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VOLUME I
RESEARCH COMPONENT
EXPERIENCES AND ATTITUDES OF HEALTH PROFESSIONALS WHO
DELIVER SERVICES FOR ADULTS WITH LEARNING DISABILITIES

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A thesis submitted to the University of Birmingham
for the degree of Doctorate in Clinical Psychology.

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Overview

This thesis was submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D.Clin.Psy.) at the University of Birmingham. It comprises a research volume (I) and a clinical volume (II).

Volume I

The research component comprises of a literature review, a research paper and a public domain paper. The literature review summarises recent literature regarding the attitudes of healthcare professionals who provide care for people with learning disabilities. The research paper describes a study explores midwives' experiences of caring for women with learning disabilities. It is intended that the literature review will be submitted to 'Journal of Applied Research in Intellectual Disabilities' and the research paper to 'Midwifery'. The public domain paper summarises both the literature review and research paper.

Volume II

The clinical component contains five Clinical Practice Reports (CPRs). CPR 1 presents a case formulation from cognitive and psychodynamic perspectives of a 30-year-old male with anxiety and intrusive thoughts. CPR 2 is an audit reviewing access to psychological therapies for clients with a diagnosis of psychosis within CMHTs. CPR 3 describes a single case experimental design of a case of a 10-year-old boy referred to CAMHS presenting with anxiety. CPR 4 details a case study of a woman with a mild learning disability referred to psychology for support around hoarding. An abstract summarising a clinical presentation (CPR 5) of a case of a 66-year-old gentleman under the care of the Older People Mental Health service for management of his depression is also presented.

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Literature review

**A systematic review of the attitudes of healthcare professionals who
provide care for people with learning disabilities**

**A systematic review of the attitudes of healthcare professionals who
provide care for people with learning disabilities**

Abstract

Background: It has been recognised that people with learning disabilities (LD) are not receiving appropriate healthcare, resulting in their health needs being inadequately cared for. Several causative factors have been proposed to account for this inequality, from difficulties in accessing services to the attitudes of healthcare professionals' delivering healthcare provision. The aim of this paper was to investigate how healthcare professionals' attitudes may have changed since Fitzsimmons & Barr's (1997) review and the impact, if any, on the quality of care available for people with LD. *Materials and Methods:* Fourteen papers were identified following a systematic literature search and were evaluated in terms of their quality. *Results:* Key themes were identified across the fourteen papers relevant to the healthcare provision for people with LD including a lack of LD training and education available, barriers which affect the provision of healthcare, how the professionals' viewed their role in the delivery of community care for people with LD and their view of specialist services. The quality assessment suggested a medium risk of bias across the literature. *Conclusions:* Healthcare professionals' attitudes towards caring for people with LD varied both across and within the studies included in the review. There appears to be multiple cognitive and social factors that influence professionals' attitudes, affecting their intentions regarding care and subsequent care provision. Limitations of the studies are noted, with a discussion of the findings in terms of a comparison to the previous review, clinical implications and recommendations for future research.

Key words: healthcare professional; learning disabilities; attitude; quality of healthcare.

Introduction

In recent decades, concerns regarding the health needs of people with learning disabilities (LD) not being adequately cared for have been well documented (e.g. ‘Valuing People’, 2001). People with LD have high prevalence of varied and complex health needs (e.g. diabetes, epilepsy), highlighting the importance of accessible and adequate healthcare for this client group (Disability Rights Commission, 2006). Unfortunately, however, they are more likely to have significant unmet health needs than the general population (Campbell, 2007; Kent, 2008).

Michael (2008) proposed that people with LD do not require specialist healthcare and that ‘reasonable adjustments’ could make services accessible for people with LD (Disability Discrimination Act, 1995). Research has tended to focus on accessibility of generic healthcare services for people with LD (e.g. Alborz et al., 2005; Backer et al., 2009). However, this client group are continuing to experience difficulties in accessing effective healthcare. There is limited research into the actual provision of health services, yet the delivery of services could act as a barrier to care (Bradbury-Jones et al., 2013) including, for example, communication issues (Bollard, 2003) and professionals lacking in experience of working with people with LD (D’Eath et al., 2005). This suggests that despite the efforts in place to provide equal access to healthcare for people with LD (e.g. DoH, 2000, 2009), there remain barriers that significantly affect the quality of healthcare this client group receive. This leaves people with LD with unmet health needs and an inequitable healthcare service (Leeder & Dominello, 2005; Ouellette-Kuntz, 2005).

With more people with LD accessing mainstream health services, health professionals are increasingly likely to come into contact with this client group. It has been recognised that in order to deliver adequate healthcare to people with LD, professionals working in

mainstream services will need to develop appropriate knowledge, skills and attitudes (NHS Executive, 1998).

Research has identified a number of barriers such as lack of training, communication difficulties and time constraints on delivering adequate healthcare for people with LD resulting in dissatisfaction with the quality of care they receive (Glasby, 2002; Disability Rights Commission 2006; Mencap, 2007). Bradbury-Jones et al (2013)'s review of the wellbeing and safety of people with LD in hospitals concluded that discrimination towards people with LD from healthcare professionals is common, with both carers (Gibbs et al., 2008) and people with LD (Iacono & Davis, 2003) experiencing negative comments from professionals.

