working with staff in residential care settings
for people with a learning disability?**

By

Natalie Catherine Smith

School of Psychology

University of Birmingham

August 2014

UNIVERSITY OF
BIRMINGHAM

University of Birmingham Research Archive

e-theses repository

This unpublished thesis/dissertation is copyright of the author and/or third parties. The intellectual property rights of the author or third parties in respect of this work are as defined by The Copyright Designs and Patents Act 1988 or as modified by any successor legislation.

Any use made of information contained in this thesis/dissertation must be in accordance with that legislation and must be properly acknowledged. Further distribution or reproduction in any format is prohibited without the permission of the copyright holder.

OVERVIEW

This thesis is composed of two volumes. Volume I, the research component, consists of a literature review, empirical paper & public domain briefing paper. Volume II, the clinical component, is comprised of five Clinical Practice Reports (CPR's) that reflect work completed on placements over the course of my clinical training.

Volume I

The first paper is a systematic review of qualitative studies exploring the experiences and views of individuals with a learning disability (LD) who receive or who have received support from residential or inpatient services. Eight studies were identified and were reviewed using the process of meta-ethnography. A quality framework was used to appraise the research. The following themes were identified as important to participants: 'feeling safe and comfortable', 'maintaining an identity and sense of belonging', 'feeling empowered/disempowered', 'opportunities to be independent and pursue activities of value', 'freedom and privacy', 'having psychosocial needs met'. It is suggested services consider these factors to ensure good quality services for people with a LD.

The second paper is an empirical study which sought to explore how psychologists experience working with staff in residential care homes for people with a LD. Eight psychologists were recruited and interviewed. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis. Themes common across participants included 'development and maintenance of a therapeutic relationship', 'theory and emotion', 'perceived restrictions', 'safety', 'developing an identity as a

psychologist’, ‘support and shared experiences’, ‘motivation’, and ‘conflict and the roles of a psychologist’. Participants experienced several barriers to carrying out effective psychological work through staff in residential care homes. The various ways they have sought to address these are discussed. A preliminary model is proposed to describe what is needed for psychologists to be effective when working with staff in residential care homes.

Both of these papers were written in preparation for submission to JARID.

The third paper, the Public Domain Briefing Paper, summarises both papers in a way that is accessible to the general public.

Volume II

Five clinical practice reports are presented in Volume II.

CPR1: This CPR was completed whilst on placement in an inpatient service for older adults. It presents the case of Gill, the daughter and carer of Pauline who had a diagnosis of dementia. Gill’s difficulties are formulated from a cognitive behavioural and systemic perspective.

CPR2: This CPR was also completed whilst on placement in an inpatient service for older adults. An audit to establish whether the service is meeting the NICE Dementia Quality Standard for the assessment and management of behaviour that challenges and non-cognitive symptoms in people with dementia is presented.

CPR3: This CPR was completed whilst on placement in a Community Mental Health Service. It reports the case of Bella, an 18-year-old woman with social anxiety. A single case experimental design was employed to evaluate the added benefit of behavioural experiments following a cognitive intervention.

CPR4: This CPR was completed whilst on placement in a Child and Adolescent Mental health Service. It reports the case of Martin, a 14-year-old boy experiencing difficulties with anxiety. A cognitive behavioural formulation and intervention is presented.

CPR5: TBC. This CPR was completed whilst on placement in a specialist mental health service for people who have a learning disability. Only the abstract is presented, as it was an oral presentation. It describes the case of Andy, a 19 year old man experiencing difficulties with anger. Cognitive behavioural and narrative approaches were used to assess, formulate and develop ways to address his difficulties.

ACKNOWLEDGEMENTS

Firstly I would like to thank Dr Gail Thomas for her enthusiasm and making the process of recruitment for the research study happen with ease. I would also like to thank all the participants who took the time to take part in the research study and the clients I have presented in my CPR's. I have learnt a lot from your experiences.

I would like to say a huge thank you to Dr Biza Stenfert Kroese. I couldn't have completed the research component without your encouragement, expertise and guidance.

Finally, I can't express my gratitude enough to my friends, Jackie and Emma, and my family for all their support, patience and encouragement during the process of writing up.

CONTENTS

Volume I - Research Component

Table of Contents

| | |
|--|----|
| Overview | ii |
| Acknowledgments | v |
| Contents | vi |
| Volume I – Research Component | vi |
| Volume II – Clinical Component | xi |
| How do adults with a learning disability experience and value the residential and inpatient services they receive? – a systematic qualitative review | 1 |
| Abstract | 2 |
| Introduction | 3 |
| 1.1 Previous literature reviews on service user views, experiences and involvement | 4 |
| 1.2 Methodological concerns around obtaining service user views | 4 |
| 1.3 Rationale | 5 |
| 1.4 Objectives | 6 |
| Method | 7 |
| 2.1 Systematic Search Strategy | 7 |
| 2.2 Inclusion and Exclusion Criteria | 8 |
| 2.3 Critical Appraisal of the literature | 10 |
| Results | 14 |
| 3.1 Quality Assessment | 14 |
| 3.2 Critical Appraisal of the literature | 22 |
| Metasynthesis | 27 |

| | |
|--|----|
| 4.1 Metasynthesis findings | 29 |
| 4.2 Feeling safe and comfortable | 31 |
| 4.3 Maintaining an Identity and Sense of Belonging | 34 |
| 4.4 Feeling Empowered/disempowered | 36 |
| 4.5 Opportunities to be independent and pursue activities of value | 39 |
| 4.6 Freedom and Privacy | 41 |
| 4.7 Having psychosocial needs met | 42 |
| Discussion | 44 |
| 5.1 Findings | 44 |
| 5.2 Limitations of Studies | 46 |
| 5.3 Limitations of Review | 47 |
| 5.4 Recommendations for future research | 48 |
| 5.5 Clinical Implications | 49 |
| Conclusion | 51 |
| References | 52 |
| How do psychologists experience working with staff in residential care settings for people with a learning disability? | 61 |
| Abstract | 62 |
| Introduction | 63 |
| 1.1 Aims | 65 |
| Method | 66 |
| 2.1 Procedure and Participants | 66 |
| 2.2 Data Collection | 69 |
| 2.3 Data Analysis | 69 |

| | |
|---|-----|
| Findings | 72 |
| 3.1 Development and maintenance of a therapeutic relationship | 74 |
| 3.2 Theory and Emotion | 79 |
| 3.3 Perceived Restrictions | 80 |
| 3.4 Safety | 85 |
| 3.5 Developing an identity as a psychologist | 88 |
| 3.6 Support and shared experiences | 90 |
| 3.7 Motivation | 91 |
| 3.8 Conflict and the roles of a psychologist | 93 |
| Discussion | 97 |
| 4.1 Motivation and Support | 98 |
| 4.2 Safety | 99 |
| 4.3 Perceived Restrictions | 99 |
| 4.4 Developing and maintaining a therapeutic relationship | 101 |
| 4.5 Theory and Emotion | 102 |
| 4.6 Developing an identity as a psychologist | 102 |
| 4.7 Conflict and the role of a psychologist | 103 |
| 4.8 Limitations of Study | 105 |
| 4.9 Future Research | 106 |
| 4.10 Recommendations | 107 |
| Conclusion | 109 |
| References | 110 |
| Public Domain Briefing Paper | 115 |
| Appendices | 119 |
| Appendix 1: JARID - Guidelines for authors | 119 |

| | |
|---|-----|
| Appendix 2: Search Strategy | 127 |
| Appendix 3: Quality Framework | 129 |
| Appendix 4: Ethical approval, participant information and consent forms | 134 |
| Appendix 5: Interview Schedule | 140 |
| Appendix 6: Example of coding | 141 |

List of Tables:

Literature Review

| | |
|---|----|
| Table 1: Search Strategy | 7 |
| Table 2: Inclusion and Exclusion Criteria | 8 |
| Table 3: Additional prompts added to Walsh and Downe's (2006) | |
| Quality Framework | 12 |
| Table 4: Strengths and limitations of papers reviewed | 15 |
| Table 5: Breakdown of quality ratings | 21 |
| Table 6: Stages of meta-ethnography analysis | 28 |
| Table 7: Identified themes and subthemes | 30 |

Empirical Paper

| | |
|---|-----|
| Table 8: Participant details | 68 |
| Table 9: Table of themes | 73 |
| Table 10: Strategies used by participants | 101 |

List of Figures:

Literature Review

| | |
|--------------------------|---|
| Figure 1: Search Results | 9 |
|--------------------------|---|

Empirical Paper

| | |
|---|-----|
| Figure 2: Preliminary model of what a psychologist needs to be effective when working with staff in residential care homes | 98 |
| Figure 3: Roles of a psychologist | 103 |

Volume II – Clinical Component

Table of Contents

| | |
|---|-----|
| Overview | ii |
| Acknowledgements | v |
| Contents | vi |
| Volume I: Research Component | vi |
| Volume II: Clinical Component | xii |
| CPR 1 – Psychological Models Clinical Practice Report | 1 |
| Abstract | 2 |
| Presenting Difficulties and Background information | 3 |
| Assessment | 5 |
| Cognitive Behavioural Therapy Formulation | 10 |
| Systemic Formulation | 20 |
| Reflections | 33 |
| References | 35 |
| CPR 2 - An audit to establish whether an inpatient organic service is meeting the NICE Dementia Quality Standard for the assessment and management of behaviour that challenges and non-cognitive symptoms in people with dementia | 38 |
| Abstract | 39 |
| Introduction | 40 |
| The Local Service | 47 |
| Aims | 48 |
| Method – Numerical Data | 50 |
| Results – Numerical Data | 52 |
| Method – Reflective data | 57 |

| | |
|--|-----|
| Results – Reflective data | 57 |
| Discussion | 61 |
| Recommendations | 67 |
| Conclusion | 72 |
| References | 73 |
| CPR 3 – Cognitive-behavioural therapy with an 18-year-old woman with social anxiety disorder: A single case experimental design | 80 |
| Abstract | 81 |
| Case Summary | 82 |
| Assessment | 84 |
| Formulation | 89 |
| Intervention | 96 |
| Design | 97 |
| Results | 103 |
| Discussion | 116 |
| Reflections | 119 |
| References | 120 |
| CPR 4: Cognitive Behavioural Therapy to Treat Anxiety in a 14 Year Old Boy: A Case Study | 124 |
| Abstract | 125 |
| Referral and Background Information | 126 |
| Assessment | 127 |
| Choosing a Psychological Model | 138 |
| CBT Formulation | 140 |
| Intervention | 148 |

| | |
|---|-----|
| Evaluation and outcome measures | 157 |
| Reflections | 162 |
| References | 165 |
| CPR 5: Oral Presentation Clinical Practice Report | 173 |
| Abstract | 174 |
| <u>Appendices</u> | 175 |
| CPR 2 | |
| Appendix 1: Detailed breakdown of statement 7 taken from the Dementia Quality Standards (NICE, 2010) | 175 |
| Appendix 2: Details on criterion and where data was collated from | 177 |
| Appendix 3: How each component of a comprehensive assessment was audited | 179 |
| CPR 3 | |
| Appendix 4: Example of a Behavioural Experiment | 181 |
| Appendix 5: Thought Record | 183 |
| CPR 4 | |
| Appendix 6: Summary of session content | 184 |
| Appendix 7: Behavioural experiment – Having an MRI scan | 185 |
| Appendix 8: Cognitive Restructuring using a thought record | 186 |
| Appendix 9: Personal Coping Plan | 187 |

List of Tables

CPR 2

| | |
|--|----|
| Table 1: Level of cognitive impairment as defined by HoNOS | 52 |
| Table 2: Severity of BPSD in service users | 53 |
| Table 3: Assessment factors completed for service users | 54 |

CPR 3

| | |
|--|-----|
| Table 1: Details of the cognitive therapy phase | 99 |
| Table 2: Details of the behavioural experiment therapy phase | 101 |
| Table 3: Data collected on the intensity of social anxiety and conviction in negative automatic thoughts on a scale of 0-100% | 104 |
| Table 4: Auto-correlation coefficients for baseline data | 106 |
| Table 5: Statistical analysis for intensity of anxiety | 109 |
| Table 6: Statistical analysis for ‘they will notice I am anxious’ | 110 |
| Table 7: Statistical analysis for ‘I will stutter’ | 112 |
| Table 8: Statistical analysis for ‘Everyone is looking at me because I am different’ | 113 |
| Table 9: Statistical analysis for ‘I look stupid’ | 114 |
| Table 10: SPIN scores | 115 |

CPR 4

| | |
|---|-----|
| Table 1: Time event chart | 133 |
| Table 2: Scores from Beck Youth Inventories II | 137 |
| Table 3: Key components for a CBT intervention as defined by James et al (2013) | 139 |
| Table 4: Goals agreed with Debbie and Martin to guide the intervention | 150 |

| | |
|--------------------------------|-----|
| Table 5: BYI-II T-scores | 158 |
| Table 6: Reliable Change Index | 159 |

List of Figures

CPR 1

| | |
|---|----|
| Figure 1: Genogram | 22 |
| Figure 2: CBT formulation adapted from Dudley and Kuyjen (2006) | 11 |
| Figure 3: Cognitive triad of depression | 14 |
| Figure 4: Six Cycles Maintenance Model – ‘Sad flower’ | 19 |
| Figure 5: Maintenance of a problem | 20 |
| Figure 6: Feedback Loop | 25 |
| Figure 7: Multiple levels of context | 32 |

CPR 2

| | |
|--|----|
| Figure 1: Dementia pathway for intervention | 45 |
| Figure 2: Effects of not completing comprehensive assessment and analysis of BPSD | 62 |
| Figure 3: Speculative diagram of factors influencing the services ability to meet the Dementia Quality Standard using Hill-Tout’s | 65 |
| Figure 4: Newcastle Model Formulation Template | 69 |
| Figure 5: Audit Cycle | 70 |

CPR 3

| | |
|--|----|
| Figure 1: A cognitive model of social anxiety | 89 |
| Figure 2: Model to illustrate how fear is maintained in social anxiety | 90 |

| | |
|---|-----|
| Figure 3: Maintenance cycle | 91 |
| Figure 4: Cognitive formulation | 94 |
| Figure 5: Graph depicting changes in intensity of social anxiety across phase A and phase B | 108 |
| Figure 6: Graph depicting changes in the conviction of the thought ‘they will notice I am anxious’ across phase A and phase B | 109 |
| Figure 7: Graph depicting changes in the conviction of the thought ‘I will stutter’ across phase A and phase B | 111 |
| Figure 8: Graph depicting changes in the conviction of the thought ‘everyone is looking at me because I am different’ | 112 |
| Figure 9: Graph depicting changes in the conviction of the thought ‘I look stupid’ | 114 |

CPR 4

| | |
|--|-----|
| Figure 1: Genogram | 134 |
| Figure 2: CBT formulation | 144 |
| Figure 3: CBT formulation illustrating a problem-maintaining pattern between Debbie and Martin | 147 |
| Figure 4: Diagram illustrating aim of intervention to change dysfunctional cycles into functional cycles | 148 |
| Figure 5: CBT reformulation illustrating interaction between Debbie and Martin | 154 |
| Figure 6: Formulation created with Martin | 155 |
| Figure 7: Reformulation created with Martin illustrating new strategies | 156 |
| Figure 8: Pre and post intervention T-scores | 157 |
| Figure 9: Weekly intensity ratings for anxiety and depression | 160 |

**HOW DO ADULTS WITH A LEARNING DISABILITY EXPERIENCE AND
VALUE THE RESIDENTIAL AND INPATIENT SERVICES THEY
RECEIVE?**

A SYSTEMATIC QUALITATIVE REVIEW

This paper is written in preparation for submission to the Journal of Applied Research
in Intellectual Disabilities (JARID) (see Appendix 1)

ABSTRACT

Background: Involving service users and spending time to understand their experiences is important to improve the quality and safety of residential and inpatient services for people with a learning disability.

Aims: This review seeks to understand how service users value and experience residential and inpatient services in order to inform future research and clinical practice.

Methods: Meta-synthesis was adopted to identify and review papers reporting on service users' experiences of inpatient and residential services. A systematic literature search of three databases was conducted to identify studies published between 2000-2014. Eight papers were identified and their quality was assessed against a framework adapted from Walsh & Downe's (2006) quality rating framework.

Results: Six themes were identified: 'feeling safe and comfortable', 'maintaining an identity and sense of belonging', 'feeling empowered/disempowered', 'opportunities to be independent and pursue activities of value', 'freedom and privacy' and 'having psychosocial needs met'.

Conclusions: Services should consider and monitor the themes identified as important to service users to help ensure the care they provide is of high quality. The findings can also help inform research into the development of quality assessment tools.

Key words: service user views, residential services, inpatient services, and qualitative systematic reviews

INTRODUCTION

Over the last thirty years much policy and research has emphasized the importance of involving service users in decision-making, inspection and evaluation of services to improve service quality and outcomes for individuals. It is now a requirement to involve service users in many aspects of the UK health and social services (Department of Health (DoH), 2001; Carr, 2004).

In 2006, despite the move towards deinstitutionalization and care in the community the lives of people with a severe learning disability (LD) was reported not to have improved significantly (DoH, 2007). In 2007 an audit of specialist inpatient and residential services for people with a LD reported widespread inadequacies and abusive practices (Commission for Healthcare Audit and Inspection, 2007). Policies such as 'Valuing People' (DoH, 2001) and 'Nothing about us without us', (DoH, 2001) have highlighted the need to involve people with a learning disability (LD) in order to improve the residential and inpatient services they receive. More recently the Care Quality Commission (CQC) undertook an inspection of Castlebeck services following abusive practices being revealed at Winterbourne View within a TV documentary (CQC, 2011). Individuals at Winterbourne View were reported not to be involved in making decisions about their care or the services they received (Flynn, 2012). A subsequent CQC national review of 150 services for people with a LD, mental health needs and challenging behaviour also demonstrated a lack of service user involvement which resulted in care not being person centered (CQC, 2012). It is clear that involving service users and understanding their experiences is important when managing risk and reducing unsafe practice (Wallcraft, 2012; DoH, 2012).

1.1 Previous literature reviews on service user views, experiences and involvement

Ramcharan & Grant (2001) highlight that the studies that have been undertaken in hospitals, staffed houses and independent living schemes have generally been in single service settings, comparing single services with past services received. Studies addressing aspects of quality of life show people with a LD experience a lack of meaningful relationships, inclusion in the community and adequate support. Service users have expressed a preference for smaller living arrangements, increased independence, more control, and an opportunity to build relationships. Participating in domestic tasks, privacy, pleasant surroundings, being with friends and friendly staff and not being with aggressive and/or noisy co-residents have been associated with increased satisfaction whereas lack of money, choice, isolation, harassment by people in local communities, institutional regimes/constraints and poor food are associated with lower levels of satisfaction (Stenfert Kroese, Gillott & Atkinson, 1998).

Most recently a thematic synthesis of the experiences of individuals with LD focused on specific interventions and services used to treat challenging behaviour. An ‘imbalance of power’ was experienced by service users and some of the stressors associated with living in a residential placement were perceived to be a cause for challenging behaviour (Griffith, Hutchinson & Hastings, 2013).

1.2 Methodological concerns around obtaining service user views

Many studies published within this field of research have focused on the methodological issues (Beail & Williams, 2014). For example, Ramacharan & Grant (2001) highlight several limitations: studies often focus on people with mild learning disabilities, they tend not to explicitly report on the relevance for policy, findings are not appropriately disseminated to impact beyond the locality of where the research

was undertaken and there are problems using the findings for long term monitoring of outcome. Moreover, issues around acquiescence and consent (Rapley & Antaki, 1996; Arscott, Dagnan & Stenfert Kroese, 1999) and ways to address these have been explored. Several recommendations have been made such as the use of pictorial aids, photos, games, open ended discussions, and interview questions that have been developed with people with a LD (Stenfert Kroese et al, 1998; Ramcharan & Grant, 2001; Young & Chesson, 2006). For those who have limited expressive and receptive language, observation and triangulation of data sources (for example, obtaining information from carers, staff and direct observations) have been advocated as appropriate methods.

1.3 Rationale

Given the association between quality of living environment and challenging behaviour (Griffith et al, 2013) and the recent focus on the lack of quality of residential and inpatient services following the Francis Report (2013) and Winterbourne Review (Flynn, 2012), the papers reviewed will focus on service users' views of inpatient and residential settings since the year 2000. So far, research has primarily focused on likes, dislikes, quality and satisfaction and has not fully addressed factors that are considered important determinants of quality by service users (McKenzie, Murray & Matheson, 1999). This review therefore aims to investigate what people with a LD living in the UK view as important aspects in their daily care and living environment via meta-ethnography. Meta-ethnography involves drawing out the central themes of importance emerging from qualitative studies. It helps small qualitative studies to have more impact on research priorities and policy development as the generalizability of the findings increases (Finfgeld-Connett,

2010). A quality framework (Walsh & Downe, 2006) will be used to assess the quality of the research reviewed. Any limitations identified will be considered when interpreting the findings.

