VOLUME I: RESEARCH COMPONENT

THE SEXUAL AND MARITAL RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

by

Najma Sultana

A THESIS SUBMITTED TO THE UNIVERSITY OF BIRMINGHAM FOR THE DEGREE OF DOCTOR OF CLINICAL PSYCHOLOGY

Department of Clinical Psychology
School of Psychology
The University of Birmingham
June 2016

THESIS OVERVIEW

This thesis is submitted in partial fulfilment for the degree of Doctor in Clinical Psychology at the University of Birmingham. It comprises of two volumes.

Volume I consists of a research component and Volume II consists of a clinical component.

Volume I explores the sexual and marital relationships of people with a learning disability across three chapters: a meta-ethnography, an empirical paper and a public dissemination report.

The meta-ethnography explores how people with a learning disability experience and give meaning to intimate and sexual relationships. Using the method suggested by Noblit and Hare (1988), the meta-ethnography synthesises twenty-one qualitative studies that were identified through a systematic search across three databases.

The empirical paper takes the form of a multiple perspective qualitative design using interpretative phenomenological analysis. It explores how five healthcare professionals and four mothers experience the process of deciding whether or not marriage is a suitable option for a person with a learning disability in the South-Asian community. It considers the experience of these decisions in the context of the current discourse around forced marriage in people with a learning disability. The public dissemination document provides a brief and accessible summary of the first two chapters. It is aimed at audiences that may have a possible stake and interest in the research findings.

Volume II consists of five clinical practice reports (CPRs) undertaken over the course of the doctoral training programme. CPR1 presents a cognitive behavioural and psychodynamic case formulation of an 18-year old female diagnosed with obsessive compulsive disorder and an ‘atypical eating disorder’. CPR 2 presents a service evaluation that explores the utility of a local four step model whereby clinical psychologists provide supervision to trainee psychiatrists delivering psychological therapy. CPR 3 presents a case study of a female with a learning disability who experienced childhood sexual abuse and re-victimisation as an adult. Cognitive models were drawn upon during formulation and intervention work. CPR 4 presents a single case experimental design that took place on an older adult inpatient unit. The aim of the intervention was to reduce incidents of verbal aggression in a 68 year old female through a staff based intervention. CPR 5 was an oral presentation of a case study. This case study discusses the use of a narrative approach when treating faecal soiling in a 6 year old boy. The presentation is summarised by an abstract. All potentially identifying markers in the reports, such as names or locations have been altered or omitted to maintain confidentiality.

DEDICATION

I would like to dedicate this thesis to my mother, Raqia, and my brother, Saqib, for their infinite amount of support over the years.

Mum, you have been my inspiration. I want you to know that your decisions and sacrifices weren’t made in vain as they brought me here. Sak, it’s because of you that I set my sights beyond the path laid out in front of me. Thank you for always believing in me.

This achievement is as much mine as it is yours.

ACKNOWLEDGEMENTS

I would like to acknowledge a number of individuals who played a part in making this thesis possible. Firstly, I would like to thank Biza Stenfert Kroese for her reassuring words and encouraging nudges. Your academic prowess was apparent at every stage of this process. I would also like to thank Dr Michael Larkin for his support during the analytic stages and for elevating my own interpretative abilities. Thank you to Laura Ogi for making this project possible when it seemed unlikely. Finally, without the participants, none of this would have possible; I hope I have done your words justice.

I am fortunate to have also had personal relationships that have supported me throughout. Kevin, I would like to thank you for being a stabilising force over the years. To my friends outside of training, thank you for keeping me grounded and for keeping me connected to a life outside of Psychology. To my cohort, it has been an absolute pleasure to have trained with you all. Thank you to my family for all of the food parcels! Finally, a special thank you to Jeff for making this journey feel possible. I look forward to starting life after training with you.

CONTENTS

VOLUME I: RESEARCH COMPONENT

A META-ETHNOGRAPHY: THE MEANING AND EXPERIENCE OF SEXUAL AND INTIMATE RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

DECIDING ON THE SUITABILITY OF MARRIAGE FOR A PERSON WITH A LEARNING DISABILITY WITHIN A SOUTH-ASIAN COMMUNITY: STAFF AND MOTHER EXPERIENCES

PUBLIC DISSEMINATION DOCUMENT

THE SEXUAL AND MARITAL RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

PART 1: A META-ETHNOGRAPHY: THE MEANING AND EXPERIENCE OF SEXUAL AND INTIMATE RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

PART 2: DECIDING ON THE SUITABILITY OF MARRIAGE FOR A PERSON WITH A LEARNING DISABILITY WITHIN A SOUTH-ASIAN COMMUNITY: STAFF AND MOTHER EXPERIENCES

VOLUME II: CLINICAL COMPONENT

CLINICAL PRACTICE REPORT 1: A COGNITIVE-BEHAVIOURAL AND PSYCHODYNAMIC CASE FORMULATION OF AN 18 YEAR OLD FEMALE DIAGANOSED WITH OBSESSIVE COMULSIVE DISORDER AND AN A-TYPICAL EATING DISORDER

CLINICAL PRACTICE REPORT 2: SERVICE EVALUATION. EVALUATING THE UTILITY OF A FOUR STEP MODEL WHEN SUPERVISING TRAINEE PSYCHIATRISTS TO UNDERTAKE PSYCHOLOGAL THERAPY

CLINICAL PRACTICE REPORT 3: A CASE STUDY OF A 43 YEAR OLD FEMALE WITH A LEARNING DISABILITY WITH EXPERIENCES OF CHILDHOOD SEXUAL ABUSE AND RE-VICITMISATION

CLINICAL PRACTICE REPORT 4: SINGLE CASE EXPERIMENTAL DESIGN OF A 68 YEAR OLD WOMAN, IN AN OLDER ADULT INPATIENT UNIT, DISPLAYING FREQUENT INCIDENTS OF VERBAL AGGRESSION

CLINICAL PRACTICE REPORT 5: A CASE STUDY PRESENTATION OF TREATING FECAL SOILING IN A 6 YEAR OLD BOY USING A NARRATIVE APPROACH

APPENDICES

LIST OF ILLUSTRATIONS

A META-ETHNOGRAPHY: THE MEANING AND EXPERIENCE OF SEXUAL AND INTIMATE RELATIONSHIPS IN PEOPLE WITH A LEARNING DISABILITY

DECIDING ON THE SUITABILITY OF MARRIAGE FOR A PERSON WITH A LEARNING DISABILITY WITHIN A SOUTH-ASIAN COMMUNITY: STAFF AND MOTHER EXPERIENCES

NO ILLUSTRATIONS

LIST OF TABLES

A META-ETHNOGRAPHY: THE MEANING AND EXPERIENCE OF SEXUAL AND INTIMATE RELATIONSHIPS IN PEOPLE WITH A LEARNING DISABILITY

DECIDING ON THE SUITABILITY OF MARRIAGE FOR A PERSON WITH A LEARNING DISABILITY WITHIN A SOUTH-ASIAN COMMUNITY: STAFF AND MOTHER EXPERIENCES

LIST OF APPENDICES

A META-ETHNOGRAPHY: THE MEANING AND EXPERIENCE OF SEXUAL AND INTIMATE RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

DECIDING ON THE SUITABILITY OF MARRIAGE FOR A PERSON WITH A LEARNING DISABILITY WITHIN A SOUTH-ASIAN COMMUNITY: STAFF AND MOTHER EXPERIENCES

A META-ETHNOGRAPHY: THE MEANING AND EXPERIENCE OF SEXUAL AND INTIMATE RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

By

Najma Sultana

Department of Clinical Psychology

School of Psychology

The University of Birmingham

June 2016

Abstract

Introduction: This review took the form of a meta-ethnography and aimed to understand how people with a learning disability (PWLD) experience and give meaning to intimate and sexual relationships, particularly in relation to achieving sexual autonomy.

Method: A systematic search of three databases using a number of key constructs and free text terms identified twenty-one studies for inclusion. The method of Noblit and Hare (1988) was used in order to synthesise the findings across studies. A quality review of these studies was undertaken in order to ensure that the findings of poor quality studies did not dominate the final synthesis.

Findings: Synthesis of findings across papers produced four key themes. The first theme suggests that PWLD are *'socialised to aversive and limiting scripts about sex'* in a way that limits their sexual expression. The second major theme reflects participants' '*desire to have a relationship because they are seen to provide access to a normal identity and to valued aspects of human experience,'* such as love and companionship**.** The third major theme reflects participants' experiences of having '*restrictions and conditions placed upon their sexual expression'***.** The final major theme reflects a tension between participants' desire to have a relationship and the restrictions placed upon their sexual expression. This tension seems to place some participants in a state of *'suspended adolescence'*.

Conclusion: By limiting the sexual expression of PWLD, we may paradoxically place them at more risk of harm, as PWLD were shown to engage in risky behaviours in an attempt to meet their sexual needs. Restricting opportunities for sexual exploration may also hinder the development of safe sexual decision making capacities of PWLD.

Introduction

Sexual and interpersonal relationships are an integral part of adulthood. Valuing People (2001) describes sex and sexuality as a basic human right. The Human Rights Act (1998) also states that people with a learning disability (PWLD) should have the right to marry and to have a private family life. Yet, individuals with a learning disability are said to have difficulty in achieving autonomy in sexual and intimate relationships (Brown, 1994; Noblit & Hare, 1988; Servais, 2006). This difficulty persists despite political and ideological shifts over the last century.

Historical and political landscape

Historically, attitudes towards the sexuality of PWLD have varied between seeing them as ‘eternal children’ and therefore ‘asexual’ (McCarthy, 1999; Taylor, 2012) to viewing them as ‘oversexed’ (Brown, 1994). In the late part of the 19th century and the earlier part of the 20th century views about the sexuality of PWLD were so negative that institutionalisation, segregation and sterilisation were imposed to stop PWLD from reproducing (McCarthy, 1999). This is said to be part of the eugenics movement which was designed to eliminate the ‘social burden’ of these individuals on society (Kliewer & Drake, 1998; Oliver, Anthony, Leimkuhl, & Skillman, 2002; Servais, 2006). Myths that surrounded PWLD at the time stated that they were promiscuous and ‘oversexed’ and that society needed protecting from their ‘defective genes’ and sexual appetite (Cuskelly & Gilmore, 2007; Servais, 2006). Therefore their sexual needs were suppressed, overlooked and ignored.

The introduction of the ‘normalisation principle’ (Nirje, 1969) and similar politically motivated publications (Bengt Nirje, 1985; Wolfensberger, 1983; Wolfensberger & Tullman, 1982) created a political and societal shift in the way PWLD were conceptualised. They began to be recognised as human beings with equal rights, including sexual rights, and attempts were made to integrate them into society.

Despite these political and ideological shifts, it is argued that these new values do not necessarily reflect a real change in the lived experience of PWLD in relation to their sexual autonomy. Simply placing individuals into communities does not necessarily facilitate community integration (Oliver et al., 2002) and Johnson, Frawley, Hillier and Harrison (2002) maintain that there is a lack of direction in policy in relation to implementing these ideas into practice.

Current knowledge about lived experience

An individual's interpersonal relationships are thought to be a protective factor against psychological distress (Heiman, 2001) and an indicator of quality of life (Cummins & Lau, 2003; Noblit & Hare, 1988). Social relationships and marriage provide a sense of security and acceptance for PWLD and a means of escaping their 'disability infused identity' (May, 2001).

However, despite what we know about the benefits of close personal relationships, PWLD are reported to have restricted social and personal networks and as a result are more likely to be socially isolated (Pockney, 2006; Sinson, 1994). A number of explanations for this disparity have been suggested. These include restricted opportunities to meet individuals due to few PWLD going out to work (Ohtake & Chadsey, 1999) and limited access to transport (Brackenridge & McKenzie, 2005). Others have suggested deficits in social skills and communication difficulties as the reasons for these limited social and personal networks (Wiener & Schneider, 2002).

The literature also suggests that the prohibitive attitudes of others may influence the opportunity for PWLD to develop sexual relationships (Hosseinkhanzadeh, Taher, & Esapoor, 2012; Yau, Ng, Lau, Chan, & Chan, 2009). Servais (2006) states that sexuality is an integral part of living an adult life, yet opportunities to develop an adult identity are not afforded to PWLD as they face a number of restrictions and prohibitions in relation to their opportunities for sexual expression.

Yau et al. (2009) state that prohibitions may be born out of a belief in the need to 'protect' PWLD as they are viewed as vulnerable. This may be seen in societies' socialisation of PWLD into the negative consequences of sex (Craft, 2004) rather than encouraging PWLD to view sexual relationships as an enhancement of their emotional and physical lives (Abbott & Burns, 2007). There is strong evidence to that suggests PWLD are more vulnerable to sexual exploitation. Horner-Johnson and Drum (2006) reviewed literature regarding sexual abuse of adults with a learning disability and found prevalence rates of 25-50%, which is significantly larger than prevalence rates found in those without a learning disability. These figures may explain why prohibitive attitudes and restrictions are placed upon PWLD.

Lesseliers (1999) and Change (2010) state that within the discourse about sexual autonomy, the voice that often goes unheard is the voice of PWLD. A recent review of qualitative and quantitative studies by Unruh, Lindstrom and Scanlon (2015) found that there are a number of barriers facing PWLD in relation to developing sexual relationships. However the evidence gathered largely consists of the views of carers and family members. Furthermore the review solely focuses on understanding the barriers to sexual education for PWLD rather understanding their experience of engaging in sexual relationships.

The current review (phase 1)

The current review seeks to answer some of the questions left unanswered in the literature. In particular, little is known about the experience and meaning of sexual and intimate relationships from the perspective of PWLD. It is thought that by synthesising research using qualitative methods, a rich account of their lived experiences on this topic can gathered.

This review will therefore take the form of a meta-ethnogrpahy and will aim to answer the following two questions:

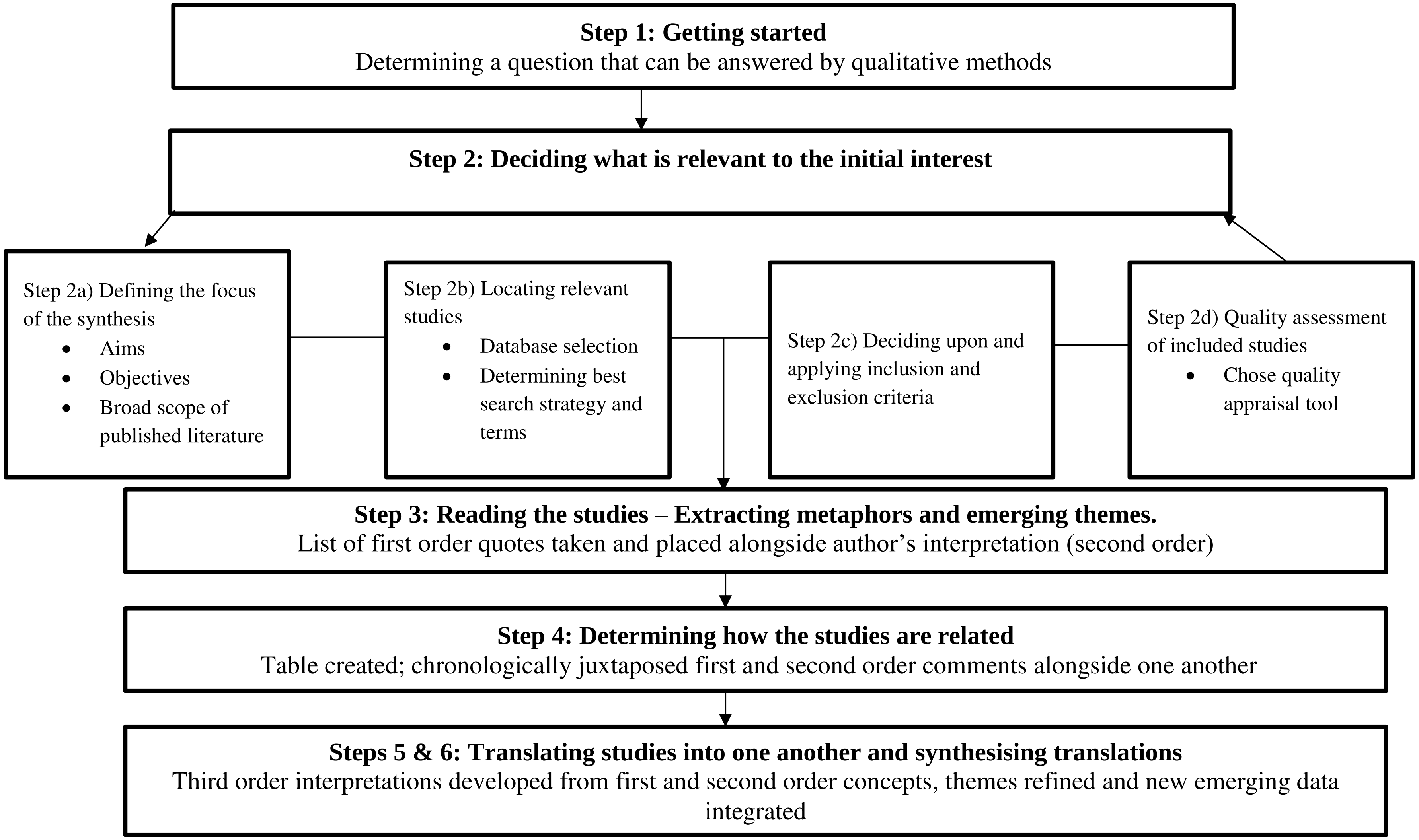
1) How are sexual and intimate relationships in PWLD experienced and given meaning?
2) What are the experiences of PWLD when trying to achieve an autonomous sexual identity?

Methodology

Atkins et al. (2008) provide a transparent method for conducting a meta-ethnography based upon the original principles outlined by Noblit and Hare (1988). The current synthesis therefore follows both approaches and thus aims to synthesise and add an additional layer of interpretation to the findings that moves beyond a narrative summation (full method of synthesis, outlined in Figure 1).

With the topic of interest set, phase one of the meta-ethnography was completed. Phase two of the approach includes the search strategy and quality appraisal.

Figure 1: Method undertaken during the process of the meta-ethnography (adapted from Atkins, et al., 2008)



Search strategy (phase 2a, b and c)

The search strategy consists of a combination of subject heading and free text searching across three databases. The three databases were selected for their ability to identity papers that may answer the question(s) of this meta-ethnography; they are PsychInfo, CINHAL and Web of Science.

Separate searches were ran on each database as each database had indexed the constructs of interest in different ways. The subject heading terms used across each database can be seen in Figure 2 and were finalised after initial scoping exercises to determine the best use of terms. Subject headings allow for umbrella terms and synonyms to be searched, particularly with the application of the ‘explode’ function. It has been argued that subject heading searches do not always yield the broadest and most accurate search results when searching for qualitative data (Shaw et al., 2004). It is thought that this is due to inconsistent indexing of articles using qualitative methodology in the databases. Therefore a combination of free text and subject heading searches was deemed the most suitable search strategy and this strategy was applied across all databases, see Figure 2 for details of free text terms. These free-text terms were selected on the basis of a review which found these terms to be the most effective in finding qualitative research across databases (Shaw et al., 2004). The Boolean operators of OR followed by AND were used to combine search constructs.

Figure 2: Variations in subject heading terms and free text terms across databases

	Learning Disability		**Relationships**		**Qualitative methodology**
Psychinfo	Exp Learning Disability OR Exp Intellectual Disability OR Exp Pervasive Developmental Disorders	**AND**	Exp Interpersonal relationships OR Exp Sexuality OR Exp Psychosexual behaviour OR Exp Intimacy	**AND**	Exp Qualitative Research Exp Phenomenology Exp Ethnography
CINHAL	Exp Learning Disorders OR Exp Intellectual Disability OR Exp Pervasive Developmental Disorders		Exp Interpersonal relations OR ExpIntimacy OR Exp Sexuality		Exp Qualitative Studies
Web of Science	Intellectual disability OR Learning disability OR Pervasive developmental disorder		Interpersonal relationships OR Sexuality OR Intimacy		Qualitative Research
Free text terms	Learning Diff* OR Learning Disab* OR Intellectual Disab*		Intima* OR Relationship* OR Sexuality OR Marriage OR Marital relations* OR Interpersonal relationship*		Qualitative OR Interview OR Experience

Key

Exp = Explode function applied

The search was conducted in December 2015. Limits were applied to the search in each database, this included searching for journal articles published in the English language between the dates of January 2005 and December 2015, in a peer-reviewed journal. As previously mentioned, attitudes regarding the sexuality of PWLD have evolved over recent decades. Therefore, it was felt important to limit the search strategy to include articles published within the last decade so that the most recent experiences of PWLD could be captured in this meta-ethnography. Limiting the search strategy in this way also served to increase the relevance of any findings and recommendations made by this meta-ethnography, in relation to current clinical practice. Furthermore, a recent review found that the publication of qualitative research in the field of learning disabilities has doubled over the last decade (Beail & Williams, 2014), increasing the confidence that a sufficient number of qualitative articles would be found within the selected time period.

Further inclusion and exclusion criteria were applied after the search results were generated see Table 1 for details.

Table 1: Inclusion and exclusion criteria

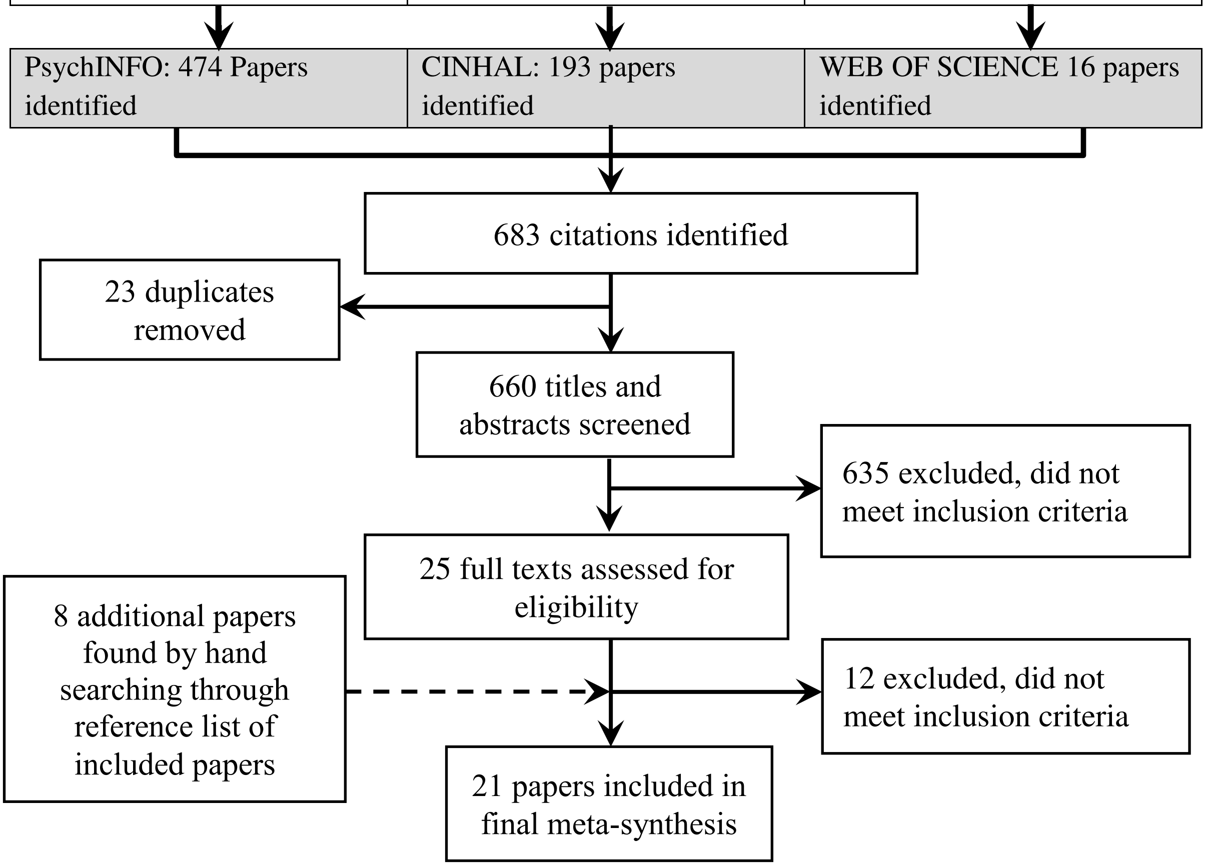
Inclusion criteria	Exclusion criteria
Publication dates between 2005 and 2015	Views of parents, carers or authors' observations without the views of PWLD
Published in peer-reviewed journal article in English	Papers that include views of individuals with a learning disability under the age of 16, where these views cannot be separated.
Individuals aged 16 and over with a learning disability. As individuals under this age cannot consent to a sexual relationship under UK law.	Papers that do not investigate the views and experience of PWLD in sexual relationships
Papers where qualitative results can be discerned and extrapolated	Papers that use quantitative methods only
Papers where the views and experiences of PWLD in relation to sexual relationships can be extrapolated from the views of others	

Search results

The search strategy across databases yielded 683 papers, including duplicates. After 23 duplicates were removed, a total of 660 papers were screened by title and abstract using the inclusion and exclusion criteria in Table 1 to determine papers of relevance. From these 660 papers a total of 635 papers were excluded as they did not investigate an area of relevance, used quantitative methodology only or did not include the views of PWLD. This left 25 papers, which were read in full to determine eligibility for inclusion. Out of these 25 papers, 12 papers were excluded, leaving 13 papers. An additional 8 papers were found by screening the reference lists of the 13 papers included. A total of 21 papers were therefore included in this meta-ethnography (see Figure 3 for full details of search strategy).

Figure 3: The search strategy used to identify papers for inclusion

PsychINFO	CINHAL	WEB OF SCIENCE
Exp Learning Disability OR Exp Intellectual Disability OR Exp Pervasive Developmental Disorders OR Learning Diff* OR Learning Disab* OR Intellectual Disab* **AND** Exp Interpersonal relationships OR Exp Sexuality OR Exp Psychosexual behaviour OR Exp Intimacy OR Intima* OR Relationship* OR Sexuality OR Marriage OR Marital relations* OR Interpersonal relationship* **AND** Qualitative Research Phenomenology Ethnography OR Qualitative OR Interview OR Experience	Exp Learning Disorders OR Exp Intellectual Disability OR Exp Pervasive Developmental Disorders OR Learning Diff* OR Learning Disab* OR Intellectual Disab* **AND** Exp Interpersonal relations OR Exp Intimacy OR Exp Sexuality OR Intima* OR Relationship* OR Sexuality OR Marriage OR Marital relations* OR Interpersonal relationship* **AND** Exp Qualitative Studies OR Qualitative OR Interview OR Experience	Intellectual disability OR Learning disability OR Pervasive developmental disorder OR Learning Diff* OR Learning Disab* OR Intellectual Disab* **AND** Interpersonal relationships OR Sexuality OR Intimacy OR Intima* OR Relationship* OR Sexuality OR Marriage OR Marital relations* OR Interpersonal relationship* **AND** Qualitative Research OR Qualitative OR Interview OR Experience



Descriptive summary of papers included in this review

In total, 21 studies met the inclusion criteria for this meta-ethnography (see Appendix 1 for a descriptive summary of each study). The papers included aimed to understand the development of sexual autonomy and/or the experience of intimate relationships for PWLD. The location and therefore the cultural context in which the studies took place varied. The majority of studies took place in the UK (including England, Scotland, Wales and N Ireland) and the Republic of Ireland. Other studies took place in various locations such as Canada (McClelland et al., 2012), the USA (Bernert & Ogletree, 2013); Hong Kong (Yau et al., 2009), Malta (Azzopardi-Lane & Callus, 2015), Taiwan (Chou, Lu, & Pu, 2015) and the Netherlands (Stoffelen, Kok, Hospers, & Curfs, 2013).

The age of participants within the included studies ranged from 16-89. The majority of the papers included both male and female participants. However, some papers only included male participants (Wheeler, 2007; Yacoub & Hall, 2009) and others only included female participants (Bernert & Ogletree, 2013; Bernert, 2011; Fitzgerald & Withers, 2013). The relationship status and the sexual orientation of participants varied across studies. Four of the papers had a specific focus on individuals who did not have a heterosexual orientation (Abbott & Burns, 2007; Löfgren-Mårtenson, 2009; McClelland et al., 2012; Stoffelen et al., 2013). Few participants lived alone or cohabited with a partner. The majority of participants included were single at the time of taking part in the research.

A mixture of qualitative methods were used across the studies, both in terms of analysis and data collection. Across studies, the most common type of data collection method was the use of semi-structured interviews. This method of data collection was used as the sole method in eleven studies. Six studies collected their data through focus groups and four studies used mixed methods. Of the four studies that used mixed methods, three studies used ethnographic observation alongside semi-structured interviews (Bernert & Ogletree, 2013; Bernert, 2011; Lofgren-Martenson, 2009) and one study used semi-structured interviews alongside focus groups (McClelland et al., 2012).

Methods of data analysis also varied across studies. Six studies used interpretative phenomenological analysis (IPA), five studies used thematic analysis and two studies used grounded theory. A further two studies used computer software packages to analyse their data (Stoffelen, Kok, Hospers, & Curfs, 2013; Yacoub & Hall, 2009). Four studies used participatory action research. However, three of these studies did not specify a method of data analysis (Bane et al., 2012; Hollomotz & The Speakup Committee, 2009; McClelland et al., 2012). Three studies used ethnographic methods for data collection, however only one of these studies made reference to a specific method of data analysis (Lofgren-Martenson, 2009).