Turnbull (1995) suggested that healthcare professionals might assume that people with LD do not smoke, consume alcohol, work or engage in sexual activity. This may inadvertently affect the essential and preventative healthcare delivered for associated health risks such as cancer. The personal view a health professional holds regarding disability may affect how people with LD are perceived, which in turn may affect clinical practice and guidance (Temple & Murdoch, 2012). Barker & Howells (1990) and Minihao et al (1993) stress the importance of health professionals' attitudes towards their patients with LD, suggesting that negative attitudes may adversely influence the quality of healthcare. Howells (1996) and Scott & Routledge (1997) also propose that negative attitudes may contribute to the barriers that people with LD face in accessing equitable healthcare.

Fishbein & Ajzen's (1975) Theory of Reasoned Action (TRA) has been commonly applied when exploring the influence of attitudes on behaviour. One's attitude can be defined as 'a person's evaluation of any psychological object or specific behaviour' (Ajzen & Fishbein, 1980). This theory proposes a link between cognitions, social behaviour and

subsequent behaviour, with one's attitude being one of the fundamental cognitive factors predicting the behaviour performed.

Fishbein's (1998) integrated behavioural model (IBM) draws upon other social psychological theories to expand upon TRA. IBM proposes that multiple factors integrate to influence one's behaviour. Applying IBM (Figure 1) to consider the cognitive and social factors determining professionals' attitudes toward healthcare provision for people with LD, suggests that variables such as age, gender and education affect beliefs regarding the provision of care. Attitudes, perceived norms and self-efficacy are, according to IBM, products of one's beliefs. Relevant beliefs include 1/ views regarding the consequences of providing care (*behavioural beliefs*) which influence one's attitude towards the provision of care; 2/ *normative beliefs* regarding the provision of care, which affects one's perception of what is deemed the norm in terms of care provision; and 3/ *efficacy beliefs* concerning specific barriers to care that affect one's belief in one's skills and abilities to provide care.

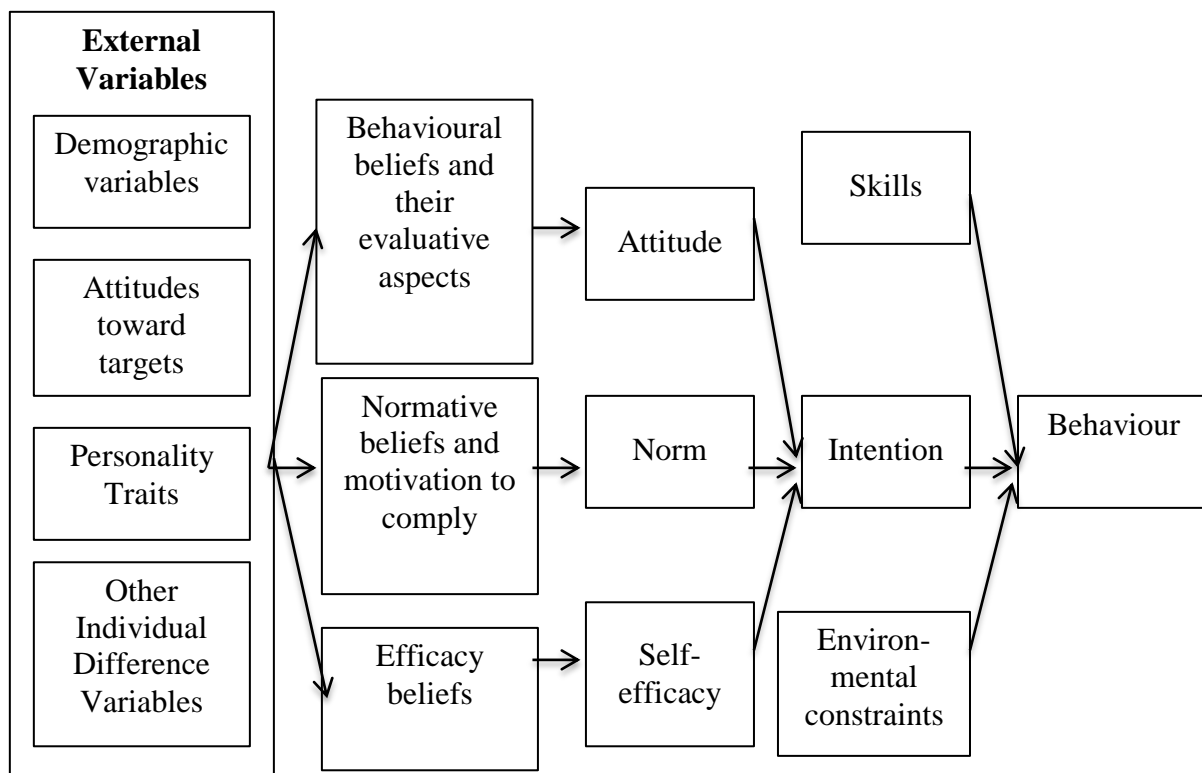


Figure 1: Fishbein's (1998) Integrated Behavioural Model (IBM).

Considering the potential significant impact of healthcare professionals' attitudes upon the quality of healthcare accessible for people with LD, there is limited research into this area (Bradley-Jones et al., 2013; Gill, Stenfert Kroese & Rose, 2002; Lewis & Stenfert Kroese, 2010). A recent review (Bradley-Jones et al., 2013) concluded that there appears to be a variety of influences on the standard of healthcare delivered to people with LD; both direct (e.g. professionals' knowledge and attitudes towards LD, communication issues, environmental factors), indirect (e.g. liaison with specialist services, education, training) and social, economic and political influences.