1.4 Objectives

To bring together and evaluate qualitative research that reports the experiences, and viewpoints of individuals with a LD who receive or have received support from residential/inpatient services in order to:

- Explore how people with a LD experience residential and inpatient services
- Identify what are the determinants of quality for people with a LD when they receive support from a residential or inpatient service

METHOD

2.1 Systematic Search Strategy

The search strategy and selection process was guided by the Centre for Reviews and Dissemination Guidance for Understanding Reviews in Health Care (2008). The Psycinfo, Cinahl and Medline databases were searched from 2000 up until April, Week 2, 2014. The search strategy used for Psycinfo is briefly summarized in Table 1 (please see Appendix 2 for more detail). Searches equivalent to this strategy were used for the other two databases.

Table 1: Search Strategy

| | |
|----------|---|
| <i>A</i> | <i>Keyword search “learning disabilit*” or “learning disorders” or “developmental disabilit*” or “intellectual disabilit*” or “mental retard*”</i> |
| <i>B</i> | <i>Keyword search “view* ADJ1 service user*” or “opinion* ADJ1 service user” or “attitude* ADJ1 service user” or “satisfaction ADJ1 service user” or feeling* ADJ1 service user” or perspective* ADJ1 service user” or “perception* ADJ1 service user” or experience* ADJ1 service user”</i> <i>(Searches were also made replacing service user with patient*, inpatient*, client*, people, individual*, women, and men)</i> |
| <i>C</i> | <i>Combine A and B</i> |

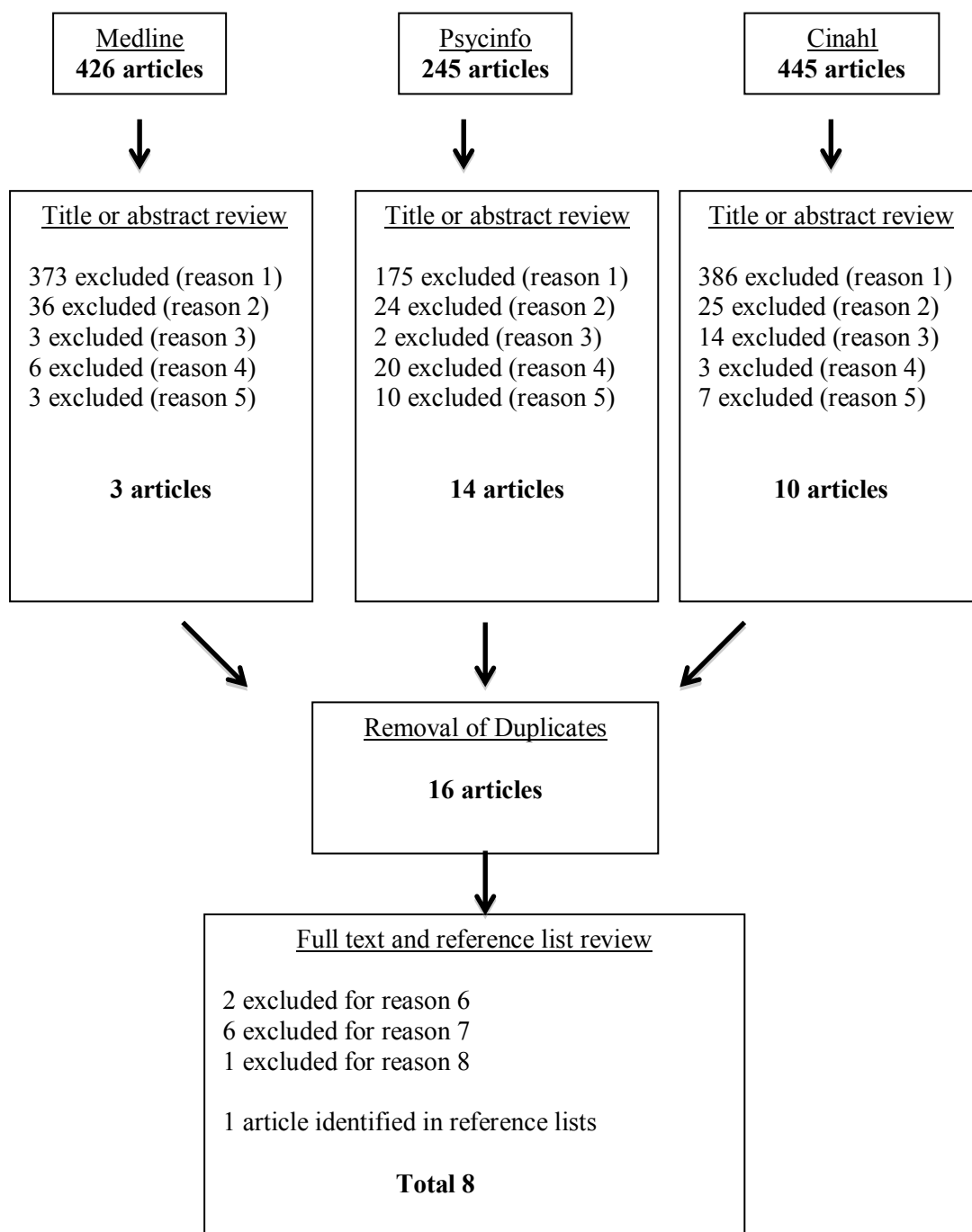
2.2 Inclusion and Exclusion Criteria

Studies were selected if they met the inclusion and exclusion criteria in Table 2.

Table 2: Inclusion and Exclusion Criteria

| <i>Inclusion Criteria</i> | <i>Exclusion Criteria</i> |
|---|--|
| Published in the English language | Participants do not live in the UK |
| Uses qualitative research methodology | Primarily reporting quantitative or descriptive data |
| Published in a peer reviewed journal | Unpublished PhD, review, book chapter or theoretical article |
| Includes adult participants who have a LD | Focus is on evaluating the methods of how service users' views are obtained |
| Reports service user views/experiences (including researchers observations/interpretations) regarding residential or inpatient services (including supported living, homes on a campus, group homes, residential care homes, psychiatric/mental health inpatient units) | Focus is on emergency admissions to a general hospital, a particular intervention or relationships with staff in residential/inpatient services |
| Quotations included in results section | Participants with and without a LD included and it is not possible to separate out the data from participants with a LD |
| | Participants who live independently or with family are included and it is not possible to separate out the data from participants who live in a residential or inpatient service |

Seven studies were identified through the database search and one study was identified as a result of searching all the studies' reference lists. See Figure 1 for a flowchart of search results and the reasons why studies were excluded.



Reasons for exclusion

| | |
|---|--|
| 1 | Not residential/psychiatric inpatient services |
| 2 | Not people with a LD |
| 3 | Not Peer reviewed |
| 4 | Theory or Review |
| 5 | Specific intervention or relationship with staff |
| 6 | Not UK |
| 7 | Descriptive/Quantitative data |
| 8 | Quotations not included |

Figure 1. Flowchart of search results

2.3 Critical Appraisal of the Literature

It is acknowledged that criteria are needed to assess the quality of research and that these need to be meaningful to the people who were intended to benefit from the research (e.g. clients, patients, policy makers or health professionals; Yardley, 2000). There is, however, disagreement about the most appropriate way to evaluate qualitative research (Katrak et al 2004; Spencer et al 2003). This is partly due to the broad range of philosophical positions and methods taken in qualitative research, making it difficult to establish a 'fits all' set of criteria. Additionally, qualitative researchers tend to see knowledge as socially constructed and avoid convincing others into accepting one truth as authoritative, a stance that conflicts with the positivist task of establishing 'good' and 'bad' studies. Consequently some researchers argue there is a need to agree on more open-ended and flexible criteria to evaluate qualitative methods (Yardley, 2000).

Given this context it is not surprising numerous frameworks have been developed over the years. Spencer et al (2003) identified 29 different checklists in their search and several attempts have been made to synthesise and summarise pre-existing frameworks (Sandelowski & Barroso, 2002; Spencer et al 2003; Walsh & Downe, 2006).

To establish appropriate criteria for this review several papers were consulted (Yardley 2000; Cesario, Morin & Santa-Donato, 2002; CASP, 2011). Walsh and Downe (2006) critically reviewed eight pre-existing frameworks, mapped them together and removed non-essential criteria to establish a framework. This framework was chosen as it emphasizes three strengths of qualitative research:

integrity, transparency, and transferability, and includes the following criteria: Scope and Purpose, Design, Sampling Strategy, Analysis, Interpretation, Reflexivity, Ethical Dimensions and Relevance and Transferability.

Yardley (2000) highlights that ‘participatory’ or ‘action’ research is a particular challenge to traditional criteria as “it seeks to create practical solutions to local problems, rather than to produce a transferable piece of knowledge which can be evaluated as an academic product” (*pp* 224). Additional prompts were therefore added to take into account factors that are considered to be pertinent within the context of ‘participatory’ or ‘action’ research and with participants who have a LD. These are detailed in Table 3. The framework in its entirety is presented in Appendix 3.

Table 3: Additional prompts added to Walsh & Downe's (2006) Quality framework

| | |
|--------------------------|---|
| Scope and Purpose | <ul style="list-style-type: none"> • Were relevant policies referred to? |
| Design | <ul style="list-style-type: none"> • Have researchers considered acquiescence and have they attempted to address it? For example: using open ended questions and 'Consistency checks' across separate interviews (Antaki, Young & Finlay, 2002; Llewellyn, 2009) • Where appropriate was information made accessible and were approaches tailored to facilitate people to speak? Were pictorial aids, photos, or games used? Were time and frequency questions avoided? (Gates & Waight, 2007; Ramcharan & Grant, 2001). • Was time allowed to build familiarity and rapport in focus groups and interviews? (Ramcharan & Grant, 2001) • Have researchers made efforts to ensure power is held equally between all parties? Did service users guide the research agenda? Were questions developed with people with a learning disability? (Chapman & McNulty, 2004) |
| Sampling Strategy | <ul style="list-style-type: none"> • Are individuals with more severe intellectual disabilities included to gain insight into their experiences? (Nind, 2008) • Is information provided on the level of learning disability? (Kaehne & O'Connell, 2010) |
| Interpretation | <ul style="list-style-type: none"> • If applicable was acquiescence considered when making interpretations? |

| | |
|--------------------------------------|--|
| Ethical Dimensions | <ul style="list-style-type: none"> • Were issues related to informed consent considered and addressed? For example, was an opportunity to absorb information over time and/or experience of making choices provided? (Nind, 2008) • Was feedback given to service users? |
| Relevance and Transferability | <ul style="list-style-type: none"> • Were the actions and outcomes of the study discussed? |

In order to help summarize the quality of the research, each paper was assessed and scored against the criteria in the framework using Cesario et al's (2002) scoring system. For each criterion a score out of 3 was given. Three points were given if it was well addressed, 2 points if it was adequately addressed, 1 point if it was poorly addressed and 0 points if it was not reported or applicable. The maximum score a paper can achieve is 24. The studies that met 75-100% of the maximum score were awarded a quality rating of 3 (Q3), studies that met 50-74% were awarded a quality rating of 2 (Q2) and studies that met less than 50% were awarded a quality rating of 1 (Q1).

RESULTS

3.1 Quality Assessment

The quality ratings, strengths and limitations of each study are summarized in Table 4 and Table 5. Seven studies received Q2 and one study received Q3 (Study 8).

Table 4: Strengths and Limitations of papers reviewed

| Authors, Date & Country | Aim/Focus | Sample | Method | Analysis | Themes/summary of findings relating to participants' experiences of services | Strengths | Limitations | Quality Rating |
|--|---|---|---|---------------------------|---|--|---|-----------------------|
| 1. Forrester-Jones, Carpenter, Cambridge, Tate, Hallam, Knapp & Beecham (2002), UK | To ascertain views of people with a mental health problem or LD on living environments, daily activities and future aspirations | 196 people with a LD and 102 people with a MH problem living in residential nursing homes (LD=38, MH=41), Hostel (LD=40, MH=5), Staffed group home (LD=71, MH=15) or supported accommodation (LD=47, MH=41) | Structured interview using open questions | Thematic content analysis | -Positive aspects of community living: locality, privacy and sense of ownership, making friends and helping others, independence and less restrictions -Problems with living situations: feelings of loneliness, boredom and worry, regimes, behaviours of other residents -Preferred activities -Least preferred activities -Feelings about the future | Provides clear recommendations as a result of findings: services should monitor and enhance social milieu, relationships, staff attitudes, behaviour, education/work/leisure opportunities | Did not demonstrate reflexivity. Consent process is unclear and does not state whether sought ethical approval. | Q2 |

| | | | | | | | | |
|---|---|---|---------------------------|--|--|--|---|----|
| 2. Barr, McConkey & McConaghie (2003), UK | To seek the views and preferences of people with a LD on current and future housing and support options. To ascertain what individuals value regarding living arrangements. | 45 people with a LD (24 men, 21 women) aged between 20 and 60 years of age. Living at home, with relatives, alone or in a residential home (18) | Focus Groups | 'Long table' approach (Kruger & Casey, 2000) to analysis of focus group data | -Social networks (to build and maintain confidence, self/family identity) -Feeling included -Reciprocal relationships -Structural aspects (having own room for privacy and to be recognized as an adult) -Privacy and Security -Feeling alone -Accommodation: more than buildings -The impact of moving Life in the community-trouble and strife | Scope and purpose of research well defined | Did not demonstrate any reflexivity | Q2 |
| 3. Longo & Scior (2004), UK | To explore service users' and carers' views on in-patient psychiatric care | Carers and 30 service users with a mild/moderate LD who were | Semi structured interview | IPA | -Lack of control -Protection and nurture versus indifference and harm -Negative aspects | Refers to generalizability of their findings, makes clear recommendations to commissioners and providers (training and | Does not explicitly address ethical issues and does not demonstrate | Q2 |

| | | | | | | | | |
|--|--|---|--------------|-----------------------|---|---|--|----|
| | received across two settings | admitted to an inpatient setting within the past 12 months. Diagnosis of a mental health problem. 14 admitted to generic psychiatry ward and 15 to a specialist unit. | | | of the environment -Positive aspects of admission (<i>themes related to carers not reported here</i>) | input from professionals specializing in LD, accessible information, involving carers). Identifies need for further research (impact of different settings on peer support and self esteem) | any reflexivity | |
| 4. McConkey, Sowney, Milligan & Barr (2004), UK (Northern Ireland) | To establish personal perceptions and preferences of present and potential living arrangements | 180 people with a LD (91 women and 89 men) aged between 22-63 living independently, in supported living, with family or in residential homes | Focus Groups | Not explicitly stated | -Support and company of friends and family -Freedom (to access local communities and activities) -Privacy (having own room) -Independence and choice (or lack of) -Supportive staff -Participation in household activities | Clearly defined scope and purpose of the study. Made recommendations to commissioners, considered generalizability, and highlighted what further research is required. | Did not demonstrate any reflexivity. Little information on how analysis was carried out. | Q2 |

| | | | | | | | | |
|--|---|--|--|--------------------------|--|--|--|----|
| | | | | | <ul style="list-style-type: none"> -Opportunities to make friends -Harassment and intimidation -Unpleasant Neighbourhoods -Behaviour of other residents <i>(Only themes related to supported living and residential homes reported here)</i> | | | |
| 5. Hubert & Hollins (2006), UK | To gain a greater understanding of the needs and experiences of men living in long stay hospital care | 20 men with a severe LD living in a locked ward | Ethnography involving around 250 hours of observation over 3 years, interviews with family and review of medical files | Grounded theory approach | <ul style="list-style-type: none"> -Loss of individual and social identity -Communication -Loss of family identity -Loss of gender identity -The effects of sensory disabilities -Emotional needs | Documented outcome of research: what was learnt about the participants was feedback. Recommendations and ideas for further research well defined | Although some reflexivity was demonstrated it was limited. | Q2 |
| 6. Parkes, Samuels, Hassiotis, Lynggard & Hall, (2007), UK | Phase 1: To explore experiences that people with a LD had of inpatient care to inform the | Phase 1: 12 people with a LD (6 male, 6 female, age range 26-54 years) who | Interviews using peer-reviewed, semi-structured schedule | Not explicitly stated | <ul style="list-style-type: none"> -Adjusting to a new environment -Behaviour of others -Security -Opportunities to make friends | Results appropriately disseminated to commissioners, managers and staff. Clear outcomes and actions made as a consequence of the | No evidence of reflexivity Limited information on how completed analysis and | Q2 |

| | | | | | | | | |
|--------------------------------------|---|--|--|---|--|---|----------------------------|----|
| | <p>development of a new service.</p> <p>Phase 2: To interview service users on their experience of the newly developed service to identify whether service improvement was still required</p> | <p>had experienced inpatient care in different hospital settings</p> <p>Phase 2: 19 people with a LD (7male, 12 female, age range 20-68 years) who experienced inpatient care in the newly developed service</p> | | | <p>-Support from staff</p> <p>-Lack of choice and involvement in treatment and decisions</p> | research are detailed | how themes evolved. | |
| 7. Owen, Hubert & Hollins (2008), UK | To develop an understanding of how women with severe LD experienced the process of hospital closure and how they adapted to their new lives over the first year | 11 women aged between 29 and 72 with challenging behaviour and a LD who moved from a locked ward to a | Ethnography involving observation for over 300 hours day and night over a period of 12-18 months | Grounded theory approach using software | Lack of preparation, Lack of involvement, Lack of support, Inadequate information transfer, Changes for the better | Ethical issues well addressed and rationalized. | No evidence of reflexivity | Q2 |

| | | | | | | | | |
|--|--|---|---------------------------|-------------------|---|--|----------------------------------|----|
| | after transition | residential care home | | | | | | |
| 8. Chinn, Hall, Ali, Hassell & Patkas (2011), UK | To elicit views about experiences of care provided | 17 people with a LD living in out of area in-patient psychiatric units. 13/17 were men. 80% had been identified as having a mild learning disability. $\frac{3}{4}$ detained under mental health act. Average age: 34 | Semi structured interview | Thematic analysis | <ul style="list-style-type: none"> -Punitive versus therapeutic treatment -Discomforting environments -Demeaning versus supportive staff relationships -Power and hierarchies -Group versus individualized treatment -Far from home | Considered interview context and addressed issues relating to acquiescence in interpretation | Limited reflexivity demonstrated | Q3 |

Table 5: Breakdown of quality ratings

| Study | Scope and Purpose | Design | Sampling Strategy | Analysis | Interpretation | Reflexivity | Ethical Dimensions | Relevance and Transferability | Score out of 24 (%) | Quality Rating |
|--------------------------------|-------------------|--------|-------------------|----------|----------------|-------------|--------------------|-------------------------------|---------------------|----------------|
| 1. Forrester-Jones et al, 2002 | 3 | 2 | 3 | 2 | 2 | 0 | 1 | 3 | 16 (67%) | Q2 |
| 2. Barr et al, 2003 | 3 | 2 | 2 | 2 | 2 | 0 | 2 | 2 | 15 (63%) | Q2 |
| 3. Longo & Scior, 2004 | 3 | 1 | 2 | 2 | 2 | 0 | 0 | 3 | 13 (54%) | Q2 |
| 4. McConkey et al, 2004 | 3 | 2 | 2 | 1 | 2 | 0 | 2 | 3 | 15 (63%) | Q2 |
| 5. Hubert & Hollins (2006) | 2 | 2 | 3 | 2 | 2 | 1 | 2 | 3 | 17(71%) | Q2 |
| 6. Parkes et al (2007) | 2 | 2 | 2 | 1 | 2 | 0 | 2 | 3 | 14 (58%) | Q2 |
| 7. Owen et al (2008) | 2 | 2 | 3 | 2 | 2 | 0 | 3 | 2 | 16 (67%) | Q2 |
| 8. Chinn et al (2011) | 3 | 2 | 3 | 3 | 3 | 1 | 2 | 3 | 20 (83%) | Q3 |
| Total | 21 | 15 | 20 | 15 | 17 | 2 | 14 | 21 | | |
| Total as % | 78% | 56% | 74% | 63% | 63% | 7% | 52% | 78% | | |

3.2 Critical Appraisal of the literature

The papers sought to provide explanations about how people with a learning disability experience, evaluate and view inpatient and residential supports rather than develop new theories. All studies were well contextualized by making reference to literature, theory, relevant policies and previous research. They also had a clear statement of their focus, rationale and aims.

All studies chose appropriate methods to address their research questions. Four studies used semi-structured interviews, two used focus groups and two used ethnography. The majority of papers provided a clear rationale for the specific qualitative methods used (Study 2, 4, 5, 7). Ethnography enabled the subjective experiences and quality of life of individuals with severe learning disabilities, who are unable to participate in interviews, to be explored (Study 5, 7). Both papers using ethnography made adequate number of observations at different times to capture the complexity and diversity of experiences. The use of focus groups also seemed a particularly appropriate method as it helps individuals feel empowered and supported so they are more likely to share their opinions with people who have similar experiences (Llewellyn, 2009). The groups were of appropriate size and duration, although study 4 reported focus groups consisting of only four participants. This is less than the recommended 8-12 participants (Stewart & Shamdasani, 1998).