Recurrent samples

The papers of Bernert and Ogletree (2013) and Bernert (2011) used the same sample but presented different aspects of the research data. This is also the case for Sullivan, Bowden, McKenzie and Quayle (2013) and Sullivan et al. (2015). As none of the data were used more than once, all papers were included in the final synthesis.

Quality analysis (phase 2d)

All research papers underwent an assessment of their quality. This was to determine whether any papers were to be excluded and to ensure that papers of ‘poor’ quality did not dominate or contaminate the final synthesis. Papers rated as having ‘poor’ quality only contributed to the final synthesis if their findings were also supported by papers of a higher quality. After a comparison of a number of quality reviews, the Critical Appraisal Skills

Programme (CASP) Qualitative Checklist was chosen as an appropriate assessment tool (Critical Appraisal Skills Programme, 2013) and can be found in Appendix 2. Adapted versions of the CASP Qualitative checklist have also been used in other meta-ethnographies (Atkins et al., 2008; Rushbrooke, Murray, & Townsend, 2014a). The CASP asks ten prompt questions which helps the assessor to be consistent and systematic when reviewing the articles across each of these ten sections. In the current meta-ethnography, a quantitative measurement was added to this checklist; similar to those used by Duggleby et al. (2010) and Rushbrooke et al. (2014b). In response to each question the following scores were applied: Yes (2), Partial (1) or No (0). The criteria for each score is listed in Table 2.

Table 2 CASP Quality checklist scoring based upon Duggleby et al., (2010) and Rushbrooke et al. (2014b)

Score awarded	Criteria for score
No **0**	If the article gave little or no information required to answer the question or make an assessment
Partial **1**	If there was a moderate amount of information, but more detail or explanation would have improved the article
Yes **2**	If the article fully addressed the information required to answer the question

A total quality score for each paper was then calculated by adding up the scores awarded in each section. A colour code was also applied to reflect the quality of the paper and can be seen in Table 3. Papers with a score of <10 were deemed to be of ‘poor’ quality (red), papers scoring between 11-15 were deemed to be of ‘acceptable’ quality (amber), and papers that scored between 16-20 were deemed to be of ‘good’ quality (green). Six papers were rated as having ‘poor’ quality, nine papers as having ‘acceptable’ quality and six papers as having ‘good’ quality. The results of the ‘poor’ quality papers will be treated with caution.

In addition, a summation of how the overall data set performs on each quality section can be seen in Table 3. In terms of the quality of the overall data set across each quality section, it is apparent that the recruitment strategy and rigour of data analysis across the papers is not of high quality. The data set performs particularly poorly on the concept of researcher ‘reflexivity’ as researchers do not adequately reflect upon their own personal influence on the research outcomes. These are important aspects in establishing the ‘trustworthiness’ and ‘credibility’ of the data set used in this synthesis (Kitto, Chesters, & Grbich, 2008) and therefore the confidence in the conclusions of this meta-ethnography cannot be strong.

Table 3: Quality assessment across all papers, presented in chronological order

	Clear aims	**Qualitative method appropriate**	**Research design**	**Recruitment strategy**	**Data collection**	**Researcher reflexivity**	**Consideration of ethical issues**	**Rigour of data analysis**	**Clear statement of findings**	**Value of the research**	**Quality Score per study**
1. Abbot & Burns, (2007)	2	2	1	1	1	0	2	1	1	2	**13/20**
2. Wheeler, (2007)	1	2	1	1	1	0	1	1	1	2	**11/20**
3. Yacoub & Hall, (2008)	2	2	2	1	1	0	1	1	1	1	**12/20**
4. Hollomotz & the speak up committee, (2009)	1	2	1	0	1	0	1	0	1	1	**8/20**
5. Kelly, Crowley & Hamilton, (2009)	2	2	1	0	1	0	1	1	1	2	**11/20**
6. Löfgren-Mårtenson, (2009)	2	2	1	0	1	0	0	0	0	1	**7/20**
7. Yau et al., (2009)	2	2	2	1	2	0	2	1	1	2	**15/20**
8. Healy, McGuire, Evans & Carley, (2009)	2	2	2	2	2	1	2	0	1	2	**16/20**
9. Bernert, (2011)	2	2	2	1	1	0	0	0	1	1	**10/20**
10. Fitzgerald & Withers, (2013)	2	2	1	1	2	1	2	1	2	2	**16/20**
11. Bane et al.,(2012)	2	2	1	0	1	0	2	1	1	2	**12/20**
12. McCelland et al., (2012)	1	2	1	0	1	0	0	1	1	2	**9/20**
13. Stoffelen et al., (2013)	2	2	0	1	1	0	1	0	1	1	**9/20**
14. Sullivan, Bowden, McKenzie & Quayle, (2013)	2	2	2	2	2	1	2	2	2	1	**18/20**

Table 3: Quality assessment across all papers, presented in chronological order

	Clear aims	Qualitative method appropriate	Research design	Recruitment strategy	Data collection	Researcher reflexivity	Consideration of ethical issues	Rigour of data analysis	Clear statement of findings	Value of the research	Quality Score per study
15. Lafferty, McCowen & Taggart, (2013)	2	2	2	2	2	0	2	1	2	2	**17/20**
16. Bernert & Ogletree, (2013)	1	2	2	2	1	0	1	1	1	2	**13/20**
17. Rushbrooke, Murray & Townsend, (2014)	2	2	2	1	1	0	2	2	2	2	**16/20**
18. Sullivan, Bowden, McKenzie & Quayle, (2015)	2	2	1	1	2	1	2	1	2	2	**16/20**
19. Wilkinson, Theodore & Raczka, (2015)	2	2	2	0	1	0	1	1	1	2	**12/20**
20. Azzopardi-Lane & Callus, (2014)	1	1	0	2	1	0	1	0	1	2	**9/20**
21. Yau, Lu & Pu, (2015)	1	2	2	0	1	0	1	1	1	2	**11/20**
Quality total by section	**36/42**	**41/42**	**29/42**	**19/42**	**27/42**	**4/42**	**27/42**	**17/42**	**25/42**	**36/42**	

Key

Score	**Description**	**Colour**
<10	Poor	🟥
11-15	Acceptable	🟧
16-20	Good	🟩

Process of synthesis (Phase 3, 4 and 5)

A process of data extraction and synthesis was carried out as suggested by Noblit and Hare (1988) and Atkins et al. (2008). At the initial stage of the synthesis the author read each paper to become familiar with the content. Following this, participant quotes (first order concepts) deemed to have relevance to the research question were extracted from each paper chronologically. The authors' (of the articles) interpretive comments within each paper (second order concepts) were also extracted and placed next to the extracted quote. Alongside this process, the author of this meta-ethnography made notes of emerging themes and metaphors in each study and placed them in a table alongside first and second order concepts (see Appendix 3 for an example). At the final stage, the author moved to a more interpretative (third order) synthesis of the findings, by collapsing and merging concepts drawn from first order and second order data.

Major themes were included if they were present in at least 25% of the papers, or if they were in distinct contrast to any of the prevalent themes.

Results

The synthesis revealed four major themes and five sub themes that encapsulated the experience of intimate relationships and the development of sexual autonomy in PWLD (see Table 4). The first major theme explores participants' **'socialisation to aversive and limiting sexual scripts'** which is reflected in the language participants used when talking about sex and intimate relationships. The second major theme reflects participants' desire to have a relationship because this was seen to **'provide access to a normal identity and to valued aspects of human experience'.** The third major theme reflects participants' experiences of having **'restrictions and conditions placed upon sexual expression'.** The final major theme reflects a tension between participants' desire to have a relationship and the restrictions placed upon their sexual expression. This tension seems to place some participants in a state of **'suspended adolescence'**.

For the purpose of assisting the reader to follow the structure of the meta-ethnography the following presentation style will be adopted:

- **Major themes** will be presented in bold text as a separate heading
- **Sub themes** will be presented in bold underlined text
- *First order (participants) and second order (authors) quotes* will be presented in italic font.

Table 4: A representation of major themes and sub themes alongside contributing studies and their quality rating

Major themes	Sub themes	Contributions	Quality
1) Sexual socialisation to aversive and limiting sexual scripts	Sex is ‘dangerous’ and ‘dirty’	1) Bernert & Ogletree (2013) 2) Fitzgerald & Withers (2013) 3) Rushbrooke, Murray, & Townsend (2014a) 4) Yau et al. (2009)	1) Acceptable 2) Good 3) Good 4) Acceptable
	Sex is ‘for making babies’	1) Azzopardi-Lane & Callus (2015) 2) Fitzgerald & Withers (2013) 3) Rushbrooke et al. (2014a) 4) Sullivan et al. (2013)	1) Poor 2) Good 3) Good 4) Good
	Traditional views about sex and sexuality	1) Bernert & Ogletree (2013) 2) Bane et al. (2012) 3) Fitzgerald & Withers (2013) 4) Healy, McGuire, Evans, & Carley (2009) 5) Kelly et al. (2009) 6) Löfgren-Mårtenson (2009)	1) Acceptable 2) Acceptable 3) Good 4) Good 5) Acceptable 6) Poor
2) Relationships providing access to a ‘normal’ identity and valued aspects of human experience	Relationships provide access to a ‘normal’ identity	1) Lafferty, McConkey, & Taggart (2013) 2) Sullivan et al. (2015) 3) Wilkinson, Theodore, & Raczka (2015) 4) Yau et al. (2009)	1) Good 2) Good 3) Acceptable 4) Acceptable
	Relationships provide access to valued human experiences	1) Abbott & Burns (2007) 2) Bane et al. (2012) 3) Healy et al. (2009) 4) Lafferty et al. (2013)	1) Acceptable 2) Acceptable 3) Good 4) Good
3) Restrictions and conditions placed upon sexual expression		1) Abbott & Burns (2007) 2) Chou, Lu, & Pu (2015)	1) Acceptable 2) Acceptable

	3) Fitzgerald & Withers (2013)	3) Good
	4) Healy et al. (2009)	4) Good
	5) Hollomotz & The Speakup Committee, (2009)	5) Poor
	6) Kelly et al. (2009)	6) Acceptable
	7) McClelland et al. (2012)	7) Poor
	8) Rushbrooke et al. (2014a)	8) Good
	9) Stoffelen, Kok, Hospers, & Curfs (2013)	9) Poor
	10) Wheeler (2007)	10) Acceptable
	11) Yacoub & Hall (2009)	11) Acceptable
4) Suspended adolescence	1) Abbott & Burns (2007)	1) Acceptable
	2) Bane et al. (2012)	2) Acceptable
	3) Bernert (2011)	3) Poor
	4) Fitzgerald & Withers (2013)	4) Good
	5) Hollomotz & The Speakup Committee (2009)	5) Poor
	6) Kelly et al. (2009)	6) Acceptable
	7) Sullivan et al. (2013)	7) Good
	8) Wheeler (2007)	8) Acceptable
	9) Wilkinson et al. (2015)	9) Acceptable
	10) Yau et al. (2009)	10) Good

Theme 1: Sexual socialisation to ‘aversive’ and ‘limiting’ sexual scripts

Sexual socialisation in this context refers to the process by which an individual acquires ideas, beliefs and values alongside shared cultural codes of conduct relating to sex and sexuality (Schneewind, 2001; Shtarkshall, Santelli, & Hirsch, 2007).

This theme makes a deduction about the sexual socialisation of PWLD from two sources. The first source consists of the original quotes of participants which are thought to reflect an element of the participants’ internal worlds (beliefs and values about sex and sexuality) as communicated through language. The second source is the authors’ comments across the studies which attempt to make sense of these communications and their possible origins. Putting the two sources together, it appears that the common sexual scripts expressed by the participants echo the implicit and explicit messages from external others (society, care givers and sex education programmes).

A number of scripts about sex emerged. Some scripts are described as ‘aversive’ as they communicate the idea that **‘sex is dangerous and dirty’**. Other scripts indicate that sexual expression is reduced to the functional matter of procreation. This is reflected in the sub theme **‘sex is for making babies’**. Finally a number of **‘traditional scripts about sex and sexuality’** were noted. These scripts communicate that sexual expression is only acceptable under certain conditions.

‘Sex is dangerous’ and ‘dirty’

Yau et al. (2009) observed that participants in their study often receive messages (from institutions and parents) about the dangerousness of sex, such as risk of pregnancy and contracting a sexually transmitted disease. In one study when asked if sex might be nice, a participant replied:

> *"No I [it] would make me horrible, make me go funny…make me go sick, I don't want to get disease no"* (female, Fitzgerald & Withers, 2013).

Rushbrooke, Murray and Townsend (2014a) found that 9 out of 14 of the females in their study ascribed to self-imposed abstinence in order to prevent aversive consequences of sex such as "*AIDS or pregnancy"*. Bernert and Ogletree (2013) similarly found that participants saw sex as something to be avoided; *"I'm scared of it, I might get hurt"* (female). Another participant stated:

> *"Worries uh…you know, what's gonna happen to my body after sex and uh, does he have any kind of problems like diseases or anything"* (female, Bernert & Ogletree, 2013).

Alongside notions of sex being dangerous, Fitzgerald and Withers (2011) comment on how participants in their study view sex as *"dirty"*. Similarly, one participant in Rushbrooke, Murray and Townsend (2014a) described sex as "*ugly*" and "*disgusting*" (female) and another described sex as "*sickening and disgustingly gross"* (female). One participant explained why he had stopped having sex with his girlfriend, the quote below suggests he viewed sex as something to be ashamed about:

> *"I am very afraid of getting my girlfriend pregnant, which I will feel very guilty about. We have stopped having sex as it was too embarrassing to try to buy condoms from the 7-eleven shops"*, (male, Yau et al., 2009).

These scripts suggest that shame and disgust in relation to sexual expression is not uncommon in some PWLD.

Sex is for 'making babies'

Other studies found simplistic and limited notions about sex, which include seeing sex for the purpose of "*making babies",* without reference to other aspects of sex, such as pleasure (Azzopardi-Lane & Callus, 2014). Some participants in the Sullivan et al. (2013) study also spoke about sex as something that happens exclusively in marital relationships and only referred to sex in the context of procreation. Rushbrooke, Murray and Townsend (2014a) observed that only 2 out of 14 of the females they interviewed associated sex with pleasure. Fitzgerald and Withers (2013) also noted an absence of positive notions about sex in the expressions of their participants.

Traditional scripts about sex and sexuality

It was noted that some participants held 'traditional' views about sex. A re-occurring concept across studies was the idea that participants had been socialised to a number of social norms. However the norms expressed were found to be quite conservative at times. For example, a number of authors commented on how there was little talk about relationships beyond the heterosexual norm (Bane et al., 2012; Fitzgerald & Withers, 2013). In Healy et al. (2009) adherence to this heterosexual norm was more explicit *"I think it should be the right way around... not two men and two women together*" (gender of participant unclear).

These conservative views have been found in studies outside of this meta-synthesis (Burns & Davies, 2011; Murphy & O'Callaghan, 2004). Löfgren-Mårtenson (2009) suggests that these views are likely to be a result of PWLD having heterosexual role models. This author also suggest that this socialisation is a product of society's unease with PWLD expressing sexuality outside of the ‘norm’ as they already deviate from societal norms in terms of their disability.

Other traditional scripts about sexuality were noted. Bernert and Ogletree (2013) found evidence of participants being socialised to the idea that sex is only acceptable in a marital relationship. One female participant stated *“I would feel dirty about it [sex]”,* but that she wouldn’t feel dirty about having sex if she was married. Similarly in Kelly et al. (2009) a participant felt kissing was permitted “*Only if they’re married”* (male). Healy et al. (2009) also noted that their participants felt it was preferable to be married before engaging in sex suggesting that some PWLD hold conservative views about when sex is permitted.

A number of different factors may explain why PWLD express aversive and limited notions about sex rather than more fulfilled notions. It may be that due to limited cognitive capacity, PWLD only hear the ‘risk’ notions about sex during socialisation. Alternatively, it may be that a reluctance to talk about sex, due to it being seen as a *“private”* and *“embarrassing”* issue (Bane et al., 2012; Chou et al., 2015) may lead PWLD to turn to alternative sources of knowledge, such as TV and pornography (Kelly et al., 2009; Yacoub & Hall, 2009; Yau et al., 2009). These sources may lead to misunderstandings about sex and sexuality in these individuals.

Theme 2: Relationships providing access to a ‘normal’ identity and valued aspects of human experience

Despite the socialisation of aversive and limiting sexual scripts, an overwhelmingly dominant theme identified is the desire of PWLD to have a relationship. Relationships are seen to **<u>‘provide access to a ‘normal’ identity’</u>** and to give rise to **‘<u>valuable aspects of human experience’</u>** such as love, care and companionship.

Relationships as providing access to a ‘normal’ identity

A number of authors suggested that relationships can provide PWLD separation from their disability identity. Sullivan et al. (2013) view *“being able to have normal relationships”* as part of the *“struggle for an ordinary life”* in PWLD. The following quote illustrates one participant’s desire to access something ‘normal’ as a ‘normal’ adult:

> *“I don’t care what anyone says, I’m just a normal person that wants a girlfriend. Like any other teenager in the world, any other grown man would want one”* (male, Wilkinson, Theodore & Raczka, 2015).

Another participant spoke about how his relationship had moved him away from dependency, towards accessing ‘normal’ community facilities:

> “*We are more independent and more going forwards instead of backwards…we go out to restaurants which I wouldn’t have before*” (male, Lafferty, McConkey, & Taggart, 2013).

Similarly, Yau et al. (2009) reported that participants viewed marriage as a way to achieve “*independence and freedom”* seeing it as a sign of “*being grown up”*. One participant suggested how marriage could remove restrictions:

> ‘*I can move out from the residential institution and can stay up late or stay out as long as I want’* (male in Yau et al., 2009).

It seems that relationships are viewed as a way to move away from the restrictions placed on PWLD due to their disability and as a way to move towards a 'normal' adult identity.

Relationships providing access to valued human experiences

The synthesis also suggests that there are valued aspects of relationships beyond the act of sex and beyond a desire to be seen as 'normal'. These concepts include wanting to be loved, cared for and to have companionship and are seen as valued aspects of human experience. Love was seen as a valued experience and as part of being in a relationship:

> *"It's nice to get married, you have a wife, you'd love her and you'll treat her...you'd have a better life and a better future"*" (male, Healy et al., 2009).

Many spoke about their desire to have relationships because of the enhancement brought to their lives through companionship. One male participant spoke about this companionship *"it would be like company for you"* in Abbott and Burns (2007). Rushbrooke et al. (2014a) found similar notions in participants' accounts:

> *"I've had a lot of stress on me, that's why I want to get a girlfriend, because I don't want to be stuck on me own, not having people to talk to me"* (male, Rushbrooke et al. 2014a).

Another participant spoke how her relationship lifted her sense of isolation:

> *"When you've got a learning disability, it can be very lonely. You end up just sitting in the house and wandering about on your own and all you …feel as if the whole world is coming down on top of you and you and [you] feel like suicide… I would have stayed in bed all day, never bothered getting up"* (female, Lafferty et al., 2013).

According to Healy et al. (2009) all of their 29 participants expressed an interest in having intimate relationships. One male participant stated "*I like having girlfriends, they make me feel good"* suggesting a sense of self-esteem and self-worth can be gained through relationships. Others felt that this was not possible for them; one male participant spoke about feeling "*sad*" as his sibling was getting married "*I mean it's not fair, I think I should be happy as well"*.

Bane et al.'s (2012) participants spoke about the care, support and security gained from being in a relationship; this was replicated across studies:

> *"It's good to have a boyfriend because they care about you and cuddle and snuggle and mind you and help you and stuff like that"* (female, Bane et al., (2012).
>
> *"Now I support Brian through thick and thin, that's what love is"* (female, Lafferty et al., 2013).
>
> "*She protects me, she supports me, she listens to me, helps me out when I need"* (female, Abbott & Burns, 2007).

Although a desire for a sexual relationship is a dominant theme across all papers, some authors comment on how certain participants do not want to be in a relationship. One woman was described as *"anti-men"* and relationships, repeatedly saying "*keep away from* *them [men]*" (Kelly et al., 2009). Similarly in Yacoub and Hall (2009) one male participant said "*not interested in women anymore, they just ruin your life*" when he was asked if he would prefer to be single or in a relationship.

This theme suggests that the majority of PWLD in the studies reviewed have a desire to be in a relationship. This desire is born out of wanting a reprieve from their disability identity and to have access to valued aspects of human experience.

Theme 3: Restrictions and conditions placed upon sexual expression

The most dominant theme throughout the analysis concerns the restrictions and conditions that others place upon the development of sexual identities and relationships in PWLD. Participants spoke of a lack of privacy and their fears of abandonment if they did not abide to the rules imposed by others.

One male participant stated "*I had my room but not my privacy"* (Yacoub & Hall, 2009). A female participant stated "*My boyfriend once went to my bedroom…they checked up on you every two minutes"* (Hollomotz & The Speakup Committee, 2009). Wheeler (2007) similarly felt that the men in their study had restrictions imposed on their sexual expression. When a participant asked if he would like to have sex with his girlfriend he responded "*No, no… I'm not allowed"*, suggesting that sexual expression was regulated by others. Notions of rules and restrictions are noted across a number of studies. Male and female participants thought this form of regulation was "*unfair"* (Healy et al., 2009; Kelly et al., 2009) and at times they felt "*uncomfortable"* and "*intimidated"* as they could not have a "*proper conversation"* with staff "*ear wiggin"* (Rushbrooke et al., 2014a).

Others spoke about being reprimanded for their sexual expression using words like *"I was caught, I got told off"* and *"We were caught red handed in bed together and that's not fair"* (Healy et al., 2009; Kelly et al., 2009). The following quote taken from a participant describes how certain levels of sexual expression are deemed to be safe by others:

> "*My mother said not to do it... she said it's alright to have a cuddle and then leave it at that and a kiss but that's all, not more than that"* (female, Fitzgerald & Withers, 2013).

A number of participants across the studies feared the consequences of not following the rules and conditions imposed on them. A female participant spoke about her fear of being "*expelled from the service*" if she did not follow the rules about relationships stating "*you'd be out like that [snaps fingers]",* (Kelly et al., 2009). Rushbrooke et al. (2014a) report similar fears; a male participant explained that he was "*frightened"* because his mother *"might hit the roof or abandon me"* if he expressed his sexuality. Similar fears of being "*disowned"* by parents were found by Abbott and Burns (2007). A participant spoke about a sense of powerlessness due to a fear of the consequences of expressing his sexuality:

> *"Can't just tell her to bog off [staff] ...scared of having services taken away. So we're in a predicament where there's nawt we can do"* (male, Abbott & Burns, 2007).

Some participants considered the limitations on their sexuality to be *"overprotection"* (Wheeler, 2007), whereas others may have perceived the restrictions as a protective factor, "*they don't want us on our own in case something might happen"* (Healy et al., 2009). In the included studies there are frequent reports of sexual abuse and exploitation across participants.

It is important to note that not all participants were being asked to limit their sexual expression. Although free sexual expression is not a dominant theme in any one study, examples of individuals having freedom to express their sexual autonomy are noted. For instance, one female participant spoke about how she was in a sexual relationship and described herself as "*quite a very sexually active person*", stating "*yes very, I do like sex, a lot*" (Rushbrooke et al., 2014a).

For the large majority however their freedom to express their sexuality and develop a sexually autonomous identity was restricted and limited by others.

Theme 4: Suspended adolescence

This theme reflects a process where by other people's fears about the vulnerability of the PWLD can conflict with the persons desire to be sexually expressive. This conflict can lead participants to be placed in a suspended state of adolescence where by their relationships are monitored and regulated by others or take place in secret.

Wheeler's (2007) participants felt that they were not treated as adults when it came to their sexuality and were "*annoyed*" by what Wheeler (2007) labels "*mothering behaviour":*

> "*I'm 25.What Mam can't get used to, and I'm not criticising her, is Mam can't get used to me growing up"* (male, Wheeler, 2007).

Hollomotz and The Speakup Committee (2009), conclude that protective others are "*keeping people"* [with a learning disability] *"in a permanent state of adolescence*" by forcing them to live "*secretive and rushed"* sexual lives. Yau et al. (2009) also suggest that the participants in their study were being *"prohibited"* and treated like *"grown- up children"*. In another study, one female participant referred to herself as a "*grown teenager"* at the age of 56 (Fitzgerald & Withers, 2013). The authors of this study commented on how the version of sexuality imposed and expressed by females in their study was *"reminiscent of that identified in adolescent girls"*.

Bane et al. (2012) also found that participants in their study were treated like children which made it hard for them to develop relationships. One participant stated "*you're kind of looked down on. You're kind of treated like children*" (gender of participant unspecified). Sullivan et al. (2013) also state that the language and descriptions used by participants in their study are *"akin to what one would expect of adolescents in a relationship where sexual behaviours are going to be experienced for the first time*". It may be that by limiting sexual expression, the development of an adult identity is also limited.

A number of authors describe the different strategies participants use in response to the restrictive climate. Some are described as accepting the restrictions and therefore are not insistent on having relationships (Abbott & Burns, 2007), others are described as negotiating safe and *"platonic"* relationships, that is, relationships without a sexual component (Yau et al., 2009). The most discussed strategy however is the strategy that resembles adolescent behaviour. That is, *"resorting to secrecy"*, which in some cases meant more *"risky"* behaviours (Kelly et al., 2009).

Yau et al. (2009) found participants devised their own strategies to satisfy their sexual needs such as engaging in "*sex in parks and other places where they can keep out of sight"*. They attribute decisions to have sex in risky and inappropriate places to the prohibition of sexual expression in safer spaces. Bernert's (2011) participants use *"protective strategies"* to assert their independence. One female participant chose to have sexual contact in a toilet with a male partner, stating "*I don't want to get into trouble* [at work or home]", where displays of affection were not allowed.

McClelland et al. (2012) found that a number of participants had sex in public places and that these were the places participants are less likely to use condoms. The quotes below suggests that this is not an enjoyable experience and a result of not being allowed to engage in sexual behaviours in their homes:

> "*The first time I had sex with someone we went to this park that was nearby and that time I only had half an hour to go on free time so I would have to be back, I hated it…it was in the winter…It was freezing cold and it was like, I was so afraid that I was going to get in to trouble"* (male, McClelland et al., 2012).

> *"If the group home isn't going to let you have sex in the group home, you are probably going to have sex outside"* (female, McClelland et al., 2012).

This final theme suggests that the current strategies used to protect PWLD may actually expose them to more risks. This theme also suggests that the development of an autonomous sexual identity is intertwined with the development of an adult identity. Therefore, it may be that by limiting the sexual expression of PWLD we may also limit their ability to become adults who can take care of their own safety and sexual lives in a responsible manner.

Discussion

This meta-ethnography highlights a number of key experiences and issues for adults with a learning disability when they attempt to develop an autonomous sexual identity. The results suggest that these processes are complex and are influenced by a number of factors at multiple levels. These include the internal psychological processes at an individual level, alongside dynamic societal processes and discourses at a broader level. The data suggest that sexual expression in PWLD is limited in a number of ways which may be born out of a need to protect these individuals. Paradoxically, it seems that this need to protect may actually expose them to more risk.

The first way in which sexual expression is limited relates to the way in which PWLD are socialised to sex. Many participants viewed sex as dirty and dangerous and therefore imposed sexual abstinence upon themselves. This was more prominent for females than males. Participants also expressed sexual scripts that determined the conditions under which sexual expression would be socially accepted. It is unclear from this meta-ethnography whether these sexual scripts were truly internalised beliefs or whether they were merely echoes of the views participants had been exposed to. What seems clear however was that the majority of participants were influenced by these scripts in a way that limited their sexual expression.

Participants often feared being abandoned or disowned by their carers. These fears may explain why participants accepted and repeated the scripts they were exposed to. In Kroger's (1993) theory of self-identity development, the capacity to withstand ‘fear of dissolution’ from parents and society is said to be crucial in developing an autonomous self-identity. It seems that for the participants in this meta-ethnography, the consequences of moving away from the imposed norms may be too costly, as these individuals are often dependent upon others for support.

This is supported by research conducted by Kroger & Green (1996) which found that individuals who are reliant upon others for ‘nurture’ and ‘security’ are less likely to develop mature and self-determined identities. Kroger & Green, (1996) describe these as self-determined ‘intra-psychic’ factors.

Societal factors apparent in discourses about ‘safeguarding’ and ‘vulnerability’ may also have a role to play in the development of restricted sexual identities in PWLD. In this meta-ethnography participants were often monitored by others and were denied a lack of privacy. It is likely that these restrictions relate to beliefs held by others that PWLD need protection from sexual exploitation and harm.

In the studies reviewed here a number of participants spoke about their experiences of being sexually exploited or assaulted. These findings are similar to other studies (Beail & Warden, 1995; Peckham, 2007; Turk & Brown, 1993) which indicate higher rates of sexual abuse and exploitation in PWLD when compared to the normative population. We can therefore see that these fears and concerns are founded to some extent. However, it appears that carers of PWLD find it difficult to balance these fears against providing safe opportunities for sexual expression. This is supported by a recent meta-ethnogrpahy (Rushbrooke, Murray, & Townsend, 2014b) in which staff members and carers report feeling the burden of two roles, the ‘protector’ and the ‘facilitator’. Notions of accountability and responsibility leave carers feeling anxious and uncertain about how to balance these roles.