A previous review conducted by Fitzsimmons & Barr (1997) on eleven studies from 1986-1996, concerning predominately student nurses' and physicians' attitudes towards people with LD, reported that many studies explored the influence of education, contact,

gender, and time in training on attitudes. Most studies used the Attitudes Towards Disabled Persons Scale (ATDP; Yuker et al., 1960) with one study designing a bespoke questionnaire.

Common findings included participants' lack of ability to clearly define a LD including a limited understanding of how LD impacts upon an individual and not being able to distinguish between LD and mental health difficulties. Nurses felt inadequately skilled to work with people with LD especially in relation to communication and identified a need for further LD education and training. It was reported that medical students held a positive yet stereotypical attitude towards people with LD (May et al, 1994) and that general practitioner's (GPs) attitudes were less positive and they had lower expectations regarding the health of people with LD (Langan & Russell, 1993). There was inconclusive support for the hypothesis that contact with people with LD, education and gender are predicting factors of professionals' attitudes towards people with LD.

Fitzsimmons & Barr (1997) recommended that alongside developing professionals' knowledge and providing experiences of caring for people with LD, consideration needs to be given to their attitudes towards people with LD in particular their concerns and anxieties around caring for people with LD. To facilitate individualised training to meet professionals' needs, it was suggested that supervision and varied clinical practice in delivering care for people with LD (including experience of service user and carer feedback) during student placements could foster positive attitudes of people with LD and challenge stereotypical views.

The limited reliability, accuracy and practical relevance of the research reviewed were recognised (e.g. student samples, small convenience samples). It was observed there was a reliance on the ATDP scale, which has questionable statistical properties and none of the studies included in the review acknowledged the limitations of the scale. Fitzsimmons & Barr

(1997) recommended that attitude scales be developed in relation to specific attitudes relevant to people with LD (e.g. community inclusion). It was also suggested that a range of healthcare professionals were included in future studies to support the accuracy and generalisability of findings. Further research was recommended on how personal characteristics influence attitudes. Fitzsimmons & Barr (1997) concluded that no studies included in their review had established a correlation between attitude and behaviour towards people with LD, strongly recommending that this needed to be a focus of future research.

Fitzsimmons & Barr (1997) concluded that given the aim of health services to deliver needs-led, person-centred care, there needs to be recognition of the rights of people with LD in accessing equitable healthcare and an understanding of how negative stereotypes and attitudes towards people with LD can influence the services they are offered. They argued that such understanding and respect for people with LD can improve current and future services to ensure people with LD receive the healthcare they both need and are entitled to.

Fitzsimmons & Barr's (1997) review did not employ a systematic search of the literature and their inclusion criterion is unclear, which could question the reliability of the review. However, some valid recommendations were made including the development of an attitude questionnaire relevant for healthcare professionals' caring for people with LD. The recent change within the LD population (e.g. move to community living) would not be represented within Fitzsimmons & Barr's (1997) review. Thus it is important to conduct an up to date literature search, which would be more representative of the current attitudes of healthcare professionals regarding the LD population. It is beneficial to have an initial review of healthcare professionals' attitudes towards people with LD (Fitzsimmons & Barr, 1997) to refer to in an area of scarce literature, regardless of its limitations. Fitzsimmons & Barr's (1997) review supports this paper to explore if there have been any changes in healthcare

professionals' attitudes towards people with LD following the community move. This paper is also able to consider if the recommendations made by Fitzsimmons & Barr (1997) have been implemented (e.g. clinical supervision and training) and if so, if there has been any impact upon healthcare professionals' attitudes towards people with LD.

Aim of literature review

The aim of this paper was to evaluate the existing evidence of healthcare professionals' attitudes towards working with people with LD and how these attitudes may affect the quality of healthcare provision for people with LD. Given Fitzsimmons & Barr (1997) reviewed the literature published up to 1996, this systematic review evaluates research papers published from 1996-2013 to establish the nature and the quality of more recent evidence on health professionals' attitudes towards people with LD which would offer a more accurate representation of current attitudes held by healthcare professionals towards people with LD following the community move.

Materials and Method

A systematic literature search was conducted following a standard procedure (Centre for Research Dissemination, 2008). A search of the subject was completed to consider what literature on healthcare professionals' attitudes towards people with LD had been published since the Fitzsimmons & Barr (1997) review. This initial search used key search terms (see Table 1), which were incorporated into a stringent search strategy employing a number of electronic databases in order for relevant literature to be identified (see Figure 2 for search strategy).

Table 1: Search terms.

Search level	Subject area	Search strategy
1	Attitudes	Search terms - ‘attitudes’ <i>or</i> ‘perceptions’ <i>or</i> ‘reactions’ <i>or</i> ‘beliefs’
2	Healthcare Professionals	Search terms- ‘health care professionals’ <i>or</i> ‘General practitioner*’ <i>or</i> ‘GP*’ <i>or</i> ‘nurse*’ <i>or</i> ‘health care staff’
3	Health professionals’ attitudes	Combine search 1 and 2
4	Learning Disabilities	Search terms – ‘learning disability*’ <i>or</i> ‘intellectual disability*’ <i>or</i> ‘mental retardation’ <i>or</i> ‘developmental disabilities’
5	Health professionals’ attitudes towards people with Learning Disabilities	Combine search 3 and 4

Databases searched were PsycARTICLES, Embase, Medline, Psycinfo and Pubmed. These databases were selected to facilitate a comprehensive search of the relevant literature. Pubmed and Medline target a range of health disciplines, which was considered important given the review aimed to include research on a variety of healthcare professionals.