Some studies documented attempts to make information accessible, to tailor communication, or develop rapport. Study 6 designed their questionnaire to help participants recall experiences by structuring it like a story. To help build rapport and put participants at ease researchers spent time with participants, asked introductory

questions, used icebreakers and allowed participants to choose where the interview took place (Studies 1-7). Researchers also made information accessible by using photos, symbols, video clips, pictorial systems and written visual or verbal information to aid discussion (Study 1, 2, 4). Study 4 was the only study that involved people with a LD when deciding upon the interview questions. Three studies explicitly considered issues relating to acquiescence in their designs. They addressed them by asking open questions, reviewing notes to check validity, and by avoiding leading questions (Study 2, 6, 8).

The sample sizes ranged from 11 to 196 participants. See Table 4 for a summary of participant details. With the exception of three studies (Study 3, 6, 8) very little information on the demographics and characteristics of participants were provided. Few studies reported information on the level of LD and none stated how it was assessed. With the exception of two studies people with more severe LD were not included because they were unable to take part in interviews (Study 5, 7). A strength of three studies was that they recruited and sought to understand the experiences of individuals who have previously been excluded from research (people with a severe LD, complex needs or those detained under the Mental Health Act) (Study 5, 7, 8).

The majority of studies recruited participants by contacting managers of services and psychiatrists working in inpatient settings. A sampling bias may have been introduced in Study 8 as the psychiatrist deemed some participants to be too unwell to participate. The inclusion and exclusion criteria were clear and a rationale was given in the majority of studies.

Two studies used thematic analysis (Study 1, 8), two used a grounded theory approach (Study 5, 7), one used the 'long table' approach (Kruger & Casey, 2000) for focus groups (Study 2), one used IPA (Study 3) and two did not explicitly state what approach they used to draw out themes. Two studies used software for analysis (Study 6, 7). All of the researchers demonstrated they had immersed themselves in the data but only a few gave sufficient detail on the process of analysis. The results of all studies indicated that the researchers had sought to understand what was important for their participants. A sufficient number of quotations were included to illustrate the subjective experiences of participants. In the majority of papers reference was made to having more than one researcher involved in the analysis and themes were cross-checked. Only one study involved participants in the analysis of the data and explicitly stated saturation of data had occurred (Study 2). Three studies commented on the interview context, immediate environment, staff presence, and/or participants' mood and presentation but did not refer to these issues in the analysis or interpretation sections (Studies 5, 7, 8).

In all papers it was clear how the interpretation of the data led to the authors' conclusions. However, it was rare that researchers acknowledged any bias that may have been introduced during analysis and interpretation. Only three out of the six studies using interviews and focus groups considered acquiescence in the interpretations they made (Study, 1, 2, 8). Studies using ethnography did not consider what impact the researcher's presence could have had on participant behaviour.

Seven studies did not address issues concerning reflexivity. Only Study 8 considered the impact they may have had on the research; they acknowledged the institutional

agendas and power issues that come into play, they noted they chose the questions, and were affiliated with the mental health trust which had provided funding and had expressed intention to develop a more cost effective local inpatient unit.

There was much variation in how well studies addressed issues relating to ethics.

Study 3 did not explicitly document anything relating to ethical issues, whereas Study 7 clearly documented how they used 'process consent', obtained approval from a research committee and gave feedback to their participants. Only three studies reported having ethical approval or explained reasons why approval was not sought (Study 6, 7, 8). Some studies provided emotional support for participants if it was required (Study 6, 8) and some used a familiar member of staff or carer to approach potential participants. Although the majority of papers stated they had gained consent from participants, issues around confidentiality, anonymity and the process of gaining consent were not adequately described.

Most papers addressed issues around transferability and relevancy well (Study 1-6, 8). However, studies rarely documented clinical outcomes and few gave feedback to their participants. Study 6 was one exception to this as they used their findings to shape a new service that was also evaluated in their study. Recommendations were made by all the researchers, some of which were appropriately shared with providers and commissioners.

Whilst the studies were found to fall short on some of the criteria it is acknowledged that poor reporting does not necessarily mean the research was conducted poorly.

With this in mind it was decided that all eight studies were of good enough quality

and that they would make a valuable contribution to the synthesis (Atkins et al, 2008).

METASYNTHESIS

Meta-ethnography is the most widely used and well developed method of synthesising qualitative data (Britten et al, 2002). It was chosen because its interpretative nature is consistent with the methods used in the studies identified by this review, it allows studies using different methods of analysis to be synthesized, and it has been described as being particularly relevant to service user experiences of care (Britten et al, 2002; Ring, Ritchie, Mandara & Jepson, 2001; Atkins et al, 2008). It can also help generate new research questions and prevent replication of research (Atkins et al, 2008).

Meta-ethnography was first described as seven distinct stages (Noblit & Hare, 1988). Researchers have since published worked examples and reflections on these stages of analysis and have elaborated on the processes involved at each stage (Britten et al, 2002; Walsh & Downe, 2005; Campbell et al (2003); Atkins et al, 2008). These elaborations were used alongside Schutz's notion of first, second and third order constructs to guide the process of analysis (Table 6). Themes and concepts relating to the research question were extracted from each paper and were then compared against one another. These were then combined alongside the researchers' interpretations to develop a better understanding of service users' views on residential and inpatient services.

Table 6: Stages of Meta-ethnography analysis (adapted from Noblit & Hare, 1988, Atkins et al 2008)

| STAGE | PROCESS |
|--|---|
| 1. Getting started | Determine a research question that could be addressed by qualitative research. |
| 2. Deciding what is relevant to the initial interest | Define the focus of the synthesis. Find relevant studies. Decide which studies are to be included. Assess quality of research. |
| 3. Reading the Studies | Familiarise self with the content and detail of the studies. Extract emerging themes and the main concepts (that reflect participants' understandings and the studies interpretations of participants' understandings). Record details of the study setting and participants to provide the context for interpretations made in each study. |
| 4. Determining how the studies are related | Create a list of themes and concepts. Juxtapose them and determine how they contrast and are related. Look for common and recurring concepts. |
| 5. Translating studies into one another/Reciprocal translation | Organise each paper chronologically. Compare the themes and concepts from paper 1 with paper 2. Synthesise these and compare to paper 3 and so on. Note any emerging themes. |
| 6. Synthesising translations | List the translated themes and subthemes in a table. Juxtapose secondary themes derived from researcher interpretations. Develop a model that links the studies interpretations and the researchers interpretations together to create a new interpretation. |
| 7. Expressing the synthesis | Write Results in preparation for publication |

4.1 Meta synthesis findings

Six themes were identified as important for people with a LD who receive residential support and inpatient services: ‘feeling safe and comfortable’, ‘maintaining an identity and sense of belonging’, ‘feeling empowered’, ‘opportunities to be independent and pursue valued activities’, ‘freedom and privacy’ and ‘having psychosocial needs met’. There was variation in how much these themes occurred within the papers. Each theme will be discussed in turn with quotations from study participants (*in italics*) and the study authors. Data from researcher observations were used in order to address the subjective experiences of individuals who have a severe learning disability and could not participate in interviews. Some studies included participants that did not meet the review’s inclusion criteria (see table 2). This was managed by only using extracts from or about participants with a LD who had experienced inpatient or residential support in the analysis. Table 7 illustrates which themes were identified in each paper.

Table 7: Identified themes and subthemes

| Theme and subthemes | Forrester-Jones et al (2002) | Barr et al (2003) | Longo & Scior (2004) | McConkey et al (2004) | Hubert & Hollins (2006) | Parkes et al (2007) | Owen et al (2008) | Chinn et al (2011) | Total |
|--|------------------------------|-------------------|----------------------|-----------------------|-------------------------|---------------------|-------------------|--------------------|------------|
| Feeling safe and comfortable | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8/8 |
| <i>The behaviour of others</i> | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8/8 |
| <i>Familiarity of the environment</i> | ✗ | ✓ | ✗ | ✓ | ✓ | ✓ | ✓ | ✓ | 6/8 |
| <i>Material Factors</i> | ✓ | ✗ | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | 6/8 |
| Maintaining an identity and sense of belonging | ✓ | ✓ | ✗ | ✓ | ✓ | ✓ | ✓ | ✓ | 7/8 |
| Feeling empowered/disempowered | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8/8 |
| Opportunities to be independent and pursue activities of value | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8/8 |
| Freedom and Privacy | ✓ | ✓ | ✗ | ✓ | ✗ | ✓ | ✓ | ✓ | 6/8 |
| Supportive staff addressing both practical and psychosocial needs | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8/8 |

4.2 Feeling Safe and Comfortable

All studies described experiences relating to how safe (or unsafe) and comfortable (or uncomfortable) participants felt in their living environment. Factors that influenced this included the ‘behaviour of others’, ‘familiarity of the environment’ and ‘material factors’.

Behaviour of others

Several study participants talked about feeling scared, bullied, stressed or unsafe because of the behaviour displayed by other residents/patients. Participants were called names, picked on and even spat on. Being unable to relate to or being bullied by others could sometimes lead to isolation as individuals sought to avoid conflict.

“Sometimes the other residents misbehave by shouting or playing up and this is frightening” (Study 4)

“People like that, when you got your back to ‘em, you’re like, cos, cos they get you know, aggressive and in a temper and that? I don’t feel safe, so most of the time I won’t have my dinner up until twenty minutes after they’ve called for dinner so that the kitchen is clear” (Study 8)

Some study participants experienced bullying, intimidation, name-calling and demeaning behaviour by staff. Participants who had experienced physical restraint perceived staff as harmful (Study 3). These experiences seemed more prevalent in mainstream psychiatric settings where participants noted they were treated unfairly compared to other patients. Phrases such as ‘*worse than a dog*’ and ‘*like a piece of*

shit on their shoe’ signifies how distressing the relationships were and how the relationships with staff could have a strong influence on the overall experience individuals had of the service (Study 8).

Participants living in the community did not report bullying from staff but had experienced name-calling, verbal abuse and physical abuse from people living in their neighbourhood.

“Stones are thrown at the windows” (Study 4)

“The children look through my window and pull faces at me” (Study 1)

Participants said they valued living in communities where neighbours were friendly and helpful as this made them feel safe.

Many study participants experienced belongings being stolen or going ‘missing’, creating a sense of loss, lack of security and safety.

“Living in (name of unit) is not the same as having your own place...sometimes things of mine get lost or go missing.” (Study 2)

‘I lost quite a few things in there...they got taken...I bought a couple of t-shirts and they went missing. Some of my money went missing as well’ (Study 6)

Familiarity of the Environment

Participants who felt safe and comfortable tended to live in familiar surroundings.

Study participants valued stability and permanency but many experienced chaos, confusion, unfamiliar staff and disorientation.

“The knowledge of the local area, and easy access within walking distance to local facilities appeared to provide an added feeling of security and belonging, in which participants felt comfortable and safe. Those using shops further away from home felt more vulnerable and uncertain” (Study 2).

“I have lived here all my life and don’t want to move from this area” (Study 2)

“They no longer had the comfort of being known by people in the immediate surroundings of the ward, including the day centre, and other units in the hospital grounds” (Study 7)

Some participants experienced uncertainty or lack of information about where they were going to live and what was happening. Rather than providing comfort, staff could behave in ways that heightened a sense of insecurity and uncertainty.

“A number of participants also said that they had not been shown around the ward by staff when they arrived which may have contributed to a sense of disorientation and unease” (Study 6)

“The constant talk of moving and the lack of information about what was happening heightened the overall sense of insecurity the women experienced.” (Study 7)

Material Factors

Some participants complained about lack of cleanliness, the quality of food and being closed in. Those who talked positively about their experiences valued having their own room, belongings, nice food, being able to lock their room, and being warm. Having a homely environment is important to participants but unfortunately this was not always experienced in hospital settings.

“The ward consisted of three huge bare rooms, like community halls rather than places in which to live” (Study 5)

4.3 Maintaining an Identity and Sense of Belonging

This theme was identified in seven papers. Study participants who had negative experiences of services were those unable to build relationships, pursue interests, culture, sexuality and religion.

There’s lots of people (at home) there they speak in my language, and it’s easier to speak in my language but I haven’t spoken my language for a long time now...”
(Study 8)

Those in hospital environments had poor experiences when their care was not individualized and staff had not got to know them. Activities were organised on a group basis rather than being tailored to the individual.

“There was little acknowledgement of their more individual qualities, and few members of staff had built up meaningful reciprocal relationships with them as individuals.” (Study 5)

Having contact with family and visiting where they previously lived was a particularly important theme and was raised in all studies. Family contact was a form of support and helped to maintain identities of ‘brother’, ‘uncle’ etc. It also maintained confidence because it helped participants feel that others valued and cared about them.

“Doing things with my family, like going to birthdays and christenings is nice, it means they still remember you and are thinking about you.” (Study 2)

If participants were not able to keep in contact with those they valued it led to a sense of loneliness.

“Leroy constantly pulled anyone he could towards the locked door of the dormitory area. If he was allowed in he hunted for his best clothes – a shirt and suit – and wanted to be changed into them. He had done this for years, because he used to wear them for his father’s visits. In fact his father had retired to the Caribbean without him, many years earlier, but Leroy continued to try to get him back, maintained the link with him, and perhaps tried to will him to come and see him, by trying to dress up for him” (Study 5)

Participants experienced few opportunities to talk about what they missed about previous homes, the move, and their previous levels of independence. It appears staff spent little time trying to understand individuals' experiences, history, family, needs, and feelings. This contributed to a loss of identity and a tendency for identities being constructed by staff. There were, however, some study participants who experienced a sense of belonging and ownership of where they lived. Being able to decorate a room according to their taste and having few rules and restrictions helped to create this.

“(I would like to) stay here, it’s the first time I feel like I belong” (Study 1)

4.4 Feeling empowered/disempowered

This theme was evident in all studies. Participants living in the community reported they did not feel involved in making decisions about where they lived or how they spent their time. Some participants reported old clothes and broken trinkets they valued had gone ‘missing’ suggesting that staff were making decisions about whether to keep or throw away their belongings (Study 2).

Within the hospital settings participants felt disempowered because they were not involved in treatment decisions and they lacked choice:

“Cos they’re putting drugs into my body, forcing me to take them and if I don’t take them, they’ll give you an injection and force it on you, I don’t like them” (Study 8)

“Well sometimes I didn’t want to take it but everyone said I had to take it. If you didn’t take it then they’d come and make you” (Study 6)

Often participants reported that they were inadequately informed about what was happening, they were not involved in meetings and their opinions were not listened to.

“no, no-one’s been listening to my opinion at the moment. As far as I’m concerned, it’s been going out of one ear and the other” (Study 8)

Participants appreciated it when they were informed and efforts were made to make information accessible:

“They gave me some leaflets and all that. Like them big long leaflets with pictures on it...I found it very helpful because if they gave it to me all in writing some of them I don’t understand but if it’s done picture with writing at the bottom I can understand it” (Study 6)

Although some study participants (both hospital and community) talked about valuing choices such as how they decorated their room, what clothes they wore and what food they ate, many participants did not appear to have these choices and they were uncomfortable that they were not able to choose who they lived with.

“it’s the same food everyday – meat, meat, meat, meat, meat, meat. Like cauli, cauli, cauli, cauli, everyday. I don’t like it. (Study 8)

“another resident is noisy – shouting all night and day and I can hear. I want her put somewhere else if you could – next door to someone else...” (Study 1)

Some study participants were asked about their future aspirations and where they would like to live as part of the research. Although they could easily express their desires it was apparent that carers had not asked them this information or knew about their wishes. Some participants directly expressed some of this lack of care planning and involvement in future living arrangements.

“I didn’t quite understand it (CPA meeting). I’ll be going somewhere else (Q) where M is. I had problems with her in the past. I am scared. I don’t want to go there. I’d like some more time here (Q) It’s too late now. They have decided (Q) The doctors and nurses.” (Study 3)

“Among these staff there seemed to be no sense of planning for a new future for the women, but simply a need to get through each day” (Study 7)

In both settings the staff could be perceived to be intimidating, judgmental or to have more power and control than the study participants. This made it difficult for participants to express themselves or any dissatisfaction they had about the service or carers.

“I wouldn’t be cross with the carers. They wouldn’t like it”(Study 1)

4.5 Opportunities to be Independent and pursue activities of value

All participants valued opportunities to engage in rewarding and enjoyable activities as this gave a sense of purpose, kept them active, developed confidence and enabled them to learn independent skills. Some participants also valued the opportunity to help other residents/patients and staff.

“Several participants highlighted the complexity of the task they can undertake and how this makes them feel good” (Study 2)

“I like helping the staff” (Study 1)

However, some participants felt there were not enough opportunities to pursue independence and activities, partly due to the reliance on staff, restrictions and regimes in place.

“All I do is wake up in the morning, have breakfast, be bored, nothing to do, so I go to sleep.....I’ve been in other places where I hit someone, they still let you do your education and sport. But this place is terrible” (Study 8)

“There is only enough to do at weekends if there are enough support staff. When staff sleep in they have to be in by 2pm so we don’t have a chance to go out”(Study 1)

Study 5 highlights the lack of activity participants could experience as a result of staff not being available.

“Others ran around in circles, some shouting or whooping. One sat, naked, roaring loudly. One banged his head repeatedly against the wall.....I could see no member of staff.”

Being in a familiar environment with good access to local amenities helped to create opportunities for independence and pursuing valued activities. It also helped participants feel less reliant on others.

“The lack of knowledge of the new area or opportunities to gain it were highlighted as particular difficulties that often led to reduced confidence in using local facilities independently” (Study 2)

“I don’t know my way around any more now that I have had to move from home, people aren’t very helpful”(Study 2)

Having the opportunity to build friendships was valued. However, regimes and restrictions could make social activities difficult:

“I made a friend, some girl there and she used to let me in her bedroom. She used to say ‘come in my room’ and everything and her mates were there and they all joined in like we all made friends together and everything but we all made mates” (Study 6)

“We used to send presents to each other. Now we are not allowed-only cards to staff”. (Study 1)

In order to manage the restrictions that were necessary participants valued having spontaneous trips out and varied activities as this helped with the boredom associated with routine.

4.6 Freedom and Privacy

Six studies reported on some of the restrictions and regimes that participants experienced (e.g. around bed times, smoking, when can telephone relatives). Participants valued their own space, being able to have time on their own and freedom to choose when they pursued activities. Those in community settings appeared to experience more freedom and privacy.

“People don’t tell me what time to go to bed and what time to get up” (Study 1)

“There are time restrictions on us. We have to go to bed at a certain time and having to stop an activity because it is time to go back in” (Study 4)

Some participants saw the restraints and lack of freedom as a punishment

“You know, it’s like a prison.....Well, it’s just a prison for people that’s got a handicap or learning disability, you know” (Study 8)

“At one point I heard her say ‘This place is a prison, there is no way of getting out alive’” (Study 7)

4.7 Having psychosocial needs met

All studies reported on the value of having both emotional and practical support from staff. Participants particularly valued having their feelings acknowledged, being listened to and having time to think about issues from the past.

“Sometimes...a bit low, yeah...and my main nurse had noticed, like, I’d been mostly quiet. And last week, I remember I was crying last week, cos I was upset over thisI was quiet for the whole day, wouldn’t say a word to nobody...and I told her, it was about that” (Study 8)

“Staff are nice. When they see that you are upset they ask you what’s wrong....”
(Study 3)

Some participants mentioned that staff were too busy to meet even some of their basic needs; they were in meetings or doing paper work. Staff could appear unfriendly, unsympathetic, disrespectful, paternalistic and inconsistent.

The impact of past experiences and losses were not fully acknowledged by staff and participants were not supported during times of change. Sometimes staff did not seem to see the importance of recognising participants’ needs and emotions leading to the ‘rejection of participants as social human beings’ (Study 5). This was particularly the case for those with more severe learning disabilities.

“...sometimes he sat with tears running down his face. Usually no one took any notice.”(Study 5)

“The mood of the staff did not improve the women’s sense of insecurity, and yet the women’s expressions of anger and anxiety rarely seemed to be understood in the context of the trauma of the move” (Study 7)

“They’re always busy, there’s only four staff there, and there’s no-one else on the ward to deal with peoples issues that come up. You know...they were never available to see you when you needed them” (Study 6)

“You try to speak to them but they ignore you. They keep saying they’re busy”.
(Study 3)

DISCUSSION

5.1 Findings

Eight papers were identified and analysed using the process of meta-synthesis for the purpose of this review. Across the studies there was consistency in what participants viewed as important in relation to the services they receive: ‘feeling safe and comfortable’, ‘maintaining an identity and sense of belonging’, ‘feeling empowered’, ‘opportunities to be independent and pursue valued activities’, ‘freedom and privacy’ and ‘having psychosocial needs met’. These themes all reflect areas of Maslow’s hierarchy of needs, particularly safety, social and esteem needs (Maslow, 1954). Participants seemed to put less emphasis on biological/physiological and self-actualization needs. This may be because biological/physiological needs tended to be the needs most met by services and safety/esteem/social needs needed to be addressed before individuals could consider issues relating to personal growth.