The current meta-ethnography suggests that tensions arise in the development of a sexually autonomous identity when sexual expression and desire is limited and restricted by others. This is said to create a state of suspended adolescence, a phenomenon noted by several authors. Participants across studies adopted risky strategies, much like adolescents, in order to meet their relational and sexual needs. Therefore in our need to protect we may actually expose PWLD to more risk. If we consider this in light of what this meta-ethnography reveals about how valuable PWLD find intimate relationships, we can see that we may find ourselves in a perpetual state of tension, as restrictions do not necessarily remove desire.

Therefore a way forward may be to support PWLD in their development of risk awareness and decision making capacities. Marcia (1989) theorised that opportunities for exploration and opportunities to exert and develop decision making capacities are important aspects in the process of adult identity development. It may be that external regulation of sexuality actually limits opportunities for PWLD to develop mature and safe sexual capacities.

Strengths and limitations

This meta-ethnography draws its strengths and confidence from the use of established methods for assessing quality and synthesising large sets of qualitative data (Atkins et al., 2008; Noblit & Hare, 1988). A systematic approach, much like the approach used in this meta-ethnography is said to go some way in limiting the uncertainty about the conclusions drawn (Sandelowski, 2004). The number of papers (n=21) included in this synthesis goes some way in adding confidence to the conclusions made. The task of extracting themes was made easier by the findings across the studies having a great deal of convergence; again, this coherence and saturation in the data set adds to the confidence in the conclusions drawn.

A limitation of this synthesis stems back to ongoing debates in the literature about measuring validity in qualitative research (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). Researchers have gone some way in defining the criteria for good quality research in qualitative studies (Guba & Lincoln, 1989; Hannes, Lockwood, & Pearson, 2010; Maxwell, 1992; Norris, 1997); allowing for the development of quality appraisal tools such as the CASP Quality checklist. However, Dixon-Woods et al. (2004) draw attention to a flaw in the current approach to quality analysis. That is, the use of quality tools that do not account for the plurality of the methods used both at data collection (focus groups, interviews, naturalistic observations) and at the level of methodological approach (phenomenological, ethnographical, grounded theory). Dixon-Woods et al. (2004) argue that current broad based criteria such as those used by the CASP Quality checklist are not sensitive enough to detect errors that may seriously limit the credibility and trustworthiness of the research. For instance, Larkin and Thompson (2011) suggest that good quality IPA will consider the context of the participants due to its ideographic focus, however the CASP Quality checklist does not ask such specific questions about ideographic contextual focus.

Nevertheless many researchers have found that despite these limitations, quality reviews allow for a focus on rigour and reporting to be undertaken (Dixon-Woods et al., 2007). Overall the current research does not address issues of transparency well, for example we cannot determine the degree to which the researchers' own biases may have influenced the findings, as the researchers do not demonstrate an engagement in reflexivity. It was also difficult to identify what methods of analysis had been used and how they were applied in some studies and thus validity cannot be adequately determined. Furthermore, it is noted that the methods of recruitment across studies were often unsatisfactory and were likely to create biases in the type of individuals included in the research. For example, many of the papers recruited individuals who had a degree of expressive language capabilities which reduces the generalisability of the findings. Authors rarely comment on the ethnicity and spiritual/ religious orientation of participants, which may have had an influence on the views expressed across studies. Atkins et al. (2008) note similar limitations and question whether these are due to the word limits often imposed by academic journals.

A new development in research methodology entails individuals with a learning disability conducting their own research, as in the case of Hollomotz and The Speakup Committee (2009). These studies were felt to be of high value as they focus on issues that PWLD feel are pertinent. However, these studies received some of the lowest quality ratings. Inclusion of these studies may therefore increase the value of this meta-synthesis (by expressing the voices of PWLD), but reduce confidence of its findings.

This review itself is open to a further flaw related to the subjectivity of its author who has a phenomenological orientation. Arguably this could have led to studies of a similar orientation receiving a higher quality rating and to these studies contributing a disproportionate amount to the overall synthesis. Attempts were made to limit this by the author being aware of this and through discussion and validation of themes with her research supervisor before finalising themes.

Future research

It is unclear from this meta-ethnography whether the sexual scripts expressed by PWLD are internalised beliefs or whether they are superficially expressed in order to conform to ideas of sexuality and sexual expression. The process by which these scripts are adopted by PWLD is also unclear and warrants further exploration. Differences in scripts across gender are also noted. It is unclear why females are more likely to hold views such as sex being dirty and dangerous in comparison to males. Further research is needed to explore participant's experience of suspended adolescence. Much of the understanding of this concept came from second order interpretations which limits the ability to understand what it is like to experience this state from the perspective of PWLD.

Clinical implications and practice recommendations

This meta-ethnography sheds light on the need to facilitate education about sexuality that moves beyond notions of risk and negative attitudes about sex. This finding is not new, as negative attitudes towards sex and sexuality in PWLD have been found in earlier research studies (McCabe, 1999; Siebelink, de Jong, Taal, & Roelvink, 2006). In a recent review about the barriers towards sex education for PWLD conducted by Sinclair et al.(2015) it is suggested that consistency in the content of sexual education programmes needs be agreed. The current review draws attention to the need to communicate a balanced view about sex and relationships within this agreed content.

A dilemma became apparent between the need to protect PWLD and the need to promote their rights. Brace (2008) noted that vulnerability and rights-based discourses do not often sit well together. However, this meta-ethnography sheds light on the downfalls of overprotection and infantilising PWLD. Services should therefore find ways of promoting safe sexual exploration that allows PWLD to take control of their own safety instead of attempting to limit sexual expression altogether. Training for carers both formal and informal should include elements that promote reflexivity and an awareness of this dilemma and the negative consequences of safeguarding in an over-protective way.

Given the value of relationships, not only in terms of the reprieve from a disability identity but also in terms of providing access to valued human experiences, it seems that fostering opportunities for the development of relationships in PWLD should be a high priority for services and political agendas.

References

Abbott, D., & Burns, J. (2007). What's Love Got to Do With It?: Experiences of Lesbian, Gay, and Bisexual People With Intellectual Disabilities in the United Kingdom and Views of the Staff Who Support Them. Sexuality, Research and Social Policy, 4(1), 28–39.

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*(1), 21. http://doi.org/10.1186/1471-2288-8-21

Azzopardi-Lane, C., & Callus, A.-M. (2015). Constructing sexual identities: people with intellectual disability talking about sexuality. *British Journal of Learning Disabilities*, *43*(1), 32–37. http://doi.org/10.1111/bld.12083

Bane, G., Deely, M., Donohoe, B., Dooher, M., Flaherty, J., Iriarte, E. G., … Wolfe, M. (2012). Relationships of people with learning disabilities in Ireland. *British Journal of Learning Disabilities*, *40*(2), 109–122. http://doi.org/10.1111/j.1468-3156.2012.00741.x

Beail, N., & Warden, S. (1995). Sexual abuse of adults with learning disabilities. *Journal of Intellectual Disability Research: JIDR*, *39 (Pt 5)*, 382–387.

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. http://doi.org/10.1111/jar.12088

Bernert, D. J. (2011). Sexuality and Disability in the Lives of Women with Intellectual Disabilities. *Sexuality and Disability*, *29*(2), 129–141. http://doi.org/10.1007/s11195-010-9190-4

Bernert, D. J., & Ogletree, R. J. (2013). Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research: JIDR*, *57*(3), 240–249. http://doi.org/10.1111/j.1365-2788.2011.01529.x

Brace, E. (2008). The sexual lives and identities of women with learning disabilities: exploring the significance of social norms and institutional practices. Retrieved from https://theses.ncl.ac.uk/dspace/handle/10443/117

Brackenridge, R., & McKenzie, K. (2005). the friendships of people with a learning disability: What do friendships mean to people with learning disabilities? Rachel Brackenridge and Karen McKenzie describe a study designed to explore the qualities that individuals look for in their friends. *Learning Disability Practice*, *8*(5), 12–17. http://doi.org/10.7748/ldp2005.06.8.5.12.c1626

Brown, H. (1994). “An Ordinary Sexual Life?”:A Review of the Normalisation Principle as It Applies to the Sexual Options of People with Learning Disabilities. *Disability & Society*, *9*(2), 123–144. http://doi.org/10.1080/09687599466780181

Burns, J., & Davies, D. (2011). Same-sex relationships and women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *24*(4), 351–360. http://doi.org/10.1111/j.1468-3148.2010.00609.x

Chou, Y.-C., Lu, Z.-Y. J., & Pu, C.-Y. (2015). Attitudes toward male and female sexuality among men and women with intellectual disabilities. *Women & Health*, *55*(6), 663–678. http://doi.org/10.1080/03630242.2015.1039183

Craft, A. (2004). *Practice Issues in Sexuality and Learning Disabilities*. Routledge.

Critical Appraisal Skills Programme (CASP). (2013). CASP Qualitative Checklist. Retrieved June 4, 2016, from http://www.casp-uk.net/

Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *16*(2), 145–157.

Cuskelly, M., & Gilmore, L. (2007). Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability): Scale development and community norms. *Journal of Intellectual and Developmental Disability*, *32*(3), 214–221. http://doi.org/10.1080/13668250701549450

Department of Health. (2001). Valuing People - A New Strategy for Learning Disability for the 21st Century - Publications. Retrieved June 4, 2016, from https://www.gov.uk/government/publications/valuing-people-a-new-strategy-for-learning-disability-for-the-21st-century

Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *Quality and Safety in Health Care*, *13*(3), 223–225. http://doi.org/10.1136/qshc.2003.008714

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., … Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy*, *12*(1), 42–47. http://doi.org/10.1258/135581907779497486

Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the Hope Experience of Family Caregivers of Persons With Chronic Illness. *Qualitative Health Research*, *20*(2), 148–158. http://doi.org/10.1177/1049732309358329

Fitzgerald, C., & Withers, P. (2013). “I don”t know what a proper woman means’: what women with intellectual disabilities think about sex, sexuality and themselves. ***British***

Journal of Learning Disabilities, *41*(1), 5–12. http://doi.org/10.1111/j.1468-3156.2011.00715.x

Guba, E., & Lincoln, Y. (1989). *Fourth Generation Evaluation*. Newbury Park, CA: sage. Retrieved from http://www.amazon.co.uk/Fourth-Generation-Evaluation-Yvonna-Lincoln/dp/0803932359

Hannes, K., Lockwood, C., & Pearson, A. (2010). A comparative analysis of three online appraisal instruments' ability to assess validity in qualitative research. *Qualitative Health Research*. Retrieved from http://qhr.sagepub.com/content/early/2010/07/28/1049732310378656.abstract

Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives. *Journal of Intellectual Disability Research: JIDR*, *53*(11), 905–912. http://doi.org/10.1111/j.1365-2788.2009.01203.x

Heiman, T. (2001). Depressive mood in students with mild intellectual disability: students' reports and teachers' evaluations*. *Journal of Intellectual Disability Research*, *45*(6), 526–534.

HM Government. (1998). Human Rights Act [Text]. Retrieved June 4, 2016, from http://www.legislation.gov.uk/ukpga/1998/42/contents

Hollomotz, A., & The Speakup Committee. (2009). "May we please have sex tonight?"– people with learning difficulties pursuing privacy in residential group settings. *British Journal of Learning Disabilities*, *37*(2), 91–97. http://doi.org/10.1111/j.1468-3156.2008.00512.x

Horner-Johnson, W., & Drum, C. E. (2006). Prevalence of maltreatment of people with intellectual disabilities: a review of recently published research. *Mental Retardation* *and Developmental Disabilities Research Reviews*, *12*(1), 57–69. http://doi.org/10.1002/mrdd.20097

Hosseinkhanzadeh, A. A., Taher, M., & Esapoor, M. (2012). Attitudes to sexuality in individuals with mental retardation from perspectives of their parents and teachers. *International Journal of Sociology and Anthropology*, *4*(4), 134.

Johnson, K., Frawley, P., Hillier, L., & Harrison, L. (2002). Living safer sexual lives: research and action. *Tizard Learning Disability Review*, *7*(3), 4–9.

Kelly, G., Crowley, H., & Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: "It"d be nice to be kind of trusted'. *British Journal of Learning Disabilities*, *37*(4), 308–315. http://doi.org/10.1111/j.1468-3156.2009.00587

Kitto, S. C., Chesters, J., & Grbich, C. (2008). Quality in qualitative research. *Medical Journal of Australia*, *188*(4), 243.

Kliewer, C., & Drake, S. (1998). Disability, Eugenics and the Current Ideology of Segregation: A modern moral tale. *Disability & Society*, *13*(1), 95–111. http://doi.org/10.1080/09687599826939

Kroger, J. (1993). On the nature of structural transition in the identity formation process. *Discussions on Ego Identity*, 205–234.

Kroger, J., & Green, K. E. (1996). Events associated with identity status change. *Journal of Adolescence*, *19*(5), 477–490.

Lafferty, A., McConkey, R., & Taggart, L. (2013). Beyond friendship: the nature and meaning of close personal relationships as perceived by people with learning disabilities. *Disability & Society*, *28*(8), 1074–1088. http://doi.org/10.1080/09687599.2012.758030

Larkin, M., & Thompson, A. (2011). Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In D. Harper & A. Thompson, *Qualitative research methods in mental health and psychotherapy: An introduction for students and practitioners* (pp. 99–116). Oxford: Wiley.

Lesseliers, J. (1999). A Right to Sexuality? *British Journal of Learning Disabilities*, *27*(4), 137–140. http://doi.org/10.1111/j.1468-3156.1999.tb00147.x

Löfgren-Mårtenson, L. (2009). The Invisibility of Young Homosexual Women and Men with Intellectual Disabilities. *Sexuality and Disability*, *27*(1), 21–26. http://doi.org/10.1007/s11195-008-9101-0

Marcia, J. (1989). Identity Diffusion differentiated. In K. Kreppner, M. A. Luszcz, & T. Nettelbeck (Eds.), *Psychological development: Perspectives across the life-span*. Amsterdam: Elsevier.

Maxwell, J. (1992). Understanding and Validity in Qualitative Research. *Harvard Educational Review*, *62*(3), 279–301. http://doi.org/10.17763/haer.62.3.8323320856251826

May, D. (2001). *Transition and Change in the Lives of People with Intellectual Disabilities*. Jessica Kingsley Publishers.

McCabe, M. P. (1999). Sexual Knowledge, Experience and Feelings Among People with Disability. *Sexuality and Disability*, *17*(2), 157–170. http://doi.org/10.1023/A:1021476418440

McCarthy, M. (1999). *Sexuality and Women with Learning Disabilities*. London: Jessica Kingsley Publishers.

McCarthy, M. (1999). *Sexuality and Women with Learning Disabilities*. London: Jessica Kingsley Publishers. Retrieved from http://www.jkp.com/uk/sexuality-and-women-with-learning-disabilities.html

McClelland, A., Flicker, S., Nepveux, D., Nixon, S., Vo, T., Wilson, C., … Proudfoot, D. (2012). Seeking safer sexual spaces: Queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction. *Journal of Homosexuality*, *59*(6), 808–819. http://doi.org/10.1080/00918369.2012.694760

Murphy, G. H., & O’Callaghan, A. (2004). Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychological Medicine*, *34*(7), 1347–1357.

Nirje, B. (1969). The normalization principle: implications on normalization. In *Symposium on normalization, SIIS, Madrid*.

Nirje, B. (1985). The basis and logic of the normalization principle. *Australia and New Zealand Journal of Developmental Disabilities*, *11*(2), 65–68.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). sage.

Norris, N. (1997). Error, bias and validity in qualitative research. *Educational Action Research*, *5*(1), 172–176. http://doi.org/10.1080/09650799700200020

Ohtake, Y., & Chadsey, J. G. (1999). Social disclosure among coworkers without disabilities in supported employment settings. *Mental Retardation*, *37*(1), 25–35. http://doi.org/10.1352/0047-6765(1999)037<0025:SDACWD>2.0.CO;2

Oliver, M. N., Anthony, A., Leimkuhl, T. T., & Skillman, G. D. (2002). Attitudes Toward Acceptable Socio-Sexual Behaviors for Persons with Mental Retardation: Implications for Normalization and Community Integration. *Education and Training in Mental Retardation and Developmental Disabilities*, *37*(2), 193–201.

Peckham, N. G. (2007). The vulnerability and sexual abuse of people with learning disabilities. *British Journal of Learning Disabilities*, *35*(2), 131–137.

Pockney, R. (2006, September 30). Friendship or Facilitation: People with Learning Disabilities and Their Paid Carers [Text.Article]. Retrieved March 21, 2016, from http://www.socresonline.org.uk/11/3/pockney.html

Rushbrooke, E., Murray, C. D., & Townsend, S. (2014a). What difficulties are experienced by caregivers in relation to the sexuality of people with intellectual disabilities? A qualitative meta-synthesis. *Research in Developmental Disabilities*, *35*(4), 871–886. http://doi.org/10.1016/j.ridd.2014.01.012

Rushbrooke, E., Murray, C., & Townsend, S. (2014b). The Experiences of Intimate Relationships by People with Intellectual Disabilities: A Qualitative Study. *Journal of Applied Research in Intellectual Disabilities*, *27*(6), 531–541. http://doi.org/10.1111/jar.12091

Sandelowski, M. (2004). Using Qualitative Research. *Qualitative Health Research*, *14*(10), 1366–1386. http://doi.org/10.1177/1049732304269672

Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, *12*(1), 48–56. http://doi.org/10.1002/mrdd.20093

Shaw, R. L., Booth, A., Sutton, A. J., Miller, T., Smith, J. A., Young, B., … Dixon-Woods, M. (2004). Finding qualitative research: an evaluation of search strategies. *BMC Medical Research Methodology*, *4*(1), 1–5. http://doi.org/10.1186/1471-2288-4-5

Shtarkshall, R. A., Santelli, J. S., & Hirsch, J. S. (2007). Sex education and sexual socialization: Roles for educators and parents. *Perspectives on Sexual and Reproductive Health*, *39*(2), 116–119.

Siebelink, E. M., de Jong, M. D. T., Taal, E., & Roelvink, L. (2006). Sexuality and People With Intellectual Disabilities: Assessment of Knowledge, Attitudes, Experiences, and Needs. *Mental Retardation*, *44*(4), 283–294. http://doi.org/10.1352/0047-6765%282006%2944%5B283:SAPWID%5D2.0.CO;2

Sinclair, J., Unruh, D., Lindstrom, L., & Scanlon, D. (2015). Barriers to sexuality for individuals with intellectual and developmental disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities*, *50*(1), 3–16.

Sinson, J. C. (1994). Normalization and community integration of adults with severe mental handicap relocated to group homes. *Journal of Developmental and Physical Disabilities*, *6*(3), 255–270. http://doi.org/10.1007/BF02578414

Stoffelen, J., Kok, G., Hospers, H., & Curfs, L. M. G. (2013). Homosexuality among people with a mild intellectual disability: An explorative study on the lived experiences of homosexual people in the Netherlands with a mild intellectual disability. *Journal of Intellectual Disability Research*, *57*(3), 257–267. http://doi.org/10.1111/j.1365-2788.2011.01532.x

Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2013). “Touching people in relationships”: A qualitative study of close relationships for people with an intellectual disability. *Journal of Clinical Nursing*, *22*(23–24), 3456–3466. http://doi.org/10.1111/jocn.12375

Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2015). The Close Relationships of People with Intellectual Disabilities: A Qualitative Study. *Journal of Applied Research in Intellectual Disabilities*. http://doi.org/10.1111/jar.12168

Taylor, M., Gomez. (2012). The S Words: Sexuality, Sensuality, Sexual Expression and People with Intellectual Disability. *Sexuality and Disability*, *30*(2), 237–245. http://doi.org/10.1007/s11195-011-9250-4

Turk, V., & Brown, H. (1993). The sexual abuse of adults with learning disabilites: results of a two year incidence survey. *Mental Handicap Research*, *6*(3), 193–216.

Unruh, D., Lindstrom, L., & Scanlon, D. (2015). Barriers to Sexuality for Individuals with Intellectual and Developmental Disabilities: A Literature Review - ProQuest. *Education and Training in Autism and Developmental Disabilities*, *50*(1), 3–16.

Wheeler P. (2007). "I count myself as normal, well, not normal, but normal enough" men with learning disabilities tell their stories about sexuality and sexual identity. *Learning Disability Review*, *12*(1), 16–27 12p.

Wiener, J., & Schneider, B. H. (2002). A Multisource Exploration of the Friendship Patterns of Children with and Without Learning Disabilities. *Journal of Abnormal Child Psychology*, *30*(2), 127–141. http://doi.org/10.1023/A:1014701215315

Wilkinson, V. J., Theodore, K., & Raczka, R. (2015a). "As normal as possible": Sexual identity development in people with intellectual disabilities transitioning to adulthood. *Sexuality and Disability*, *33*(1), 93–105. http://doi.org/10.1007/s11195-014-9356-6

Wilkinson, V. J., Theodore, K., & Raczka, R. (2015b). "As normal as possible": Sexual identity development in people with intellectual disabilities transitioning to adulthood. *Sexuality and Disability*, *33*(1), 93–105. http://doi.org/10.1007/s11195-014-9356-6

Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, *21*(6), 234.

Wolfensberger, W., & Tullman, S. (1982). A brief outline of the principle of normalization. *Rehabilitation Psychology*, *27*(3), 131.

Yacoub, E., & Hall, I. (2009). The sexual lives of men with mild learning disability: A qualitative study. *Journal of Learning Disabilities*, *37*(1), 5–11. http://doi.org/10.1111/j.1468-3156.2008.00491.x

Yau, M. K., Ng, G. S., Lau, D. Y., Chan, K. S., & Chan, J. S. (2009). Exploring Sexuality and Sexual Concerns of Adult Persons with Intellectual Disability in a Cultural Context. *The British Journal of Development Disabilities*, *55*(109), 97–108. http://doi.org/10.1179/096979509799103089

DECIDING ON THE SUITABILITY OF MARRIAGE FOR A PERSON WITH A LEARNING DISABILITY WITHIN A SOUTH-ASIAN COMMUNITY: STAFF AND MOTHER EXPERIENCES

By

Najma Sultana

Department of Clinical Psychology

School of Psychology

The University of Birmingham

June 2016

Abstract

Introduction: Safeguarding people with a learning disability (PWLD) from forced marriages has recently come to the forefront of policy agendas. The majority of these cases are said to occur in the South-Asian community (SAC) and involve PWLD who have questionable capacity to consent to marriage. Parents and staff members are likely to be most implicated in decision making about marriage suitability in PWLD yet little is understood about how both groups experience this decision making process.

Method: Nine participants were recruited and took part in this study. Five were healthcare professionals recruited from a community team which provides support to PWLD. Four were mothers of a person with a learning disability recruited from third sector organisations. Semi-structured interviews were undertaken with all participants and interviews were analysed using interpretative phenomenological analysis.

Results: The analysis across groups revealed three superordinate themes. The first theme, *'An uncertain future'* sets the context for why mothers consider marriage as an option. The second theme, *'Managing multiple roles, commitments and responsibilities'* describes similarities and differences in mothers and staffs experiences of their roles and responsibilities. It elaborates upon how these groups perceive marriage as a risky option for a number of reasons. **'***Navigating through muddy waters'* elaborates upon the difficulties each group experiences during the process of deciding whether or not marriage is a suitable option for a PWLD in the SAC.

Discussion: These results are considered in the light of psychological theories relating to stigma, tolerating uncertainty and making decisions when there are uncertain outcomes.

Introduction

In 2015 the Forced Marriage Unit's expertise was sought in relation to 141 cases of suspected forced marriage involving individuals with a disability (Forced Marriage Unit, 2016). These figures include individuals with a learning disability but do not provide the exact proportionality of people with a learning disability (PWLD) being forced to marry. In 2010, 298 professionals took part in a governmental survey that sought to gain further insights into forced marriages involving PWLD (Clawson & Vallance, 2010). This survey identified that these professionals had been involved in 71 cases of forced marriage involving PWLD. In 70% of these cases the person with a learning disability was said to have questionable capacity to consent to marriage. The majority of forced marriage cases are said to occur in the South Asian Community (SAC; Rauf, Saleem, Clawson, Sanghera, & Marston, 2013). The term 'South-Asian' (SA) usually refers to individuals who originate from Bangladesh, India, Pakistan, and Kashmir (The British Sociological Association, 2005).

In addition to the Government publications, research undertaken in clinical settings indicates that PWLD from the SAC are more likely to be married than their white counterparts and to have questionable capacity to consent to marriage (Beber & Biswas, 2009; O'Hara & Martin, 2003).

In 2014, growing media and political interest culminated in forced marriage being made a criminal offence (Baksi, 2012; Anti-social Behaviour, Crime and Policing Act 2014). It has been argued that the introduction of this law may marginalise and stigmatise a minority group and prevent victims from coming forward (Enright, 2009; Gill, 2011). Sabbe, Temmerman, Brems and Leye (2014) recommend a move away from top-town policy frameworks in order to avoid minority groups feeling targeted and stigmatised and to involve these communities in facilitating change.

In addition to the introduction of the law, guidance on forced marriage in PWLD has been published. This guidance focuses on what motivates parents to force their child to marry from a solely political and safeguarding perspective (Clawson & Vallance, 2010; HM Government, 2014). A limitation of this perspective is that it primarily focuses on ‘abuse’, ‘cultural beliefs’ and ‘a lack of understanding of human rights in the UK’ as reasons for why parents consider marriage as an option for their child. These are important factors, however this also inhibits a richer psychological understanding of these motivations from being developed. The guidance also encourages staff to prioritise safeguarding over cultural sensitivity, rather than seeing the reciprocal relationship between the two as being important when addressing forced marriage. Stenfert Kroese and Taylor (2011) add that viewing the problem of forced marriage from a single ethnocentric perspective prevents services from engaging with these families in a meaningful way to resolve these cross-cultural tensions.

Heer, Rose, and Larkin (2012) have proposed the use of an experiential-contextual framework when attempting to understand the experience of SA families who care for a PWLD during their interactions with Western services. It is thought that this framework may shed light on parents’ motivations to consider marriage as an option. This framework implicates stigma, the experience of being in a minority group, processes of acculturation and beliefs about disability as important aspects to consider when attempting to understand the experiences of these families.

The available literature suggests that families from the SAC believe that marriage can provide a ‘cure’ for a learning disability and families may therefore seek marriage as a preferred option over medical or social interventions (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004; Rauf et al., 2013; Sheridan & Scior, 2013). However, contrasting evidence highlights that not all individuals from the SAC believe that marriage can provide a cure

(Fatimilehin & Nadirshaw, 1994). Evidence suggests that families from the SAC can hold both theological and medical based explanations for the causes of a disability (Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010). It may be that processes of acculturation can explain why some parents believe marriage can provide a cure and others do not. Berry (1997) describes a process whereby individuals who have migrated to a new country adapt to the beliefs, values and norms of that society. Stenfert Kroese and Taylor (2011) propose that acculturation can make parents more open to considering alternative options to marriage, such as using services to support their child to become independent; therefore relinquishing the need for marriage as a care option.

Alongside acculturation, the framework of Heer et al. (2012) suggests that the concept of stigma is crucial to understanding the experiences of SA carers. Evidence suggests SA adolescents believe that having a family member with a learning disability can bring about associated shame and stigma on the family and can also hinder the marriage prospects of siblings (Sheridan & Scior, 2013). Similarly, in one case study parents from the SAC were concerned that stigma would affect their whole family if their child with a learning disability was not married (Hepper, 1999). Other studies have suggested that stigma may be experienced as a barrier to marriage rather than a motivating factor (Bywaters et al., 2003; Heer, Larkin, & Rose, 2015). Hussain, Atkin and Ahman (2002) found that parents from the SAC feared being rejected or shunned due to the stigma of having a child with a learning disability; as a result they were too afraid to approach family members in search of a potential suitor. However, due to the paucity of reearch in this area, it remains unclear what role acculturation and stigma play in parents' decisions about marriage for their child with a learning disability.

Alongside the role of stigma and beliefs about disability, a number of studies suggest that families from the SAC have significant fears about who will provide care for their child when they are unable to do so (Bywaters et al., 2003; Heer, Larkin, & Rose, 2015). Evidence suggests that marriage is considered to be a way to secure a settled future for PWLD when parents are no longer able to undertake this role (Heer et al., 2015; Hussain et al., 2002; Stenfert Kroese & Taylor, 2011). Evidence also suggests that mothers in particular, take on the long-term caring responsibilities for their child with a learning disability (Crabtree, 2007; Edwardraj et al., 2010; Eisenhower & Blacher, 2006). It may be that they therefore feel most responsible for securing a future for their child with a learning disability.

In summary, the limited research to date suggests that the cultural influences on parents are more complex than suggested by the current guidance (e.g. Clawson & Vallance, 2010; HM Government, 2014). The majority of the evidence considered so far consists of case studies, making it difficult to generalise the findings. Without an understanding based upon empirical evidence and psychological theory we cannot develop constructive and collaborative relationships with SA families and risk alienating this population.