Along with key search terms, inclusion and exclusion criteria formed part of the systematic search. Inclusion criteria were:

- Published in an English language journal.
- Published between 1996-2013 (to form an up-to-date literature review since Fitzsimmons & Barr’s 1997 review).
- Published in a peer-reviewed journal.
- Participants are physical healthcare professionals.

Exclusion criteria -

- Studies primarily investigating other disabilities (e.g. physical health) where results specific to LD could not be extracted.
- Studies concerning mental health professions (e.g. psychiatry, mental health nurses) or LD nurses.
- Studies concerned with staff experiences of caring for people with LD.
- Included in the review by Fitzsimmons & Barr (1997).

Subsequent to the database search, abstracts of the identified articles were examined to identify papers related to the aim of the review. Those deemed irrelevant were excluded. The relevant articles were subject to a manual reference and citation search to identify any papers that may have been overlooked.

Fourteen articles were deemed suitable for the literature review - nine GP studies, two student doctor studies, two nurse studies and one student nurse study.

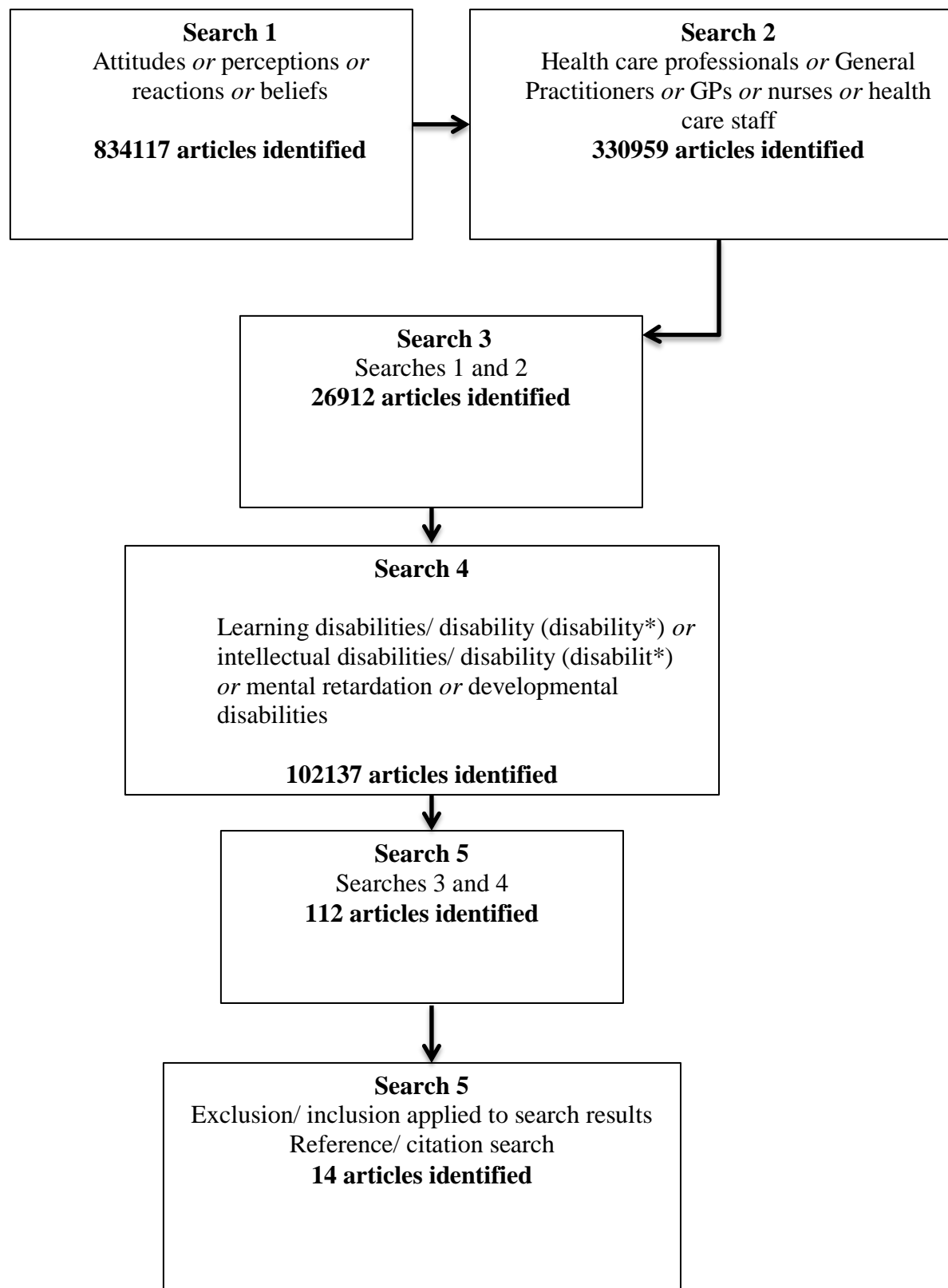


Figure 2: Search Strategy

As part of the systematic literature procedure, the quality of the studies was assessed using an assessment tool designed to evaluate the quality of non-randomised studies, the Risk of Bias Assessment Tool for Nonrandomized Studies (RoBANS; Kim et al, 2013). RoBANS is a valid tool assessing bias of non-randomised studies, which includes questionnaire designs. It is deemed to be consistent with the Cochrane Risk of Bias tool (Higgins et al., 2011) and a suitable tool to apply when conducting systematic reviews (Centre for Reviews and Dissemination, 2009; Moher et al., 2009; Park et al, 2011). The results of this review will only comment on the quantitative data reported in the included studies. It is recognised that five of the included studies reported qualitative data. However, these data are largely anecdotal, with limited detail on method and analysis reported.