Participants’ experiences reflect those documented in previous reviews by Ramcharan & Grant (2001), Stenfert Kroese et al (1998) and Griffith et al (2013). The theme of ‘Feeling empowered/disempowered’ particularly resonates with Griffith et al’s (2013) findings of adults who received interventions for challenging behaviour experiencing lack of choice, imbalance of power, loss of autonomy, violence, restrictions and lack of freedom. Participants in the studies included in the current review reported they were not informed about treatments available, their length of stay, future accommodation or medication options. They often felt restricted in when and what they could do and felt scared or unsafe due to other residents’/patients’ challenging behaviours. The behaviour of staff and the presence of regimes seemed to have the

greatest influence on the level of freedom, privacy, independence, sense of identity, self-actualization and empowerment individuals had. Some staff behaviour was experienced as abusive in inpatient settings; participants experienced name-calling and had to wait unnecessarily for their basic needs to be met. It was also noted that participants were often reluctant to express negative views about staff, possibly due to fear they would have to leave the service with no alternative service available to them (Merriman & Beail, 2009; Jingree & Finlay, 2013).

Attachment theory has been applied to challenging behaviour, staff/service user relationships and to inform the delivery of mental health services for people with LD (Clegg & Wansdall-Welfare, 1995; Bucci et al, 2014). It has been argued that establishing a secure base, psychologically and physically, is necessary before any intervention can be successful and that developing good relationships with staff can address service users' attachment needs. Staff can provide security and modulate anxiety by containing distress by giving service users information and by being consistent (Clegg & Wansdall-Welfare, 1995; Adshead, 1998; Bucci et al, 2014). Indeed, participants in this review valued it when staff spent time to get to know them, listen to them and when care was person centered. A secure base may have been particularly important to participants as many were experiencing various forms of loss including hobbies/interests, family contact, independence, control, choice, faith, community, family, and freedom. Such losses as well as ill health and other stressors can activate the attachment/help seeking system in adults (Bowlby, 1982). In order to be a 'container' for distress staff need to be able to hold and process service users' anxiety. This is difficult if staff are having to process and manage their own anxieties (Adshead, 1998). Indeed, some of the authors suggest staff found it

difficult to be person centered and provide psychosocial support due to the restraints and pressures they were facing. It is this pressure that may have led staff to demonstrate the abusive or neglectful behaviour highlighted in this review (Adshead, 1998). Continuity of care and stability also influences security (Schuengal & van Ijzendoorn, 2001), conditions that participants valued but unfortunately many did not seem to experience.

It is important to note that participants expressed positive as well as negative experiences of services. Consistent with previous studies positive experiences tended to be more apparent within a community residential setting rather than inpatient or large institutional settings (Ramcharan & Grant, 2001). Specialist, local care with good access to family, amenities and friends was more likely to lead to better experiences. These environments provided a secure, safe base with less loss and more independence.

5.2 Limitations of studies

The quality of the studies may have impacted on the trustworthiness and rigour of this review's findings. There is much guidance and literature on how to conduct research with people with LD. Despite this, the quality assessment indicates studies did not always adequately address them. Interpersonal dynamics between researcher and participant and the possibility of misrepresenting participants' views and experiences were not fully explored. Also, only one paper involved service users in the choice of questions meaning the data only represents experience circumscribed by the researchers' interests (Ramcharan & Grant, 2001). Although some studies used icebreakers and introductory questions to help participants feel comfortable to express

their views it seemed that little time was spent to develop trust and relationships with equal power. Consistency checks were not carried out and little detail was provided on how informed consent was obtained. Little information was also provided on how researchers bias may have impacted on interpretations, limiting the trustworthiness of the findings.

5.3 Limitations of Review

It is possible that some useful and relevant work, such as audits and evaluations, were not picked up from the literature search as they tend to be published in newsletters, websites, and the publications of professional bodies/societies rather than peer reviewed academic journals. It is also possible that the appraisal of the papers' strengths and weaknesses does not accurately represent the quality of the research; researchers may have considered some methodological issues but did not report them due to journal word count restrictions.

There was a significant variation in how researchers approached their study, the type of services assessed and the participants recruited. The process of meta-synthesis made it difficult to pick up the subtle differences in how participants experience different services. There is some debate about whether qualitative studies of such different theoretical approaches can be integrated (Dixon-Woods et al, 2006). Britten et al (2002), however, argue that studies from different settings should be included as it helps to achieve the higher level of abstraction that meta-ethnography aims for. The limited number of papers included in the review may also be a limitation. More studies that adequately address the methodological limitations identified in this review would help to describe the key themes in more detail (Britten et al, 2002),

prevent important themes not being identified, and increase the trustworthiness of findings.

Despite these limitations the consistency across the studies and previous reviews suggests that the findings are valid and should be considered when developing residential services for adults with LD.

5.4 Recommendations for future research

All themes identified in the meta-synthesis relate to domains viewed as important in assessing quality of life (Schalock & Verdugo, 2002). Quality of life has been viewed as a particularly important concept to consider when evaluating and commissioning ‘best value’ residential and inpatient services (Cambridge, 2000; Schalock et al, 2000)). It is important to further determine what is important for people with LD in relation to quality of life as researchers, service providers, and carers can interpret and experience ‘quality’ differently (Mitchell & Sloper, 2001). The findings of this review provide insight into what service users view as important and therefore what factors services should be monitored. The review’s findings can help inform further research into the development of valid assessment tools for the quality of individual care and service trajectories (Barelds et al, 2010).

The current findings also highlight the need to further develop our understandings of organisational cultures, the role of staff and the application of attachment theory in inpatient and residential settings (Hatton et al, 1999; Gillet & Stenfert Kroese, 2003; Bucci et al, 2004; Clegg & Sheard, 2002). Exploring how staff can be supported to manage constraints, restrictions and to develop person centered, compassionate

support could reduce residents' challenging behaviour (Griffith et al, 2013). This in turn could lead service users to feel safer and less intimidated by the behaviour of other residents.

Social Pedagogy is an approach that may warrant further exploration in future research as it can help build trusting collaborative relationships. It values individuals' cognitive abilities but also considers their emotional lives and how they express themselves through behaviour. Group meetings, interviews and creative activities (e.g: making a DVD) are employed to help individuals express their ideas, hopes and values (Carter et al, 2012; Stephens, 2009). Providing service users with communication skills, self-advocacy training and opportunities to make choices could also help to address issues around acquiescence, as individuals would be better supported to express their views (Mc Villy, 1995).

5.5 Clinical Implications

Consistent with participants' experiences synthesized in this review, the Department of Health's report following Winterbourne review (2011) raised concerns about the lack of person centered planning and the involvement of service users and their families in the services they receive. The report recommended service users should receive support in the community; they should have strong links with family and their home community; if inpatient admissions are necessary these should be in small inpatient settings and out of area placements should be avoided. The Mansell report (DoH, 2007) and subsequent publications such as Jones (2013) have also made recommendations around location, person centered values and interventions for challenging behaviour. It is apparent that many valid recommendations and actions

required have been available for decades but have not been implemented widely (Jones, 2013). As well as research into how service providers can address barriers to the effective implementation (for e.g: organisational culture) of such recommendations, services need to ensure staff understand the importance of meeting recommendations and exploring the desires and values of service users. The potential outcomes of involving service users in the assessment, planning and provision of care needs to be better communicated to help prioritise service user involvement (Kent & Read, 1998) and to ensure it is implemented (Wallcraft, 2012). Staff training on service user involvement, how to develop collaborative relationships, and share information in a transparent and accessible manner may facilitate this.

Expressing views as part of a group, through an advocate, contributing to self-advocacy groups or house meetings could also help people with a LD to feel more empowered and confident in expressing their views (Hoole & Morgan, 2010). In addition to this, staff could explore service users awareness of their rights and inform them of ways to make complaints to increase safety and choice (Griffith et al, 2013).

CONCLUSION

The experiences documented by papers in this review illustrate that despite policies and wanting to be involved (Hoole & Morgan, 2010), people with a LD are still not fully involved in decisions about how their care is provided and quality assessed. More and better quality research is required to fully explore what is important to adult service users receiving residential or inpatient care supports. However, the themes identified in this review are considered robust enough to inform users and providers of services as well as commissioners and be used by all stakeholders as a basis for developing assessment tools to gauge the quality of residential services for adults with LD.

REFERENCES

- Antaki, C., Young, N., & Finlay, M. (2002). Shaping clients' answers: departures from neutrality in care-staff interviews with people with a learning disability. *Disability & Society*, 17, 435-455.
- Arscott, K., Dagnan, D., & Stenfert Kroese, B. (1999). Assessing the ability of people with learning disability to give informed consent to treatment. *Psychological Medicine*, 29, 1367-1375.
- Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC Medical Research Methodology*, 8, 21.
- Barelds, A., van de Goor, I., van Heck, G., & Schols, J. (2010). Quality of care and service trajectories for people with intellectual disabilities: Defining the aspects of quality from the client's perspective. *Scandinavian Journal of Caring Sciences*, 24, 164-174.
- Barr, O., McConkey, R., & McConaghie, J. (2003). Views of people with learning difficulties about current and future accommodation: The use of focus groups to promote discussion. *Disability & Society*, 18 (5), 577-597.
- Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27 (2), 85-96.
- Britten, N., Campbell, R., Pope, C., Donovan, J., Myfanwy, M., & Pill, M. (2002). Using meta-ethnography to synthesize qualitative research: A worked example. *Journal of Health Service Research and Policy*, 7, 209-215.

- Cambridge, P. (2000). Using 'best value' in purchasing and providing services for people with learning disabilities. *British Journal of Learning Disabilities*, 28, 31-37.
- Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003). Evaluating meta-ethnography: A synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine*, 65, 671-84.
- Care Quality Commission. (2011). *CQC review of Castlebeck group services*. London: Care Quality Commission.
- Carr, S. (2004). *Has service user participation made a difference to social care services?* London: Social Care Institute for Excellence.
- Carter, S., Cameron, F., Walton, M., & Houghton, J. (2012). Never mind what I like, it's who I am that matters: An investigation into social pedagogy as a method to enhance the involvement of young people with learning disabilities. *British Journal of Learning Disabilities*, 41, 312-319.
- Centre for Reviews and Dissemination. (2008). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. University of York.
- Cesario, S., Morin, K., & Santo-Donato, A. (2002). Evaluating the level of evidence of qualitative research. *Journal of Obstetric, Gynaecologic and Neonatal Nursing*, 31, 708-714.
- Chapman, R., & McNulty, N. (2004) Building bridges? The role of research support in self advocacy. *British Journal of Learning Disabilities*, 32, 77-85.
- Chinn, D., Hall, I., Ali, A., Hassell, H., & Patkas, I. (2011). Psychiatric in-patients away from home: Accounts by people with intellectual disabilities in specialist

- hospitals outside their home localities. *Journal of Applied Research in Intellectual Disabilities*, 24, 50-60.
- Commission for Healthcare Audit and Inspection. (2007). *A life like no other: A national audit of specialist inpatient healthcare services for people with learning difficulties in England*. Retrieved from:
[https://www.warwickshire.gov.uk/Web/corporate/wccweb.nsf/Links/6EA919F805F3B54180257885002E4C6B/\\$file/A+Life+Like+No+Other.pdf](https://www.warwickshire.gov.uk/Web/corporate/wccweb.nsf/Links/6EA919F805F3B54180257885002E4C6B/$file/A+Life+Like+No+Other.pdf)
- Critical Appraisal Skills Programme. (2002). *Critical Appraisal Skills Programme (CASP) – Making sense of evidence*. London: Public Health Resource Unit.
- Department of Health. (2001). *Involving patients and the public in healthcare*. London: Department of Health.
- Department of Health. (2001). *Valuing People: a new strategy for learning disability for the 21st century – a White Paper*. London: Department of Health.
- Department of Health. (2001). *Nothing about us without us*. London: Department of Health.
- Department of Health. (2007). *Services for people with learning disability and challenging behaviour or mental health needs or The Mansell Report*. London: Department of Health.
- Department of Health. (2012). *Department of Health review: Winterbourne View Hospital – Interim report*. London: Department of Health.
- Dixon-Woods, M., Shaw, R.L., Agarwal, S., & Smith, J.A. (2004). The problem of appraising qualitative research. *Quality and Safety in Healthcare*, 13, 223-225.
- Finfgeld-Connett, D. (2010). Generalisability and transferability of meta-synthesis research findings. *Journal of Advanced Nursing*, 66 (2), 246-254.

- Flynn, M. (2012). *South Gloucestershire Safeguarding Adults Board: Winterbourne View Hospital – A serious case review*. South Gloucestershire Safeguarding Adults Board.
- Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M., & Beecham, J. (2002). The quality of life of people 12 years after resettlement from long stay hospitals: Users' views on their living environment, daily activities and future aspirations. *Disability & Society*, 17 (7), 741-758.
- Francis R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. London: The Stationery Office.
- Gates, B., & Waight, M. (2007). Reflections on conducting focus groups with people with learning disabilities: Theoretical and practical issues. *Journal of Research in Nursing*, 12 (2), 111-126.
- Gillet, E., & Stenfert-Kroese, B. (2003). Investigating organizational culture: A comparison of a 'high' – and a 'low' – performing residential unit for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 279-284.
- Griffith, G., Hutchinson, L., & Hastings, R. (2013). "I'm not a patient, I'm a person": The experiences of individuals with intellectual disabilities and challenging behavior – A thematic synthesis of qualitative studies. *Clinical Psychology Science and Practice*, 20, 469-488.
- Hatton, C., Rivers, M., Mason, H., Mason, L., Emerson, E., Kiernan, C., Reeves, D., & Alborz, A. (1999). Organizational culture and staff outcomes in services for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 43 (3), 206-218.

- Hoole, L., Morgan, S. (2010). 'It's only right that we get involved': Service –user perspectives on involvement in learning disability services. *British Journal of Learning Disabilities*, 39, 5-10.
- Hubert, J., & Hollins, S. (2006). Men with severe learning disabilities and challenging behaviour in long-stay hospital care. *British Journal of Psychiatry*, 188, 70-74.
- Jingree, T., & Finlay, W. M. L. (2013). Expressions of dissatisfaction and complaint by people with learning disabilities: A discourse analytic study. *British Journal of Social Psychology*, 52, 255-272.
- Jones, E. (2013). Back to the future: Developing competent residential services for people with intellectual disabilities and challenging behaviour. *Advances in Mental Health and Intellectual Disabilities*, 7(1), 5–17.
- Kaehne, A., & O'Connell, C. (2010). Focus groups with people with learning disabilities. *Journal of Intellectual Disabilities*, 14, 133-145.
- Katrak, P., Bialocerkowski, A. E., Massy-Westropp, N., & Grimmer, K. A. (2004). A systematic review of the content of critical appraisal tools. *BMC Medical Research Methodology*, 4, 22.
- Kent, H., & Read, J. (1998). Measuring consumer participation in mental health services: Are attitudes related to professional orientation? *International Journal of Social Psychiatry*, 44 (4), 295-370.
- Krueger, R. A., & Casey, M. A. (2000). Focus groups: A practical guide for applied research, 3rd ed. Thousand Oaks, CA: Sage Publications.
- Care Quality Commission. (2012). *Learning Disability Services Inspection Programme: National Overview*. London: Care Quality Commission.

- Llewellyn, P. (2009). Supporting people with intellectual disabilities to take part in focus groups: reflections on a research project, *Disability & Society*, 24 (7), 845-856.
- Longo, S., & Scior, K. (2004). In-patient psychiatric care for individuals with intellectual disabilities: The service users' and carers' perspectives. *Journal of Mental Health*, 13 (2), 211-221.
- McConkey, R., Sowney, M., Milligan, V., & Barr, O. (2004). Views of people with intellectual disabilities of their present and future living arrangements. *Journal of Policy and Practice in Intellectual Disabilities*, 1 (3-4), 115-125.
- McKenzie, K., Murray, G., & Matheson, E. (1999). An examination of the importance of aspects of services to people with a learning disability. *British Journal of Learning Disabilities*, 27, 25-29.
- McVilly, K. R. (1995). Interviewing people with a learning disability about their residential service. *British Journal of Learning Disabilities*, 23(4), 138-142.
- Merriman, C., & Beail, N. (2009). Service user views of long term individual psychodynamic psychotherapy. *Advances in Mental Health and Learning Disabilities* 3, 42-47.
- Mitchell, W., & Sloper, P. (2001). Quality in services for disabled children and their families: What can theory, policy and research on children's and parents' views tell us? *Children and Society*, 15, 237-52
- Nind, M. (2008). Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. *Economic and Social Research Council National Centre for Research Methods Review Paper*.

- Noblit, G. W., & Hare, R. D. (1988). *Meta ethnography: synthesising qualitative studies*. London: Sage Publications.
- Owen, K., Hubert, J., & Hollins, S. (2008). Moving home: The experiences of women with severe intellectual disabilities in transition from a locked ward. *British Journal of Learning Disabilities*, 36, 220-226.
- Parkes, C., Samuels, S., Hassiotis, A., Lynnggaard, H., & Hall, I. (2007). Incorporating the views of service users in the development of an integrated psychiatric service for people with learning disabilities. *Journal of learning Disabilities*, 35, 23-29.
- Ramcharan, P., & Grant, G. (2001). Views and experiences of people with intellectual disabilities and their families (1): The user perspective. *Journal of Applied Research in Intellectual Disabilities*, 14, 348–363.
- Rapley, M., & Antaki, C. (1996). A conversation analysis of the ‘acquiescence’ of people with learning disabilities. *Journal of Community and Applied Social Psychology*, 6 (3), 207-227.
- Ring, N., Ritchie, K., Mandara, L., & Jepson, R. (2011). *A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews*. NHS: Quality Improvement Scotland.
- Retrieved from:
<http://www.healthcareimprovementscotland.org/his/idoc.ashx?docid=04df262c-ec20-40e1-aef7-d2aa3ad03c06&version=-1>
- Sandelowski, M., & Barroso, J. (2002). Reading qualitative studies. *International Journal of Qualitative Methods*, 1, 1.

- Schalock, R. L., Bonham, G. S., & Marchand, C. B. (2000). Consumer based quality of life assessment: A path model of perceived satisfaction. *Evaluation and Program Planning*, 23, 75-85.
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.
- Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2013). Quality in qualitative evaluation: A framework for assessing research evidence. London: Cabinet Office. Retrieved from:
http://www.gsr.gov.uk/downloads/evaluating_policy/a_quality_framework.pdf
- Stenfert Kroese, B., Gillott, A., & Atkinson, V. (1998). Consumers with intellectual disabilities as service evaluators. *Journal of Applied Research in Intellectual Disabilities*, 11 (2), 116-128.
- Stephens, P. (2009). The nature of social pedagogy: an excursion in Norwegian territory. *Child & Family Social Work*, 14, 343-51
- Stewart, D. W., & Shamdasani, P. N. (1998). Focus group research: Exploration and discovery. In Bickman, L., & Rog, D. J. (Eds.), *Handbook of applied social research methods* (pp. 505-526). Thousand Oaks, CA: Sage Publications.
- Townson, L., Macaulay, S., Harkness, E., Chapman, R., Docherty, A., Dias, J., ... McNulty, N. (2004). We are all in the same boat: doing 'people-led research'. *British Journal of Learning Disabilities*, 32 (2), 72-6.
- Wallcraft, J. (2012). Involvement of service users in adult safeguarding. *The Journal of Adult Protection*, 14 (3), 142-150.
- Walsh, D., & Downe, S. (2005). Meta-synthesis method for qualitative research: a literature review. *Journal of Advanced Nursing*, 50 (2), 204-11.

- Walsh, D., & Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery*, 22 (2), 108-19.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.
- Young, A. F., & Chesson, R.A. (2006). Obtaining views on health care from people with learning disabilities and severe mental health problems. *British Journal of Learning Disabilities*, 34, 11-19.

**HOW DO PSYCHOLOGISTS EXPERIENCE WORKING WITH STAFF IN
RESSIDENTIAL CARE SETTINGS FOR PEOPLE WITH A LEARNING
DISABILITY?**

This paper is written in preparation for submission to the Journal of Applied Research
in Intellectual Disabilities (see Appendix 1)

ABSTRACT

Background: Whilst psychologists working with people with a learning disability routinely work with care staff in residential care homes there is a lack of research investigating how psychologists can effectively assess, collaborate and engage with staff groups.

Aims: This research seeks to explore psychologists' experiences of working with staff in residential care homes in order to develop an understanding of how psychologists manage the work and help generate clinical solutions to psychological problems.

Methods: Seven clinical psychologists and one counselling psychologist were interviewed using a semi-structured interview focusing on participants' interactions with staff. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis.