Contributing to decisions about capacity to consent to marriage is often a central task for healthcare professionals. This is particularly true when concerns are raised about whether a person with a learning disability is being forced to marry. Specific guidance on assessing capacity to consent to marriage has largely developed through case law. The most significant contribution to the guidance concerns the case of Sheffield City Council v E (2005). The ruling was undertaken by Judge Munby who stated that in order for an individual to consent to marriage he or she must be “mentally capable of understanding the duties and responsibilities that normally attach to marriage”. The individual must also “understand the nature of the marriage contract”, which Judge Munby described as “a simple contract, that does not require a high degree of intelligence to comprehend”. Alongside this guidance, an assessment of capacity to consent to marriage must be made within the framework of the Mental Capacity Act (MCA; 2005). The MCA (2005) states that an individual must be able to understand the information relevant to the decision, retain the information and weigh up the information as part of the decision making process.

Current definitions of forced marriage mention consent and duress as central concepts in determining whether or not a person is being forced to marry (HM Government, 2014; Stobart, 2009). It has been argued that it is not always easy to make distinctions between arranged and forced marriages using notions of consent and duress (Anitha & Gill, 2009; Enright, 2009) and this is thought to be particularly true where PWLD are concerned. Firstly, duress is not always apparent in PWLD due to high levels of acquiescence (Rauf et al., 2013). Secondly, there is evidence to suggest that professionals do not feel confident in using the MCA (2005) to make decisions about consent in general (Willner, Jenkins, Rees, Griffiths, & John, 2011). In addition to a lack of confidence, a number of research studies identify that staff face many ethical dilemmas when assessing capacity to consent to marriage in PWLD from the SAC. Staff are reported to feel unsure about how to move forward on this issue as they can see that parents believe they are acting in their child’s best interest when arranging a marriage (Stenfert Kroese & Taylor, 2011). O’Hara and Martin (2003) report that staff experience cross-cultural tensions between the need to be culturally sensitive and the need to safeguard vulnerable adults. These findings were supported by Summers and Jones (2004). In addition to the experience of cross-cultural tensions, Summers and Jones (2004) found a lack of guidance available to support staff to undertake an assessment of capacity to consent to marriage, leading health-care professionals to experience uncertainty when undertaking this task. Since this publication, further guidance on this issue has become available (Clawson &

Vallance, 2010; HM Government, 2014, see Appendix 1). However, it has been suggested that the current guidance is not well integrated into policy and practice; resulting in inconsistent applications of the guidance in clinical practice (Wind-Cowie, Cheetham, & Gregory, 2012). In a recent study, Heer, Rose, and Larkin (2016) also report that staff still experience uncertainty and cross-cultural tensions when working with families from the SAC on issues related to marriage in PWLD, despite the introduction of new guidance. No empirical research has yet been undertaken in order to understand staff's experiences of applying the MCA (2005) in light of this new guidance and the recent criminalisation of forced marriage.

Parents and health care professionals are arguably the most likely people to be involved in decisions about marriage suitability for a PWLD. Evidence suggests that both groups are faced with a difficult task when asked to make a decision about a PWLD's suitability for marriage. Further to this, research suggests that cross-cultural tensions are experienced between these two groups when trying to resolve differences in beliefs about marriage suitability. Little is understood about how and why these tensions are experienced and therefore how to move forward on this issue in a collaborative manner. It is thought that by undertaking qualitative research, a rich understanding of parents and staffs perspectives can be explored and new insights on how to move forward on this issue can be developed.

Aim

The current research aims to gain an understanding of the experiences of those most involved in making decisions about marriage suitability for a PWLD in the SAC. To this end this research seeks to answer the following questions:

1) What are the experiences of parents and health care professionals when evaluating marriage suitability for an individual with a learning disability from the SAC?
2) How do sociocultural and legislative contexts shape the experiences of these individuals when making these decisions?
3) What can we learn about why tensions exist between parents and healthcare professionals when deciding whether or not marriage is appropriate?

Method

Interpretive phenomenological analysis (IPA) was chosen as its epistemological position is compatible with the aims of this research. IPA is concerned with how a particular phenomenon is made sense of and experienced from the perspective of a small and purposively selected sample of individuals (Larkin & Thompson, 2011; Smith, Flowers, & Larkin, 2009). In this case, the phenomenon of interest is the process of evaluating whether or not marriage is a suitable option for a PWLD from the SAC. As previously mentioned, rich accounts of how this process is experienced are currently missing from the literature. Furthermore, as IPA focuses on how a single phenomenon is experienced and made sense of, it allows for a multifaceted understanding of that phenomenon to be gathered through a multiple perspective design (Larkin & Griffiths, 2004; Smith et al., 2009). A multiple perspective design was felt to be most suitable to gain an understanding of cross-cultural tensions in relation to this phenomenon. Finally, IPA also focuses on the experience of the person in their socio-cultural and personal context (Larkin, Watts, & Clifton, 2006), which was thought to be particularly relevant to the aims of this study given the recent changes in legislation .

Ethical approval

Sponsorship and ethical approval was sought and obtained from the local University ethics research governance department (Appendix 2) and the National Research Ethics Committee (NRES; Appendix 3). Research and innovation approval was also sought from the host NHS site (Appendix 4).

Recruitment

Recruitment took place through purposive and snowballing sampling methods using the inclusion and exclusion criteria presented in Tables 1 (parents) and 2 (staff). The author presented details of the research at two team meetings (see Appendices 5 and 6 for participant information sheets). These meetings were attended by healthcare professionals who worked in a community team for PWLD across Birmingham. Interested clinicians were asked to contact the author through a secure e-mail account or through the local collaborator based within the team. Clinicians were also asked to approach parents on their caseloads to determine expressions of interest. Four staff members were recruited through this method and one through snowballing (word of mouth). No parents were recruited through this method. Clinicians often stated ‘it wasn’t the right time’ to approach parents on their caseload.

Therefore, third sector organisations who provide support to carers of a person with a learning disability from the SAC were approached. Two such organisations passed on details of the research to parents using their services. Five participants expressed an interest in taking part. The author met with these participants at the third sector organisations in order to explain the research, to check whether or not participants met the inclusion criteria, and to check whether or not an interpreter was required. One participant did not meet the inclusion criteria as their child was not deemed to have a learning disability by the Department of Health's, (2001) criteria, cited in Valuing People (2001).

Table 1 : Inclusion and exclusion criteria for Parents

Inclusion	Exclusion
South-Asian heritage	Ongoing investigations regarding forced marriage accusations
Parent of a person who is over the age of 16 and has a learning disability as defined by Department of Health (2001): • A significantly reduced ability to understand new or complex information and to learn new skills • A reduced ability to cope independently (impaired social functioning) • These difficulties need to have started before adulthood, with a lasting effect on development.	Parent of a child under the age of 16 that does not have a learning disability (as defined by the Department of Health's, 2001 criteria)
Must have had an experience of either of the following: • Considering marriage as a possible option for their child • Currently in the process of arranging a marriage for their child • Completed the process of arranging a marriage for their child	Family members who are not parents

Table 2 : Inclusion and exclusion criteria for staff

Inclusion	Exclusion
Health care professional who was / is part of a multi-disciplinary team Experience of contributing to the decision about whether a client with a learning disability from the SAC is able to consent to marriage.	Currently involved in an active assessment of capacity to marry

Participants

A total of nine participants met the inclusion criteria and took part in this study (see Table 3 for further details of participants). Four were mothers of a child with a learning disability (mothers n=4) and five were healthcare professionals in varying professional roles (staff n=5). Participants were homogenous in that they all shared an experience of making an evaluation about the suitability of marriage for a PWLD from the SAC. For mothers this involved either arranging a marriage or attempting to arrange a marriage and for staff this involved undertaking an assessment of capacity to consent to marriage. The sample size meets the requirement for a multiple perspective design in IPA (Smith et al., 2009).

Table 3: Details of participants, including a summary of the context of their decision about marriage suitability

	Name[1]	Relationship / Role	Age	Heritage	Context of decision about marriage suitability
Parents	Aisha	Mother	51	Second generation, Pakistani	Aisha was actively looking for a suitable partner for her 23 year old daughter. She declined one request for her daughter's hand in marriage as she felt the possible suitor would not make a compatible partner as he had mental health difficulties. Aisha was accused of forcing her daughter to marry, however the police did not pursue this claim further.
	Reshma	Mother	46	First generation, Pakistani	Reshma has considered getting her 17 years old son with severe Autism married in the past. She has approached family members from Pakistan to get a sense of her options. She however has not pursued this further and was not actively looking for a marriage partner for her son at the time of the interview.
	Mandeep	Mother	49	Second generation, Indian	Mandeep had spoken to others in her community to explore options of finding a suitable marriage partner for her 25 year old son. She was actively exploring her options at the time of the interview.
	Amarjit	Mother	63	First generation, Indian	Amarjit had been taken to court accused of forcing her son with Downs Syndrome to marry; consequently she was not actively looking for a marriage partner at the time of the interview.
Staff	Sarah	Speech and Language Therapist	38	White British	Sarah had contributed to a decision about capacity to consent to marriage in a male with a mild learning disability, in his early 20's. Sarah also undertook a communication assessment with this individual as part of this process.
	Kate	Speech and Language Therapist	56	White British	Kate contributed to a decision about capacity to consent to marriage in a female refugee, in her early 20's who had also undergone a process of female genital mutilation. Kate also undertook a communication assessment.
	David	Psychiatrist	50	White British	David spoke about a number of cases that he had been involved in where he was asked to give an opinion about capacity to consent to marriage in PWLD from the SAC.
	Razia	Speech and Language Therapist	43	British/ Indian	Razia contributed to a decision about capacity to consent to marriage in a female with Downs Syndrome, in her early 20's. Razia also undertook a communication assessment with this individual.
	Emma	Trainee Clinical Psychologist	27	White British	Emma spoke of her experience of undertaking a capacity assessment and being the final decision maker alongside her supervisor. She described the PWLD as a male in his 40's with a moderate learning disability.

1. Names have been anonymised in order to protect participants' identities

Procedure

Developing the interview schedules

Two separate semi-structured interview schedules were developed under the guidance of an individual who has extensive experience in the use of IPA and is a prominent author in this field (see Appendices 7 and 8 for interview schedules). Particular attention was given to the sensitive nature of the topic and how to therefore structure the interview schedules in a way that would progressively encourage participants to move from description to reflection. For both groups, the interview schedules were used as a guide and interviews were largely led by what participants felt to be important. Topics included probes about how participants made sense of marriage and their experience of deciding upon whether or not marriage was appropriate.

Interviews

Interviews with the mothers were undertaken in a private place of their choice. Two took place in participants' homes and two took place at the third sector organisation from which they were recruited. Two participants spoke English as a second language. An interpreter was offered in both cases however participants declined this offer stating a preference to undertake the interviews in English. Interviews lasted between 60 and 100 minutes.

Four staff interviews took place in a private space at their work base. One interview took place in a private space at the University of Birmingham. Interviews lasted between 55 and 80 minutes. All interviews were recorded for transcription purposes.

Data analysis

The method of analysis followed Smith, Flowers and Larkin (2009) and Larkin and Thompson (2011):

Stage one, familiarity and mapping: The author became familiar with the mothers' transcripts (listening to the interviews in full and reading each transcript once). The location of the data of interest was also mapped during this process. This process was repeated for the staff group.

Stage two, notations: Transcripts were re-read, starting with the mothers' transcripts. Initial notes commented upon three distinct aspects of the data, 1) objects of concern 2) the participants use of language (metaphors, pauses, changes of tense) and 3) possible ideas of meaning and sense making in the participants' accounts. This was repeated for the staff group.

Stage three, idiographic focus: For each participant, patterns of meaning and experience were grouped together in a table. Case summaries for the mothers were also generated (see Appendices 9-12). At this stage patterns of meaning were not given a name. This was so that analysis across groups could be undertaken at a later stage.

Stage four, within group analysis: Patterns of data within each group were then analysed to gain an understanding of what experiences and meaning making participants in each group shared. This process culminated in a table of shared experiences within in each group (see Appendices 13 and 14).

Stage five, across group analysis: Up until this stage the data from each group had largely been analysed separately. This was to ensure that meaning central to each group was not lost. In stage five the experiences of the two groups were brought together by comparing the within group analysis of both groups. This analysis revealed participants shared concerns and experiences related to responsibility, risk, the future of the PWLD and the vulnerability of the PWLD.

Stage six, bringing together patterns of meaning across the data set

With these shared concerns and experiences in mind, patterns of meaning, divergence and convergence across the groups was noted. At this stage the researcher named the patterns of meaning in the data **(**see example in Appendix 15) and created a narrative summation of the findings.

Credibility checks

A number of credibility checks were undertaken during the analytic process as suggested by Elliott, Fischer and Rennie (1999) and Yardley (2000). As part of these checks, at various stages of the analysis, the author consulted with her research supervisor and an additional researcher from the University of Birmingham, both of whom have extensive experience in using qualitative methods. Furthermore, participants were given the option to take part in credibility checks at the beginning of each interview, however all participants declined. Therefore additional credibility checks were undertaken with two lay people from the SAC. Patterns of meaning in the data were discussed with each individual on two separate occasions. Furthermore the author kept a reflexive diary in an attempt to have an awareness of times where their own experiences may influence the interpretation of data. This was felt to be particularly important as the author is of South-Asian origin. This reflexive aspect involved writing down the authors preconceptions about marriage, forced marriage and the relationships of PWLD. Through this process the author was reminded of her own beliefs about the grey area between arranged and forced marriage, as a result of being exposed to narratives within her community about duty, obligation and elders being wise in the matter of finding compatible marriage partners. The author maintained this reflexive stance to consider how these stories may not reflect the experience of PWLD and their parents due to the specific needs and vulnerabilities of PWLD.

Results

The analysis of participants' accounts produced three major themes which are made up of eleven subthemes. Nine of these subthemes reflect shared experiences across the groups. The remaining two subthemes reflect experiences that are unique to each group. A thematic structure of the analysis can be seen in Table 4.

The following presentation style will be adopted:

- **Major themes** will be presented in bold text as a separate heading
- **<u>Sub themes</u>** will be presented in bold underlined text
- *Transcript extracts* will be presented in italic font.

The first major theme encapsulates a shared experience of **'an uncertain future',** in which participants experience the future security of the PWLD as uncertain. This sets the context for why mothers may consider marriage as an option. The second theme captures participants' experiences of **'managing multiple roles, commitments and responsibilities'** in their caring roles. The weight of balancing these multiple roles and commitments was felt across both groups. The final theme elaborates upon how decisions about marriage suitability for a PWLD are made sense of through legal and socio-cultural frameworks. A lack of clarity brought about by each framework gives rise to participants' experiences of **'navigating through muddy waters'** during the decision making process.

Table 4: Thematic structure of the analysis and contribution across participant groups

Subordinate themes	Sub themes	Aisha	Reshma	Mandeep	Amarjit	Sarah	David	Kate	Razia	Emma
An uncertain future	Anticipated absence of current support network	✓	✓	✓	✓		✓		✓	
	Services unable to resolve this uncertainty	✓			✓	✓	✓			
	Marriage as an option that provides hope for a positive future	✓		✓	✓					
Managing multiple roles, commitments and responsibilities	Facilitating a valued life	✓	✓	✓	✓	✓				✓
	Deciding upon the acceptability of risk	✓	✓	✓			✓			✓
	Feeling the weight of responsibility	✓		✓	✓		✓	✓		✓
	A weight too heavy to bear						✓	✓	✓	
Navigating through muddy waters	An impossible task	✓	✓			✓	✓			✓
	Muddier waters		✓	✓			✓	✓	✓	
	Seeking clearer waters	✓		✓	✓	✓	✓	✓		

Theme One: An uncertain future

Participants described feeling concerned about who will provide future care for the PWLD. The first subtheme elaborates upon how the **'anticipated absence of the current support network'** brings about a sense of uncertainty. The second theme reflects how participants experience **'services as unable to resolve this uncertainty'**. The final subtheme reflects **'marriage as an option that provides hope for a positive future'.** This final theme will draw upon accounts from the mothers only as this was not reported by staff participants.

Anticipated absence of the current support network

Six participants reflected on their awareness that the current support system (provided by the parents) could not be sustained forever and would one day be absent. The excerpts below provide typical examples of the experience of anticipated absence across groups:

> *"It is a bit harder because sometimes I'm thinking- I'm thinking… I'm getting older, what if I die and who will look after him? That's all I'm worried about"* (Reshma, mother).

> *"The parents I work with […] I can't explain it, but these are really unwell people, and you can see why they're thinking, 'Oh my God!' Who's going to look after my child"* (David, staff).

Mothers used statements, such as *"what if, I walk out this house and get hit by a bus… where does that leave my daughter?"* (Aisha) and *"I mean anything could happen to me now at my old age"* (Amarjit) in their descriptions of this anticipation and uncertainty about their child's future. Their use of emotional language, such as *"scared"* (Aisha), *"worried"* (Reshma and Amarjit) and *"difficult"* (Mandeep) gives a sense of how frightening this anticipation and uncertainty is for mothers.

Staff accounts such as *"I can understand, they're [parents] thinking when we're not there, there will be some other person who will look after you"* (Razia) and *"you can see why they're thinking oh God!''* (David) suggests that staff empathise with parents and also anticipate the absence of care in the future.

Services as unable to resolve this uncertainty

Four participants experienced services as unable to provide a solution that would resolve the uncertainty about future care arrangements. For example:

> '*It's alright for the time being but when he grows older, I mean he can come here 'till 40* [third sector organisation], *after that what's happening? We don't know if he can get the services or not… If his condition gets worse what happens? Nobody can give us an answer'* (Amarjit, mother)

Amarjit gives a sense that there are a lot of questions and concerns about her son's future that are left unanswered by current service provision. Aisha speaks of a lack of service support and how this has led her to consider marriage as an option for her daughter:

> *"…but because she's not getting any help from any of the governmental services […] hence the reason why we – I am then having to try and help her find somebody that we, feel, will look after her and keep a safe"* (Aisha, mother).

It is interesting to consider that neither Amarjit nor Aisha have stated they would not consider using services as an alternative option to marriage, only that services do not seem sufficient.

Sarah and David, as staff members, share Amarjit's and Aisha's experiences relating to service deficiencies. In the exerpt below Sarah describes her experience of reassuring parents that other options to marriage are available, however in the same excerpt she seems to realise that she herself is disappointed by the current service provision:

> *"It doesn't mean we can't find them some of the strands that they were looking for out of a marriage, like relationships, like support, like care, all of those things from other ways and reasons and because sometimes they're not… always available [services], which is quite disappointing, in terms of what you, kind of, want to offer […] we are a service that has its limitations"* (Sarah, staff).

Similarly, David describes his experience of having *"sympathy"* with these families as they *"quite rightly know"* that when the time comes "*they will not get any help, I see it happening all the time".*

David’s account gives a sense of how helpless he may feel as an observer. Both Kate and David’s accounts reflect an awareness that they are unable to resolve the uncertainty about future care arrangement for parents using current provision.

Marriage as an option that provides hope for a positive future (unique to mothers)

This theme elaborates on the way in which three mothers consider marriage to be an avenue that can provide hope for their child’s future well-being and security. It draws upon an experience that is unique to the mothers who took part in this study.

Amarjit was taken to court, accused of forcing her son with Down’s syndrome to get married. In the account below Amarjit describes why she pursued marriage as an option for her son:

> *‘They settled [her children], they got their families, they’re ok, they’re settled, but what about him? There should be someone who can listen to him, he listens to her, and she listens to him. There should be someone, somebody should be there- not have to stay on his own’. (Amarjit, mother).*

Amarjit’s excerpt suggests she had hoped marriage would provide her son with a sense of stability *(“settled”)* and companionship. When asked how she sees the future for her son now that marriage is no longer an option, she stated:

> *"God- uh- be honest, at the moment, I don't think of anything. [...] you tell me what the answers are then? No. We can't do anything... That's life, we don't know what's going to happen, when it happens – it happens [her passing away], nobody will be coming to see him... leave it to his luck."* (Amarjit, mother).

Amarjit's excerpt gives the impression of someone who is powerless and who has lost all sense of hope that she will find a companion and a secure future for her son. Her son's future is once again experienced as unsettled.

Mandeep and Aisha also spoke about their hopes of what marriage could provide their child. Aisha hoped that marriage could provide her daughter with a *"husband", "a lover"* and a *"friend", "just like a normal person"*. For Mandeep, her son getting married would mean she could see him "*settling down"* to *"what he wants"* before she dies, therefore removing "*that stress and burden off"* her. It is thought that the burden she hopes to remove is the burden of uncertainty rather than the burden of care.

The major theme of **'an uncertain future'** gives us insight into why mothers are motivated to consider marriage as an option for their child with a learning disability. This theme also suggests that staff may feel helpless in their roles when attempting to reassure parents that services can provide alternative options to marriage.

Theme Two: Managing multiple roles, commitments and responsibilities

The second major theme elaborates upon participants' experiences of managing their many roles, commitments and responsibilities. The first subtheme captures participants' experience of their role in **'facilitating a valued life',** that is as close to normal as possible for the PWLD. The second subtheme **'deciding upon the acceptability of risk'** reflects how striving for normality can be difficult to manage when there are competing concerns around vulnerability; this reflects participants' roles as guardians and protectors and their commitment to safeguarding. With these roles in mind participants reflected upon their experience of **'feeling the weight of the responsibility'**. The final subtheme reflects an experience that was unique to staff participants and suggests that staff experience the responsibility for making the final decision around capacity as **'a weight too heavy to bear'.**

Facilitating a valued life

Six participants described a commitment to facilitating a valued life for the PWLD that is as close to normal as possible. Mothers expressed this commitment in the context of everyday tasks and interactions whereas staff expressed this commitment in the context of contributing to a capacity assessment. The following two excerpts compare typical experiences across groups:

> *"I've always put him in the centre and worked round him, and that's how he's progressed [...] He has voiced his own opinions that he wants to get married, have kids, wants to live independent and I just want to achieve his goals for him, and, having me around while he's doing it is going to be a comfort you know just let him live his life"* (Mandeep, mother).

Mandeep's expression of how she has *"always put* [her son] *at the centre"* demonstrates her lifelong commitment and role to creating a valued life for her son. Her expression *"just let him live his life*" suggest that barriers get in the way of her achieving "*his goals for him"*. Emma's excerpt below suggests she honours her commitment to facilitating a valued life for a PWLD by undertaking a balanced and considered capacity assessment:

> *"I feel very strongly that, you know [...] just because somebody's got a learning disability, doesn't mean that they can't lead a normal life and they don't want the same things. Sex and relationships is such a core part of human life. [...] but, also, they're quite a complicated part of human life and I think sometimes if you've got, like, a learning disability, it can be quite hard to understand and navigate them, and that leaves people very vulnerable."* (Emma, staff).

Emma's account suggests that this commitment and her role as a facilitator is not easily honoured when there are competing concerns around safety.

Further accounts suggested that mothers and staff honour a commitment to facilitating a valued life in different ways. Amarjit (mother) reflects her commitment, *"we've never treated him like a disabled person, we've always treated like a normal boy"* during her every day interactions with her son. Aisha (mother) described how her commitment to facilitating a valued life was experienced as a process of *"cultivating her [daughter] to try and give her a good life"*, suggesting that a "*good life"* is something that has to be built through a commitment.

Similar to Emma's account, where she was seen to make decisions in a balanced and considered manner, Sarah (staff) spoke of how she too ensured that others within her team "*think through"* whether they are setting the *"bar too high"* for PWLD during capacity assessments in a way that would prevent PWLD from living "*a normal family life just like anybody else*". Therefore, mothers' commitment to their role as a facilitator seems to manifests itself in the form of a life-long journey and process whereas staffs commitment manifests itself during their undertaking of a discrete task namely a capacity assessment.

Deciding upon the acceptability of risk

This theme describes the experience of five participants when making decisions about how much risk is acceptable for the PWLD. For some, their role as protector could conflict with their commitment to facilitating a valued life for the PWLD, thus creating a dilemma for these participants. Emma speaks of this dilemma when being asked to make a decision about an individual's capacity to consent to marriage. In the following account we see her emphasis on caution:

> *"…and I was very cautious that I didn't want to be, you know, or you, kind of, feel that you don't want to go too far one way and be like, 'No, of course not, they're too vulnerable,' and take their, kind of,… freedom away and their right to choose, but, equally, you don't want to leave somebody vulnerable"* (Emma, staff).

Emma's account suggests that risk is made sense of from a safeguarding perspective. Aisha experiences this dilemma from a mothers' perspective, in every day decisions. She refers to times when her daughter has met strangers with whom she has made contact on the internet. She seems to be speaking of a difficulty in getting the balance right between protecting her daughter and giving her the freedom to experience a valued life in the context of every day decisions:

> *“I’m one of them ones that want to give my child, my daughter that freedom because I was never given that freedom … but I’m on two sides of the scale now where I wanna give her that freedom but because of her difficulties I find it really hard to give her that freedom- because of what’s happened in the past. Not my past, her past” (*Aisha, mother).

Across accounts there were differences in how decisions about risk were experienced alongside how much risk participants felt was acceptable. Mandeep (mother) spoke about wanting to *“protect’* her son but not at the cost of his *“freedom”* and described her experience of “*letting go and letting* [him] *have* [his] *freedom.”* Reshma (mother) on the other hand appeared to have decided that her son’s vulnerability was too great for her to allow him to leave her side. Reshma stated *“I can’t trust anyone else with him”*, this related to her fear that others may *“hit”* her son and he wouldn’t be able to tell her about this due to his communication difficulties. David (staff) described his experience of making decisions about the acceptability of risk as “*extraordinarily tough”* as clients can often feel like they’re a “*prison”* as they “*don’t understand* why *people are protecting”* them.

What becomes clear is that when making a decision about the acceptability of risk, whether in the context of everyday decisions or a capacity assessment, the same dilemma is encountered; freedom versus protection from harm.

As well making decisions about the acceptability of risk in everyday situations, mothers, like staff made decisions about how much risk is acceptable when considering marriage as an option. It seemed that mothers would only consider marriage as an option if the longevity of the marriage could be guaranteed:

> *"I thought that you know- because I know that if you take him back home, because he's got British passport, they will give the girls because- even if you –whatever girl you wanna choose- but they just want to come, come to this country just for the stay"* (Reshma, mother).

Reshma speaks of her uncertainty about marriage as an option. It seems as though the value of a British passport is not enough to ensure the longevity of the marriage and therefore she feels marriage is not a risk she can take. Similarly, Aisha spoke about a time where she declined a family members request for her daughters hand in marriage as the potential suitor had a mental health problems, stating *"how are two difficulties together gonna work?*". This suggests that for Aisha two "*difficulties*" could not guarantee that the marriage would last and therefore marriage in this case was not an option she was willing to pursue.

Feeling the weight of responsibility

Six participants described the heaviness of their roles in terms of how much responsibility they felt. Staff members experienced the weight in relation to a decision specific task, whereas mothers experienced this weight as a longstanding, continuous pressure.

Mandeep described her responsibility towards her 25 year old son as akin to *"having a child in junior school, you've still got to fetch them, bring them you know, it's constant''*. Aisha described her responsibility for her daughter's safety as "*constantly on [her] mind" and* described how "*micromanaging everything"* when *"nobody understands"* has led her to experience a "*proper nervous breakdown".* Amarjit located the weight of her caring responsibilities on her shoulders, "*He was 13 or 14 when all of the responsibilities came onto my [points to shoulders]"*. Prior to this time, she received support from extended family members. Mother's experiences seem to reflect a continuous and constant pressure that is solely theirs.

Staff experienced their responsibilities in the context of contributing to a capacity assessment. They experienced this responsibility as heavy, as suggested by phrases such as "*I find the responsibility weighs very heavily"* (David), "*It's too important to undertake that duty lightly"* (Sarah) and "*I don't think it's a decision that can be taken lightly"* (Emma). This heaviness was experienced in relation to the power they felt that their opinion had over another person's life. For example:

> *"It's only our opinion, and we only ever offer it as an opinion, but it could make a difference to somebody's life"* (Sarah, staff).

> *"If I say, 'in my opinion, this person lacks the capacity,'… I'm… from their perspective, I'm condemning them to a pretty rubbish life. … Yeah, that's quite heavy, I think and it is that black and white"* (David, staff).

Therefore although staff experience their responsibility in the context of a discrete task, the weight of the responsibility they feel is extremely heavy. Furthermore, Staff's use of words like "*condemn*" (David) and "*make a difference to somebody's life"* (Sarah) suggest that this decision was seen as final and unchangeable; perhaps increasing the experiential weight of the responsibility.

A weight too heavy to bear

In light of the difficult task of balancing and managing multiple roles and responsibilities, three staff members reflected on an experience of not wanting to be the final decision maker; as if the burden would be too heavy to bear. This experience is unique to staff. David expressed an experience of relief as a result of not having to make the final decision about capacity, *"Fortunately, for me, it's not my decision. Erm, so it's a bit of a, a copout, really"*. Similarly, Razia described her sense of relief as she did not have to relay the final decision to the parents, "*I'm glad I wasn't the person".*

Kate elaborates upon the reluctance in the team to take on this responsibility:

> *"Very often people want us to be the decision-maker as well as the assessor. So we had to keep batting that back to people. [...] I think sometimes, yeah, er, people would prefer not to take that responsibility because it feels enormous, so they'd like to hand it onto somebody else"* (Kate, staff).