Inter-rater reliability was established through a colleague assessing seven papers with the RoBans quality assessment tool and their scores checked against those of the author. 100% agreement was reached across all seven papers.

Results

Table 2 details the aims, samples, methodologies and key findings of the fourteen studies included in the review as well as the outcome of the quality assessment. The quality of the studies was assessed using the RoBANS. The RoBANS determines the level of risk of bias based on six domains, selection of participants, confounding variables, measurement of exposure, blinding of outcome assessment, incomplete outcome data and selective reporting. For the purpose of this review, the RoBANS was modified to evaluate the quality of non-experimental studies only. The domain *blinding of outcome assessments* was therefore omitted as no papers included in the review used outcome assessments.

The studies are listed in alphabetical order and numbered. The remainder of the review will refer to the studies by their corresponding number as detailed in the table below.

Table 2: Main findings of included studies					
Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
1. Bond, Kerr, Dunstan & Thapar (1997). UK.	To compare the attitudes of GPs from two regions and explore the potential factors underlying their attitude	463 qualified GPs, 257 responses (55% response rate)	Intellectual disability attitude (Kerr et al, 1996) questionnaire mailed to GPs. The questionnaire included 20 statements concerning a range of issues relevant to the health care for people with LD. The participant indicated what extent they agreed with each statement between strongly agree and strongly disagree. Analysis – ANOVA and factor analysis.	Medium risk of bias	GPs agreed they held responsibility for medical care and had a role in health promotion and screening for people with LD. GPs reported that LD services provided useful support and valued input. Older GPs were more likely to demonstrate less positive attitudes. GPs reported that the move to community for people with LD would greatly increase their workload.

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
2. Dovey & Webb (2000). New Zealand.	To explore how GPs viewed their role in the provision of healthcare for people with LD and any issues they experienced in providing healthcare to this client group.	Random sample of 250 out of 698 registered GPs, 137 responses (55% response rate).	Intellectual disability attitude questionnaire (Kerr et al, 1996) posted to 250 randomly selected GPs. Questionnaire adapted in terms of language for New Zealand participants. Open-ended questions added to inform quantitative information. Analysis – Mann Whitney U tests, cluster analysis and thematic analysis.	Medium risk of bias	54% of GPs reported feeling that they had little influence over care of people with LD. Role acknowledged by 62%. GPs acknowledged reliance on recommendations from specialist services. 69% agreed usefulness of CLDT. GPs reported that extra time and funding was needed deliver good quality care and they had a lack of specific LD training and experience. Older GPs showed more agreement that medication was treatment of choice and that history taking was unlikely to help. Female GPs were more likely to expect increase in workload from people with LD moving into the community. GPs felt it was inappropriate to make distinction between people with LD and other patients.

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
3. Gill, Stenfort Kroese & Rose (2002). UK.	To investigate GPs' attitudes and emotions to providing healthcare for people with LD.	613 GPs, 310 responses (51% response rate).	A questionnaire comprising of an attitude scale and an emotion scale specifically designed for this study was mailed to GPs. Analysis – Pearson correlations to explore relationships, T tests to explore difference in attitude scores in relation to demographic information, qualitative comments regarding experiences.	Low risk of bias	No significant difference in mean attitude scores between GPs who had or hadn't received LD training. Limited LD training reported. GPs who had more experience of working with people with LD recorded higher attitude scores than GPs with limited experience. GPs with frequent contact showed more positive attitudes than those least frequent. Personal contact levels showed no difference in terms of attitude score. Negative associations between age and attitude and time as GP and attitude reported. Females had higher mean attitude scores than males. Positive attitude towards people with LD reported with low frequency of negative emotions and moderate frequency of positive emotions. Frustration/ relaxation cited as most frequent, frightened/ optimistic least frequent. Negative association between attitude scores and score on negative emotion scale.

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
4. Kerr, Dunstan, Thapar (1996). UK.	To measure the attitudes of GPs to providing primary healthcare for people with LD.	242 GPs, 126 response rate (52%).	<p>A 'learning disability attitude questionnaire' (Kerr et al, 1996) was constructed for the study. Responses were marked from strongly agree to strongly disagree.</p> <p>The questionnaire was mailed to GPs.</p> <p>Analysis - chi square test, Mann Whitney U-test and cluster analysis.</p>	Medium risk of bias	<p>GPs agreed to their role in providing healthcare for people with LD.</p> <p>GPs disagreed they were responsible for health checks/ hearing and eye assessments.</p> <p>GPs agreed there should be screening checks offered to people with LD, with varying interest in fulfilling this view of role.</p> <p>GPs reported to value specialist services.</p>

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
5. Lennox & Cook (2000). New Zealand	To understand the barriers faced by student doctors in their provision of healthcare to people with LD.	289 student doctors, 157 returned questionnaires. 54% response rate.	Questionnaire specifically designed for this study. Descriptive statistics reported. Specific analysis unknown.	Medium risk of bias	18% of students felt adequately trained in providing healthcare for people with LD with 98% prepared to receive further information on health care of people with LD. 94% believed health care would be improved if received further education. Students reported limited experience of people with LD and 58% did not feel confident in treating people with LD. Students did not view GPs as having a lead role in provision of healthcare for people with LD. Barriers cited included communication with people with LD, limited consultation times, continuity of care, liaison with other health professionals, limited funding and a lack of awareness of resources available for people with LD.