Findings: Themes common across participants included 'development and maintenance of a therapeutic relationship', 'theory and emotion', 'perceived restrictions', 'safety', 'developing an identity as a psychologist', 'support and shared experiences', 'motivation', and 'conflict and the roles of a psychologist'.

Conclusions: Participants experienced several barriers to carrying out effective psychological work with staff in residential care homes. The various ways they have sought to address these are discussed. A preliminary model is proposed to describe what is needed for psychologists to be effective when working with staff in residential care homes.

INTRODUCTION

There is a high prevalence of mental health, behavioural and complex bio-psycho-social difficulties in the learning disability (LD) population (Deb, Thomas & Bright, 2001; Cooper et al, 2007). Over the last fifty years there has been a significant change in the care provided to people with LD, namely a move from institutional care to community residential care homes. Consequently specialist LD psychologists often work in residential care homes in the community. Behavioural interventions form a large part of a psychologist's workload in this setting and it requires effective communication between professionals, staff and service users. Psychologists rely on care staff participating in meetings, playing an active role in the formulation process, and implementing recommendations.

Staff are not only important in the implementation of behavioural strategies; over the last couple of decades there has been increasing evidence for the use of cognitive-behavioural, cognitive, systemic and psychodynamic therapies with individuals who have a LD (Willner, 2005). Stenfert Kroese et al (2014) recommend psychologists work with staff when providing CBT for individuals with a learning disability as it can help ensure the maintenance and generalisation of improved psychological wellbeing and reduce the need for longer-term therapy.

Research literature indicates that staff can have difficulties in implementing, maintaining and generalising behavioural interventions, which leads to increased dependence on specialist services (Hill-Tout, 1992; Allen, 1999). Factors identified as barriers in the application of behavioural approaches include institutional

constraints, external pressure, limited resources, staff attitudes, organisational resistances and perceived inflexibility (e.g. Corrigan, Kwartarini & Pramana, 1992; Allen, 2001). Psychological factors such as staff beliefs, attributions and well-being have been well researched and identified as having an impact on the outcomes for residents in community settings (Mansell et al 2008; Rose, 2011; Whittington & Burns 2005). Staff behaviour and interactions with service users have also been reported to contribute to challenging behaviour (Farrell et al, 2010). The documentation of abuse in Winterbourne View, a hospital for people with LD, further highlights the importance of addressing organisational and staff factors (Flynn, 2011). Following this report the Department of Health recommended services adopt Positive Behaviour Support, an approach that addresses staff, context and wider environmental change (DoH, 2012; Allen, 2009).

Some research has focused on care staff's experiences of psychologists in different settings (Ingham & Clarke, 2009; Burrow & Foster, 2010) and their perception of what the barriers are to implementing behavioural approaches successfully (Corrigan et al 1992). However, no study has explored the difficulties psychologists encounter when working collaboratively with staff or how these difficulties are addressed in clinical practice. Some professionals have published their anecdotal reflections on their experiences of working psychologically in organisations and how they have addressed difficulties through the application of theory (e.g. Obholzer, 1994; Hill-Tout, 1992; Smyly, 2006; McBrien & Candy, 2012). McBrien & Candy (2012) touched upon the psychologist-staff relationship when they identified factors such as staff stress and management style as possible reasons why staff do not always collaborate with healthcare professionals. They suggest psychologists take time to

understand the staff's perspective in order to manage feelings of frustration and powerlessness they may experience. Although these publications are useful they are anecdotal; they did not employ systematic methods to collect and analyse data. One exception to this is a study by Hart (2010) that sought educational psychologists' views on effective practice in classroom behaviour management using thematic analysis. The focus, however, was on establishing effective behavioural strategies and did not explore psychologists' experiences of working with staff.

Thus, there is a lack of research into psychologists' experiences of their interactions with care staff in residential care homes for people with a LD. Psychologists need to carefully consider how they collaborate and engage with staff and organisations (Hill-Tout, 1992). It is important this is addressed as problems associated with working in community settings can make it difficult for professionals to meet the needs of service users (Goodman, Woolley & Knight 2002) and to implement the necessary changes.

1.1 Aims

This research aims to address this lack of evidence by exploring how psychologists experience working with staff in residential care homes using a qualitative research method.

METHOD

The methodology used for this study was Interpretative Phenomenological Analysis (IPA). IPA focuses on how individuals make meaning of their experiences. This approach was thought to fit well with the aims of the research.

2.1 Procedure and Participants

Ethical approval from NHS Trust R&D departments and the University of Birmingham was obtained (see Appendix 4). Psychologists from two NHS Trusts in the West Midlands were approached by email and at a meeting for a local LD Special Interest Group. They were asked to make contact by email if they were interested in taking part in the research and (i) they were a qualified clinical or counselling psychologist, (ii) their clinical work involved working with staff in residential care homes for people with LD and (iii) if they had spent at least one year in a post involving this type of work. Once email contact was made, written consent was obtained and demographic information was collated, following which a face-to-face interview was completed. Seven qualified clinical psychologists and one qualified counselling psychologist were recruited. A sample of eight is thought to be sufficient when using IPA methods (Smith, Flowers & Larkin, 2009). Participants' post-qualification experience ranged from two to 21 years. All participants had undertaken further training or obtained additional qualifications that addressed ways of working with staff. The proportion of participants' clinical work involving staff ranged from 25 to 70%. Seven participants were female and one was male (see Table 8 for demographic details).

Each participant was given a transcript of their interview and the opportunity to withdraw from the study within two weeks of receiving it. Participants were informed that if any unsafe practice was disclosed and it had not been appropriately addressed the researcher would follow NHS Trust policies. There were no incidents where this procedure had to be followed. Contact details were provided if participants wished to discuss any concerns or distress they experienced as a result of the interview (appendix 4).

Table 8: Participant details

| Participant Number | Number of years qualified | Number of years working in a role that involved working with staff in residential care homes | Proportion of clinical work spent working with staff | Further training that addresses working with staff |
|--------------------|---------------------------|--|--|---|
| 1 | 7 years | 7 years | 50% | MSc in Systemic Practice DBT and Advanced Formulation training |
| 2 | 10 years | 10 years | 70% | Advanced professional diploma in Positive Behaviour Support |
| 3 | 7 years | 7 years | 50% | CAT and Narrative Therapy Training |
| 4 | 2 years | 2 years | 50% | Advanced professional diploma in Positive Behaviour Support |
| 5 | 12 years | 9 years | 10% | Systemic Family therapy training |
| 6 | 15 years | 15 years | 25% | Diploma in Cognitive Therapy. Systemic and attachment training |
| 7 | 8 years | 8 years | 50-70% | MSc Intervention in Learning Disability |
| 8 | 21 years | 21 years | 25% | Intermediate Family Therapy and Level II Narrative Therapy Qualifications |

2.2 Data collection

Data was collected between July 2013 and September 2013. All interviews were undertaken at the participants' place of work. The interviews ranged from 48 minutes to 81 minutes (mean= 62 minutes) and were audio recorded with the consent of the participant. Each interview focused on the participant's experiences of working with staff in residential care homes for people with LD. As the focus of the research was on participants' personal experiences of working with staff, open-ended questions were asked during a semi-structured interview according to IPA methodology (See Appendix 5). A pilot interview was carried out with a clinical psychologist to help develop and refine questions included in the interview schedule. There was a particular focus on the difficulties associated with the work, when the work goes well, and participants' interactions with staff. Prompts were used where appropriate during the interview. The tapes were transcribed verbatim before analysis.

2.3 Data Analysis

Each interview transcript was analysed using IPA, a systematic qualitative analysis (Smith, Flowers & Larkin, 2009). In IPA the researcher tries "to make sense of the participant trying to make sense" of their experiences (Smith, 2011, p.10). Findings from IPA studies are presented as themes that are shared across participants. The ways in which themes are represented by individuals are also commented upon (Smith, 2011).

The analysis involved several stages. First, one transcript was read several times so the researcher became familiar with and immersed in the data. 'Free' or 'open' coding was completed during this phase. This involved making notes on any

interpretations and ideas. The second stage involved a close line-by-line analysis and coding of the participant's experiences and understandings. Recurrent themes, key words and phrases from the transcript were then extracted and noted. Psychological knowledge and theory were used to interpret what the reported experiences might mean for the participant. This process was then repeated for each transcript. The researcher noted repeated patterns and themes in subsequent transcripts whilst also documenting new, emerging themes (Smith & Osborn, 2003). Once this was completed thematic connections were made within and across transcripts. These themes were then organised into a list of superordinate and subthemes. The number of participants falling under each theme was noted. Restructuring and reordering of themes was a continuous process throughout analysis (See appendix 6 for more detail). A research psychologist reviewed the themes and quotations to ensure aspects of the data were not over or under represented.

IPA acknowledges participants' experiences are accessed by the researcher through a process of 'inter-subjective meaning- making' (Smith, Flowers & Larkin, 2009).

There is therefore a need for the researcher to be aware of and reflect on her own experiences and assumptions and how these impact on the interpretations made. Prior to conducting this research the researcher had various experiences of working with staff. She spent three years working as an assistant psychologist which involved working with staff in residential care homes for people with a LD and complex epilepsy. As a trainee psychologist she worked with staff in a residential care home for people with a LD and she worked with staff in an inpatient service for older adults with dementia. It was felt that her experiences would facilitate the interpretive process of analysis. As these experiences may also introduce bias the researcher

documented any assumptions held and kept a reflexive diary when collecting and analysing data.

FINDINGS

Superordinate themes common across participants included ‘development and maintenance of a therapeutic relationship’, ‘theory and emotion’, ‘perceived restrictions’, ‘safety’, ‘developing an identity as a psychologist’, ‘support and shared experiences’, ‘motivation’, and ‘conflict and the roles of a psychologist’. Subthemes were identified within each superordinate theme. See Table 9 for the themes identified for each participant. Quotes were chosen to illustrate the themes and were taken from all participants.

Table 9 – Table of Themes

| Superordinate Themes and Subthemes | | | | | | | | | |
|--|---|---|---|---|---|---|---|---|-------|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | Total |
| 1. Development and maintenance of a therapeutic relationship | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| <i>Being interested and compassionate</i> | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| <i>Trust, respect and confidence</i> | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | × | 7 |
| <i>Transparency and honesty</i> | ✓ | ✓ | ✓ | ✓ | × | ✓ | ✓ | ✓ | 7 |
| 2. Theory and Emotion | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| 3. Perceived restrictions | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| <i>Culture</i> | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| <i>Resources</i> | ✓ | ✓ | × | ✓ | ✓ | ✓ | ✓ | ✓ | 7 |
| 4. Safety | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| <i>Something hidden</i> | × | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | × | 6 |
| <i>Use and impact of policies</i> | ✓ | × | ✓ | × | × | ✓ | ✓ | ✓ | 5 |
| <i>Responsibility</i> | ✓ | ✓ | ✓ | × | × | ✓ | ✓ | ✓ | 6 |
| 5. Developing an identity as a psychologist | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| <i>Style and personality</i> | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| <i>Being a good psychologist</i> | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| 6. Support and shared experiences | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |
| 7. Motivation | ✓ | ✓ | ✓ | ✓ | × | ✓ | ✓ | ✓ | 7 |
| <i>Justice</i> | ✓ | ✓ | × | × | × | × | ✓ | × | 3 |
| <i>Feedback</i> | ✓ | ✓ | ✓ | ✓ | × | ✓ | ✓ | ✓ | 7 |
| <i>Challenge</i> | ✓ | ✓ | ✓ | ✓ | × | ✓ | ✓ | ✓ | 7 |
| <i>Potential for change</i> | × | ✓ | ✓ | × | ✓ | ✓ | ✓ | ✓ | 6 |
| 8. Conflict and the roles of a psychologist | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 8 |

3.1 Development and Maintenance of a Therapeutic Relationship

All participants emphasized the importance of building relationships with staff when they received referrals for service users living in a residential care home. When participants had a good relationship with staff their recommendations tended to be implemented and the outcome of the work was positive. Less positive experiences of working with staff tended to have occurred earlier on in participants' careers when they had not spent time developing relationships with staff; they were "*invisible*" or a 'hit and run professional' (McBrien & Candy, 2012). That is, they had simply gone in and out of the home and left some forms for staff to fill in. Following these early experiences participants viewed the staff-psychologist relationship as integral to their intervention and some drew comparisons with the therapeutic relationship they build in individual therapy with service users. Key factors that participants saw as significant in contributing to the development and maintenance of a good therapeutic relationship with staff and consequently the outcome of their work are presented under the following subthemes: 'being interested and compassionate', 'trust, respect and confidence', 'interpersonal style' and 'transparency'.

Being interested and compassionate

Participants thought it was important to take time to hear *all* staff members' stories and to understand their expectations of the psychologist's work. Some participants made the effort to be available on the phone and visited homes regularly so they could get to know all staff.

Most participants talked about the importance of defining the objectives of the work and clarifying the staff team's goals in the first few sessions. These processes helped

participants develop alliance and compassion for the staff team. Some participants, however, found it difficult to achieve this due to both external (not being able to arrange meetings with staff) and internal (ability to hold all staff's stories in mind) factors.

"I don't know how you can hold onto so many different voices if there's just one person...I don't th... you know effectively... if you're just one person going in. I think you need somebody else there" (Participant 8, Lines 169-171)

Participants clearly demonstrated compassion and understanding for both the service users and for the staff, although for some participants it took more thought and effort for the latter.

"It is very easy to align yourself very quickly with the client and forget that staff are actually do...trying sometimes to do their best" Participant 1 (Line 161-163)

"Um and again I have always umm feel you know 'you have to go in and try to understand this, you have got to have a think about this'. 'You have got to think why the staff member is performing...and the team in this way as well'. There must be some reason because again, meaning and context. There has to be." (Participant 1, 394-397)

Participants demonstrated their compassion towards staff by directing their attention to the staff's affective experiences, reflecting back their feelings and giving them space to express any distress.

“Sometimes that’s all people really need as a staff team is a bit of space to say ‘sometimes it’s a really hard job...but I don’t want to say that to people in case they think I’m not very caring’. It is a very hard job, I couldn’t do it. So yay, for getting up and coming in every day, you know you got hit yesterday and you still came in this morning, that’s a really good thing.” (Participant 7, Lines 1056-1061)

The level of compassion demonstrated for staff and service users varied amongst participants. The participant who showed the most compassion and felt the greatest sense of injustice for service users reported the most feelings of anger and frustration towards staff. The amount of experience participants had of working with staff seemed to influence their level of compassion. Having more experience of working with the staff teams and hearing their stories helped participants to fully appreciate the difficulties and challenges staff face and how they can become burnt out.

Trust, Respect and Confidence

All participants spoke positively about staff and at times it seemed they felt the need to act as their advocate: defending the staff from blame. Some participants found staff would only trust them once they had experienced what they could do as a psychologist. Staff’s previous experience of psychology also had an influence on trust.

“So some people have had really good experiences of psychology before and are like, ‘oh yeah this is really good and we can...we are really looking forward to having you in and we’ve really found this helpful before’ and are enthusiastic and some people are like ‘you’re just going to come in and tell us off about things, so you’re just going

to come in and tell us all the things we're doing wrong and then not be very helpful and then get them to fill out lots of forms and then disappear''. (Participant 7, Line 420-426,)

One participant talked about a particularly positive experience of working with a staff team over several years. She was able to build trust through the different pieces of work, to the point where she felt like an “*extended part*” of the staff team (Participant 2, line 13). In contrast, when these opportunities were not in place or there was little trust in the relationship participants felt they were an outsider or unwanted.

Having confidence and showing confidence in staff skills also seemed to help participants build mutual respect and trust leading to a better collaboration.

“there might be some talking about...well we have some expertise in some areas but they are likely to have their expertise in working in that particular residential home with that particular person umm so it's a slightly different sort of standing point and I think that mainly staff teams umm appreciate that...response to that.....umm (pause) because it is it is you know its recognising that they have skills and also it is working more collaboratively and perhaps people are feel more able to share their true feelings or concerns or worries” (Participant 8, lines 16-22)

Interpersonal style

Overall an informal, open and honest approach was seen as an effective way of building trust with staff, particularly if the staff team were young, inexperienced and not used to working with professionals. Being “*human*”, “*down to earth*”, “*lively*”

and using humour were important ways participants promoted a genuine and trusting relationship.

However, participants also commented that this approach had to be tailored and carefully judged as sometimes formality was required for staff to feel safe. One participant noted that being informal conflicted with the expectations associated with a professional and that it could undermine authority:

“ ... they’d respect you more in some ways. I’ll do what he says you know...whereas if you’re a bit more open, I think some people see you as a bit more amateurish in some ways” (Participant 5, Line 804-811).

Transparency and honesty

Participants often talked about staff having expectations of psychologists coming in and fixing the problem and/or blaming the staff. When this expectation was evident participants experienced staff as being less collaborative and engaged with the work.

“Well why are you talking to me, I thought that you’ve come to stop so and so doing something or make so and so less sad or...” (Participant 7, Lines 416-417)

All participants attempted to address this by taking time to explain the psychologist’s role and being open and honest from the beginning. This helped to break down defensive attitudes in the staff, manage their expectations and so dissipate the psychologist’s own sense of disappointing staff and feeling under pressure. Some participants made contracts with staff to increase transparency so they had a *“context for what is going to change or what might be different”* (Participant 6, Lines 419-

420). To maintain transparency participants broke down information, adapted forms and described psychological interventions in plain language. Talking openly with staff about ruptures in the therapeutic relationship and any difficulties in implementing recommendations also helped to maintain an effective working relationship.

3.2 Theory and Emotion

Participants used their intuition, emotions and knowledge to inform their work with staff, understand what was happening within residential homes, and to maintain motivation.

“But you can sense it, you can sense there’s a problem, er, but people won’t tell you”
(Participant 5, Line 203)

“So when I go into a home and I see those basic needs are not met I am...I do get really hacked off I have to say.....It [anger] is helpful in that it will spur me on and motivate me to make those changes you know, I don’t go in and go ‘well that’s ok, it doesn’t really matter.’” (Participant 1, 388-393)

They frequently referred to psychological models (e.g.: Systemic including Narrative, CBT, Behavioural, Positive Behaviour Support and Community Psychology) to describe and make sense of their experiences. For example, two participants took a narrative approach to explain their experiences and many participants used techniques drawn from CBT such as reframing and problem solving to address difficulties and uncomfortable emotions.

“I might just stop and think ‘right well I’m feeling like this about this and because of that what do I need to do about that, what’s the best likelihood of success for changing this’ and then you’ll draw on what you’ve used before or what you’ve heard other people have used before” (Participant 6, Lines 725-728).

Participants reported that they could not apply theory in a formulaic systematic approach as the referrals and staff teams varied and the work was unpredictable in nature. As well as knowing the theory participants stated it was important to be reflective, flexible, creative and to set goals.

Balancing theory and emotion is something participants said they learnt experientially rather than through study. Participants recalled early experiences where their approach was less balanced, collaborative, flexible and pragmatic. Terms such as “*gung-ho*” and “*like a bull in a china shop*” were used. These approaches tended to lead to unrealistic expectations, frustration and disappointment.

3.3 Perceived Restrictions

All participants experienced times where they felt restricted in what they are able to achieve as a psychologist leading to feelings of injustice, powerlessness and frustration. The expressions ‘*hitting a brick wall*’ and ‘*wading through mud*’ were used to reflect these experiences. Key subthemes identified were ‘culture’ and ‘resources’.

Culture

Participants emphasised the importance of considering the context of the referral and the culture amongst the staff team. They did this by asking professionals who had worked in the home about their knowledge and experience of how the service operates.

Services that had a medical, hierarchical or institutional ethos were seen as more constraining because the values did not fit well with the collaborative approach favoured by participants. Whilst taking a flexible and patient approach was seen to be helpful when working in these environments, this did not guarantee success. Two participants recalled experiences where they had tried to adjust their work around the constraints imposed by the system but met further resistance and found this difficult to comprehend:

“they just wouldn’t the management just wouldn’t put the training on. So even though the staff wanted that, wanted to help the person. They just wouldn’t. But not even when we offered to do it in like 3 or 4 staff at a time and do it multiple times, not even when we....” (Participant 4, Lines 196-205)

Participants viewed the manager as having a heavy influence on the culture and philosophy of the residential service. They had satisfying experiences of working with staff when managers valued psychology, supported staff, shared a similar value base, and put less emphasis on activities that ‘crowd out good care’ such as form filling and chores (Whitby & Gracias, 2013). This led to a sense of ‘togetherness’ and the staff working as a team. Participants found cultures that valued, supported and

empowered staff helped them to work collaboratively and communicate effectively.

It facilitated positive changes for both staff and service users.

“it’s easier for it to go well if you got a staff group that are already in that position...who you know work perhaps a bit as a team” (Participant 8, lines 60-62)

Some participants had experiences where staff could not implement recommendations because they conflicted with managerial policy or the manager did not support them:

“it’s (psychology recommendation) not coming from a top down perspective and staff feel a bit powerless and ineffective in being able to implement it” (Participant 4, line 185-187).