Kate's description of *"batting back"* the responsibility, suggests this is a responsibility that she does not want to bear.

The major theme of **'managing multiple roles, commitments and responsibilities'** suggests that mothers and staff have more in common than what sets them apart. They have similar commitments and experience similar dilemmas when trying to manage the demands of their roles. Within these roles they also have to make decisions about how much risk is acceptable. In relation to decisions about marriage and risk, staff place an emphasis on safeguarding and mothers place an emphasis on whether or not the marriage will last. Both groups described feeling the weight of the responsibility of their roles. Staff described this responsibility as being lifted by not having to make the final decision in the capacity assessment; mothers described no such relief in their roles and responsibilities.

Theme Three: Navigating through muddy waters

The analysis revealed that both groups were using different frameworks to make sense of whether or not marriage was a possible option for a PWLD. Staff used a legal framework (based upon the Mental Capacity Act, 2005) and mothers used a socio-cultural framework (based upon societal and cultural values). However neither framework seemed to provide the clarity or structure that participants desired during this decision making process. This gave rise to a sense that participants were **'navigating through muddy waters'**. This major theme reflects a shared experience of ambiguity and uncertainty across participant accounts when making decisions about the possibility of marriage for a PWLD.

The first subtheme describes how evaluating marriage suitability for a PWLD is experienced as **'an almost impossible task'** in both groups due to the lack of clarity afforded by each framework. Participants reflect upon how this impossible task is made 'muddier' by a number of additional factors. This is captured in the second subtheme **'muddier waters'.**

Finally this theme will draw upon the ways in which the two groups go about **'seeking clearer waters'** in their attempts to remove ambiguity in the decision making process.

An almost impossible task

Five participants spoke about having to undertake an almost impossible task of deciding whether or not marriage is a suitable option for a PWLD, due the ambiguity brought about by their sense making frameworks. For staff members this task related to using a legal framework that did not provide clear guidance on how to deal with the degree of complexity they experienced in clinical practice.

For mothers their impossible task related to finding a suitable partner for their child in a society where stigma made the path to finding this partner unclear and uncertain, for example:

> *"it's really, really hard when you – when you're a Muslim in a Western society, very, very, very confusing, very, very, hard- what do you do? What is the best thing to do? Do you let your daughter go out and find somebody for themselves? Or do you help them? Do you let them go out with boys or don't you? There's a stigma attached to it all and that's how I found my life starting to get really, really difficult. Because I didn't know what to do"* (Aisha, mother).

Aisha seems to be reflecting on how from her socio-cultural framework as *"a Muslim in a Western society"*, she is unclear about the best way to find a marriage partner for her daughter and fears that she will experience stigma whatever her path. It is almost as though through a process of acculturation, the rules about how to find a marriage partner have become unclear.

Reshma also describes how stigma and societal values from her socio-cultural framework make the path to finding a partner unclear:

> *"I think in the Asian community a lot of people look at, oh is that person good-looking, is the facial features right have they got a good job or are they capable of doing a job, basically what they call a full package. I think that's what puts a lot of things down when it comes to disability children [...] where they can't do anything for themselves and he's not going to be able to support the woman [wife] so I think that's what makes it hard to think about marriage for him because what Asian communities look for he won't provide that"* (Reshma, mother).

Reshma's account suggests that the usual socio-cultural rules of how people are matched in her community are based upon values, such as having a *"good job"*, being "*good-looking"* and matching like for like. It seems that these values and rules place her son at a disadvantage; making the path to finding a partner unclear and uncertain. Reshma's earlier reference to the value of a British passport "*because he's got a British passport, they will give the girls [...] but they just wana come for the stay"* suggests that a British passport can introduce a new rule about the possibility of arranging a marriage for her son.

For staff, ambiguity, whilst undertaking a capacity assessment was experienced on a number of levels. Firstly, David and Sarah felt that the process was always subjective, and this subjectivity therefore created a lack of clarity about how they should arrive at the final decision in consistent manner:

> *"It's always hard, because there isn't a set, there isn't a - 'This is where you need to get to.' So it, kind of, it always… comes down to subjectivity"* (Sarah, staff).

> *"The major difficulty is a difficulty across, across all capacity assessments, not just marriage, is that… people want it to be objective, and I think it's always subjective. That's the difficulty. It is an opinion, you know, I think all these things add up to this, but someone else might think they add up to that"* (David, staff).

Staff also felt there was a lack of clarity in the legal definitions themselves. Sarah described her experience of "*flailing around in the dark*" when trying to assess capacity:

> *"And there just seems to not be any of that clarity anywhere that, that somebody, kind of, to go, 'Well, legally, this is what capacity to marry is.' Erm… that's the thing that I find ... It hinges on capacity, but there's no clarity about what that capacity would look like. So it hinges on something that doesn't exist"* (Sarah, staff).

Emma reflected on how the legal framework does not adequately clarify the conceptual divide between an arranged and forced marriage when the PWLD expresses a desire to get married:

> *"There's so many more shades of grey in there …like, you know, 'cos he'd said, 'Yes,' and wanted an arranged marriage… but didn't have the understanding to know what he was signing up for. So then, is that an arranged marriage? That's, in the eyes of the law a forced marriage, but it's like, yeah, it's just way more complicated"* (Emma, staff).

Emma's account suggests that choice and desire are not adequately taken in account within the legal framework, creating a lack of clarity in the decision making process.

Both groups appear to experience a sense of uncertainty and a lack of clarity in their respective tasks. For mothers, stigma and evolving rules about how to arrange a marriage in the SAC bring about a lack of clarity in relation to the best way of finding a suitable partner for their child. For staff, the lack of clarity in the legal framework makes the process of arriving at a final decision unclear and open to inconsistencies.

Muddier waters

The tasks that participants face are perceived as impossible due to the lack of clarity involved in the process. This theme reflects four participants' accounts of how these muddy waters are made 'muddier' by a number of contextual factors.

For staff, the challenge seems to be "*balancing values and principles"* (Emma) in situations that evoke emotions such as *"anger"* (Razia). Staff accounts give a sense that emotions and personal values muddy the waters further when contributing to decisions about capacity, for example:

> *"It's important to be able to suspend… some of your own beliefs and not try and bring those to bear. I think it becomes incredibly difficult, if we start getting involved with whether, whether it's right or wrong and what you bring in and what you leave behind"* (Kate, staff).

> *"I have trouble getting my head around the status of women in, in Islam, full stop. Yeah, something I find difficult, on a personal level. So I bring that bias to the party"* (David, staff).

These excerpts suggest that both participants experience personal biases as muddying the water. However, David views them as an inevitable part of a bias in the process, whereas Kate believes that they can be *"suspended"* or separated from the process.

In a later excerpt, Kate speaks of experiencing discomfort when she considers the situation from her perspective as a mother:

> *"It's very hard not to use language that's judgemental on one part or the other […] I suppose, if I, if I allowed myself to think what I, my reaction would be, I would think that… I would think that I would be a rotten mum, if I let my daughter get into that situation"* (Kate, staff).

This discomfort may be why she prefers to suspend her own values and beliefs.

Mothers are said to experience their child's vulnerability and the unclear intentions of others as muddying the waters further during their task of finding a suitable partner. Two typical accounts are presented below:

> *"Well, it, it just depends on if he finds anybody who's compatible to him…to make sure that he's not being abused or… you know what I mean? It's hard and it's, it's, erm, it's an area where it's very difficult for parents"* (Mandeep, mother).

> *"These days you know it's really difficult to find a partner who understands. If you could find the partner that's really you know like, caring and you know who will look after his money and want to support, but these days you can't always find the partners like that"* (Reshma, mother).

Both accounts suggest that the unclear intentions of others and their child's vulnerability culminate in making the path to finding a suitable partner unclear.

Seeking clearer waters

This theme describes six participants' experiences of attempting to reduce the ambiguity during the decisions making process. Staff describe attempts to reduce their ambiguity by producing facts and evidence and by removing personal values and emotions from the equation, for example:

> *"Quite often it's having a lot of those discussions, a lot of bringing it back to the, kind of, the facts, the evidence*" (Sarah, staff).

> *"I think… the most satisfactory thing is to be a scientist and to provide evidence"* (Kate, staff).

These account demonstrate the value of facts and evidence in the decision making process. For parents however, attempts to reduce ambiguity and uncertainty in their search for a suitable partner is very much an emotionally led process. Amarjit and Mandeep described their willingness to sacrifice their own cultural heritage and values in order to try and secure a partner for their child:

> *"I don't mind, if she's English or what. He should be with someone, if he can't get married, is there any chance he can live with someone? Like in this country, friends, boyfriend, girlfriend they live together. We don't mind for him to live like that he can live like that – but the social workers say he can't live like that either"* (Amarjit, mother).

This contrasts greatly to Amarjit's earlier account where she states *"I don't trust love marriage"* because she fears that they are more fickle. Like Amarjit, Mandeep also states a preference for her son to marry somebody who is Asian. However, she acknowledges that stigma may "*limit"* her son's options; she is therefore willing to consider options that could mean a loss in cultural heritage:

> *"I'd be happy if they were in the same religion and culture, so they can carry on their culture and legacy. But, if, if that's not the case, because he's more limited, I'd rather have him happy"* (Mandeep, mother).

Despite attempts to make the waters clearer, three participants reflect upon how the process of making the right decision for the PWLD can never be made clear. Aisha states *"there's no guarantee"* that marriage can keep her daughter *"safe"* and so all she can do is "hope". Similarly, Amarjit reflects upon how the possibility of marriage provides her with a sense of *"relief"* but that it did not *"give the guarantee that they're* [potential suitor] *going to stay".*

David (staff) shared a similar experience that the muddy waters may never be made clear because of the decision making framework available to him:

> *"What I'm trying to get across, I just, I just think capacity, I, I think the Mental Capacity Act is… rubbish [...] I, I don't think, in the UK, we have* ever *found a good way to deal with capacity… and it kind of comes back to haunt us all the time"* (David, staff).

The major theme of navigating through muddy waters provides a sense of how unclear, uncertain and complex it can feel for participants when deciding whether marriage is a suitable and possible option for a PWLD.

Discussion

This study aims to develop a rich understanding of the experiences of staff and parents when making decisions about marriage suitability for a PWLD in the SAC. It recruited small samples of healthcare professionals and mothers, consistent with the idiographic focus of IPA and the aims of this research.

The major theme ‘An uncertain future’ and its subtheme ‘Anticipated absence of the current support network’ suggest that both staff and mothers are acutely aware that one day the support network provided by the parents will cease to exist. This produced a sense of apprehension and uncertainty about the future security of the PWLD. This experience has been found in research involving SA carers (Heer et al., 2015) and white British carers of PWLD (Cairns, Brown, Tolson, & Darbyshire, 2014; Pryce, Tweed, Hilton, & Priest, 2015).

The current findings indicate that mothers are turning to statutory services to provide a solution to their uncertainty. However, similar to the staff in this study, mothers perceive the service provision to be inadequate, this is reflected in the subtheme ‘Services as unable to resolve this uncertainty’. Pryce et al. (2015) in their explanatory thematic framework, suggest that parents of a PWLD engage in a process of ‘tolerating uncertainty’ when it comes to unanswered questions about the future care for their child. The majority of the parents in their study managed this uncertainty by choosing not to think about the future. In contrast, mothers in this study seemed to be acutely aware of this uncertainty and in most cases were actively planning to find a solution through marriage. The framework of Pryce et al. (2015) was developed from interviews with white British carers and may therefore explain its limited applicability to mothers in this study.

As well as hope for a solution to this uncertainty, marriage was seen as able to provide companionship, a settled future and a partner that would love their child. This was reflected in the subtheme ‘Marriage as an option that provides hope for a positive future’. In contrast to previous findings, (Clawson, 2013; Rauf et al., 2013), finding a ‘cure’ through marriage was not mentioned as a motivating factor by mothers in this study.

Furthermore, the major theme of ‘Navigating through muddy waters’ suggests that for mothers, when deciding upon possible marriage options for their child, stigma and acculturation make the rules for arranging a marriage unclear. In SAC’s marriages are usually arranged on the basis of matching like for like in terms of wealth and social standing (Wray, 2009). However, the stigma of having a child with a learning disability seems to make it difficult for mothers to engage in this transactional process and they therefore consider alternative options. Reshma for example, considered a UK passport (for the partner) as a valuable transactional object in her attempt to mitigate the effects of stigma. Some mothers tried to be flexible in other ways, as represented by the subtheme ‘seeking clearer waters’. For example, abandoning the idea of an arranged marriage altogether at the cost of losing their cultural identity and heritage. These insights suggest that our current understanding of why and how parents from the SAC consider marriage as an option is far more complex than that presented by the current socio-political discourse (e.g. Clawson, 2013; Rauf et al., 2013).

The experience of responsibility was another central concept across participants’ accounts, as represented by the major theme ‘Managing multiple commitments, roles and responsibilities’ Mothers described their responsibility as a life-long role, confirming the findings of previous studies (Eisenhower & Blacher, 2006; Heer et al., 2015). Mothers’ narratives about responsibility suggest an engagement in a life-long process of building a valued life and future for the PWLD.

Staff's narratives about responsibility relate to their contribution to an assessment of capacity to consent to marriage. Evidence suggests that when staff do not feel confident in completing capacity assessments they engage in displacement activities (requesting communication assessments) and become reluctant to take on the responsibility for the final decision (Willner et al., 2011). Similar responses were found in the current study, suggesting a lack of confidence in the current sample of staff. It may also be that staff's hesitance to take on the final decision is a reflection of conflict between their dual identities of protector and facilitator (Jingree, 2015). A meta-ethnography suggested that staff found it difficult to get the balance right between their roles of facilitator and protector when working with PWLD (Rushbrooke et al., 2014). This study suggests that these tensions may apply to decisions about capacity.

The major theme of 'navigating through muddy waters' suggests that some staff members were unsatisfied by the current guidance available to them when contributing to and making decisions about capacity to consent to marriage. A lack of clarity in the definition of what capacity to consent to marriage is and how to make distinctions between arranged and forced marriage in cases where a PWLD expresses a desire to get married may result in inconsistent applications of the law. Furthermore laws that lack a clear definition of the disability on which a person's rights are being denied are argued to be a form of structural discrimination (Corrigan, Markowitz, & Watson, 2004). This lack of clarification has historically been evident when establishing benchmarks for capacity to consent to a sexual relationship (British Medical Association: The Law Society, 2008; Murphy, 2003) mirroring the capacity to consent to marriage issue. Ambiguous definitions may also jeopardise possibilities of shared understanding and co-working between parents and staff.

The findings of this study, as reflected in the subtheme ‘Feeling the weight of responsibility’, also indicate that decisions about capacity are not considered to be ‘time-specific’ as defined by the Mental Capacity Act (2005) but are instead seen as judgments that will have indefinite implications for the PWLD. Research suggests that sexual education sessions tailored to the needs of PWLD can improve capacity to consent to sex (Dukes & McGuire, 2009) and we may therefore anticipate that this is also true for capacity to consent to marriage.

Finally, despite experiencing the same dilemma in relation to risk (freedom versus protection from harm), the two groups of participants differed in how they evaluated and made sense of risk when it came to marriage as reflected in the subtheme ‘Deciding upon the acceptability of risk’. Both groups saw marriage as a risky option due to the uncertain outcomes involved (e.g. exploitation). Theoretical perspectives on risk taking suggest that emotions, cognitions, previous experiences, institutional and socio-cultural factors all influence decisions about risk when there are uncertain outcomes (Breakwell, 2014; Sunstein, 2010). More specifically, theoretical perspectives suggest that emotions and the value attached to an outcome can make it more likely that a risk will be taken when outcomes are uncertain (Finucane, Alhakami, Slovic, & Johnson, 2000; Slovic, 2013). In this case, it may be that mothers were more inclined to pursue marriage as an option as they placed greater emphasis on the perceived benefits and had an emotional investment in the perceived outcome. Staff on the other hand may base decisions upon less emotive frameworks and may have more experience of the unfavourable outcomes of marriage in PWLD, thus making them more cautious in their decisions. Therefore, cross-cultural tensions may be brought about by differences in the meaning and value attached to marriage during evaluations about risk.

Clinical and research implications

Although IPA does not endeavour to make large scale generalisations, it may be that these findings go some way in understanding what it is like to be a mother or a healthcare professional when making decisions about marriage in PWLD. The major theme ‘Navigating through muddy waters’ highlights the need for clearer guidelines about what the benchmark for capacity is and how desire and choice can be accounted for in the legal framework. Where appropriate, marriage should be seen as a capacity that can be learnt and PWLD should be given more opportunity to develop their capacity in this area through service provisions. Consultations should be undertaken with parents and PWLD in order to ascertain their views on how to move forward on this issue, so that we can move away from placing top-down impositions on a relatively voiceless minority group.

The subthemes ‘Deciding upon the acceptability of risk’ and ‘An impossible task’ suggest that mothers from the SAC view marriage as an uncertain and risky option due to their child’s vulnerability and the unclear intentions of others. This insight should encourage services to open doors for communication with parents in order to find ways to support these families to consider more certain and less risky options. Another way forward may be to create a safe space from which staff and parents can collaboratively explore the issues. The major theme ‘Navigating through muddy waters’ sheds light on the different decision making frameworks that mothers and health care professionals use when making decisions about marriage suitability. Collaborative sessions could be facilitated with staff and parents where the aim is for each group to develop an understanding of the others decision making framework (socio-cultural and legal). This may encourage the development of relationships built on trust and promote shared agendas.

Limitations

It was felt important to present a balanced understanding of mothers' and staffs' psychological experiences in this sensitive area. However, a multiple perspective design meant that at times it was difficult to honour the idiographic focus of IPA and the results important to each of the two groups. Furthermore, divergence across mothers and staff accounts in terms of sense making resources (legal and socio-cultural frameworks) and tasks (capacity assessment versus finding a suitable partner) meant that saturation across accounts was limited in some instances.

There are also limitations related to how the sample was recruited. Staff members did not feel comfortable enough to approach parents on their caseload, to take part in this research. This provides a sense of how difficult staff may find broaching the subject of marriage when working with these families. Therefore future research should consider ways to reduce this tension in the recruitment process. Difficulties in obtaining richness and interpretation of meaning in mothers' (Reshma and Amarjit) accounts are apparent as a result of language barriers. However, this was unavoidable as these mothers stated a preference to conduct the interviews in English without an interpreter present. This may have led to the over representation of particularly reflective accounts that contained a clear expression of meaning, such as those of Aisha and Mandeep. The author attempted to avoid this by using accounts provided by all participants.

It is recognised that the voices of PWLD are not represented in the current study and is therefore a limitation of this multiple perspective design. It is recommended that the current study is undertaken on a larger scale in order to improve the confidence in the assertions made and the generalisability of the findings to samples outside of this research study.

In conclusion, this study provides unique insights into the difficulties experienced by mothers and healthcare professionals when making decisions about marriage suitability for a PWLD. The findings suggest that there is a need move away from ethnocentric thinking so that parents and staff can find collaborative ways to move forward on this issue.

References

Anitha, S., & Gill, A. (2009). Coercion, Consent and the Forced Marriage Debate in the UK. *Feminist Legal Studies*, *17*(2), 165–184. http://doi.org/10.1007/s10691-009-9119-4

Baksi, C. (2012). Forced marriage to be criminalized. *The Law Society Gazette*. Retrieved from http://www.lawgazette.co.uk/news/forced-marriage-to-be-criminalised/66004.fullarticle

Beber, E., & Biswas, A. B. (2009). Marriage and family life in people with developmental disability. *International Journal of Culture and Mental Health*, *2*(2), 102–108. http://doi.org/10.1080/17447140903205317

Berry, J. W. (1997). Immigration, Acculturation, and Adaptation. *Applied Psychology*, *46*(1), 5–34. http://doi.org/10.1111/j.1464-0597.1997.tb01087.x

Breakwell, G. M. (2014). *The Psychology of Risk* (2 edition). New York: Cambridge University Press.

British Medical Association: The Law Society. (2008). *Assessment of Mental Capacity: Guidance for Doctors and Lawyers*. John Wiley & Sons.

Bywaters, P., Ali, Z., Fazil, Q., Wallace, L. M., & Singh, G. (2003). Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: considerations for service providers and the disability movement. *Health and Social Care in the Community*, *11*(6), 502–509. http://doi.org/10.1046/j.1365-2524.2003.00456.x

Cairns, D., Brown, J., Tolson, D., & Darbyshire, C. (2014). Caring for a Child with Learning Disabilities Over a Prolonged Period of Time: An Exploratory Survey on the Experiences and Health of Older Parent Carers Living in Scotland. *Journal of Applied Research in Intellectual Disabilities*, *27*(5), 471–480. http://doi.org/10.1111/jar.12071

Clawson, R. (2013). Safeguarding people with learning disabilities at risk of forced marriage. *Social Work and Social Sciences Review*, *16*(3), 20–36.

Clawson, R., & Vallance, P. (2010). *Forced Marriage and Learning Disabilities: Multi-Agency Practice Guidelines*. HM Government.

Corrigan, P. W., Markowitz, F. E., & Watson, A. C. (2004). Structural levels of mental illness stigma and discrimination. *Schizophrenia Bulletin*, *30*(3), 481–491.

Crabtree, S. A. (2007). Family responses to the social inclusion of children with developmental disabilities in the United Arab Emirates. *Disability & Society*, *22*(1), 49–62. http://doi.org/10.1080/09687590601056618

Department of Health. (2001). Valuing People - A New Strategy for Learning Disability for the 21st Century - Publications. Retrieved June 4, 2016, from https://www.gov.uk/government/publications/valuing-people-a-new-strategy-for-learning-disability-for-the-21st-century

Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*, *53*(8), 727–734. http://doi.org/10.1111/j.1365-2788.2009.01186.x

Edwardraj, S., Mumtaj, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010). Perceptions about intellectual disability: a qualitative study from Vellore, South India. *Journal of Intellectual Disability Research: JIDR*, *54*(8), 736–748. http://doi.org/10.1111/j.1365-2788.2010.01301.x

Eisenhower, A., & Blacher, J. (2006). Mothers of young adults with intellectual disability: Multiple roles, ethnicity and well-being. *Journal of Intellectual Disability Research*, *50*(12), 905–916.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, *38*(3), 215–229. http://doi.org/10.1348/014466599162782

Enright, M. (2009). Choice, Culture and the Politics of Belonging: The Emerging Law of Forced and Arranged Marriage. *The Modern Law Review*, *72*(3), 331–359. http://doi.org/10.1111/j.1468-2230.2009.00747.x

Fatimilehin, I. A., & Nadirshaw, Z. (1994). A Cross-Cultural Study of Parental Attitudes and Beliefs About Learning Disability (mental Handicap). *Mental Handicap Research*, *7*(3), 202–227. http://doi.org/10.1111/j.1468-3148.1994.tb00127.x

Finucane, M. L., Alhakami, A., Slovic, P., & Johnson, S. M. (2000). The affect heuristic in judgments of risks and benefits. *Journal of Behavioral Decision Making*, *13*(1), 1–17. http://doi.org/10.1002/(SICI)1099-0771(200001/03)13:1<1::AID-BDM333>3.0.CO;2-S

Forced Marriage Unit. (2016). *Forced Marriage Unit Statistics 2015*. HM Government. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/505827/Forced_Marriage_Unit_statistics_2015.pdf

Gill, A. (2011). *Exploring the viability of creating a specific offence for forced mariage in England and Wales: Report on findings*. Univeristy of Roehampton.

Heer, K., Larkin, M., & Rose, J. (2015). The experiences of British South Asian carers caring for a child with developmental disabilities in the UK. *Tizard Learning Disability Review*, *20*(4), 228–238. http://doi.org/10.1108/TLDR-12-2014-0044

Heer, K., Rose, J., & Larkin, M. (2012). Understanding the Experiences and Needs of South Asian Families Caring for a Child with Learning Disabilities in the United Kingdom:

An Experiential-Contextual Framework. *Disability & Society*, *27*(7), 949–963. http://doi.org/10.1080/09687599.2012.699276

Heer, K., Rose, J., & Larkin, M. (2016). The Challenges of Providing Culturally Competent Care Within a Disability Focused Team A Phenomenological Exploration of Staff Experiences. *Journal of Transcultural Nursing*, *27*(2), 109–116. http://doi.org/10.1177/1043659614526454

Hepper, F. (1999). "A woman"s heaven is at her husband's feet'1? The dilemmas for a community learning disability team posed by the arranged marriage of a Bangladeshi client with intellectual disability. *Journal of Intellectual Disability Research*, *43*(6), 558–561. http://doi.org/10.1046/j.1365-2788.1999.00226.x

HM Government. (2014). *Multi-agency practice guidelines: Handling cases of Forced Marriage*.

Hussain, Y., Atkin, K., & Ahman, W. (2002). *South Asian disabled young people and their families*. Policy Press, Joseph Rowntree Association.

Jingree, T. (2015). Duty of Care, Safety, Normalisation and the Mental Capacity Act: A Discourse Analysis of Staff Arguments about Facilitating Choices for People with Learning Disabilities in UK Services. *Journal of Community & Applied Social Psychology*, *25*(2), 138–152. http://doi.org/10.1002/casp.2202

Katbamna, S., Ahmad, W., Bhakta, P., Baker, R., & Parker, G. (2004). Do they look after their own? Informal support for South Asian carers. *Health & Social Care in the Community*, *12*(5), 398–406. http://doi.org/10.1111/j.1365-2524.2004.00509.x

Larkin, M., & Griffiths, M. D. (2004). Dangerous sports and recreational drug-use: rationalizing and contextualizing risk. *Journal of Community & Applied Social Psychology*, *14*(4), 215–232.

Larkin, M., & Thompson, A. (2011). Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In D. Harper & A. Thompson, *Qualitative research methods in mental health and psychotherapy: An introduction for students and practitioners* (pp. 99–116). Oxford: Wiley.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102–120. http://doi.org/10.1191/1478088706qp062oa

Murphy, G. H. (2003). Capacity to consent to sexual relationships in adults with learning disabilities. *Journal of Family Planning and Reproductive Health Care*, *29*(3), 148–149. http://doi.org/10.1783/147118903101197520

O'Hara, J., & Martin, H. (2003). Parents with learning disabilities: a study of gender and cultural perspectives in East London. *British Journal of Learning Disabilities*, *31*(1), 18–24. http://doi.org/10.1046/j.1468-3156.2003.00197.x

Pryce, L., Tweed, A., Hilton, A., & Priest, H. M. (2015). Tolerating Uncertainty: Perceptions of the Future for Ageing Parent Carers and Their Adult Children with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, n/a-n/a. http://doi.org/10.1111/jar.12221

Rauf, B., Saleem, N., Clawson, R., Sanghera, M., & Marston, G. (2013). Forced marriage: implications for mental health and intellectual disability services. *Advances in Psychiatric Treatment*, *19*(2), 135–143. http://doi.org/10.1192/apt.bp.111.009316

Rushbrooke, E., Murray, C. D., & Townsend, S. (2014). What difficulties are experienced by caregivers in relation to the sexuality of people with intellectual disabilities? A qualitative meta-synthesis. *Research in Developmental Disabilities*, *35*(4), 871–886. http://doi.org/10.1016/j.ridd.2014.01.012

Sabbe, A., Temmerman, M., Brems, E., & Leye, E. (2014). Forced marriage: an analysis of legislation and political measures in Europe. *Crime, Law and Social Change*, *62*(2), 171–189. http://doi.org/10.1007/s10611-014-9534-6

Sheffield City Council v E. (2005). Sheffield City Council v E (2004) EWHC 2808 (Fam) - Mental Health Law Online. Retrieved July 18, 2016, from http://www.mentalhealthlaw.co.uk/Sheffield_City_Council_v_E_(2004)_EWHC_2808(Fam)

Sheridan, J., & Scior, K. (2013). Attitudes towards people with intellectual disabilities: A comparison of young people from British South Asian and White British backgrounds. *Research in Developmental Disabilities*, *34*(4), 1240–1247. http://doi.org/10.1016/j.ridd.2012.12.017

Slovic, P. (2013). *The Feeling of Risk: New Perspectives on Risk Perception* (1 edition). Routledge.

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research* (Reprint edition). Los Angeles: SAGE Publications Ltd.

Stenfert Kroese, B., & Taylor, F. (2011). “It”s OK, you get used to it’: Forced marriage and learning disabilities. *Journal of Critical Psychology, Counselling and Psychotherapy*, *11*(4), 156–164.

Stobart, E. (2009). *Multi-Agency Practice Guidelines: Handling Cases of Forced Marriage*. HM Government.

Summers, S. J., & Jones, J. (2004). Cross-cultural working in community learning disabilities services: clinical issues, dilemmas and tensions. *Journal of Intellectual Disability Research*, *48*(7), 687–694. http://doi.org/10.1111/j.1365-2788.2004.00601.x

Sunstein, C. (2010). *Risk and Reason: Safety, Law, and the Environment* (New Ed edition). Cambridge England : New York: Cambridge University Press.