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
6. Lennox, Diggins & Ugoni (1997). Australia.	To understand the barriers that GPs experience in their provision of healthcare for people with LD and their views upon these issues.	1000 randomly selected GPs, 526 returned questionnaires (58%).	<p>Questionnaire designed specifically for this study was mailed to participants.</p> <p>The questionnaire had 24 items, with responses ranging from strongly agree – strongly disagree. Participants were also asked to list the three most significant barriers to providing health care for people with LD and ways in which these barriers could be overcome/ minimised.</p> <p>Analysis – descriptive statistics.</p>	Medium risk of bias	<p>People with LD constituted 0.7% of GPs caseload. Two-thirds of GP agreed they felt inexperienced. Two-thirds also felt confident when treating people with LD. 86% of GPs deemed themselves as the primary professional in healthcare provision for people with LD.</p> <p>Common barriers cited as communication difficulties, lack of knowledge of specific health conditions affecting people with LD, length of consultations, insufficient funding, lack of continuity of care.</p> <p>GPs agreed they would be able to provide better health care if they undertook further training and education.</p>

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
7. Lennox, Diggins & Ugoni (2000). Australia.	To explore GPs view of the importance of attending to health care issues for people with LD and their role in providing this level of care.	1000 randomly selected GPs, 526 returned questionnaires (58%).	<p>Questionnaire specifically designed for this study to ascertain participant's attitudes towards health care issues for people with LD.</p> <p>Participants responded never – always, in relation to the importance of the health care issues, the GPs responsibility in addressing the issues, how often they addressed the issues in consultations and their intention to attend to the issues in future.</p> <p>Descriptive statistics presented. No details of analysis reported.</p>	Medium risk of bias	<p>Most GPs agreed it was their role and responsibility to facilitate or ensure that health care issues were attended to in consultations with people with LD (e.g. review of medication, thyroid testing, health screening, nutritional and lifestyle advice, annual health reviews).</p> <p>GPs rated the level of importance of attending to healthcare issues at least 93%. GPs addressing healthcare issues in current care rated as 14-42% and intention to address in future care 53-91%.</p>

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
8. Lewis & Stenfert Kroese (2010). UK.	To study the attitudes and emotional reactions of nurses in their provision of healthcare for people with LD.	1450 questionnaires distributed to qualified nurses across 58 NHS hospital wards. Response rate – 20%.	<p>A self report attitude and emotional reaction questionnaire was developed specifically for this study.</p> <p>The questionnaires were distributed among ward staff and returned anonymously.</p> <p>The questionnaire included two hypothetical vignettes, an attitude scale and an emotional experience scale. Participants read the vignettes and completed the attitude/ emotional scales.</p> <p>Analysis – descriptive statistics, Wilcoxon-signed rank tests, Spearman’s rho correlation and Kruskal-Wallis Chi.</p>	Low risk of bias	<p>Nurses reported that their skills and training were inadequate to meet the healthcare needs of people with LD.</p> <p>Nurses’ age and gender was reported to have no effect upon their attitudes or emotions in healthcare provision for people with LD.</p> <p>Nurses held significantly less positive attitudes and experienced fewer positive emotions in response to people with LD compared to other patients with disabilities.</p> <p>It was noted that nursing staff reported difficulties in the provision of care for people with LD.</p>

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
9. Lin, Hsu, Chou, Yen, Wu, Chu & Loh (2008). Taiwan.	To explore GPs attitudes to the provision of healthcare for people with LD.	2286 qualified GPs, 331 returned questionnaires (16% response rate).	A structured questionnaire was developed specifically for this study and mailed to potential participants. Analysis – t-tests, chi square and ANOVA to determine statistical significance. A gap analysis and opportunity algorithm prioritised the potential issues of healthcare development for people with LD.	Medium risk of bias	GPs generally did not feel satisfied with the level of healthcare provided to people with LD or with their level of knowledge of LD healthcare issues. GPs who had received LD training were likely to feel more satisfied with their provision of healthcare than GPs with no training. Area of LD healthcare provision with the greatest opportunity for improvement was multi agency working. GPs gender and educational level was correlated to their view of importance of healthcare. Age, practice setting and level of LD training were statistically correlated to the perception of satisfaction toward provision of healthcare.

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
10. McConkey & Truesdale (2000). Northern Ireland.	To investigate nurses' contact with people with LD and willingness for future contacts.	1008 sample size, 269 qualified nurses (for the purposes of this review of healthcare professionals' attitudes, the data only relevant to nurses will be included). Response rate 28%.	<p>Participants recruited through opportunity sampling method. Participation was anonymous and voluntary.</p> <p>Questionnaire based on previous research (McConkey, 1990) referred to participant's previous contact with people with LD and willingness to have future contact.</p> <p>Analysis – chi-square tests and spearman rank order correlations applied to individual scores. Pearson correlation and one-way analysis of variance applied to total scores.</p>	High risk of bias	<p>Nurses who had regular contact with people with LD had significantly higher confidence scores compared to those who had no contact.</p> <p>Nurses who had regular contact with people with LD in their personal life were significantly more willing to have contact than were those who had no contact. Female nurses were more willing to have contact with people with LD than male nurses.</p>

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
11. Ouellette-Kuntz, Burge, Cleaver, Isaacs, Lunskey, Jones & Hastie (2012). Canada	To explore the attitudes of medical students towards people with LD.	346 student doctors. 275 returned questionnaires. 79% response rate.	Adapted questionnaire from Ouellette-Kuntz et al (2003) and the Community Living Attitudes Scale-Short form (CLAS). Descriptive statistics, t-tests used to compare mean CLAS scores for variables.	Medium risk of bias	Significant differences in attitude scores were reported by students who had experience with people with LD. No significant differences were reported in terms of gender, age, level of personal contact with a person with LD, level of LD training on their attitude scores.