Managers sometimes restricted participants’ access to the staff team or they viewed the problem being within the staff team. This could create a culture of ‘blame’ where staff felt they had done something wrong and the psychologist was there to reprimand them.

“That’s happened to me before so I arrived, the manager’s... the manager believes that the staff team are a problem, that they’re not pulling their weight or they’re not doing the right thing or whatever...they are not doing a good enough job”

(Participant 3, Lines 553-557)

Overall participants found it difficult to influence the culture within the home as they felt many factors were out of their control (e.g: how the managers worked, organisational policies, type of staff employed)

“But I think culture shift is very hard, especially if there is some older staff in there, who started doing this from 20 or 30 years ago when it was a very different landscape” (Participant 7, lines 277-279)

Several participants referred to changes needing to be made at a political level and in the way individuals are selected for employment in residential homes. To help improve their experiences of working in residential care homes some participants felt research was needed to address how they could better influence culture.

Resources

Many participants often felt under pressure; they wanted more time to meet and work with staff teams. Time to reflect was valued by all participants but some felt they did not have enough time to do this.

“It [not having enough time allocated to working with staff] does lead to me feeling umm that I am not doing as good a job as I would like and it’s feeding into quite a lot of dissatisfaction into my job role at the moment” (Participant 2, Lines 246-247)

“But I...uuh...I think one of the, one of the issues is the pressure of work, so the number of people that you need to see, um the amount of things that you need to do, and having that time to think and plan um and making sure that therapeutically we

aren't fitting into that pattern that we so often see with services where they just react to all the time so that we're being more proactive more, considered." (Participant 6, 777-782)

Little money, high staff turnover, poorly trained, stressed and low numbers of staff were seen to be barriers to psychological work. Having few staff made it more difficult to find the time to meet, communicate and implement recommendations. Staff members who were not motivated by service users' best interests also made it difficult to implement change.

"I did sit alongside the keyworker and say this is really important for the client and this is the reason. I had shown it quite clearly. 'Yes, I agree, yeah, yeah.' Umm but I think there is a degree of understanding that is free and then there is a degree of understanding that is peppered with acute frustration and I think I eventually concluded they just didn't have the clients best interests at heart to want to do it for him" (Participant 1, lines 354-359)

Participants felt it was important for staff to feel supported by each other and their manager in order to reduce burnout, maintain motivation and compassion and that often not enough time was allocated to this.

3.4 Safety

All participants made reference to safeguarding procedures, risk or abuse. The following subthemes were identified; ‘Something Hidden’, ‘Using Policies’, and ‘Responsibility’.

Something Hidden

Participants had experiences of staff trying to give a good impression and being reluctant or apprehensive about sharing information with the psychologist.

“But then as you go in and in again each time there are more little things that make you think this doesn’t all add up to what you told me in the first interview”

(Participant 2, Lines 403-405)

“Sometimes they’re always a bit, oh well yes, nodding, smiling and then you go away and nothing changes then you go, but they seemed really keen when I was in there.”

(Participant 7, Lines 591-593)

Sometimes staff seemed to agree to recommendations at a superficial level; they ‘do it for show until you go away...until you’re happy’. (Participant 4, Line 292)

Intuition and attending to the culture, staff’s attitudes, level of collaboration, practices, language and beliefs were seen as important

“It happens doesn’t it and...and we don’t always pick it up and that that yeah, I don’t really know what can be done about that really um and I suppose thinking about it

those attitudes that I'm talking about...ummm that you hear from staff, the warning signs that perhaps that these things might be happening but that's difficult because you don't have any proof that these things are happening..."(Participant 3, Lines 324-329)

"....they will say stuff that absolutely sets alarms bells off in your head and you think how can you talk about people in such a way"(Participant 2, Lines 28-29)

Use and Impact of Policies

All participants seemed confident about how to follow safeguarding procedures when needed. Participants, however, varied in how satisfied they were about the outcome. Following safeguarding procedures could lead to feelings of inadequacy and sadness, particularly when a service user is removed from their home and the problems within the home continue. One participant felt it was a punitive process, especially as staff were not effectively supported or resourced to make the appropriate changes.

"You try and hold the service user in the middle of everything....and it's a bit like you've failed them because actually you know that things aren't gonna get that much better for them" (Participant 4, Lines 274-275)

Participants talked about how reporting services had a negative impact on their relationship with staff. After referrals were made staff *"were a bit more sort of cautious"* (Participant 8, Line 126).

Other participants viewed potential outcomes as positive: service users could be reallocated to more appropriate residential services and it provided structure for change to occur.

“...some services who have may be... staff have found it very difficult to access training or managers have found it very difficult to try and get staff to go to training. When there’s a safeguarding process that gives them some containment and some structure to do that in.” (Participant 7, Lines 344-345)

Responsibility

All participants recognised that reporting unsafe practice was part of their role. Some felt the need to tell staff that psychologists could report to social services if they felt service users were at risk.

Having to rely on intuition and make decisions as a sole practitioner was experienced as anxiety provoking in the context of risk. Participants often felt frustrated and sad when they could not implement necessary changes.

“I mean it’s hugely... it’s hugely concerning and it’s uh quite, quite anxiety provoking it is, it’s it’s one of the most difficult things because you are pretty powerless, pretty powerless in terms of um if it was just us making recommendations in isolation”
(Participant 6, lines 531-534)

There appeared to be some reluctance to explore these feelings of anxiety. When talking about risk and safeguarding procedures participants tended to use the term

‘we’ rather than ‘I’, indicating that they felt that this is a collective responsibility. Sharing the risk and being supported by a multi-disciplinary team seemed to help participants feel confident and comfortable with the process. Safeguarding policies helped participants take a pragmatic approach to manage a distressing aspect of their work:

“...it sadly resulted in him [Service user] having a heart attack. Umm at that point then, we had logged everything as a department, and we then contacted the CQC around that particular home and that provider and I don’t think they...when I left that Trust I think they had just, I think they were under review or they were due to close.”(Participant 1, Lines 372- 376)

3.5 Developing an Identity as a Psychologist

Style and Personality

Participants spent a lot of time making sense of and justifying their role and style of working. Although the underlying values held by participants were similar, there was diversity in the psychological models and approaches used. It was important for participants to use a model that fitted well with their personality, beliefs and style. Finding the right style and model is something that participants developed over time and had an impact on their confidence.

“I feel more confident with how you approach people and whatever (coughs) yeah I prefer working as I work, more systemically with staff groups.”

(Participant 8, lines 626-627)

Being a good psychologist

Many participants described times they felt they had not been a good psychologist.

This tended to be when they hit barriers or when they did not meet staff's or their own expectations. Some participants noticed it could be easy to undervalue the work they had done and the skills they have.

"I think when I was first working, when I was first qualified, it was quite disheartening, it was 'I should be able to go in and change the world and it's not changing and that must mean I'm a rubbish psychologist'" (Participant 7, Lines 595-597)

"...afterwards I got really good feedback because although it feels like you don't do very much...afterwards the manager and the couple of the staff said, 'Oh that was really good, thank you for that we are really appreciative of having the time and the kind of space to think about it and we've come up with some really good ideas'" (Participant 3, Lines 152-156)

It was therefore important for participants to reflect and reframe outcomes that were initially seen as negative and to highlight their positive experiences of working with staff. This helped to develop self-compassion, maintain confidence and motivation, justify their work and the value of psychology.

Breaking down what they do and making the less obvious and more complex aspects of their work explicit also seemed to help make sense of what psychological skills they were using, how their work was beneficial and why the work can take time.

“So if we’re seeing the practical things change but we are also seeing the attitude of the staff changing because of what we’re doing and some of that is as I say explicit and some of that is more umm implicit in the work that we’re doing or is not an explicit goal of the work”(Participant 5, Lines 328-332)

“is kind of knowing...appreciating...although the solution might be simple the assessment might be quite multidimensional as well as complex. And being comfortable with going in and saying actually I am on my 4th session and I am still assessing and that’s ok.”(Participant 1, Lines 806-810)

Many participants tended to speak generally and theoretically about their experiences and the way they work rather than recalling specific experiences. They distanced themselves from their experiences by using the terms ‘You’ and ‘We’ rather than ‘I’. Interestingly, two participants said they used a similar strategy when talking to staff to avoid blame and judgment.

3.6 Support and shared experiences

Participants found it important to have support from other professionals to develop self-compassion and contain some of the difficulties associated with the work. Talking with other professionals validated their concerns, reassured them that they were doing everything they could and provided ideas on how to work with staff teams.

“until I got everybody else involved...’cos it made me feel, it was my first, it was my first qualified job actually that and it made me feel inadequate and ‘am I doing

something wrong, is there something else I could be doing” (Participant 3, Line 250-252)

Supervision was described as useful to help reflect, reframe, normalise, establish the role of a psychologist, and manage feelings. Two participants also said they had found it helpful to reflect on their experiences during the interview itself and that they would find it helpful to hear about other psychologists’ experiences.

3.7 Motivation

Justice

Participants were primarily motivated in their work by the desire for justice and a better quality of life for service users. Half of the participants also wanted justice for the staff team as they recognised they were underpaid, under-supported and over-criticised.

Feedback

Participants expressed enjoyment and satisfaction in their work when they had received good feedback from service users and staff teams. Seeing staff have “*light bulb moments*” and observing changes in how they engaged with psychology and service users was also seen as rewarding feedback.

“...next time I went back they were like 'right we have decided we are going to do X, Y, Z and we are going to do, we have put these behavioural plans in place, and we are going to sort this’ ...and it was like 'wow' you have actually started doing everything all that I wanted you to” (Participant 2, Lines 112-115)

Challenge

It was clear through all accounts given that the work can be challenging. However, the challenge was something that participants could find exciting and positive.

Participants were accepting of their imperfections in how they worked with staff and recognised that they were continuously learning. Many participants identified they wanted to pursue further training or that they already received training so they could better address the challenge.

“...I like working with staff, even maybe staff groups who have a reputation for being more challenging. I think that’s quite... I mean I like that challenge, how do we get these people get them talking together get them to work more collaboratively and not you know not ...how do we move forwards?” (Participant 8, Lines 480-482)

Although participants tended to accept the challenges they commented it could be hard work to persist when nothing seems to be changing. One participant noted it was important for her to be aware when she lacked motivation as despondency could be transferred to the team.

Potential for change

Some participants were optimistic, enthusiastic and emphasised that although working with staff teams was unpredictable it was exciting or *“like living on the edge”* (Participant 3, Line 600).

“....and it’s kind of like a two in one isn’t it. You’ve helped the client and you’ve helped the support worker feel like they can do their job for another day” (Participant 3, 538-539)

Participants saw they could make more of a difference for service users when they involved staff.

I think I’d been there about three months when I realised to do any individual work that’s going to be effective with the service users in this setting, I’m going to have to do more work with staff (laughter) (Participant 6, Lines 739-742,)

3.8 Conflict and the roles of a psychologist

Participants described staff teams as often being ‘stuck’, desperate for a solution and wanting to be rescued. Terms such as “*wave a wand*”, “*magic*” and “*fix*” were used to describe staff expectations. In their early career participants often felt the pressure to respond to this by fulfilling the role of an ‘expert’ who knows the answers.

“I might have got better at just thinking well what’s my responsibility to sort out. I think perhaps I used to own or take on board a lot of things um or personalise a lot of things um and something’s are would fall within my remit my responsibility and other things don’t so that might have changed over time, my ability to see yeah, that I’m a cog in a machine rather than feeling like I’m a machine and I’ve got to do it all”
(Participant 6, Lines 712-717)

Paradoxically participants found staff did not respond well to the expert approach.

“They don’t like it. Although they’re asking for solutions they don’t seem to like it when you give in to them (laughter) Cos there will also be ‘yes, buts’ kind of thing”
(Participant 3, Lines 95-97)

When an ‘expert’ approach was unsuccessful it could lead participants to doubt their abilities, blame themselves and/or the staff team. Participants also noted they could be treated like an “outsider”, they were “not wanted” or were seen as a “hassle” by the staff team due to their different values and ideas.

“‘this is the way we do things, we don’t want anybody to come in and change it’” (Participant 4, Lines 214-215)

Participants moved away from an ‘expert’ role by involving staff and acknowledging their skills. This empowered staff to take ownership of the intervention they needed to implement.

“I tend to sort of try to have conversations that are quite empowering actually saying you know ‘you are doing a good job but this might help. Let’s draw on the strengths of what you are doing’. Even though sometimes it feels as if there are very few strengths at least if you can build on them it gives staff some confidence”
(Participant 1, Lines 250 - 254)

To help staff adjust to a more collaborative role psychologists sometimes took a more ‘expert’/‘adviser’ role in the first few sessions to gain respect and “hook them in”.

Many participants also spent time explaining their role to staff in order to adjust their expectations and familiarise them with a collaborative approach.

“...it might actually be yeah let’s look about how we can try give them an answer and it might be about going down a more behavioural route. It might be about looking at... you know... you know you kind of building on that rather than us offering them something too different that they are not going to buy into. Then in fact that’s what we do with the staff team I was talking about earlier....” (Participant 8, Lines 297-301)

One participant noted she had learnt that when she tried to move too fast she was perceived as a ‘hassle’. The majority of participants found it important to take time, be flexible and tailor their work to how ‘ready’ the organisation is for psychological help.

“But if we are not going to be able to do that today then I don’t mind, it’s not... I’m not that bothered I can come back another time. This might just be an introductory meeting. So I think being flexible and not going in with too set ideas about what your agenda is and what you’re going to achieve that day”(Participant 4, lines 593-598)

“There might be some realities but then it’s about perhaps trying to be flexible in terms of ‘well is there a way we can do this” (Participant 6, Lines 450-452)

Participants were thoughtful in how they addressed and challenged staff’s attitudes, language, practices and beliefs in order to stay in a collaborative role:

“...without saying ‘maybe what you’re doing is not really very good’ if you say to them ‘well actually I think the way you’re working might be making things just a bit harder how about we try and make your job a bit easier’” (Participant 7, lines 954-958)

“That sort of lively curiosity that doesn’t go in with ‘Ok, I am here to assess that you are not doing a very good job’.” (Participant 1, Lines 221-223)

Being collaborative could conflict with participants’ responsibility to follow safeguarding policies and report unsafe practice:

“...that can affect your relationship with staff then because it’s like ‘well you’re going and telling on us” (Participant 7, Lines 336-338)

Some participants managed this conflict by recognising compassion can be about setting boundaries, being honest and giving staff what they need rather than what they want.

“...being supportive is to help an organisation appreciate when some things aren’t ok” (Participant 6, Line 542)

DISCUSSION

The findings in this study provide an insight into how psychologists experience working with staff in residential services for people with LD. Participants identified several factors that they perceived to influence their ability to work at their full potential and be effective as a psychologist. These are summarised in a preliminary model in Figure 2 and they are based on some of the themes identified by the author. It is important to note that the relative importance of each factor and how critical they are for effective working with staff remains to be established by future research. The factors are presented in cogs as the model proposes psychologists need to be supported, motivated, feel safe in the work they are doing, have certain resources in place, have developed an identity as a psychologist and have an effective relationship with staff teams in order to work at their full potential as an agent of change. The themes represented in Figure 2 are discussed further below. Participants also sought to make sense of the dynamics and roles when working with staff. This is discussed further within the theme 'Roles of a psychologist and conflict'.



Figure 2: Preliminary model of what a psychologist needs to be effective when working with staff in residential care homes

4.1 Motivation and Support

Several factors associated with job-related causes of stress and burnout were identified by participants: high workload, time pressures, cultural issues restricting ability to implement change, and role conflict (Schaufeli & Buunk, 2003). Despite this, participants were optimistic and enjoyed the challenges. Support and participants' desire for justice, challenge and positive feedback helped them to maintain motivation and optimism.

4.2 Safety

The Mid-Staffordshire enquiry (Francis, 2013) and Winterbourne Review (Flynn, 2012) have highlighted the need for psychologists to consider their work with staff and residential care homes within the context of service-user safety. Participants talked about some of the anxiety associated with reporting services and picking up on abuse. Intuition and noticing the culture, staff's attitudes, level of collaboration, practices, language and beliefs were seen as important to pick up on things that were hidden (Marsland, Oakes & White 2007). Although participants felt supported and were confident in following procedures there seemed to be a reluctance to explore feelings of anxiety and the possibility of missing warning signs or abuse. This may reflect a lack of confidence around identifying risk.

4.3 Perceived Restrictions

Due to the increase in professionals delivering psychological interventions McBrien & Candy (2012) argue psychologists, now more than ever, need to work at multiple levels. Indeed, all participants recognised the importance of considering the context, system and culture before attempting to implement any changes with staff.

Culture, particularly in institutional contexts, was perceived to have great influence on staff attitudes, beliefs and behaviour. The influence of the psychologist was at times experienced as weak in comparison to the culture (Allen, 1999). Many managed the frustration associated with this by considering the staff not to be ready for change. 'Organisational readiness for change' has been reported as necessary for successful implementation of change, in both business and health settings (Weiner, Amick & Lee, 2008). The term has been defined as "members' shared resolve to implement

change” (change commitment) and “shared belief in their collective capability to do so” (change efficacy) (Weiner, 2009, p.2). Participants in this study talked about several factors that positively impact on staff’s change commitment and change efficacy. These factors included resources available, flexibility of service policies, staff training and support from the manager. Staff members’ engagement with psychologist participants varied depending on whether their suggestions and ideas resonated with their values and their managers’. Participants reported that they found it particularly difficult to deliver their services when staff members were not motivated by the service users’ best interests.

One model that has been applied to the field of organisational change and is already well known to psychologists is the Transtheoretical Model of Change (Prochaska, Prochaska & Levesque, 2001). Psychologists often use the model and its processes to inform individual therapy. Participants referred to the stages of the model, although not explicitly, when making sense of their experiences with staff. The ways participants worked with staff in the different stages of the model are summarised in Table 10. In order to work through these stages participants often stressed the importance of having the support of the manager and there being a ‘top-down approach’.

Table 10 – Strategies used by participants

| Stage | Strategies used by participants at each stage |
|-----------------------------------|---|
| Pre-contemplation & Contemplation | <ul style="list-style-type: none"> -Exploring the problem with staff, listening to everyone's story -Talking about expectations of psychology, past experiences and staff's anxieties -Increasing empathy staff have for service users, modeling a person centred approach -Highlighting the stress associated with current strategies and that change may help reduce this |
| Preparation | <ul style="list-style-type: none"> -Empowering staff to use their own skills -Increasing confidence |
| Action and Maintenance | <ul style="list-style-type: none"> -Providing adapted ABC forms and checklists to aid understanding of the recommendations -Regular visits and reviews -Being approachable and available on the phone for problem solving -Providing necessary skills/training or recommending training -Providing time to reflect -long-term involvement |

4.4 Developing and maintaining a therapeutic relationship

Research in the field of individual therapy has identified that developing a good therapeutic relationship is essential in engaging service users. The perceived quality of the therapeutic process correlates more highly with service user outcome than which particular interventions are used (Lambert & Barley, 2001). All participants in the current study stressed the importance of taking time to build relationships with staff teams. They made sense of how they could successfully relate to staff with the following subthemes: 'being interested and compassionate', 'trust, respect and confidence', 'interpersonal style' and 'transparency'. All of these are variables that

have been described in the literature to influence the development and maintenance of therapeutic relationships (Lambert & Barley, 2001). Consistent with the literature on psychotherapeutic outcomes the current participants tended to report better results when they had a good therapeutic relationship with staff.

Although the level of compassion for staff varied, all participants emphasised the pressures staff are under. Some participants encouraged staff to increase self-compassion and to support one another. The Mid Staffordshire Public Enquiry (Francis, 2013) also stresses the importance of addressing staff pressures and having compassion for staff; burnout and stress in staff have been found to have a significant impact on service user outcomes (Rose, Horne, Rose & Hastings 2004); support for staff has been found to relate to patient safety (Dixon-Woods et al, 2013) and it has been argued that compassion for service users requires staff to be compassionate for themselves and each other (Beck, 2013).

4.5 Theory and Emotion

Participants talked about needing to use both theory and their emotions to inform their work. All participants referred to how their experience, rather than their training, was integral to developing their intuition.

4.6 Developing an identity as a psychologist

Participants put importance on making sense of their role and finding a psychological model that suited their style and values. This was a process that seemed to help participants develop confidence and their identity as a psychologist. This in turn helped them to realise their full potential as agents of change.

4.7 Conflict and the role of a psychologist

It has been suggested that Karpman's Drama Triangle (1968) can be used in social and health care settings to help practitioners and managers manage conflict, increase collaboration and personal and organisational growth (Burgess, 2007). Karpman's Drama triangle (1968) and an adaptation of The Empowerment Dynamic triangle (Emerald, 2009) help to illustrate the different roles participants found themselves playing and the conflict they experienced (Figure 3).