The British Sociological Association. (2005). Equality and Diversity, Language and the BSA: Ethnicity and Race. Retrieved June 4, 2016, from http://www.britsoc.co.uk/the-bsa/equality.aspx

Willner, P., Jenkins, R., Rees, P., Griffiths, V. J., & John, E. (2011). Knowledge of Mental Capacity Issues in Community Teams for Adults with Learning Disabilities. *Journal of Applied Research in Intellectual Disabilities*, *24*(2), 159–171. http://doi.org/10.1111/j.1468-3148.2010.00573.x

Wind-Cowie, M., Cheetham, P., & Gregory, T. (2012). *Ending forced marriage will take more than a change in the law*. Retrieved from http://www.demos.co.uk/files/Forced_marriage_-_web_4_.pdf?1335277742

Wray, H. (2009). Moulding the migrant family. *Legal Studies*, *29*(4), 592–618. http://doi.org/10.1111/j.1748-121X.2009.00132.x

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215–228. http://doi.org/10.1080/08870440008400302

PUBLIC DISSEMINATION DOCUMENT

THE SEXUAL AND MARITAL RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

by

Najma Sultana

Department of Clinical Psychology

School of Psychology

The University of Birmingham

June 2016

THE SEXUAL AND MARITAL RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

This research was undertaken by Najma Sultana under the supervision of Dr Biza Stenfert Kroese as part of the fulfilment for a Doctorate in Clinical Psychology. The research has two parts. The first is a meta-ethnography that explores the experience of people with a learning disability (PWLD) in intimate and sexual relationships. The second part consists of a research project that looks into experience of mothers' and healthcare professionals' when deciding if marriage is a suitable option for a PWLD in the South-Asian Community (SAC).

PART 1: A META-ETHNOGRAPHY: THE MEANING AND EXPERIENCE OF SEXUAL AND INTIMATE RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

Introduction

Intimate and personal relationships are said to positively influence the quality of life of PWLD (Cummins & Lau, 2003; Power, Green, et al., 2010). However, evidence suggests that PWLD are more likely to be socially isolated (Pockney, 2006) and to have difficulties in achieving autonomy in sexual relationships (Brown, 1994; Löfgren-Mårtenson, 2004). It is thought that this is because the sexual and relational needs of PWLD are overlooked (Brown, 1994; Noblit & Hare, 1988; Servais, 2006) and at times are restricted by others (Hosseinkhanzadeh et al., 2012). Little is understood about how PWLD make sense of and experience sexual relationships in light of these difficulties (Change, 2010; Lesseliers, 1999).

Aims

This meta-ethnography aimed to address this gap in the literature by answering the following two questions:

1) What are the experiences of PWLD when trying to achieve an autonomous sexual identity?
2) How are the sexual and intimate relationships of PWLD experienced and given meaning?

Method

Key words relating to the research aims were placed in a number of databases (PsychInfo, CINHAL and Web of Science). Inclusion and exclusion criteria were then systematically applied to the articles generated by the search; leaving a total of 21 papers for inclusion in this meta-ethnography. The research articles also underwent a quality review to ensure that studies of poor quality did not dominate the results of the final synthesis.

Synthesis

This meta-ethnography then set out to synthesis the studies in a very specific way, using the method of Noblit and Hare (1988). This method moves beyond a summary of the current literature. It involves a process whereby the author adds an additional layer of interpretation to the findings across studies, so that new knowledge from a large body of research can be obtained.

Results and conclusions

Four major themes were extracted and synthesised from the data

Socialisation to aversive and limiting sexual scripts: The first major theme gave a sense that PWLD are socialised to ideas about sex and relationships that are aversive and limiting. For example, many PWLD expressed ideas that ‘sex is bad’ and that sex is only ‘for making babies’. PWLD also expressed views that sex is only for married heterosexual couples.

Relationships providing access to a ‘normal’ identity and valued aspects of human experience: The second major theme suggests that PWLD value relationships because they are seen to provide love, companionship, support and a way to distance themselves from their disability identity**.**

Restrictions and conditions placed upon sexual expression: The third major theme reflects the ways in which other people place restrictions and limitations on the sexual expression of PWLD. It is thought that this is because informal and formal carers want to protect PWLD from harm. PWLD can be too afraid to say anything about these restrictions as they fear ‘abandonment’ and losing their homes.

Suspended adolescence: The final theme suggests that tensions between a PWLD’s desire to be in a relationship and the restrictions they face can place them in a permanent state of adolescence. Some people even engaged in risky strategies, much like adolescents, in order to get their sexual and relational needs met. This suggests that restricting the sexual expression of PWLD paradoxically places them at further risk of harm. It may also be that external regulation of sexuality limits opportunities for PWLD to develop mature and safe sexual capacities.

PART 2: DECIDING ON THE SUITABILITY OF MARRIAGE FOR A PERSON WITH A LEARNING DISABILITY WITHIN A SOUTH-ASIAN COMMUNITY: STAFF AND MOTHER EXPERIENCES.

Introduction

Parents and healthcare professionals are arguably the most likely people to be involved in decisions about the suitability of marriage for People with a Learning Disability (PWLD) in the South-Asian Community (SAC). Research suggests that tensions are experienced between parents from the SAC and staff during decisions about the appropriateness of marriage for PWLD (Heer, Rose, & Larkin, 2016; Hepper, 1999; Stenfert Kroese & Taylor, 2011; Summers & Jones, 2004).

Recent statistics suggest that PWLD from the SAC are being forced to marry and in a number of cases their capacity to consent to marriage is unclear (Clawson & Vallance, 2010; Forced Marriage Unit, 2016). However much of our knowledge about why parents force their child with a learning disability to get married comes from case studies (e.g. Hepper, 1999; Summers & Jones, 2004) and policy guidelines (Clawson & Vallance, 2010; HM Government, 2014). A rich psychological understanding of these motivations from the perspective of the parents is therefore absent from the current literature.

Research also suggests that staff experience a tension between their safeguarding roles and the need to be culturally sensitive when undertaking an assessment of capacity to consent to marriage (Heer et al., 2016; Stenfert Kroese & Taylor, 2011; Summers & Jones, 2004). Little is known about staffs' experiences of undertaking capacity assessments in light of the recent criminalisation of forced marriage (Baksi, 2012).

It is thought by undertaking qualitative research a rich understanding of parents' and staffs' perspectives can be explored and new insights about how to move forward on this issue can be developed.

Aim

This research aimed to answer the following questions:

1) What are the experiences of parents and healthcare professionals when evaluating marriage suitability for PWLD from the SAC?
2) How do sociocultural and legislative contexts shape the experiences of these individuals when making these decisions?
3) What can we learn about why tensions exist between parents and healthcare professionals when deciding whether or not marriage is appropriate?

Method

The method of Interpretative Phenomenological Analysis (IPA) was used to gather and analyse the data in this study. IPA aims to explore how concepts are understood and made sense of in groups of people who share an experience of the same phenomenon (Smith et al., 2009). The experience in this case is making a decision about whether or not marriage is a suitable option for a PWLD in the SAC. In line with the required sample size for an IPA study, four mothers and five staff members took part in this study. All participants took part in a semi-structured interview. Interviews transcripts were analysed using the methods suggested by Larkin and Thompson (2011) and Smith et al. (2009).

Results

The analysis produced three major themes that captured participant's experiences:

An uncertain future: The first major theme suggests that both groups of participants experience the future security of the PWLD as uncertain. Participants were aware that the support network provided by parents will one day cease to exist. Mothers were looking to services for an alternative option to marriage but perceived the available service provision to be inadequate. This set the context for why mothers may consider marriage as an option.

Managing multiple roles, commitments and responsibilities: The second theme captures participants' experiences of the demands of varying roles. For example, being a facilitator of freedom can conflict with the role of protector. Mothers experienced their roles as a continuous pressure and a life-long commitment. Staff discussed their roles in the context of undertaking a discrete intervention; a capacity assessment. However, in both cases the weight of responsibility was felt. Furthermore, both groups described an experience of weighing up decisions about risk when deciding whether or not marriage was a suitable option.

Navigating through muddy waters: The final theme elaborates upon how decisions about marriage suitability for a PWLD are made sense of in different ways by mothers and staff. Staff made sense of how appropriate marriage was through a legal framework whereas mothers made sense of this using a socio-cultural framework (based upon the norms and values of their society). A lack of clarity brought about by each framework gave rise to participants' experiences of 'navigating through muddy waters' during the decision making process.

Conclusions

At present it seems as though mothers and healthcare professionals experience the decision making process as unclear and uncertain. Furthermore, there seems to be a lack of a safe space from which mothers and healthcare professionals can collaboratively explore their concerns with one another.

This insight should encourage services to find ways to support families to consider more certain and less risky options in collaboration with service providers.

References

Baksi, C. (2012). Forced marriage to be criminalized. *The Law Society Gazette*. Retrieved from http://www.lawgazette.co.uk/news/forced-marriage-to-be-criminalised/66004.fullarticle

Brown, H. (1994). “An Ordinary Sexual Life?”:A Review of the Normalisation Principle as It Applies to the Sexual Options of People with Learning Disabilities. *Disability & Society*, *9*(2), 123–144. http://doi.org/10.1080/09687599466780181

Change. (2010). Talking about sex and relationships: The voews of young people with learning disabilities. Retrieved June 6, 2016, from http://disability-studies.leeds.ac.uk/files/library/change-final-report-read-copy.pdf

Clawson, R., & Vallance, P. (2010). *Forced Marriage and Learning Disabilities: Multi-Agency Practice Guidelines*. HM Government.

Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *16*(2), 145–157.

Forced Marriage Unit. (2016). *Forced Marriage Unit Statistics 2015*. HM Government. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/505827/Forced_Marriage_Unit_statistics_2015.pdf

Heer, K., Rose, J., & Larkin, M. (2016). The Challenges of Providing Culturally Competent Care Within a Disability Focused Team A Phenomenological Exploration of Staff Experiences. *Journal of Transcultural Nursing*, *27*(2), 109–116. http://doi.org/10.1177/1043659614526454

Hepper, F. (1999). “A woman”s heaven is at her husband’s feet’1? The dilemmas for a community learning disability team posed by the arranged marriage of a Bangladeshi client with intellectual disability. *Journal of Intellectual Disability Research*, *43*(6), 558–561. http://doi.org/10.1046/j.1365-2788.1999.00226.x

HM Government. (2014). *Multi-agency practice guidelines: Handling cases of Forced Marriage*.

Hosseinkhanzadeh, A. A., Taher, M., & Esapoor, M. (2012). Attitudes to sexuality in individuals with mental retardation from perspectives of their parents and teachers. *International Journal of Sociology and Anthropology*, *4*(4), 134.

Larkin, M., & Thompson, A. (2011). Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In D. Harper & A. Thompson, *Qualitative research methods in mental health and psychotherapy: An introduction for students and practitioners* (pp. 99–116). Oxford: Wiley.

Lesseliers, J. (1999). A Right to Sexuality? *British Journal of Learning Disabilities*, *27*(4), 137–140. http://doi.org/10.1111/j.1468-3156.1999.tb00147.x

Löfgren-Mårtenson, L. (2004). “May I?” About Sexuality and Love in the New Generation with Intellectual Disabilities. *Sexuality and Disability*, *22*(3), 197–207. http://doi.org/10.1023/B:SEDI.0000039062.73691.cb

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). sage.

Pockney, R. (2006, September 30). Friendship or Facilitation: People with Learning Disabilities and Their Paid Carers [Text.Article]. Retrieved March 21, 2016, from http://www.socresonline.org.uk/11/3/pockney.html

Power, M. J., Green, A. M., & WHOQOL-Dis Group. (2010). Development of the WHOQOL disabilities module. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *19*(4), 571–584. http://doi.org/10.1007/s11136-010-9616-6

Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, *12*(1), 48–56. http://doi.org/10.1002/mrdd.20093

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research* (Reprint edition). Los Angeles: SAGE Publications Ltd.

Stenfert-Kroese, B., & Taylor, F. (2011). "It"s OK, you get used to it': Forced marriage and learning disabilities. *Journal of Critical Psychology, Counselling and Psychotherapy*, *11*(4), 156–164.

Summers, S. J., & Jones, J. (2004). Cross-cultural working in community learning disabilities services: clinical issues, dilemmas and tensions. *Journal of Intellectual Disability Research*, *48*(7), 687–694. http://doi.org/10.1111/j.1365-2788.2004.00601.x

APPENDICES

A META-ETHNOGRAPHY: THE MEANING AND EXPERIENCE OF SEXUAL AND INTIMATE RELATIONSHIPS OF PEOPLE WITH A LEARNING DISABILITY

APPENDICES

Appendix 1: Summary of the studies included in the meta-ethnography

Study and aims / research question	**Sample**	**Methodology**	**Themes**	**Strengths**	**Limitations**
1. Abbott and Burns (2007) UK (Included England, Wales, Scotland & Northern Ireland) Aimed to explore the experience of relationships, in those whose who are lesbian, gay and bisexual	N = 20 9 female 11 male Age: 18+	Interviews Grounded theory	Talk about love Reluctance to come out Discrimination Social isolation Lack of support Physical vs non-physical Secrecy Normality	Detailed discussion about development of interview schedule	No discussion for why grounded theory was selected as the method of analysis
2. Wheeler (2007) South Wales, UK Aimed to explore the experience of sexuality and sexual identity in males with a learning disability	N = 12 Males Age 16 -42	Semi-structured Interviews Interpretative Phenomenological Analysis (IPA)	Agency and autonomy as common threads in all themes Similarity between the participants and men without learning disabilities Dissimilarity between the participants and men without learning disabilities	Recommendations for policy are clear and succinct	Not all of the themes reflect an experiential element, which raises questions about whether the method of IPA was appropriately applied
3. Yacoub and Hall (2009)	N = 17 Males	Software used – QUALRUS	Knowledge Experiences	Provides a good description of how the analysis was undertaken.	Made no attempts to check the validity of the results, for example

Study and aims / research question	**Sample**	**Methodology**	**Themes**	**Strengths**	**Limitations**
Aimed to explore the sexual lives and behaviour of men with a mild learning disability	Age: 29-65	Constant comparison method	Attitude and feelings Complex themes (related to sexual orientation)	Recruited until the data was saturated	through triangulation
4. Hollomotz and The Speakup Committee (2009) Aimed to explore self-advocates' views on achieving sexual autonomy in residential group settings	N = 15 Gender unclear 18+	Participatory action research Four focus groups Method of analysis is unclear	Pursuing privacy in residential group settings	Through the use of participatory action research allowed pwld to discuss issues of importance to them	Presents data but no discussion of how the analysis was undertaken, therefore it is difficult to evaluate its credibility
5. Kelly, Crowley, and Hamilton (2009) Ireland Experience of relationships and sexuality in Ireland	N = 15 7 females 8 males Age: 23-41	Focus groups segregated (males and females) Thematic analysis	Desire Prohibition Sexual knowledge	Makes clear recommendations for change in policy	No discussion about relational reflexivity or triangulation.
6. Löfgren-Mårtenson, (2009)	N = 13 Male and female	Interviews Ethnography	Role models and alternative sexualities	Good explanation of the theoretical orientation of symbolic interaction was	Not explanation of how interviews were analysed

Study and aims / research question	**Sample**	**Methodology**	**Themes**	**Strengths**	**Limitations**
Aimed to understand the opportunities and hindrances of young people with a learning disability when expressing a variety of sexual identities	Age 16-27		Even sexuality is individual	used to analyse the observational data	Little descriptive information was given about participant demographics
7. Yau et al., (2009) Hong Kong Explored sexual attitudes and concerns of pwld in a Chinese cultural context	N = 12 9 Female 3 Male Age: 22-44	Content analysis Thematic analysis	Concepts of dating and marriage Striving for normality and acceptance Sexuality Struggling on with own strategies	The authors made the reader aware that a number of participants had difficulties in expressing ideas clearly, allowing the reader to interpret the results with caution	Method of how they combined the two methods of analysis is unclear
8. Healy, McGuire, Evans and Carley (2009) Republic of Ireland Looked at the sexual knowledge, aspirations, experiences and barriers in relation to sexual relationships of pwld	N = 29 17 males 12 females Age: 18+	Focus groups based on age. Thematic analysis The results from one focus group (age 13-17, n= 3) were excluded from the current analysis.	Personal relationships Personal relationships and the role of relatives Relationships within the service Companionship	There was a clear explanation of the procedure that was undertaken during the focus groups; making the method of data collection replicable	No explanation of how thematic analysis was applied to the data

Study and aims / research question	Sample	Methodology	Themes	Strengths	Limitations
9. Bernert (2011) USA Aimed to explore how sexuality is experienced among females with an intellectual disability	N = 14 Female Age: 18-89	Semi-structured interviews and ethnography	Disability centred environments and disability identity Adult identity and expression of autonomy Protective policies and programmes and sexual limitations	Took place in naturalistic environments Credibility checks through triangulation	Description of analysis is fairly limited
10. Fitzgerald and Withers (2011) UK Aimed to understand how women with a learning disability conceptualise and develop sexual identities	N = 10 Female Age: 19-64	Thematic analysis Semi-structured interview	Sex and sexuality Regulated beings Women with intellectual disabilities Suspended adolescence Prohibition Stereotypical views	A number of credibility checks undertaken such as triangulation and the keeping of a reflective diary to limit the contamination of the researchers own experiences on the process of analysis	A limited about of original data such as quotes and participants excerpts has been included. Making it difficult to validate the interpretations made.
11. Bane et al., (2012) Republic of Ireland Explored the relationship	N = 97 52 female 45 male Age: 18+	16 focus groups Participatory action research	Having a boyfriend or a girlfriend Support	Involved individuals with a learning disability in directing the research and presented the research paper in an accessible manner.	Lack of clarity about the method of analysis used to generate themes

Study and aims / research question	Sample	Methodology	Themes	Strengths	Limitations
experiences of pwld to understand what support they may need to develop sexual autonomy				Credibility checks were undertaken by asking participants whether the themes resonated with them.	
12. McCelland et al., (2012) Canada Aimed to examine sexual health attitudes and behaviours in relation to the development of sexual autonomy in pwld	N= 10 Male, female and transgendered individuals Age: 17-26 Mixture of sexual orientations	Two focus groups 10 semi-structured interviews Participatory action research	Living arrangements, rules and autonomy Sex and sexual spaces	Pwld involved in generation of interview schedules and research topics	Unclear how participants were recruited No description of the interview schedule
13. Stoffelen et al., (2013) Netherlands Aim was to understand the lived experiences homosexual people with an intellectual disability	N = 21 19 male 2 female Age: 18+ Homosexual orientation	Interviews NVivo version 8. Analysis process unclear	Sexual experiences Gay or lesbian identity Support Family Partner	Large sample size The researchers present a number of quotes to support their commentary	No description of analysis at all beyond naming the software used Themes names do not seem to move beyond description
14.	N = 10	Semi-structured	Touching other people in	Clear description of their	Authors only included

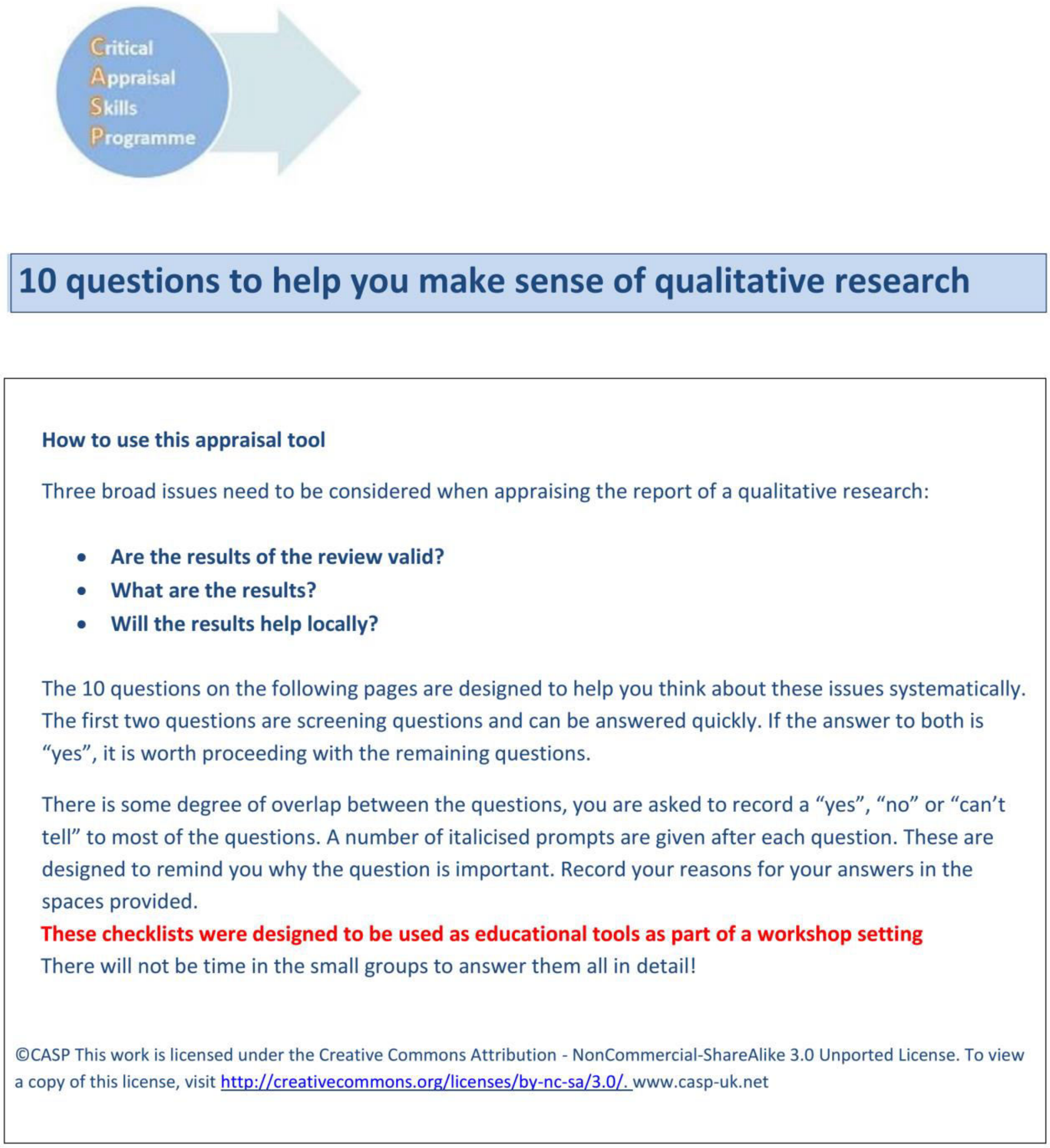
Study and aims / research question	Sample	Methodology	Themes	Strengths	Limitations
Sullivan, Bowden, McKenzie & Quayle, (2013) Scotland To explore the experiences of close and sexual relationships of pwld	6 male 4 female Age: 31-60	interviews IPA	relationships No freedom or fun Being touched	procedure for data analysis	Individuals with language abilities that allowed them to take part in the research. This limits the generalisability of the results
15. Lafferty, McConkey and Taggart (2013) Ireland Aim was to gain an insight into the close relationships of 8 couples with a learning disability	N = 16 (8 heterosexual couples) 8 female 8 male Age: 26-65 4 married 3 engaged 1 dating (but not cohabiting)	Dyadic and one to one interviews Grounded theory	Comradeship: being together is what matters Happiness and contentment Mutual support and complementary reciprocation Coping with the ups and downs of relationships Continuation and commitment	Participants were recruited through support workers who decided who was in an established relationship. This may have meant that not all potential participants were approached to take part.	Some participants' accounts were drawn upon a lot more than others. It is not clear which participants contributed to which theme.
16. Bernert and Ogletree (2013) USA Aimed to explore sexuality in the lives of	N = 14 Female Age 18-89 1 married 9 single	Ethnography 48 in-depth interviews alongside observations. Occurred over a two year period	Sexual experiences Conditions for sex Negative perceptions of sex	Research took place over two years and data was collected over a series of interviews allowing for these participants to develop rapport and therefore to become more open about their	Limited explanation of how data was analysed.

Study and aims / research question	Sample	Methodology	Themes	Strengths	Limitations
women with a learning disability	3 divorced 1 widowed Age 18-89			experiences.	
17. Rushbrooke, Murray and Townsend (2014a) England Aimed to add to existing literature on sexuality and intimate relationships in pwld	N = 9 5 female 4 male Age: 21-58	IPA Semi-structured interviews	Desiring relationships Expressing sexuality Having relationships Who has control?	Clear description of how the themes were generated and how the data was analysed	Researchers do not critically examine their own role in the data analysis
18. Sullivan, Bowden, McKenzie and Quayle (2015) Scotland This study aimed to explore how people with learning disability perceive and experience close relationships	N = 10 6 males 4 females Age: 31-60	IPA Semi-structured interviews	Relationships feeling safe and being useful Who is in charge Struggling for an ordinary life	Very thorough account of the analysis process	Only recruited pwld who are themselves advocates and so this data may not generalise beyond this specific group

Study and aims / research question	Sample	Methodology	Themes	Strengths	Limitations
19. Wlkinson, Theodore and Raczka (2015) London: UK The aim was to investigate the development of sexual identity pwld	N = 4 2 males 2 females Age: 19-22	IPA Semi-structured interviews	Struggle for a normal as possible adult identity The struggle for sexual identity as a normal adult identity	Justified why they chose IPA Provided a clear explanation of their topic guide, with examples	Does not provide details on how participants were recruited
20. Azzopardi-Lane and Callus (2014) Malta Aim was to explore the experience of sexuality and relationships in pwld	Recruited from a self-advocacy group N= 19 Age: 20-60	Participatory action research Focus groups Thematic analysis-	Sexuality- the perceptions of people with intellectual disability	Pwld were involved in all stages of the research project, providing then with a voice	A limited amount of detail is provided on the final sample that agreed to take place
21. Chou, Lu and Pu (2015) Taiwan Aimed to understand the sexual attitudes and experiences of pwld	N = 11 6 males 5 female Age: 20-40	Mixed methods: Survey of sexual attitudes (data excluded from current review) IPA Focus groups	Controlled by parents staff or society Viewing pornography on the internet or loving a person in secret as alternative sexual activities Support in getting married but	Credibility checks took place. A number of researchers were involved in generating the final themes to be included	No details of the questions and procedure that took place during data collection in the focus groups

Study and aims / research question	Sample	Methodology	Themes	Strengths	Limitations
			having difficulty in finding a partner Wanting to have the same rights as normal people but less confident about parenting Women's experiences of being sterilised, raped or sexually abused		

Appendix 2: CASP Qualitative checklist



Critical
Appraisal
Skills
Programme

10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- **Are the results of the review valid?**
- **What are the results?**
- **Will the results help locally?**

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.
These checklists were designed to be used as educational tools as part of a workshop setting
There will not be time in the small groups to answer them all in detail!