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
12. Stanley (1998). UK.	To identify ways of improving the quality and effectiveness of healthcare for people with LD within the NHS trusts included in the study.	153 GPs, 88 returned questionnaires. 57% response rate.	Questionnaire designed specifically for this study. Descriptive statistics and cross tabulation reported.	High risk of bias	GPs reported that training on LD would be of benefit yet little consistency when cross-tabulated. Identified training needs – common medical conditions, communication, role of specialist LD services. No clear consensus regarding lead responsibility of healthcare provision for people with LD. 40% of GPs reported difficulty in accessing specialist services with 37% acknowledging they had tried to access these services. No clear consensus regarding the workload people with LD generate.

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
13. Stein (2000). UK.	The aim of the study was to examine GPs' beliefs about the provision of healthcare for people with LD; their confidence in meeting these healthcare needs and view of training needs; perceived training requirements; their attitude towards specialist LD services and level of contact with such services.	64 GP practices approached to take part in study, 64 qualified GPs included out of 290 GPs in area, 48 returned questionnaires. 75% response rate.	A questionnaire specifically designed for this study. Descriptive statistics reported.	High risk of bias	Training on common medical conditions affecting people with LD and communication skills; and information on specialist LD services were deemed valuable. GPs felt confident some - most of the time in provision of healthcare for people with LD. Majority were willing to meet healthcare needs but expressed support from specialist teams or additional remuneration. Limited actual contact with specialist LD services. Varied reports regarding offering key screening to people with LD. No consensus regarding view of impact of healthcare provision for people with LD on workload.

Author, Year and Origin	Study aims	Sample	Methodology including measures and data analysis	Quality assessment	Key findings
14. Temple & Mordoch (2012). Canada.	To report the results of a cross-sectional survey of student nurses view of disability and their role within healthcare profession for people with disabilities.	401 questionnaires distributed nursing students. 119 returned questionnaires. 30% response rate.	Questionnaire specifically designed for this study. Scale data analysis, descriptive statistics used to describe sample and bivariate statistics used to detect differences.	Medium risk of bias	Student agreed they felt confident in caring for people with LD. 98% agreed that nurses have an important role in meeting health needs of people with LD. They reported that specialist LD nurses should have the main role in caring for people with LD. 48% considered LD to be an individual's problem. 6% were sensitive to the stigma of with living with a LD. Emotional reactions varied to people with LD, reporting they occasionally or rarely felt awkward and rarely - to never felt frightened. 96% did not believe that people with LD should be a lower priority for health care.

Methodological Quality Assessment

The results of the quality assessment are summarised in Table 3 and visually presented in Figure 3. Five domains are considered in assessing the study's level of risk of bias. An overall score of high, medium or low risk was calculated for each study based upon the levels of risk across the five domains. The total risk of bias was also calculated across the included studies (adapted from Sanders et al., 2014; Ju, Jeong & Kim, 2013) to review the overall level of bias for each domain. A detailed explanation of how the quality was assessed is presented in Appendix A.

Table 3: Methodological Quality Assessment (modified RoBANS, Kim et al., 2003)

Study	Selection of participants	Confounding variables	Measurement of exposure	Incomplete outcome data	Selective outcome reporting	Outcome (mean score)
1. Bond, Kerr, Dunstan & Thapar (1997)	3	3	3	2	1	2.4 (med)
2. Dovey & Webb (2000)	1	3	3	2	1	2 (med)
3. Gill, Stenfert Kroese & Rose (2002)	1	1	1	1	1	1 (low)
4. Kerr, Dunstan & Thapar (1996)	3	1	3	2	2	2.2 (med)
5. Lennox & Cook (2000)	1	3	3	2	2	2.2 (med)
6. Lennox, Diggins & Ugoni (1997)	1	3	3	2	2	2.2 (med)
7. Lennox, Diggins & Ugoni (2000)	1	3	3	2	2	2.2 (med)
8. Lewis & Stenfert Kroese (2010)	1	3	1	1	1	1.4 (low)
9. Lin et al (2008)	3	1	3	2	2	2.2 (med)
10. McConkey & Truesdale (2000)	3	3	3	2	2	2.6 (high)
11. Ouellette-Kuntz et al (2012)	3	3	1	1	1	1.8 (med)
12. Stanley (1998)	3	3	3	2	2	2.6 (high)
13. Stein (2000)	3	3	3	2	2	2.6 (high)
14. Temple & Mordoch (2012)	3	3	3	2	1	2.4 (med)
Total (mean score)	30 (m= 2.1 – med)	36 (m= 2.6 – high)	36 (m=2.6 – high)	25 (m=1.8 – med)	22 (m=1.6 – med)	149 (total m=2.1 – med)

Key and explanation:

Low risk of bias = 1, Medium risk of bias = 2, High risk of bias = 3

Outcome (mean) score – Low risk of bias = 1 – 1.49, Medium risk of bias = 1.50 – 2.49, High risk of bias = 2.50 – 3.

The lower the number, the lower the risk of bias and thus the higher the quality of the paper.