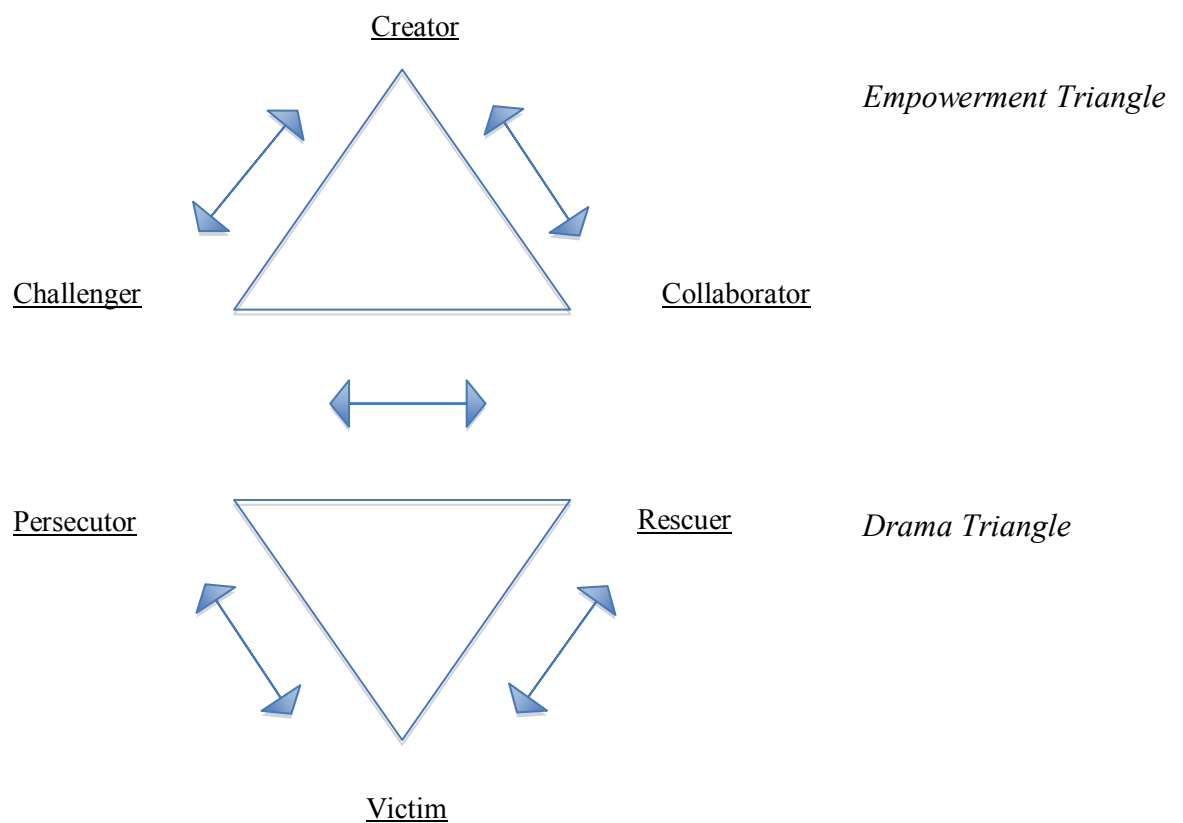


Figure 3: Roles of a psychologist - Adapted from the Empowerment Dynamic (TED) Triangle and Karpman's drama triangle

Early on in their careers participants tended to take the role of a 'hero-innovator' (Georgiades & Phillimore 1975) or 'rescuer'. This approach often failed when working with staff, leading participants to feel they were 'not wanted' or that they

were not a good psychologist. They became the 'victim' in the drama triangle.

Experience, resilience and knowing their limitations helped participants move away from a position of 'rescuer' or 'victim' to a 'collaborator' role. They provided staff teams with opportunities for reflection, problem solving and formulating together.

Despite working within a 'collaborator' role some participants found they still experienced frustration and self doubt. Participants who managed these feelings of frustration most effectively tended to move away from a 'victim' role and took on a 'creator' role. They were flexible and accepted staff's readiness for change can vary depending on the culture and the resources available. They gave organisations time, set and adjusted goals to fit the context of the situation, and used reframing in supervision.

Participants found it difficult to stay within the empowerment triangle when they were confronted with unhelpful attitudes, safeguarding issues and were obliged to report services. These responsibilities conflicted with the 'collaborator' role and could lead some participants to feel they were viewed as a 'persecutor' by staff.

Participants described how they could move away from a 'persecutor' role by taking on a 'challenger' role. This involved an explorative and reflective approach where staff could see the psychologist was making an effort to understand their point of view.

Cultural issues and staff not being used to collaboration (Tyler, Pargament & Gatz, 1984) were also said to make it difficult for participants to stay within the empowerment triangle. Participants attempted to address this by developing contracts

to set out the scope of the work, sharing expectations and using their therapeutic relationship skills.

4.8 Limitations of the study

It is likely that as a trainee psychologist the researcher had an impact on how participants answered questions. There seemed to be a tendency to inform and convince the researcher of the theoretical model preferred by the participant and an assumption that the researcher may be judging them on the quality of their work. Interviews conducted by a different professional may have led to different and more diverse experiences portrayed by participants. Bias may have also been introduced during the analysis as the researchers had experience of working with staff teams in residential care homes and inpatient units. However, attempts were made to address this by keeping a reflective diary of assumptions held and by having themes checked by another research psychologist.

All participants recognised the importance of working successfully with residential staff and were keen to make sense of their experiences and gain further training. This may be why they volunteered to take part in the research. The experiences of psychologists who perhaps have less interest in this type of work and/or are less skilled may be different, possibly less positive.

Another limitation of this research is that it only looks at staff in residential care settings within one geographical region. It is possible that psychologists working with staff in different settings may have different experiences thus limiting the generalisability of these findings.

4.9 Future research

The findings of how psychologists experience and work with staff are preliminary and not generalisable. Therefore more extensive research is necessary to establish which factors influence the effectiveness of psychologists in residential settings and to develop effective ways psychologists can implement change through staff.

There is also a need to develop theoretical models and assessment tools to help psychologists address risk and difficulties associated with organisational culture in a more systematic way. Many of the theories and models used in healthcare have been taken from the business sector and the assessment tools are said to have limited evidence for reliability and validity (Weiner, 2009). Within the psychology literature Hill-Tout (1992) has proposed a model to assess staff teams' functioning and resources but again its validity and reliability has yet to be assessed. Some studies looking at the psychometric properties of cultural assessment tools have paid particular attention to patient safety but this was only done within the context of an inpatient setting (Sarac et al, 2011). Following the Francis Report it was suggested that a Special Interest Group in Patient Safety is formed within the BPS (Kapur, 2014). This group could also address safety within residential care homes and carry out further research.

4.10 Recommendations

Further research is necessary before firm recommendations can be made. However, the participants working in residential care homes for people with a LD found the following helpful:

- Spend time to develop an effective collaborative relationship with staff teams. Address any ruptures, demonstrate compassion and transparency.
- Gain support from other professionals and clinical supervision to help reframe, reflect, manage difficult emotions and formulate complex dynamics present in services
- Create opportunities to acknowledge the difficulties of working in a residential home and to share experiences (Obholzer, 1994).
- Consider the timing of the intervention. When homes are facing much change (e.g: staff leaving, new management) it can reduce staff's capacity to successfully engage with psychology (Smyly, 2006).
- Take account of organisational culture by adjusting expectations. Drawing on familiar models such as the Transtheoretical Model may help to do this (Prochaska, Prochaska & Levesque, 2001).
- Direct efforts to where there is the greatest potential for change and focus on what is possible (Georgiades & Phillimore, 1975).

The drama and empowerment triangles used here to reflect on the roles psychologists take may also be used to formulate the dynamics between psychologists, multi disciplinary staff, residential home staff, managers, and service users.

To further address cultural issues psychologists could make effective use of their skills by building alliances with commissioners and providers to fully address concerns that were highlighted by participants (training, how staff are employed and supervision for staff) and by the Winterbourne Review (Flynn, 2012). This may involve producing evidence of why supervision and training are effective and needed for residential staff. Psychologists taking consultancy roles in healthcare bodies may also be a way to influence and develop appropriate (psychological) ways of working with risk in residential care homes (Kapur, 2014).

CONCLUSION

Most participants found their work with staff in residential care homes rewarding and enjoyable work as it was perceived to potentially have a great impact on service users' quality of life. However, consistent with previous research, institutional constraints, external pressure, limited resources, staff attitudes and inflexibility were viewed as barriers to effective psychological interventions. Participants sought to address these challenges through seeking support from other professionals and by developing a compassionate therapeutic relationship with members of staff. Understanding and being aware of the restrictions was important for participants to be self-compassionate and manage frustration.

Despite having some effective solutions to the difficulties they experienced participants still felt restricted in their ability to implement change at a higher level. Further research and psychologists working more closely with commissioners and providers may help to generate further solutions.

REFERENCES

- Allen, D. (1999). Mediator analysis: An overview of recent research on carers supporting people with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research*, 43 (4), 325-339.
- Allen, D. (2009). Positive behavioural support as a service system for people with challenging behaviour. *Psychiatry*, 8 (10), 408-412.
- Beck, A. (2013). Compassion care post Francis: How relevant is staff experience? *Clinical Psychology Forum*, 249, 10-12.
- Burgess, R. (2005). A model for enhancing individual and organisational learning of 'emotional intelligence': The drama and winner's triangles, *Social Work Education: The International Journal*, 24 (1), 97-112.
- Burrow, A., & Foster, I. (2010). Special educational needs staff's perceptions of clinical psychologists: What are the implications for merged children's services? *Clinical Psychology Forum*, 206, 7-12.
- Cooper, S-A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill health in adults with intellectual disabilities: Prevalence and associated factors, *The British Journal of Psychiatry*, 190, 27-35.
- Corrigan, P., Kwartarini, W., & Pramana, W. (1992). Staff perception of barriers to behaviour therapy at a psychiatric hospital, *Behavior Modification*, 16, 132-144.
- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability: prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years, *Journal of Intellectual Disability Research*, 45, 495– 505.
- Department of Health. (2012). *Transforming care: A national response to Winterbourne View Hospital, final report*. London: Department of Health. Retrieved from <http://www.dh.gov.uk/>

- Dixon-Woods, M., Baker, R., Charles, K., Dawson, J., Jerzembek, G., Martin, G., ... West, M. (2013). Culture and behaviour in the English National Health Service: Overview of lessons and a large multimethod study, *BMJ Quality & Safety*, online first. [need url, doi or use citation that others used when referencing this work: 23, 106-115 – but note that year is (2014) in that case.]
- Emerald, D. (2009). *The power of TED – The empowerment dynamic*, Edinburgh: Polaris Publishing Group.
- Flynn, M. (2012). *South Gloucestershire Safeguarding Adults Board: Winterbourne View Hospital – A serious case review*. South Gloucestershire Safeguarding Adults Board.[location? Retrieved from address?]
- Francis R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. Executive summary*. London: The Stationery Office.
- Georgiades, N. J., & Phillimore, L. (1975). The myth of the hero-innovator and alternative strategies for organizational change. In Kiernan, C., & Woodford, F. P. (Eds.) *Behavior modification with the severely retarded*, (pp. 313-319). New York, NY: Associated Scientific.
- Goodman, C., Woolley, R., & Knight, D. (2003). District nurses' experiences of providing care in residential care home settings, *Journal of Clinical Nursing*, 12, 67-76.
- Hart, R. (2010). Classroom behaviour management: educational psychologists' views on effective practice. *Emotional and Behavioural Difficulties*, 15 (4), 353-371.
- Hill-Tout, J. (1992). Challenging behaviour and the service organisation: Who gets punished for failure? *Clinical Psychology Forum*, 49, 2-7
- Ingham, B., & Clarke, L (2009). The introduction of clinical psychology to an inpatient autistic spectrum disorder and intellectual disabilities service: Impact and reflections, *Clinical Psychology Forum*, 204, 30-34.

- Kapur, N. (2014). Mid Staffordshire Hospital and the Francis report: What does psychology have to offer? *The Psychologist*, 27 (1), 16-20
- Karpman, S. (1968). Fairy tales and script drama analysis. *Transactional Analysis Bulletin*, 7(26), 39-43.
- Lambert, M., & Barley, D. (2001). Research summary on the therapeutic relationship and psychotherapy outcome, *Psychotherapy*, 38(4), 357-442.
- Mansell, J., Beadle-Brown, J., Whelton, B., Beckett, C., & Hutchinson, A. (2008) Effect of service structure and organisation on staff care practices in small community homes for people with intellectual disabilities, *Journal of Applied Research in Intellectual Disabilities*, 21, 398-413.
- Marsland, D., Oakes, P. & White, C. (2007). Abuse in care? The identification of early indicators of the abuse of people with learning disabilities in residential settings, *The Journal of Adult Protection*, 9 (4), 6-20.
- Maslow, A. (1954). *Motivation and personality*. New York: Harper.
- McBrien, J. & Candy, S. (1998). Working with organizations, or: why won't they follow my advice? In Emerson, E., Hatton, C., Bromley, J., & Caine, A. (Eds.). *Clinical psychology and people with intellectual disabilities. The Wiley series in clinical psychology* (pp. 265-279). New York: John Wiley & Sons Ltd.
- Obholzer, A. (1994). Fragmentation and integration in a school for physically handicapped children. In Obholzer, A., & Zagier, V. (Eds.). *The unconscious at work - Individual and organisational stress in the human services* (pp.84-93). London: Routledge.
- Prochaska, J. M., Prochaska, J. O., & Levesque, D. (2001). A transtheoretical approach to changing organisations. *Administration and Policy in Mental Health*, 28(4) 247 – 261.

- Rose, D., Horne, S., Rose, J., & Hastings, R. (2004). Negative emotional reactions to challenging behaviour and staff burnout: Two replication studies. *Journal of Applied Research in Intellectual Disabilities*, 17 (3), 219 – 223.
- Rose, J. (2011). How do staff psychological factors influence outcomes for people with developmental and intellectual disability in residential services? *Current opinion in Psychiatry*, 24 (5), 403-407.
- Sarac, C., Flin, R., Mearns, K. & Jackson, J. (2011). Hospital survey on patient safety culture. *BMJ Quality and Safety*, 20, 842–848.
- Schaufeli, W., & Buunk, B. (2003). Burnout: An overview of 25 years of research and theorizing. In Schbracq, M., Winnubst, J., & Cooper, C (Eds.). *The handbook of work and health psychology*, (pp 383 - 425). Chichester: John Wiley & Sons Ltd.
- Smith, J. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5 (1), 9-27.
- Smith, J., Flowers, P. & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, method and research. London: Sage.
- Smith, J., & Osborn, M. (2003). Interpretative phenomenological analysis. In Smith, J. (Ed.) *Qualitative psychology* (pp 25-50). London: Sage Publications Ltd.
- Smyly, S. (2006). Who needs to change? Using systemic ideas when working in group homes. In Baum, S., & Lynggard, H. (Eds). *Intellectual disabilities – a systemic approach* (pp.142-163). London: H Karnac (Books) Ltd.
- Stenfert Kroese, B., Jahoda, A., Pert, C., Trower, P., Dagnan, D., & Selkirk, M. (2014). Staff expectations and views of cognitive behaviour therapy (CBT)

- for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27 (2), 145-153.
- Tyler, F. B., Pargament, K. I., & Gatz, M. (1983). The resource collaborator role: A model for interactions involving psychologists. *American Psychologist*, 38(4), 388-398
- Weiner, B. (2009). A theory of organisational readiness for change. *Implementation Science*. 4 (67), 1-9.
- Weiner, B., Amick, H., & Lee, S. Y. D. (2008). Conceptualization and measurement of organisational readiness for change: A review of the literature in health services research and other fields. *Medical Care Research and Review*, 65, 379-435.
- Whitby, P., & Gracias, S. (2013). Reflecting on the Francis report. *Clinical Psychology Forum*, 249, 13–17.
- Whittington, A., & Burns, J. (2005). The dilemmas of residential care staff working with the challenging behaviour of people with learning disabilities. *British Journal of Clinical Psychology*, 44, 59-76.
- Willner, P. (2005). The effectiveness of psychotherapeutic interventions for people with learning disabilities: A critical overview. *Journal of Intellectual disability research*. 49 (1),73-85.

PUBLIC DOMAIN BRIEFING PAPER

**Residential care homes for people with a learning disability: the experiences of
psychologists and service users**

Outline

The research described below was carried out by Natalie Smith, Trainee Clinical Psychologist, at the University of Birmingham. It was submitted as partial fulfilment for the degree of Doctorate in Clinical Psychology.

Literature review

Background: Involving service users and spending time to understand their experiences is important to improve the quality and safety of residential and inpatient services for people with a learning disability.

Aims: This review seeks to understand how service users value and experience residential and inpatient services in order to inform future research and clinical practice.

Methods: A systematic literature search of three databases was conducted to identify studies, published between 2000-2014, reporting on service users' experiences of inpatient and residential services. Eight papers were identified and their quality was assessed against criteria from Walsh & Downe's (2006) quality framework. Central themes of importance emerging from the qualitative studies were identified using a process called meta-ethnography.

Results: Six themes that were important to service users when receiving inpatient or residential supports were identified: 'feeling safe and comfortable', 'maintaining an identity and sense of belonging', 'feeling empowered/disempowered', 'opportunities

to be independent and pursue activities of value', 'freedom and privacy', 'having psychosocial needs met'.

Conclusions and implications: Services should consider and monitor the themes identified to help ensure the care they provide is of high quality and meets the needs of service users. The findings can also inform research into the development of quality assessment tools.

Research Component

Background: Whilst psychologists working with people with a learning disability routinely work with care staff in residential care homes there is a lack of research investigating how psychologists can effectively assess, collaborate, and engage with staff groups.

Aims: This research seeks to explore psychologists' experiences of working with staff in residential care homes in order to develop an understanding of how psychologists manage the work and to help generate clinical solutions to psychological problems.

Methods: Seven clinical psychologists and one counselling psychologist were interviewed using a semi-structured interview focusing on the difficulties associated with working with staff, when the work goes well, and participants' interactions with staff in residential care homes. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis.

Findings: Themes common across participants included ‘development and maintenance of a therapeutic relationship’, ‘theory and emotion’, ‘perceived restrictions’, ‘safety’, ‘developing an identity as a psychologist’, ‘support and shared experiences’, ‘motivation’, and ‘conflict and the roles of a psychologist’.

Conclusions: Participants experienced several barriers to carrying out effective psychological work through staff in residential care homes. Participants sought to address these challenges by employing various strategies such as seeking support from other professionals and by developing a compassionate therapeutic relationship with members of staff.

Clinical Implications: Further research is necessary before firm recommendations can be made. However, the participants’ accounts suggest spending time to understand and develop awareness of the restrictions can help to create self-compassion and manage any frustration when working in residential care homes. Building alliances with commissioners and providers to fully address concerns and barriers to psychological work (e.g.: training, how staff are employed and supervision for staff) may also help.