Screening Questions

1. Was there a clear statement of the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider
- What was the goal of the research?
- Why it was thought important?
- Its relevance

---

2. Is a qualitative methodology appropriate?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?

Detailed questions

3. Was the research design appropriate to address the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

---

4. Was the recruitment strategy appropriate to the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT:Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

---

6. Has the relationship between researcher and participants been adequately considered?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? ☐Yes ☐Can’t tell ☐No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

---

8. Was the data analysis sufficiently rigorous? ☐Yes ☐Can’t tell ☐No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings? ☐Yes ☐Can't tell ☐No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

---

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix 3: Example excerpt from table of first order, second order and third order constructs

Article	Themes from article	First order concepts (Original quotes)	Second order constructs (Authors comments)	Third order concepts
Sullivan, Bowden, McKenzie & Quayle (2013)	Touching people in relationships is: Wrong	Keith *"My friend…I said to my Mother, um, I'm going to invite her to stay with at my house and she turned around and said well if you're going to do that don't come back to the house…I phoned her Mother to say that, Um, I'll have to ask her to leave because my Mother says if I'd if I have her in the house then she's going to disown me'.*	Author: Many people spoke about sexual touching and how it was seen by others as wrong and a negative thing to do	Prohibition 'Threat of disowned' – similar to people fearing losing residency in other papers
IPA		*Lucy* *Somebody said we were having sex, but we weren't having sex at all, we were just chatting […] and they took us down and put us in detention together"*	Authors noted how participants distanced themselves from saying they were having sex.	
	Unsafe to talk about:	*"Int: …Have you got any close relationships* *Chloe: No (quick response, definite tone)* *Int: Have you had a close relationship in the past* *Chloe: I've got a relationship with a boy here […] but he doesn't do nothing like that [clear tone"]*	In circumstances that could be interpreted as having sex this possibility was defended against	
		Ben: *"I used to stay overs. I used to, first I used to sleep on the floor in her room, she had a double, a single bed, then her sister got a camp bed and I used to stay overnight"*		Secrecy?
		John: *"Um. She makes me a coffee, I make her a coffee, we have a coffee, we'll listen to a CD in the bedroom or we'll*		

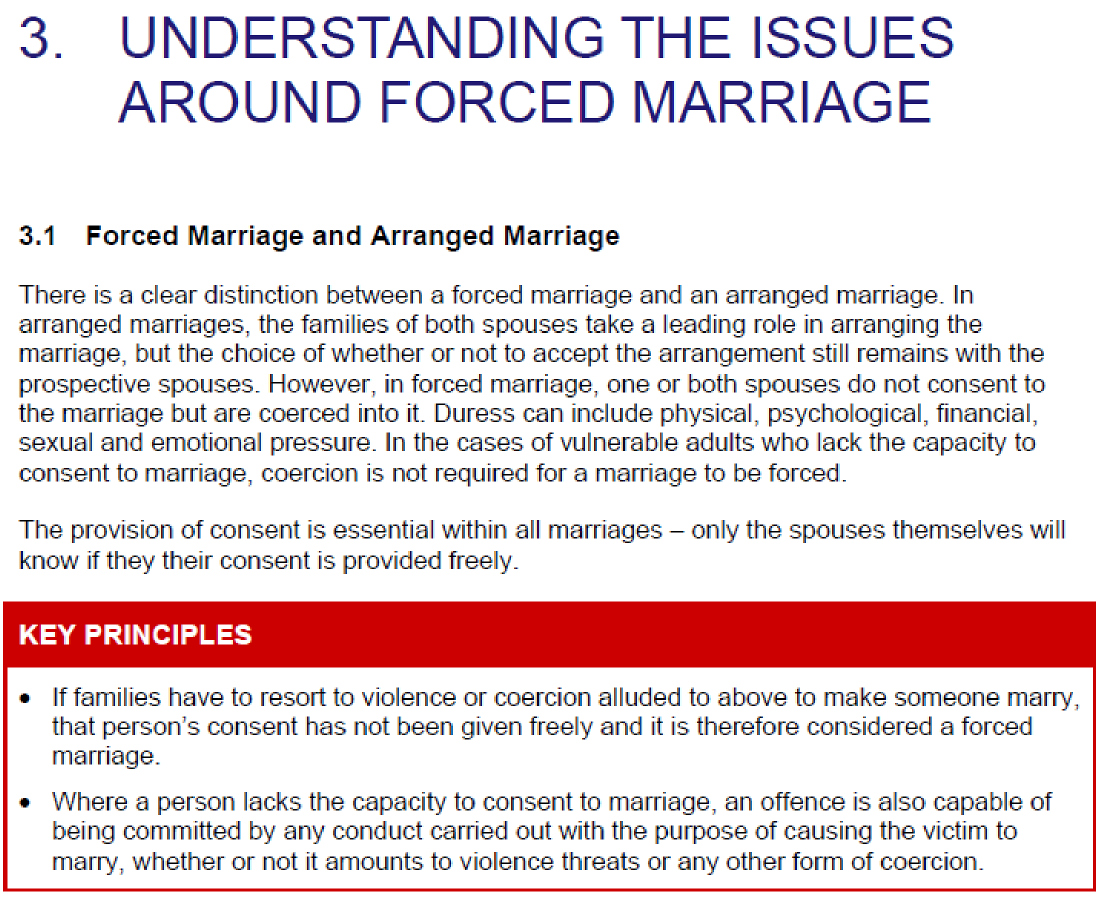
		got a lovely walk. We'll have lunch together"		Meaning of relationships Desire Companionship
	No freedom or fun:	John: *"No I'm not allowed. I can't […] they don't let me […] it's just the rules in this place. They don't let anybody stay overnight"*	Author's state: "The language and descriptions are akin to what one would expect of adolescents in a relationship where sexual behaviours are going to be experienced for the first time. This could reflect an inner conflict between the understanding of sex being wrong and sex being a natural process.	Suspended adolescence? External management of the relationship Prohibition
		"Int : what do you think relationships are' *Chloe: I think they just male love, ken man and wife and he just makes love to her […] its about like, how to make babies and how like that. And how the, how the man puts his penis in the, the lady's vagina and then makes the egg and then there's a baby"*	Authors: it would seem from this description of what was taken from the sex and relationship group that sex happened in marriage and was for the purpose of procreation	Sexual socialisation Sexual socialisation – biological, lack of pleasure Marriage, traditional, conservative views
	Being touched	No quotes extracted	Authors note a lack of sexual pleasure in the description. Also offer the	

			alternative that this is due to expressive language difficulties Talked about importance of physical contact, holding hands	

DECIDING ON THE SUITABILITY OF MARRIAGE FOR A PERSON WITH A LEARNING DISABILITY WITHIN A SOUTH-ASIAN COMMUNITY: STAFF AND MOTHER EXPERIENCES

APPENDICES

Appendix 1: Excerpts of government guidance of handling cases of forced marriage (HM, Government, 2014; Clawson & Vallance, 2010)



3. UNDERSTANDING THE ISSUES AROUND FORCED MARRIAGE

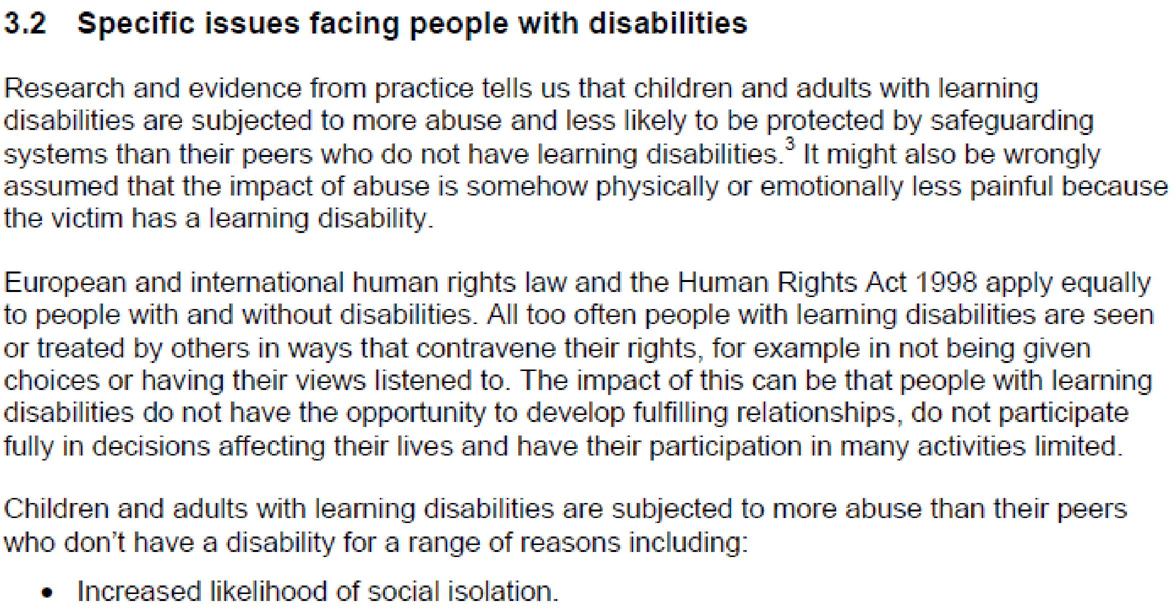
3.1 Forced Marriage and Arranged Marriage

There is a clear distinction between a forced marriage and an arranged marriage. In arranged marriages, the families of both spouses take a leading role in arranging the marriage, but the choice of whether or not to accept the arrangement still remains with the prospective spouses. However, in forced marriage, one or both spouses do not consent to the marriage but are coerced into it. Duress can include physical, psychological, financial, sexual and emotional pressure. In the cases of vulnerable adults who lack the capacity to consent to marriage, coercion is not required for a marriage to be forced.

The provision of consent is essential within all marriages – only the spouses themselves will know if they their consent is provided freely.

KEY PRINCIPLES

- If families have to resort to violence or coercion alluded to above to make someone marry, that person’s consent has not been given freely and it is therefore considered a forced marriage.
- Where a person lacks the capacity to consent to marriage, an offence is also capable of being committed by any conduct carried out with the purpose of causing the victim to marry, whether or not it amounts to violence threats or any other form of coercion.



3.2 Specific issues facing people with disabilities

Research and evidence from practice tells us that children and adults with learning disabilities are subjected to more abuse and less likely to be protected by safeguarding systems than their peers who do not have learning disabilities.[3] It might also be wrongly assumed that the impact of abuse is somehow physically or emotionally less painful because the victim has a learning disability.

European and international human rights law and the Human Rights Act 1998 apply equally to people with and without disabilities. All too often people with learning disabilities are seen or treated by others in ways that contravene their rights, for example in not being given choices or having their views listened to. The impact of this can be that people with learning disabilities do not have the opportunity to develop fulfilling relationships, do not participate fully in decisions affecting their lives and have their participation in many activities limited.

Children and adults with learning disabilities are subjected to more abuse than their peers who don’t have a disability for a range of reasons including:

- Increased likelihood of social isolation.

- Dependency on parents or family members and carers for practical assistance in daily living including intimate and personal care.
- Impaired capacity to resist or avoid abuse or understand that a situation is abusive.
- Speech, language and communication needs.
- Lack of access to a trusted person if wanting to disclose.
- For children and adults living in residential care, an additional dependency on staff for daily care and possibly no access to an independent person who can advocate on their behalf.
- Being more easily coerced or eager to please.
- Human rights not being recognised or respected.

Children and adults with learning disabilities are less likely to be safeguarded from harm than people without learning disabilities. Considering the age range of victims, the transition period between child and adult services for young people with learning disabilities is a time of particular vulnerability. Professionals are sometimes unable to recognise that abuse is taking place for a range of reasons including:

- Over identifying with parent or carer – this can lead to reluctance in accepting abuse is taking place or seeing it as being attributable to the stress of caring for a person with disabilities.
- Lack of knowledge about the impact of the learning disability on the child or adult.
- Lack of knowledge of the child or adult's usual behaviour.
- Confusing behaviours that indicate a person might be being abused with those associated with disability (e.g. behaviour that challenges).
- Accepting what are perceived to be "cultural norms".
- Lack of clear guidance in safeguarding policies and procedures.
- Not recognising forced marriage for what it is.
- Physical injuries, e.g. bruising, explained by the person's disability rather than abuse.
- Reliance on parents to speak for their child or explain behaviour or symptoms.
- Difficulty for professionals to remain confident in their own expertise when challenged by a parent or carer.
- The belief that a child or adult with a learning disability cannot communicate their wishes and feelings, or it is thought too difficult to obtain their views.[4]

3.3 Capacity to consent and the Mental Capacity Act 2005

The Mental Capacity Act 2005 applies to all people aged 16 and over. It aims both to empower people to make decisions for themselves whenever possible and to protect those who lack capacity to do this. The Act starts from the basis that, unless proved otherwise, all adults have the capacity to make decisions. Individuals may lack capacity if they are unable to:

- Understand information given to them.
- Retain that information for long enough to be able to make the decision.
- Weigh up the information available to make the decision.
- Communicate their decision to others.

Some key motives for forcing people with learning disabilities to marry include:

- Obtaining a carer for the person with a learning disability.
- Obtaining physical assistance for ageing parents.
- Obtaining financial security for the person with a learning disability.
- Believing the marriage will somehow "cure" the disability.
- A belief that marriage is a "rite of passage" for all young people.
- Mistrust of the "system", mistrust of external (e.g. social care/health) carers.
- A fear that younger siblings may be seen as undesirable if older sons or daughters are not already married.
- The marriage being seen as the only option or the right option (or both) – no alternative.

Appendix 2: Confirmation of Sponsorship

Appendix 3: National Research Ethics Committee favourable opnion

[redacted]

[redacted]

Appendix 4: Research and Innovation approval from host Trust

[redacted]

[redacted]

[redacted]

[redacted]

Appendix 5: Participant Information parents

UNIVERSITY OF
BIRMINGHAM

Participant information sheet

Title:

The experience of arranging a marriage for a son or daughter with a learning disability within the South-Asian community

My name is Najma Sultana. I am a trainee clinical psychologist from the University of Birmingham. Please take the time to read the information carefully so that you may decide whether or not you would like to take part in the research that I am doing as part of my training.

What is the research about?

I am interested in finding out about your experience of arranging a marriage for your son or daughter with a learning disability.

I am interested in what it is like to be you and how people from inside and outside of your community have responded to your wish to arrange this marriage.

Why have I been invited to take part?

You have been invited to take part as it is thought that you are a parent of a person with a learning disability and you have attempted to or have arranged a marriage for them within your community.

We would really like to hear about your experiences of arranging or attempting to arrange this marriage so that we can better understand what it is like to be you.

Do I have to take part?

It is entirely up to you to decide. If you do wish to take part then you will be asked to sign a consent form. You can also withdraw from the research at any time if you change your mind and you do not have to give a reason.

The services that you or your child currently receive will in no way be affected by your decision to take part or withdraw.

After the interviews have taken place, you will have one month to tell us if you would prefer that we did not use your data in the final results of this research. This is because after this time your results may have already been included in the final report.

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

- You may contact me at any time on the details below if you would like to ask more questions.
- I will contact you by telephone to confirm you meet the criteria set out by the research and we can then arrange a time and a place for us to meet to carry out the interview.

- Before we start the interview I will ask you to sign a consent form, if you are still happy to take part. If you would like to carry out the interviews away from your home address we may be able to pay for your travel costs.
- We will spend about 1- 1.5 hours together, talking about your experiences. I will ask you to talk freely about what you feel comfortable with and there is no expectation for you to talk about any part of your experiences that you do not feel comfortable with.
- The interview will also be recorded if you agree, so that it may be transcribed an analysed at a later date.

Sample question: Can you tell me about your experience of arranging a marriage for your son or daughter with a learning disability?

- I will also ask if you would like to look over the results of the report and discuss these with me in a telephone conversation in order to check that you agree with the way that I have analysed the results. It is up to you whether you would like to take part in this process.

What if there is a problem?

If during this study you become unhappy with any aspect of the research, please speak to me or my academic tutor. If you remain unhappy and wish to complain formally, you can do this through contacting the University of Birmingham's research department. The details of people you can contact can be found below.

What are the possible risks and benefits of taking part?

It is unlikely that there will be a great risk to you if you agree to take part. Some people may find it upsetting to talk about some of their experiences. If this happens during the interview I will pause or stop the interview. You can then decide if you wish to carry on, it will be entirely up to you. I will also leave you with a list of people you can contact if you feel you would like more support.

The aim of this research is to help professionals work in a way that better meets the needs of people similar to you. But we cannot promise that this research will directly help you or others within your family.

Who will find out what I say?

The things we talk about will remain private. This means that after we have met I will transcribe the interview in a way that removes all details that could make you identifiable. I will give you a number and a false name. My supervisors and I will then look over these transcripts after your details have been removed so we can analyse the results. All of your details will be kept on a password protected USB device that only I will know the password to. These details will be destroyed once the study has come to an end.

There may be significant circumstances where I will need to breach this confidentiality. This will only include situations where I am concerned for your safety or the safety of someone else or if I become aware of something that could be seen as a criminal activity.

The results of this study will be viewed by University supervisors and a clinical supervisor within the University of Birmingham and will be made publicly available from the University of Birmingham's library.

What happens next?

I will contact you via the telephone to a) double check you meet the criteria for the research, b) confirm you still wish to take part and c) arrange a time for us to conduct the interview.

Further information:

If you have any more questions please contact me on the number below.

Also if you would prefer to conduct the interview in a language other than English then please let me know during our telephone conversation and I will arrange for an interpreter to attend the interview.

You can also request to have this information sheet sent to you in your preferred language by contacting me on the number below.

Thank you for reading this information sheet.

Contact Details:

Chief investigator:

Name: Najma Sultana

Role: Trainee clinical Psychologist and Chief Investigator

Employer:

E-mail: [redacted]

Address:

School of Psychology
University of Birmingham
Edgbaston
Birmingham
B15 2TT

Academic Supervisor:

Name:	Biza Stenfert-Kroese
Role:	Senior Lecturer and academic supervisor
Employer:	University of Birmingham
Contact:	[redacted]

Clinical Supervisor:

Name:	Dr Laura Ogi
Role:	Clinical Psychologist
Employer:	
Contact:	

University of Birmingham's research department:

Head of Research Governance and Ethics

Dr Sean Jennings

Research Governance Officer

[redacted]

Telephone: [redacted]

E-mail: [redacted]

List of organisations who can provide you with support:

Mind

www.mind.org.uk

Tel: 0845 766 0163

Careline

www.careline.org

Tel: 0845 1228622

(Confidential counselling over the telephone)

Carers Trust

www.carers.org (for information and support)

www.hft.org.uk/bmeguide (for a list of services designed to support carers within black, minority and ethnic communities).

Appendix 5: Participant Information staff

UNIVERSITY OF
BIRMINGHAM

Participant Information Sheet

Title:

The experience of working with South-Asian families who are arranging a marriage for their son or daughter with a learning disability whose capacity to consent to marriage has been called into question.

My name is Najma Sultana. I am a trainee clinical psychologist from the University of Birmingham. Please take the time to read the information carefully so that you may decide whether or not you would like to take part in the research that I am doing as part of my training.

Please read this information sheet alongside the separate sheet that includes definitions of terms that will be used in this sheet.

Why are we doing this study?

Arranged marriages are thought to be common in the South-Asian community. This also includes the arranged marriages of people with a learning disability.

Research suggests that sometimes questions around the individual with a learning disabilities capacity to consent to marriage can put professionals in a situation where they are asked to make difficult decisions.

We are interested in what it is like to be you, so that we can learn how to develop this area of clinical practice.

Why have I been invited to take part?

You have been selected to take part as it is thought that you have in the past worked with or are currently working with a South-Asian family who wish to or have arranged a marriage for an individual with a learning disability whose capacity to consent to marriage has been called into question.

Please check that you meet the following criteria before you decide whether or not to take part:

'South-Asian':

The families that you have worked with or are currently working with are from a South-Asian descent (includes Bangladesh, Bhutan, India, Pakistan, Maldives, Nepal and Sri-Lanka).

'NHS employee'

In this instance an 'NHS employee' refers to any member of the multi-disciplinary team, (i.e a community team for learning disabilities) who is part of the process of determining whether or not the individual has capacity to consent to marriage.

'Arranging a marriage'

Arranging a marriage can refer to a number of instances:

a) an attempt to arrange a marriage for the individual with a learning disability that did not progress for a number of reasons (e.g. denied a Visa)

b) if the family that you are working with are currently in the process of arranging a marriage for their family member with a learning disability

c) if the marriage has already taken place prior to or subsequent to concerns about the individuals capacity to consent.

Do I have to take part?

It is entirely up to you to decide. If you do wish to take part then you will be asked to reply to this e-mail to confirm this. You can also withdraw from the research at any time if you change your mind and you do not have to give a reason.

After the interviews have taken place, you will have one month to tell us if you prefer that we do not use your data in the final results of this research. This is because after this time your results may have already been included in the final report.

What is the process if I agree to take part?

- You will be asked to confirm your interest to take part by responding to this e-mail.
- I will then contact you by telephone and arrange a time and a place for us to meet to carry out the interview. I will ask you to sign a consent form when we meet
- We will spend about 1- 1.5 hours together, talking about your experiences. I will ask you to talk freely about what you feel comfortable with and there is no expectation for you to talk about any part of your experiences that you do not feel comfortable with.
- The interview will also be recorded, if you are happy with this, so that it may be transcribed an analysed at a later date.

- This interview will ask you open questions about your experiences of working with families of a South-Asian descent who have arranged or wish to arrange a marriage for an individual with a learning disability whose capacity to consent to marriage has been questioned.

Sample question: Can you tell me about your experience of working with these families where there are concerns about an individual's capacity to consent to marriage?

What if there is a problem?

If during this study you become unhappy with any aspect of the research, please speak to me or my academic tutor. If you remain unhappy and wish to complain formally, you can do this through contacting the University of Birmingham's research department. The details of people you can contact can be found below.

What are the possible risks and benefits of taking part?

It is unlikely that there will be a great risk to you if you agree to take part. Some people may find it upsetting to talk about some of their experiences. If this happens during the interview I will pause or stop the interview. You can then decide if you wish to carry on, it will be entirely up to you.

Whilst an aim of the study is to understand whether clinical practice can be improved and if so how, it cannot be promised that the research will help you in your role directly.

This research may however highlight common difficulties within community teams across professionals who work within multi-disciplinary settings and provide a platform to share knowledge and experience.

Will my taking part in this study be confidential?

All of the information about your participation in this study will be kept confidential. You will not be directly identifiable in any of the published results.

You will have an identification number assigned to you and you will be given a false name to ensure anonymity.

There may be significant circumstances where the researcher will need to breach confidentiality due to their duty as a researcher. These circumstances include situations where the researcher is concerned for your safety or the safety of others.

My supervisors and I will then look over these transcripts after your details have been removed so we can analyse the results.

All of your details will be kept on a password protected USB device that only I will know the password to. These details will be destroyed once the study has come to an end.

The results of this study will be will be made publicly available from the University of Birmingham's library.

What happens next?

If you do not wish to take part no further action is required.

If you wish to take part, please e-mail me [redacted] I will then contact you via e-mail shortly.

Further information:

If you would like to discuss any part of this research in order to help you make a decision or at any point during the research then please do not hesitate to contact me on the number below or via e-mail.

Contact Details:

Chief investigator:

Name: Najma Sultana

Role: Trainee clinical Psychologist and Chief Investigator

Employer:

E-mail: [redacted]

Address:

School of Psychology

University of Birmingham

Edgbaston

Birmingham

B15 2TT

Academic Supervisor:

Name: Biza Stenfert-Kroese

Role: Senior Lecturer and academic supervisor

Employer: University of Birmingham

Contact: [redacted]

Clinical Supervisor:

Name: Laura Ogi

Role: Clinical Psychologist

Employer:

Contact:

University of Birmingham's research department:

Head of Research Governance and Ethics

Dr Sean Jennings

Research Governance Officer

[redacted]

Telephone: [redacted]

E-mail: [redacted]

Appendix 7: Interview schedule parents

Q1: Can you tell me about your family?

Prompts:

Who’s important?

Who is around?

Ways of living that are central to the family, family structure

Q2: How would you describe your family and your cultural heritage?

Prompts:

Migration history – How does that fit with the family’s views and ways of being.

Are there any differing views in the family? What is that influenced by?

Q3 What are your beliefs about marriage? Are these influenced by your cultural heritage in any way?

Prompts:

Is it important, if so why?

What are the reasons for why people marry?

Is there any influence on the British values/ have your views changed over time in any way? Why?

Q4: Can you tell me about X (child with a LD), how do they fit into the family story?

Prompts:

Likes, dislikes, process of adjusting to them having ‘special needs’, functioning, any idea of their views about marriage

Q5: Can you tell me about how marriages usually happen/ come about?

Prompt:

Was it any different for x?

Was anything easier or difficult?

Q6 What happened when you began to explore the possibility of arranging a marriage for x/ How have you gone about making a decision about marriage for your son/ daughter?

Prompts:

Who was involved?

Who did you approach?

Were any services involved? Such as health care or social services?

Did you anticipate/ experience any problems?

What was helpful?

Q7: What were your reasons for arranging this marriage?

Prompt

Were these motivations the same as or different in any way to other times when you’ve sought to arrange a marriage for your other children?

Q8: How do you see the future for X?

Q9: In your opinion what could services do the same or differently in the future when working with families with your heritage who wish to arrange a marriage for their son / daughter?

Appendix 8: Interview schedule staff

Q1: What was your involvement in the process of working with these families and the individual when the persons capacity to marriage was called into question?

Prompts:

What was your role?

Q2: How did you first hear about the possibility of X getting married?

Prompts :

Journey / process

What were your initial thoughts / feelings?

What happened then?

What was important to consider when you undertook/ contributed to the decision about capacity?

Q3: How would you describe your relationship with X and their family before this?

Q4: Can you tell me about how your relationship with the family developed during this process? What about your relationship with X?

Prompt:

Did anything change about your relationship with the family / X

What do you think X would say about the process?

What do you think the family would say about the process?

Q5: Can you tell me about how this case was talked about within the team?

Prompts:

If you were to describe the mood/ temperature in the team, how would you characterise it?

Who was involved, how did things develop

How were views expressed?

How were differences resolved? Both within the team and with the family?

Q6: ('stepping away from the service for a while'…) In terms of the impact of this case on you personally, what was it like?

Q7: In your cultural experience what does marriage mean to you, what is it about?

Q8: What are your expectations of marriage and what role do you think they might have had on your experience of this process?

Q9: What advice would you give to another clinician who finds themselves in a similar situation?

Q10: In your opinion what could services do the same or differently in the future when working with families from the SAC who wish to arrange a marriage for their son / daughter?

Appendix 9: Case summary Aisha (mother)

Aisha is a 51 year old female of Pakistani heritage. She was born in the UK and would be classed as second generation in terms of her migration history.

Aisha currently lives with her husband, daughter and son. They recently moved back to the Midlands.

Aisha values relationships with her family in particular. This may relate to her experiences of having a forced marriage and having to leave her family behind. Aisha had to cut all ties with her family in order to have a ‘love marriage’. That is to marry a person that she fell in love with that her family did not chose for her.

She described feeling that she was living a life of servitude, she didn’t know her own identity because she was a Muslim woman. She describes wanting ‘out of her life’, ‘wanting to have her own life’ and struggling with her own identity. Aisha was particularly concerned with her daughter’s vulnerability and preserving her daughter’s virtue.

Appendix 10: Case summary Reshma (mother)

Reshma is a single Mum, she has four children. Two girls and two boys. The eldest son and daughter are married and live away from home. The youngest daughter lives at home and her son is 16 and has autism and a moderate learning disability.

She was born in the UK, but moved to Pakistan at 6 months old. She came back into the UK at age 10/11. Her father first moved to the UK during WW11, he then moved back to Pakistan and had three children and moved back to the UK after 18 years, following the war.

They visited Pakistan for 8 weeks, came back to the UK and after two years her husband dies. He fell off a roof whilst he was working. Their son was 5 months old at the time her husband died. They stayed in this country after that.

This Mum talks about the special bond she has with her child, how he is special and how she puts him first over herself and others. She sees him as a gift from God and this will her love for him brings a great deal of value and satisfaction in being his Mum. She does however blame herself for his disability at times and this may explain why she puts him first as well.

'I'm saying maybe he's got er learning difficulty of that maybe it's got effect of that because I was sad when I was in front of him I just couldn't talk to him'.

Appendix 11: Case summary Mandeep (mother)

Mandeep is a single Mum, she had an arranged marriage and she described her marriage as ‘failing’ as he wasn’t contributing towards the family. Her son has a learning disability as a result of contracting tb meningitis during childhood and he also has epilepsy.

Because of her experiences with her own arranged marriage she is more open to the idea of loved marriages. She also talks about times changing in relation to the expectation. As a single parents she feels she doesn’t want to or have to put her culture on them

Migration history. Her parents were from India. Dad came over into the country first. Talks about him ‘working hard’.

Appendix 12: Case summary Amarjit (mother)

Amarjit is a 63 year old female. She is of Indian heritage and is therefore first generation. She is also Sikh. She was born in India and came to the UK at age 13-14, she married into the UK to her husband. She had not met him before and had only seen a picture of him. She talks of taking a chance with this situation. She had not undertaken much of the care giver role for her son with Down syndrome. She provided for the house through work. However when her Mother in law passed away she then had to take on the care giving responsibility, which seemed to be a surprise to her. It exposed to stigma that she had no experienced before. She often asks why he had this difficulty, but finds solace in comparing him to others in the sense that he is not that bad. She finds a physical disability as worse than an intellectual disability as they require more hands on physical care.

She talks about not trusting love marriages. Also of difficult experiences of being taken to court, accused of arranging her son to marry. She sees him as normal. Wants to focus on the cans and not the cant's. She does not want him to be alone.

Her husband's friend who they have known for a long time in India has a niece. He mentioned to the parents that his niece was coming from India on a 6months visa and if they were interested then they could arrange for them to meet to see how they get on. He took a picture of his wife of the girl in college and stated 'my wife'. Told she couldn't go ahead with the marriage. Took away freedom (passport) and pushed the 'cant's' on him again.

Appendix 13: Example of mother's transcript analysis

Emerging concept	**Line no**	**Quote / excerpt**	**Commentary**
An uncertain future	P1_889-902	I have actually asked my sister-in-law, what should I do? What should I do!? I don't know where to go and I don't know what to do… But I am just scared because I'm – I'm 50. I don't know what- what's around the corner what if, what if, my thoughts are now, ***what if,*** I walk out this house, go down the road, go across the road get hit by a bus… Where does that leave my daughter? There is nobody else, because I've lived my life for 25 years outside of this city, they haven't had much to do with my daughter … So if anything happens to me who's going to look after my daughter? Yes, her father will… But… How is he going to look after her future? Because I'm the one that does all the thinking in this family, I think (laughs)	
	P2_470-474	P: it is a bit harder because sometimes I'm thinking like that I'm thinking… I'm getting older is what if I die and who will look after him? That's all worried about, me. And er then I was thinking it's up to God or Allah, you know, whatever happens, we can't do it… Will help me.	
	P4_270-276	P: something could – I mean anything could happen to me now, old age, we don't know and he's young, we're old, if we have to go then we have to go. I: And what you worried about?	