APPENDICES

Appendix 1: JARID Author Guidelines



Appendix 2: Search Strategy

1. PsycINFO; LEARNING DISABILITIES/ OR LEARNING DISORDERS/ OR DEVELOPMENTAL DISABILITIES [+NT]/; 30616 results.
2. PsycINFO; ("learning disabilit*" OR "developmental disabilit*" OR "intellectual disabilit*" OR "mental* retard*").ti,ab; 49479 results.
3. PsycINFO; INTELLECTUAL DEVELOPMENT DISORDER/ [Limit to: English Language and Publication Year 2000-2014]; 8840 results.
4. PsycINFO; 1 OR 2 OR 3 [Limit to: English Language and Publication Year 2000-2014]; 25219 results.
5. PsycINFO; CLIENT ATTITUDES/ OR CLIENT SATISFACTION/ [Limit to: English Language and Publication Year 2000-2014]; 10332 results.
6. PsycINFO; ((view* ADJ1 patient*) OR (opinion* ADJ1 patient*) OR (attitude* ADJ1 patient*) OR (satisfaction ADJ1 patient*) OR (feeling* ADJ1 patient*) OR (perspective* ADJ1 patient*) OR (perception* ADJ1 patient*)).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 5732 results.
7. PsycINFO; ((view* ADJ1 inpatient*) OR (opinion* ADJ1 inpatient*) OR (attitude* ADJ1 inpatient*) OR (satisfaction ADJ1 inpatient*) OR (feeling* ADJ1 inpatient*) OR (perspective* ADJ1 inpatient*) OR (perception* ADJ1 inpatient*)).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 42 results.
8. PsycINFO; ((view* ADJ1 "service user*") OR (opinion* ADJ1 "service user*") OR (attitude* ADJ1 "service user*") OR (satisfaction ADJ1 "service user*") OR (feeling* ADJ1 "service user*") OR (perspective* ADJ1 "service user*") OR (perception* ADJ1 "service user*")).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 221 results.
9. PsycINFO; ((view* ADJ1 client*) OR (opinion* ADJ1 client*) OR (attitude* ADJ1 client*) OR (satisfaction ADJ1 client*) OR (feeling* ADJ1 client*) OR (perspective* ADJ1 client*) OR (perception* ADJ1 client*)).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 1452 results.
10. PsycINFO; ((view* ADJ1 people) OR (opinion* ADJ1 people) OR (attitude* ADJ1 people) OR (satisfaction ADJ1 people) OR (feeling* ADJ1 people) OR (perspective* ADJ1 people) OR (perception* ADJ1 people)).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 459 results.
11. PsycINFO; ((view* ADJ1 individual*) OR (opinion* ADJ1 individual*) OR (attitude* ADJ1 individual*) OR (satisfaction ADJ1 individual*) OR (feeling* ADJ1 individual*) OR (perspective* ADJ1 individual*) OR (perception* ADJ1 individual*)).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 2793 results.
12. PsycINFO; ((view* ADJ1 women) OR (opinion* ADJ1 women) OR (attitude* ADJ1 women) OR (satisfaction ADJ1 women) OR (feeling* ADJ1 women) OR (perspective* ADJ1 women) OR (perception* ADJ1

- women)).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 408 results.
13. PsycINFO; ((view* ADJ1 men) OR (opinion* ADJ1 men) OR (attitude* ADJ1 men) OR (satisfaction ADJ1 men) OR (feeling* ADJ1 men) OR (perspective* ADJ1 men) OR (perception* ADJ1 men)).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 187 results.
 14. PsycINFO; "user involv*".ti [Limit to: English Language and Publication Year 2000-2014]; 141 results.
 15. PsycINFO; "focus group*".ti [Limit to: English Language and Publication Year 2000-2014]; 896 results.
 16. PsycINFO; (("service user" ADJ1 evaluate*) OR ("service user" ADJ1 feedback)).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 8 results.
 17. PsycINFO; CLIENT PARTICIPATION/ OR CONSUMER ATTITUDES/ [Limit to: English Language and Publication Year 2000-2014]; 8321 results.
 18. PsycINFO; ((experience* ADJ1 women) OR (experience* ADJ1 men) OR (experience* ADJ1 individual*) OR (experience* ADJ1 people) OR (experience* ADJ1 patient*) OR (experience* ADJ1 inpatient*) OR (experience* ADJ1 service user*)).ti,ab [Limit to: English Language and Publication Year 2000-2014]; 8829 results.
 19. PsycINFO; 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 [Limit to: English Language and Publication Year 2000-2014]; 34867 results.
 20. PsycINFO; 4 AND 19 [Limit to: English Language and Publication Year 2000-2014]; 245 results.

Appendix 3: Quality framework adapted from Walsh and Downe (2006)

| Stages | Essential Criteria | Specific prompts |
|--------------------------|---|---|
| Scope and Purpose | <p>Clear statement of, and rationale for, research question/aims/purposes</p> <p>Study thoroughly contextualized by existing literature</p> | <ul style="list-style-type: none"> • Clarity of focus demonstrated • Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing • Link between <i>policy</i>, research and existing knowledge demonstrated • Evidence of systematic approach to literature review, location of literature to contextualize the findings, or both |
| Design | <p>Method/design apparent, and consistent with research intent</p> <p>Data collection strategy apparent and appropriate</p> | <ul style="list-style-type: none"> • Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting appropriate • Were data collection methods appropriate for type of data required and for specific qualitative method? • <i>If focus groups, were appropriate group sizes and duration used?</i> • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? • Was triangulation of data sources used if appropriate? • <i>Was acquiescence considered</i> |

| | | |
|-------------------|--|---|
| | | <p><i>and were attempts made to address it?</i></p> <ul style="list-style-type: none"> • <i>Was information made accessible and were approaches tailored to facilitate people to speak?</i> • <i>Was time allowed to build familiarity and rapport?</i> • <i>Did people with a learning disability help guide the agenda/and type of questions asked?</i> |
| Sampling strategy | Sample and sampling method appropriate | <ul style="list-style-type: none"> • Selection criteria detailed, and description of how sampling was undertaken • <i>Information provided on level of learning disability</i> • Justification for sampling strategy given • <i>Those with more severe learning disabilities included?</i> • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained |
| Analysis | Analytic approach appropriate | <ul style="list-style-type: none"> • Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) • Was it appropriate for the qualitative method chosen? • Was data managed by software package or by hand and why? • Discussion of how coding systems/conceptual frameworks evolved • How was context of data retained during analysis • Evidence that the subjective meanings of participants were portrayed • Evidence of more than one researcher involved in stages |

| | | |
|-----------------------|---|--|
| | | <p>if appropriate to epistemological/theoretical stance</p> <ul style="list-style-type: none"> • Did research participants have any involvement in analysis (e.g. member checking) • Evidence provided that data reached saturation or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion/rationale if it was not |
| Interpretation | <p>Context described and taken account of in interpretation</p> <p>Clear audit trail given</p> <p>Data used to support interpretation</p> | <ul style="list-style-type: none"> • Description of social/physical and interpersonal contexts of data collection • Evidence that researcher spent time ‘dwelling with the data’, interrogating it for competing/alternative explanations of phenomena • <i>Was acquiescence considered when making interpretations?</i> • Sufficient discussion of research processes such that others can follow ‘decision trail’ • Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation led to conclusions |
| Reflexivity | <p>Researcher reflexivity demonstrated</p> | <ul style="list-style-type: none"> • Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher’s influence on stages of research process • Evidence of self awareness/insight |

| | | |
|--------------------------------------|--|---|
| | | <ul style="list-style-type: none"> • Documentation of effects of the research on researcher • Evidence of how problems/complications met were dealt with |
| Ethical Dimensions | Demonstration of sensitivity to ethical concerns | <ul style="list-style-type: none"> • Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • <i>Were issues related to informed consent considered and addressed?</i> • Evidence of fair dealing with all research participants • Recording of dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed • <i>Was feedback given to service users?</i> |
| Relevance and transferability | Relevance and transferability evident | <ul style="list-style-type: none"> • Sufficient evidence for typicality specificity to be assessed • Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies • Discussion of how explanatory propositions/emergent theory may fit other contexts • Limitations/weaknesses of study clearly outlined • Clearly resonates with other knowledge and experience • Results/conclusions obviously supported by evidence • Interpretation plausible and makes sense |

| | | |
|--|--|---|
| | | <ul style="list-style-type: none"> • Provides new insights and increases understanding • Significance for current policy and practice outlined • Assessment of value/empowerment for participants • Outlines further directions for investigation • Comment on whether aims/purposes of research were achieved • <i>Comment on actions and outcomes of the study discussed?</i> |
|--|--|---|

Appendix 4: Ethical approval, information and consent forms

PARTICIPANT INFORMATION SHEET

Title of Project: How do Clinical Psychologists experience working with staff in residential care homes for people with learning disabilities?

Researchers: Natalie Smith (Trainee Clinical Psychologist), Dr Biza Stenfert Kroese (Senior Lecturer, Consultant Clinical Psychologist), Dr Gail Thomas (Consultant Clinical Psychologist).

Hello, my name is Natalie Smith. This project is being undertaken as part of my Clinical Psychology Doctorate at the University of Birmingham. It aims to explore the experiences of Clinical Psychologists when working with staff in residential care homes for people with learning disabilities.

- **What is the purpose of this research?**

The purpose of the study is to gather information on the experiences psychologists have of working with staff in residential care homes for people with learning disabilities. It is hoped the research will help to gain a better understanding of how psychologists make sense of their experiences of working with staff. It may also provide the first step to developing a model psychologists can use when working in residential care homes.

- **Why have I been invited to take part?**

You have been chosen to take part because you are a qualified Clinical Psychologist working for a learning disability service and you have had experience of working with staff in residential care homes for people with learning disabilities.

- **What will happen to me if I agree to take part?**

I will ask you to take part in an interview with me, lasting up to one hour. This will take place at your place of work or another mutually convenient location and will be recorded using a Dictaphone. The recording will be listened to and transcribed. I will be the only person to listen to the interview. My research supervisor, Dr Biza Stenfert Kroese, will have access to the transcripts which will be made anonymous. That is, your name and any potentially identifying details will be removed from the transcripts and the tape recordings will be deleted immediately after the interview has been transcribed. You will be sent a copy of your transcript to check before it is included in the analysis and you can request that sections are removed if you don't want them to be included. Transcripts will be kept securely for 10 years.

- **What will happen if I do not want to carry on with the study?**

You are free to withdraw from the study up to two weeks after the interview. This can be done by contacting me. There are no consequences for withdrawing. Please make a note of your participant number in case you decide to withdraw. In the event of your withdrawal all data relating to you will be destroyed.

- **Will my taking part be kept confidential?**

All information will be anonymised and stored safely in a locked filing cabinet or in electronic password protected files. Only my research supervisor and I will have access to the information.

Specific words or phrases you use in the interview may be quoted in the research report. This may inadvertently identify you to others. Complete anonymity can therefore not be ensured. However, the transcript of your interview will be shown to you before the analysis is carried out and the report is written so you can identify any quotes you do not want to be included.

- **Benefits and disadvantages of taking part**

The interview may cause you to think about an aspect of your work that you find frustrating or stressful. You are free to take a break at any time, move on to the next question or stop the interview completely. If references to unsafe practice are disclosed during the interview you will be asked whether it has been disclosed elsewhere and whether the procedures outlined in your trust policies have been followed. If the unsafe practice has not been disclosed, I will discuss the issue with my research supervisor and trust policies on reporting unsafe practice will be followed.

You will not receive any payments for taking part in this research. You may find it beneficial for yourself and for service users to contribute to a potentially useful research project that may have some impact on future clinical practice.

- **What will happen to the results of the research study?**

Your responses to the interview questions will be analysed by me and included in the write up of the research project. The research will be presented to members of the School of Psychology at Birmingham University and to local NHS Trusts. It is also possible that the research project will be published in an academic journal. Your identity would remain confidential in all of these circumstances. A summary of the research findings will be made available to you.

- **What happens if I have any further concerns?**

If you are concerned about any issues related to the interview or your experiences of working with staff it is advised you discuss this with your clinical supervisor. You may also contact Dr Biza Stenfert Kroese if you would like to address any emotional distress that arises as a result of taking part in the interview.

If you have any concerns or complaints you can discuss these with me in the first instance. If I cannot answer your queries or you still have concerns you may wish to contact the research supervisor Dr Biza Stenfert Kroese. Contact details are provided on the next page.

Contact Details

Name: Natalie Smith (Trainee Psychologist)

Name: Dr Biza Stenfert Kroese (Research Supervisor, Consultant Clinical Psychologist)

17/03/2013

CONSENT FORM

Project: How do Clinical Psychologists experience working with staff in residential care homes for people with learning disabilities?

Participant Identification Number:

Researcher: Natalie Smith

Please initial box

1. I confirm that I have understood the information sheet dated 03/09/2012 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason or there being any consequences. ☐
3. I understand that the research interview will be audio-recorded ☐
4. I understand that I will be able to withdraw from the research up until two weeks after the interview and that my interview data will be destroyed after withdrawal. ☐
5. I understand that the data collected during this study will be looked at by the researcher and research supervisors at the University of Birmingham. ☐
6. I understand that direct quotes from my interview may be published in any write-up of the data, but that my name will not be quoted. I will have the opportunity to look at the interview and identify any quotes I do not want to be included in a write up. ☐
7. I understand that if I disclose unsafe practice for the first time during the interview confidentiality will be breached and my trust's policies will be followed ☐
8. I agree to take part in the Research project ☐

Name of participant

Date

Signature

.....

.....

.....

Name of researcher

Date

Signature

.....

.....

.....

Appendix 5 - Interview schedule

Can you tell me about the kind of work you do with staff in residential care settings?

What approaches have you used when working with staff? How did it go?

How do you know when your work has gone well/not so well?

What are the rewards and challenges of the work?

What are your expectations of working with staff?

What do you think staff think about your work?

How do staff relate to you?

What would improve your experience of working with staff?

Appendix 6: Example of coding

The annotated text below illustrates the initial stages of analysis. On the left hand side of the transcript notes were made on what is interesting, significant and important to the participant (free/open coding). The notes include paraphrasing, summarizing, initial interpretations, comments on language and any contradictions. The right hand side notes were made following close line by line analysis of the transcript. They are more concise phrases/emerging themes that capture what the participant and how they make sense of their experiences. After the first transcript was annotated emerging themes were listed together and were arranged into clusters under a superordinate theme.

These stages were then completed for each transcript. The researcher made note of any new emerging themes and any quotations that could further illustrate or develop themes previously identified. When new emergent themes were identified earlier transcripts were reviewed to identify any data that reflected the new theme.

Once all transcripts were analysed a final table of superordinate themes and subthemes was constructed by reducing, reorganizing, redefining and prioritizing themes. This process continued when writing up the results.

*Gone well
when service
user is the
focus*

*Working
together*

*Trained staff
Addressing
staff needs*

*Using
accessible
and
meaningful
information.
Breaking
down the
difficulty, no
jargon*

*Not working
alone*

*Presence in
the homes –
2 or 3 times
a week.*

*Access to
information
about what
is happening
in the home
is important.
Staff clear
on what is
happening*

Umm, times it has gone well, I think have been times when you've had a really **motivated staff team**, so you've got a staff team that have got really **good values** and see their job as improving the quality of life of the people that they're working with. If you can get the whole staff team on board, so if you get a manager signed up to change as well as kind of the newest person through the door, that's always been really helpful, getting staff teams together and having a few sessions, going through basics of what's challenging behaviour, what's autism, what's a learning disability, what's a communication difficulty, what does that look like if you're a staff member rather than us. Then sometimes if we just go in and use jargon and that doesn't work well at all, going in and saying if you woke up with a really bad cold and a really bad headache and you couldn't say I've got a really bad headache and I don't know here the Paracetamol is you might be a little bit cross and throw something and that kind of, that's been really helpful. Umm working **collaboratively** with other colleagues is really good as well, so I've got one case where I work really collaboratively with a nurse

Hmm

And she's able to go in kind of two or three times a week and feedback to me things that so that we've got a really quick communication pathway.

Ok

And she takes the lead on kind of the physical health things which are really important for this client and affect her behaviour and we have a very clear understanding with the staff team that if they say things to me if gets passed to the nurse

***Motivation,
culture/values of
staff team.***

***Influence of
manager
Opportunity to
have meetings and
communicate
/access to staff***

Resources

Empathy

Transparency

***Team work –
colleagues,
support and
collaboration from
other
professionals***

***Transparency –
open about who
communicate with.
Helps build trust?***

addresses difficulties staff are facing straight away. Know work is going well as staff value the psych – they contact psych for support. Not wanting to disappoint staff, wanting to be a good psychologist

Understanding of the difficulties staff face. Giving them skills

Giving staff information and a voice as a way of engaging Importance of having support from manager – barrier if not on board? making sure everyone knows who the psychologist is. Understand staff experiences directly from them

If they say things to the nurse, it gets passed to me so you don't get different information going in different areas.

Um, and we've always been really responsive as well, so if they ring on a Thursday afternoon, with a 'oh my god, this is really difficult', somebody will be out or somebody will be on the phone kind of within 24 hours so they see us as helpful and responsive and collaborative and engaged rather than 'we can't get hold of you because we said there was a problem and then three weeks later somebody's phoned us'. And that's been really helpful I think and we've also been really proactive in working with the family carers who are involved and also other health professionals, GPs and hospital staff and making sure that, because I think staff sometimes make it really hard to be heard by GPs and by acute hospitals and one of the roles we've taken is being really supportive of and helping staff take people and helping to navigate the hospital system, working with the psychiatrist and so that's been really useful and I think that's been a good template now about how we're trying to engage the staff teams... So whole staff groups, making sure that the **managers are on board** because if you tell staff to change things and the manager isn't on board, it goes a bit horribly wrong and making sure that we've got carers on board, making sure that we go and do observations they know who we are, they've got our phone numbers, they've got our mobile phone numbers, so they can get us if we're kind of busy and out, that's been really good and what's not worked so well? Um referrals, where only the manager of the service ever meets with you.

Support from other professionals

Being available

*Feedback and feeling valued
-> Motivation*

Being a good psychologist

Empathy

Empower

Advocate for staff

Pride

Influence of manager

Restriction

Developing a relationship with staff

Being available and interested

| | | |
|--|--|---|
| | Ok | <i>access to the staff</i> |
| <i>Stuckness if manager not on board.</i> | Generally doesn't work very well. Um...because the people who are actually doing the work aren't the people you're talking to and you might go and see a manager and say this might help or I think this needs to change and have you looked at it this way and then they're not feeding that back down to the staff and then the staff are then still in a really difficult position and then they think a psychologist is coming and nothing is changing. | <i>Expert vs collaborator</i> |
| <i>Giving advice or feedback via manager does not work – less collaborative.</i> | Umm So that doesn't work very well and sometimes you have to be, sometimes you have to be quite clear to the managers... 'really good that you're really engaged, but actually I need to talk to the people that do the work, who are doing the (laughter) 12 hour shifts'. | <i>Communication barriers- Hierarchical nature, motivation and power of management.</i> |
| <i>When work doesn't go well staff perceptions of you can be effected</i> | Hmm 'cos you're not doing personal care at 7 o'clock in the morning which is when the behaviour is occurring | <i>Psychologist blamed?</i> |
| | Hmm and you're doing something else in the office, so that's generally not worked well, it's not worked well, not being explicit with staff teams about their role and I think if you're not clear that there's a responsibility on both sides, that doesn't work well. | <i>Being transparent and honest with managers. Need to inform manager about the role taking as a psychologist.</i> |
| <i>Making information accessible and useful for staff.</i> | Hmm Um, we found difficulties...where actually where we...checking out staff who are good English speakers and might not have English as a first language... checking out that they can read your forms | <i>Empathy</i> <i>Positive feedback</i> |
| <i>Feedback and collaborate with staff. Recognise skills. Positive</i> | | <i>Defining/making sense of role of psychologist</i> <i>Responsibility – shared expectations, have to make it explicit</i> <i>Inclusive</i> |

*Making
sure all
staff can
be
involved*

*Not
wanting to
blame staff
—
understan
d why not
engaged.*

*adapt
approach-
es to staff
team.
Thinking
of staff
needs &
skills*

Yeah

And fill them in, 'cos some people have got brilliant spoken English

Hmm

But forms are really hard. If you don't check it out, you will get a really good staff member who has been disengaged from the process because they can't fill in any of the information that you've asked for, um, so that's been a **learning curve**. Where we have kind of gone 'ok, so can you read and write English as well as you speak English?' 'no, not really'. Ok, so what can we do so that you can help fill in these forms in as well. Is it that actually we need you to meet with you separately and get more information or do we need to get them translated um, that was a learning curve where I worked in an area where there was a lot of non-English speaking staff which is, yes, I learnt very quickly, that's been an issue and um actually yeah night staff, not engaging with night staff, not a good idea, 'cos night staff are often there with early risers and people who aren't going to bed late and people who might be really anxious...

Flexible

Advocate for staff.

***Learning from
experience***

***Importance of involving
everyone. Value and
respect for all staff.***

Initial list of themes from participant 7 organised into clusters with emerging superordinate themes

| |
|---|
| Support and sharing experiences |
| Working as a team – ‘we’ |
| Support from other professionals |
| Value of Reflection |
| Support to manage barriers and expectations |
| Value of supervision |
| Conflict and role of a psychologist |
| Expert vs collaborator |
| Blame and depersonalisation |
| Empowerment |
| Pressure to be a ‘rescuer’ |
| Advocate for staff |
| Developing a style and identity as a psychologist |
| Formal vs informal |
| Flexibility and creativity |
| Diplomacy and patience |
| Problem solving skills |
| Understanding the roles of a psychologist/Implicit skills of psychologist |
| Theory driven and goal focused |
| Experience and learning |
| Being a good psychologist |
| Using CBT on self |
| Resilience |
| Acceptance |
| Developing a therapeutic relationship |
| Being available and interested |
| Empathy, compassion and understanding for staff |
| Respect and value for staff |
| Inclusive |
| Shared expectations/alliance |
| Transparency |
| Honesty |

| |
|---|
| Safety |
| Need to address staff anxiety |
| Having to prove self |
| Motivation |
| Justice |
| Unpredictability/stuckness seen as a challenge |
| Satisfaction |
| Praise and feedback |
| Justice/advocate for staff and service user |
| Potential for change |
| Restrictions/Facilitators |
| Culture and resources |
| Conflict in values between staff and psychologist |
| Relationship with manager/ Influence of manager |
| Readiness for change |
| Healthcare model vs business model |
| Hierarchical structure |
| Access to staff |
| Lack of training |
| Motivation of staff |
| Emotions evoked |
| Anger |
| Hopelessness/hopeful |
| Anxiety |
| Pride/enthusiasm |
| Safety |
| Being well supported |
| Something hidden |
| Responsibility |
| Impact of policies |