- The responsibility		P: Yeah, I'm worried, that's what I'm worried about now. They got their families and everything, where he stands we don't know and he don't know himself. P: it feels it, it-it feels it's been really hard over the last few years, it feels like I'm micromanaging everything, and nobody understands	
	P1_794-802	P: I've gone through some tough times. I've come near enough to proper nervous breakdown…erm I have actually.my… the one who saved me was my sister, my youngest sister, she is the only one I can turn to	
	P4_115-116	P: he was 13 or 14 when all of the responsibilities came onto my [points to shoulders]	
- Services cannot be relied upon to a secure a future	P1_1136-1147	When she went through her educational statement in school, they said that she would get one-to-one. She never got that one-to-one, not properly. She maybe got it for a year or so she – she got it in her – in her erm nursery and junior school erm but again she – but only given certain amounts of time to get this one-to-one and then when she hits 16 she never had any think she never had any help whatsoever. Finished. Completely disappeared.	
	P4_587-591	P: Yeah trust is going, yeah, he – he comes here… It's alright for time being couple of times he comes here if he grows I mean he can come here 'till 40, after that what's happening? We don't know if can get the services or not… If his condition got worse	

		what happens? Nobody give us an answer	
Marriage as a multi-functional yet risky option	P3_172_176	But, obviously, with my child with learning disabilities, I'd always be there for him, as long as I live, but, to see him in a relationship, settling down, while I'm alive, takes that stress and burden off myself…	To reduce burden of the worry about the future
	P1_1154-1162	but because she's not getting any help from any of the governmental services, she's not being able to overcome the difficulties, hence the reason why we – I am then having to try and help her find somebody that we, ***feel,*** (Doubt?) will look after her and keep a safe.	
	P1_1217-1221	S: I'm hoping, I'm gearing- I'm teaching her to be able to do these things herself. I don't want her husband to be her mother. I don't want her husband to be her father. I want her husband to be her husband; to be her husband, and her lover- and a friend, all in one. Just like a normal person. That's what I want for her.	
	P3_228-230	P: It is tough, but it's scary, but, obviously, it's a challenge, and you wanna give that person the best quality of life, and what he wants.	Marriage can give her son a good quality of life
	P4_176-179	I don't mind, if she's English or what. There should be someone who can listen, he listened to her, her listened to him. Should be someone, somebody should be ***there,*** not have to do is stay on his own. But can't give the guarantee of the others hunna? Can't	

	P4_301-304 P4_153-156 P1_822-830	give the guarantee, that they're going to stay. Nobody can. I: okay so you are saying that marriage was the answer but it was a solution? P: yeah a solution or a bit relief, some peace of mind, thinking, yeah he's got a.. partner or whatever, to talk to, he's not on his own. … He wanted to get married, why can't he do it? What we want – that's what we want to know why can't he get married? Why? He got the feeling, he understand I mean, he understand- why? He's not that bad P: because I want her to be able to – I don't want – because of the difficulties … I don't want her getting married to a stranger, I want to be able to know what the family is like that she is going to get married into I: yeah P: so then I know, that she's going to be safe… I: so what – how would that guarantee that safety? P: there's no guarantee in it, I can only hope and do as much research as I can on a family before I say yes… there's no guarantees erm but we can only do our best	
The search for an	P1_912-917	I - for me, I feel that if we could find somebody who would love	

idea partner as an almost impossible task Vulnerability – Independence		her for, love her for who she is, because some of the boys that she did get involved with knew straightaway that there was something – and that's why, why they would take advantage of. I – I want somebody that will take her for *who* she is and what she is what she knows erm and not just.. take advantage of her.	
	P1_1020-1024	I: somebody who's quiet because [name] is quiet… Somebody who's not materialistic… And somebody who would be able to take care of her needs and I think her needs is that her only need I believe, is that she just wants somebody to love her. Her mum and dad's love is not enough. We can shower her with love but it's not enough	
	P1_1222-1228	I: Do you think that she is capable of finding somebody with those qualities herself? P: Nah. I don't think so because of the amount of times that she's – I've only explained about one or two incidents, there's been more than one or two incidents and she'll not find anybody because they all just take advantage of her, and she just takes everybody at face value. Even now sometimes takes people at face value.	Choosing right partner depends on what is valued in the culture
	P2_416-424	It's just about choosing the right partner, you can't – you can't find the right partner for him.	
	P2_562_573	P: and these days you know it's really difficult to find a partner, who understand. You know because that he – if you could find the partner that's like that's really you know like, caring and you know like look after his money and to want to support, but these days you can't find the partners like that, especially in our Asian	

		culture I: what is it about the culture that stops that? P: I don't know I can't answer that question [Laughs] I can't answer that question	
Vulnerability – Independence	P2_390-394	…that's right and you know, that's why I can't send him any trip or anything like – if anything happened and he ca-he-can- he can't answer me if anything happened to hit you? He can't say. He just, he won't remember. He needs someone there. He doesn't know how to cross the road, even now as well	
	P3_183_184	… Well, it, it just depends on if he finds anybody who's compatible to him	
	P3_196-203	P…to make sure that he's not being abused or… you know what I mean? It's <u>hard</u> [strongly], and it's, it's, erm, it's an area where it's very difficult for parents… because, obviously, he… he will get frustrated, but then he needs to be explained to, and… who's going to give that kind of support back to him? I:: Yeah. P: … And it's very hard to find that ideal person.	
	P3_212-219	And they want to be independent, but, obviously,… by being independent, it's control of your finances, but, obviously, with [name] somebody needs to be, is <u>appointed</u> to control his finances. And, you know what I mean, there's quite a lot, there's, there's a, there's a world out there where you're not gonna find people who are genuine, and that's the hardest thing	

		for parents.	
	P3_457-459	I think the world is… can be corrupted, and I think you, you can't be too naïve… You've got to look at everything.	
	P4_447-450	it just leave it to see how the things goes, how their reaction is and first thing how the girls reaction is. We know the boy is-our son is like this, it's er life of the girl, girls life, we were going to see, how her reactions are. '	
Stigma & what's valued	P4_324-327	P: she was here the six months, then erm sometimes they been shopping together. They been all right, she told us *he's not that **bad***, she told us, not that bad. Then we got a bit of relief that they could er,	Value in society is reduced so have to consider other options or ways to increase value
	P4_436-438	P: Do that yeah because- it depends, if the girl says yes, 'cos the girl says 'he's not that bad', she says that, then why should we mind, why should the boys side mind it	
	P2_452_463	I think in the Asian community a lot of people look at, oh is that person good-looking, is the facial features right have they got a good job or are they capable of doing a job, basically what they call a full package. I think that's what puts a lot of things down when it comes to disability children because no parent would want their child to get married to a disability person where they can't do anything for themselves and he's not going to be able to support the woman. So I think that's what makes it hard to think about marriage for him because what Asian communities look for he won't provide	

	P3_211-212 P4_447-450	The stigma is, oh, who, who wants to marry somebody who's got a learning disability? And they want to be independent it just leave it to see how the things goes, how their reaction is and first thing how the girls reaction is. We know the boy is-our son is like this, it's er life of the girl, girls life, we were going to see, how her reactions are. '	It's up to the girl to make the decision. Different to how it usually is. Feeling at her mercy?
Scaffolding the future structure of the marriage Preserving, enhancing or accepting their child's worth in an implicit cultural currency	P1-739-743 P1_807-820	erm…I think it lessons they value, I think it erm it is talked about she'll be talked about and I don't want that but they'll talk about her from the point of view that she's- she's been with you know she's been talking to boys this that and the other and that's not good. But they don't understand, that she doesn't understand so she is- in her mind I think that she is looking for a lifetime partner, somebody that's going to stay with her and that's – she's seen me and her dad , together, and I think that's her ***ideal*** – what she wants in life erm… And that's what I want to give her, that's why want to get her, but if – if our name is dragged through the dirt she's not gonna get that	Stigma attached to having relationships outside of marriage, reduces her daughters value Value or virtue in securing a future for females

Negotiating the value placed on continuing cultural heritage	P1_725-735	Scared of common type of thing because if – if – I do end up speaking to somebody who is – who's Asian, or from the same social group as her or anything like that, I don't know whether my family knows them and I feel then it's not going to give [name] a good chance of finding a lifetime partner, because even nowadays, the culture comes into it, you know if they find out that she is like being with somebody or- Don touch her!	
	P2_410-414	it's like erm…from the back home I thought that you know- because I know that if you take him back home, because he's got British passport and they will give the girls because- even if you –whatever girl you wanna choose, but they just want come, come to this country just for the stay	An awareness of the value of British citizenship
	P3_188_190	Obviously,… if it was abroad, it's a lot difficult, because, obviously, he's gonna be on benefits for the rest of his life, and, if I'm not around, who would be supporting him?	An awareness of the value of an income
	P3_416-420	P: But he's been told so many times, 'It doesn't matter.' But then, you know what I mean, it's nice to have your culture,… I: Yeah. P: … but you don't know who you might fall in love with.	
	P3_232-234	Yeah, if he had a love marriage, and if it was outside the family, that's fine, but I would've preferred, like I said, with the child with the learning difficulty, well, with all my sons, that I would prefer if it was an Asian girl, so you can carry on your culture.	

	P3_388-391	So, you lose that culture. But… as we sat down and spoke, he's always says, 'Oh, mum, I can't, there's no Asian girls.' … His, you know what I mean, 'cos he's more limited now…	
	P4_175-176	Because, if she get pregnant, I know it's hard in our society to see, girl can't live like this, but if- I don't mind, if she's English or what.	
	P4_168-174	I don't mind, if she's English or what. He should be with someone, if he can't get married, is there any chance he can live with someone? Like in this country, friends, boyfriend, girlfriend they live together. We don't mind for him to live like that he can live like that – but the social workers say he can't live like that either	
	P4_205-211	P: Oh, it's different, love marriage I: so how is it different? P: be honest, my son is- my son is love marriage [son without LD], but I don't trust love marriage, no. I don't know what time she has to go, if er is arguments happen, or their situations gone different, like It-a- we can say English people,'til they got the money and everything girls all right, otherwise they leave husband.	

Appendix 14: Expert from emerging staff themes

Emerging theme	Line no	Quote / excerpt	Notes
Navigating through a complex and emotive task without a clear frame of reference	P1_Pg3/77-84	So we can assess people and a lot of their life choices that they're going to be based on, this decision that can sometimes feel quite arbitrary and… we, sort of, pluck out of the air of, 'Well, they seem to know this or… not know this.' Erm… and sometimes, I guess, it feels a bit like it depends what people want the answer to be; how complicated they make the question, which feels wrong…	Personal biases in the process A sense of unfairness
	P1_Pg3/86-91	Well, that,… actually, if we see somebody that… you, that the feel from the team is they, kind of, want to protect, erm, and that are quite patriarchal and, kind of,… saved from making a bad decision, then the bar seems to sometimes get pushed to be higher than for somebody else, maybe, where the bar's quite low.	Shifting bar- not consistently applied
	P1_Pg3/92-93	I: What sort of factors might influence, erm… you know, say, so protecting that need to protect? P:…In fact, just risk, just, kind of, what risk people could, could see. (Talking about forensic case- changing bar)	
	P1_482-484	it's always hard, because there isn't a, there isn't a set, there isn't a [chuckles], 'This is where you need to get to.' So it, kind of, it always… comes down to subjectivity	Vague process
	P1_465-	I think sometimes it's about having those discussions, and that's,	

	471	erm, where I’m quite happy to, kind of, weigh in as the team, and not, kind of, taking over as, ‘Yes, it does,’ or, ‘No, it doesn’t,’ but, kind of, asking some of the questions of… ‘Do we think that’s an insufficient answer because it’s not our answer, or because we think it’s just not… an answer at all?’	
	P1_725-728	so, yeah, I think a lot of the time I, it, it’s about try, because I think that can be quite difficult, and I find it quite difficult and sometimes I don’t have a relationship before a capacity assessment with somebody	Importance of building a relationship with pwld
	P1_1315-1326	P: I guess it helps… to think through, ‘I we expecting the right amount or are we expecting more from our guys with learning disabilities than we’d expect from someone without a learning disability?’ which seems inordinately unfair to expect more of people, erm… than anybody else would, would expect. I guess, it, that, in terms of my experience,… I: Yeah. P: … quite often… relates back when we’re having these discussions to… I went to see the registrar before I got married and I don’t remember him asking me 18 different questions…	
	P3_42-44	I think the biggest issue for me… is that… I feel I’m completely out of step with colleagues with my capacity assessments	
	P3_62-67	Social workers are forever saying, ‘This person has the capacity, you know, to choose where they live, to follow the care plan.’ I say, ‘No, they don’t.’ And we, we, it just, kind of, goes nowhere.	

		And, if I'm not the decision-maker, then… actually, the social workers' view normally holds sway.	
	P3_89-91 P3_96-99	the main issue is that… within… within… the, sort of, framework for making, for assessing capacity, I, I put most emphasis on weighing up the pros and cons. … … actually, truly weighing up the pros and cons, understanding the emotional impact and responsibilities, I think a lot of clients can't do that, but other people don't seem to put that same emphasis on. So that gets very difficult.	
	P3_221-238	P:… And because, and I've been surprised at how… er, by the change. I mean, he communicates much better now, he makes better eye contact. It's almost like he's les autistic [chuckles] as a result of this process. I: Yeah. P:So,… I think I would've said, when I first met [name], that, that almost certainly he didn't have the capacity to marry, because of weighing up the pros and cons,… I: Yeah. P:… weighing the balance. Now I'm not so sure. I'm right on the borderline	Capacity unclear, changeable, uncertainty for him?
	P3_250-254	Erm… but it's a tricky one, 'cos I'm, I'm, you know, there's no, I'm, I'm, actually,… I'm actually pretty clear in my mind that, if he… if he lacked, if, if he lacked capacity, it would be, it would still be in his best interests, I think. Best interest doesn't come into it with marriage.	
	P3_641-		

	644	The, the, the major difficulty is a difficult across, across all capacity assessments, not just marriage, is that… [long pause]… people <u>want</u> it to be objective, and I think it's always subjective. That's the difficulty. It is an opinion	
	P3_1070-1072	So I think that's where the bias comes in, is I, I see the autism, I see the impact with autism where other people, perhaps, don't give that so much weight.	
	P3_281-284	but I have trouble getting my head around the status of women in, in Islam, full stop [nervous laugh]. Yeah, something I find difficult, on a personal level. So I bring that bias to the party [chuckles]	
	P3_990-995	I <u>know</u> that my threshold is different. NS: Why do you think your threshold is different? SH: Because I think **[0:54:05]** always, you know, I think it's impossible for everyone to have the same threshold, because everyone looks at things differently. Erm, it's partly, I think, because I, I see the autism more than other people.	
	P2_467-478	P:that's what we're really trying to assess is their communication. We're not assessing in relation to the decision, we're just assessing their communication. And I guess that takes me right back to where I started, which is…what's the speech therapist's [chuckles] job in all of this? I: Yeah. P: It isn't, it isn't our job to have an opinion about the… subject	Feels contradictory, as later excerpts suggest they do contribute to the assessment (weight of responsibility)

	P2_252-257 P2_282-285 P2_297-303 P4-71-75 P4_79-80 P4_275-280	or the outcome of the assessment. Our job is to assess the communication… quite often the question I have to stop and ask myself is, 'This is really complex and it raises all sorts of strong emotions in everybody involved, so what is the speech and language therapy job here? What's, what's my task? What do they want me to do?' It doesn't matter what I think about… whether it's right for anybody to get married, whether it's right for anybody to have an arranged marriage or… That's not my question. And I think that's the, that's the thing I sometimes have to do in, lots of times in the job, is to think, stop a minute,… [long pause]… I know there are really complicated questions […examples, marriage, FGM reversal limits chances of pregnancy etc] […]all of those things are a question for another day. That's not what I've been asked to do. So I think those sorts of things are quite complicated, but, erm… I think it is, your own practice is to set those things aside and to think just about the question in front of you, and I think that's really important, to be focused on what we're be asked to do as health professionals So, like, one, the initial one I, I was involved with, erm… had this severe learning disability and married. And that **[0:03:16]**, 'How can you, how can you get, you know, that person, how can that person be married?' you know, because there's no understanding at all, you know. Yeah, yeah. That's it, you know. You have that feeling, you know if she has children, you know, who will take on that responsibility?' you	Reducing question removes complication and uncertainty / ambiguity Difficult emotio

		know. ‘What do, how will she look after the children?’ and those kind of questions crept in my mind, you know, but I wasn’t ask, I wasn’t giving them any suggestions, but I was just analysing in my mind, you know, thinking…	
The facts and the evidence – emotions are managed differently	P1_1101-1103	yes, quite often it’s having a lot of those discussions, a lot of bringing it back to the, kind of, the facts, the evidence	
Getting pulled in different directions? Some people rely on evidence and make the process as scientific and logical as possible where as others go on instinct, experience.	P1_1104-1114	And a lot of the time, when I’m seeing people, I’m scribbling frantically, writing exactly, exactly what somebody has said to exactly what question, which is why it’s handy having, kind of, some set-ish questions out, erm… to be able to go back and go, ‘What part of that wasn’t enough?’ Erm… ‘What else would you want them to say in that?’ And sometimes it’s, the people have, don’t, they don’t know what else they want someone to say; they just want it to be a more and more…thorough answer.	Value in facts, personal emotions are unwelcome, introduce inconsistency
	P1_1221	I try very hard to not let it influence my role in my work. [her perceptions of marriage]	
	P3_315-311	I might do a home visit, for instance, and, so, someone with a mild learning disability, usually with autism, who was married years ago, maybe they’ve had one or two children,… and… the wife… seems to me, whenever I have a chance to **[0:16:50]**, to be desperately unhappy. … Erm… sometimes, a year or two down the line, I’m proved right, because… she leaves and the whole thing breaks down	Gets drawn into worries about the future. Makes decision based upon previous experiences of marriages ‘breaking down’

	P3_357-362	And, in my experience, that… the marriage has been a positive influence on that client's life in, maybe, 10-20% of cases. In other cases it's negative, because they… they can't cope with the stress; the expectations on them, sometimes. Erm, and then, when, if they did have children, it's almost always a complete disaster, in my experience.	
	P3_308-312	I don't, well, I don't want, I don't really, I suppose I don't really talk about my views, as I say, really. It, it doesn't feel like I need to talk about that explicitly in order, you know, unless there's act, actually some… something that could be classified as abuse or potential safe-guarding. It's not really something I talk about.	
	P5_ 483-489	I think it's important that you have that, because I think, otherwise, if you come in too cold,… you don't really understand the person. … So I don't think it was, erm… I, I think it helped,… I think it made the decision… more complex, but I think it meant that it was a more… erm… it was a… better decision, because you've understood the whole person.	Emotions make the decision making process more complex but more or a holistic well-balanced decision
	P5_1175-1192	I think I did have to think. I think I, I probably think about a lot of this stuff anyway, a lot of the time [chuckles]. Erm… it's always something that I, kind of, read up about; it's something that I'm quite interested in, in different cultures. I'm… I've, kind of, done quite a bit of volunteer work abroad, so I've done some, er, volunteer work in slums in India, [..]So I… would like to think I'm quite aware of those sort of values [uncertain], but I guess there's always things like this that bring them to the forefront, and I think it's really helpful to be, kind of, open and, to thinking about them. I don't think you can… er, well, I think you're aiming for failure if you try and separate out your values, put them to one side and then do a job,	Important to be culturally sensitive and aware

		because I think we’re humans and… you’re actually just ignoring any biases that you might have. I think you’re better to be aware of those biases and then be able to address them, and to be able to…erm… rather than just, kind of, say, ‘Oh no, I’m not biased at all,’…	
	P5_1194-1202	…because, obviously, like, you, you can’t change where you come from. Erm, I can’t change how I’ve been brought up and the values and ideas that I’ve been brought up with. Erm… I can become aware of them… and challenge them [chuckles]… and be aware of where they’ve developed from, but, yeah, I think… if you ignore them, you’re just asking for trouble	
	P2_985-995	I think that’s something that, erm, it’s important to be able to suspend… some of your own beliefs and not try and bring those to bear, erm, because then, I think, people from my background might actually say that arranged marriages weren’t a good thing, because, you know, how could you know that you were going to learn to love somebody? You, you might not know that. That would be… So, I think, erm… yeah, I think it, I think you have to be, I think you have to take a bit of time to think around… not bringing your own thoughts… to those things.	
	P2_998-1009	But, actually, it’s not important what I believe. What, what I need to do is to… make the assessment around… the points of both the law and the person’s wellbeing. It’s not about my beliefs, so I have to keep those to myself, but	
	P2_1049-	My very first thing would be, always, ‘What are you being asked to do?’… because I think it becomes incredibly difficult, if we start getting involved with whether, whether it’s right or wrong	

	1055	and what we believe and what another culture believes, and what… what you bring in and what you leave behind. I don't, I, I think that's really hard.	
	P2-269-280	So, emotionally, I would, I would always try not to, to feel like I was going to battle on anybody's side, if you like. I don't, I don't think, erm, I suppose… it was my… at an emotional level, at a personal level, erm,… I wanted [name] to be able to get married, because I could see that she could understand and it was definitely what she wanted. And, for the other girl, I wanted her to be protected from what I could see, appeared to me, to be some sort of abuse. But my job was to just be able to demonstrate what their language understanding was, so that they could both be judged to have… in [name]'s case, to have capacity, and, in the other girl's case, to not have capacity. And that, that was all, as far as my job goes	In her use of language even though she is saying she is neural and objective it sounds like she had an agenda
	P2_560-565	… I think… the most satisfactory thing is to be a scientist and to provide evidence. Er, you're not going to persuade somebody by saying, 'I'm right and you're wrong.' Just go round in circles. So, I think to be able to provide document, well-documented evidence to set in front of somebody.	
	P4_423-426	Mmm As I said, you know,… clear-cut, like, likes and dislikes are too different to the actual things, you know. So… in a way I thought, You know…It's hard, isn't it? It's hard at that time, but whatever is, needs to be said and done, it has to be done at that time. What's a fact is a fact, isn't it?	Defensive, seeking reassurance?

	P4_642 P4_374-380 P4_1032-1041 P4_1061	I: What was that like for you, then, having to offer that opinion? P: … That was the fact, isn't it? So, my opinion was a factual thing. What I stated was what I found, you know. … think so. My opinion and my approach, my assessments are two different things. Yeah. NS: Mmm, OK. How do you find a way to separate the two of them? I look it from a professional point of view, whereas my marriage and, you know, things like that, that's my personal view, my personal opinion. But, when I'm doing assessment, it's very professional. Yeah. P:… Just don't be judgemental, be very subjective, er, very objective, not subjective [correcting], yeah. Not subjective, but be very objective, you know. … And… based on the facts, really, and information. I: Why, why would you say that's important? P:… But that's, that's it is, isn't it? That is important, whatever facts they are, you know. As a professional, you will only give your opinion, whatever, based on the factual information. You're giving a bias, like a unbiased opinion	

Appendix 15: Example of how experiences across groups were compared

Getting it right: The acceptability of risk when the YPwLd's well-being is at stake **Getting it right: Balancing the roles of protector and facilitator of freedom**			
staff	P1_Pg3/86-91	Well, that,… actually, if we see somebody that… you, that the feel from the team is they, kind of, want to protect, erm, and that are quite patriarchal and, kind of,… saved from making a bad decision, then the bar seems to sometimes get pushed to be higher than for somebody else, maybe, where the bar's quite low.	Decisions are based on how vulnerable the person is perceived to be. Based on this people express different thresholds. Also how they see their role.
	P1_Pg3/92-93	I:What sort of factors might influence, erm… you know, say, so protecting that need to protect? P:…In fact, just risk, just, kind of, what risk people could, could see. (Talking about forensic case- changing bar)	
	P1_1315-1326	I guess it helps… to think through, 'I we expecting the right amount or are we expecting more from our guys with learning disabilities than we'd expect from someone without a learning disability?' which seems inordinately unfair to expect more of people, erm… than anybody else would, would expect.	Awareness of different thresholds. Reflecting upon whether this is fair. Perhaps they want a consistent approach.
	P3_42-44	I think the biggest issue for me… is that… I feel I'm completely out of step with colleagues with my capacity assessments	
	P3_641-644	The, the, the major difficulty is a difficult across, across all capacity assessments, not just marriage, is that… [long pause]… people <u>want</u> it to be objective, and I think it's always subjective. That's the difficulty. It is an opinion	
	P3_990-995	P:I <u>know</u> that my threshold is different. I: Why do you think your threshold is different?	

		P: Because I think **[0:54:05]** always, you know, I think it's impossible for everyone to have the same threshold, because everyone looks at things differently. Erm, it's partly, I think, because I, I see the autism more than other people.	
	P5_237-247	…internally, I wanted to do, I didn't want to be, kind of, like… what's the word? Er like over-protective. … I wanted to, kind of, like, promote independence and…all of those values,… but, at the same time, you don't want, yeah, you, kind of,… don't want to leave someone vulnerable.	
	P5_237-236	…sex and relationships is such a core part of human life. You know, we… we'd, kind of, be stupid to think that peop, just because somebody has a learning disability, that they wouldn't want those things. Erm, but, also, they're quite a complicated part of human life [chuckles], and I think sometimes [chuckles], if you've got, like, a learning disability, it can be quite hard to understand and navigate…them, and that leaves people very vulnerable.	
	P5_198-213	You know, saying whether somebody can or can't… have… sex or get married, erm… felt like quite a lot of pressure, and I was very cautious that I didn't want to be, you know, or you, kind of, feel that you don't want to go too far one way and be like, 'No, of course not, they're too vulnerable [certain],' and take their, kind of,… <u>freedom</u> away and their right to choose, but, equally, you don't want to leave somebody vulnerable to… erm… you know, a forced marriage or, erm… unwanted, kind of, sexual advances. … Erm… and I think that was really… that was really hard. Erm… yeah, erm, yeah, I <u>really</u> struggled with that.	Some staff try and make the decision more balanced
	P3_862-863	But… what I struggle with is, is the long term [sighs] outlook for these kind of clients…	

	P3_875-880	[…] Erm… she just doesn't get it, and she never will get it. And I find that extraordinarily tough… because I, perhaps I over-empathise. I **[0:48:33]** from her point of view, she's in a prison, because she hasn't got the life that she wants, doesn't understand why people are protecting her, why people think she's vulnerable.	
	P2_676-684	Erm, quite often people have quite a fixed view. Often quite, erm… I think the word might be 'paternalistic'… You know, 'somebody else knows best'. 'Better to let those people decide.' And that's really difficult.	
	P2_698-701	often families can be very protective, they believe protective, but, actually, they might be denying somebody a fulfilling experience or… whatever it happens to be. So it's interesting, sort of, two sides of the coin.	Familes and staff can be over-protective
Mothers	P1_634-646	I'm one of them ones that want to give my child, my daughter that freedom because I was never given that freedom … but I'm on two sides of the scale now where I wanna give her that freedom but because of her difficulties I find it really hard to give her that freedom- because of what's happened in the past. Not my past, her past	
	P3_271-277	Erm, I suppose he could, erm, be, like, financial abuse. Obviously, he's not going to tell you… tell you much, but, obviously, erm, it's… financial or… you know what I mean, it's the way he might behave… or… [pause] because, obviously, erm… he'd be, you know what I mean, you don't want him to fear too much, but, obviously, you, you've got to protect him as well.	
	P3_572-578	my child with learning difficulties is, it's like… you're constant… it's like you're with a child you're in junior school, so you've still got to fetch them, bring them. Yeah.	

		P: But, the thing is, it's letting go and letting them have their freedom. … And, sometimes, they'll make choices, which they know can be wrong, but, to them, it could be	
	P2-390-394	P: that's right and you know, that's why I can't send him any trip or anything like – if anything happened and he ca-he-can- he can't answer me if anything happened to hit you? He can't say. He just, he won't remember. He needs someone there. He doesn't know how to cross the road, even now as well	
	P2_399-400	He doesn't know the danger. He doesn't know the danger.	
		Parents and acceptability of risk	
Mothers	P1_822-830	P:because of the difficulties … I don't want her getting married to a stranger, I want to be able to know what the family is like that she is going to get married into so then I know, that she's going to be safe… I:so what – how would that guarantee that safety? P: there's no guarantee in it, I can only hope and do as much research as I can on a family before I say yes… there's no guarantees erm but we can only do our best	Risk here seems to be that the person will be vulnerable or at risk Risk is that the marriage will not work and marriage does not provide that long term future security
	P4_301-306	yeah a solution or a bit relief, some peace of mind, thinking, yeah he's got a.. partner or whatever, to talk to, he's not on his own. But can't give the guarantee of the others hunna? Can't give the guarantee, that they're going to stay. Nobody can.	
		' it just leave it to see how the things goes, how their reaction is and first thing how the girls reaction is. We know the boy is-our son is like this, it's er life of the girl,	For Amarjit her

	P4_447-450	girls life, we were going to see, how her reactions are. ‘	object of concern is marital breakdown.
	_324-327	P: she was here the six months, then erm sometimes they been shopping together. They been all right, she told us *he’s not that bad*, she told us, not that bad. Then we got a bit of relief that they could er,	So she felt that as the other woman said he’s not that bad, the risk was acceptable as he is not that bad
	P4_436-438	…do that yeah because- it depends, if the girl says yes, ‘cos the girl says ‘he’s not that bad’, she says that, then why should we mind, why should the boys side mind it	Scaffolding the future structure of the marriage – parents solve the problem about risk in this way – based on cultural values and social norms
	P1_880-803	The potential- yeah and I was like, but that’s not going to work one she has difficulties and if he has a mental breakdown and they get married, how on earth are they going to – how is that marriage gonna work? because she has difficulties well, but then I don’t think that to difficulties together gonna work.	
	P2_410-414	it’s like erm…from the back home I thought that you know- because I know that if you take him back home, because he’s got British passport and they will give the girls because- even if you –whatever girl you wanna choose, but they just want come, come to this country just for the stay	For Reshma the value of a British Passport is still not enough of a reason for her to take the risk, as her object of concern is that the longevity of the marriage cannot be assured