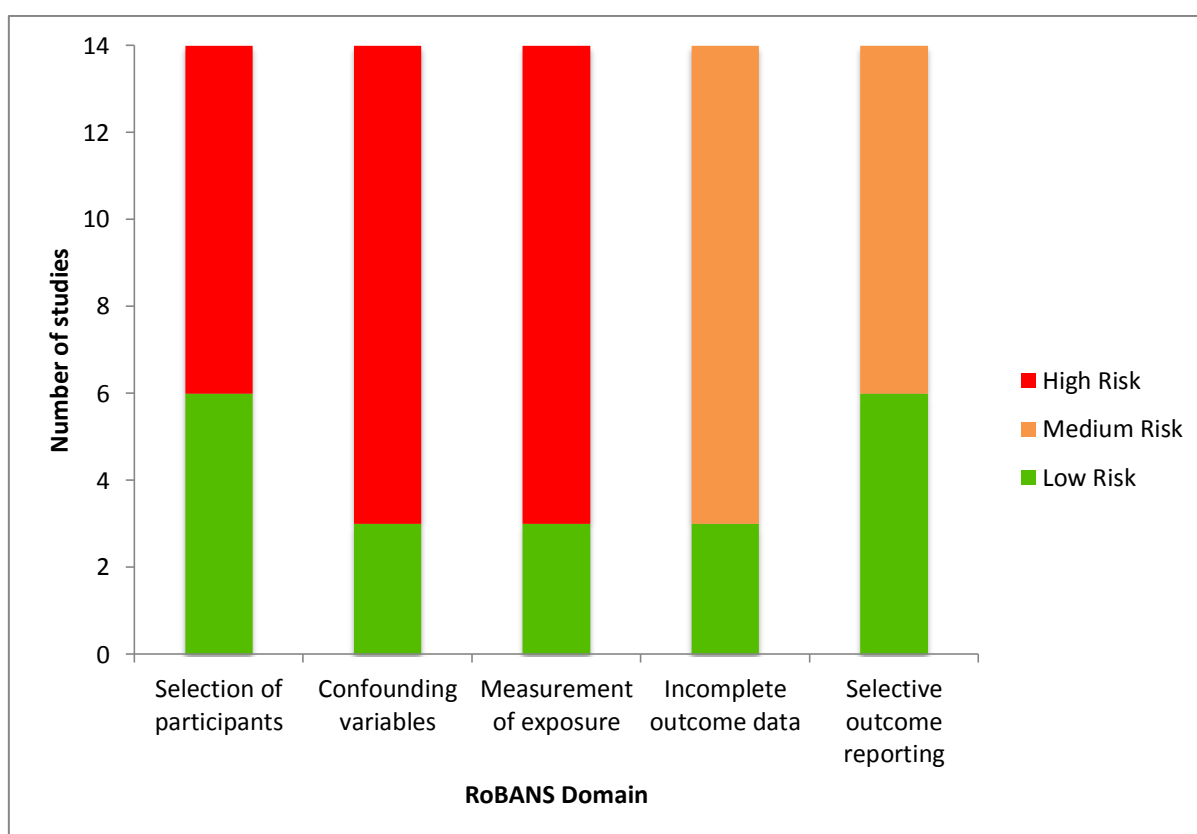


Figure 3: Quality assessment results for the domains included in review.

Results from quality assessment

Selection of participants

This domain assesses for selection bias created by inadequate sampling. A minority of papers were deemed to be at low risk of selection bias as the authors stated that their sample was representative of the population, and they gave a valid explanation upon which they based this decision. Eight of the papers were classified as at high risk of selection bias as it was not stated whether steps had been taken to ensure the sample was representative of the population. They were also said to be high risk if the participants were drawn from a limited sample i.e. one recruitment site only. These studies' (1, 4, 9 – 14) findings need to be interpreted cautiously given the limited generalisability as a result of selection bias. It is of

note that the sampling method used in all the studies meant the participants were self-selecting, which in itself creates a bias, as health professionals with negative attitudes may have opted not to take part. Across all the studies, the level of risk for selection bias was deemed to be medium, suggesting that the findings of the papers included in this review need to be considered with caution.

Confounding variables

This domain considered the studies' acknowledgement of confounding variables on the findings in relation to selection bias. Three papers were considered to be at low risk of bias given their consideration of confounding variables during the study's design and analysis. The remaining papers were assessed as being at high risk of bias given their lack of consideration of confounding variables, which could have influenced the results. For this reason, with the exception of studies 3, 4 and 9 the findings should be interpreted with care given the high risk of confounding variables with a potential influence on professionals' attitudes towards people with LD. Across the fourteen studies, the level of risk of confounding variables was deemed to be high. This suggests that the reported findings may have been influenced by variables that were not controlled during the study, thus again the results should be interpreted with caution.

Measurement of exposure

All fourteen studies collected data through self-report questionnaires. Studies 3 and 8 reported high internal consistency and good test-re-test reliability, which suggests robust psychometric properties of the measures used. Study 11 used a questionnaire designed by the author in a previous study and was the only paper to use the Community Living Attitudes

Scale-Short form (CLAS), which has been shown to have adequate internal consistency, test-retest reliability and construct validity. However, one criticism of this paper is that it was designed in 1998 and therefore may not take into consideration the change in society's views towards people with LD (e.g. on community integration). Given the availability of the acceptable statistical properties of the questionnaires used in studies 3, 8 and 11, they are deemed to be at low risk of performance bias.

A limitation of the measures used in studies 1, 2, 4 – 7, 9, 10, 12 - 14 is the lack of psychometric validation, which questions both the reliability and validity of the findings. Given the lack of psychometric validation of these studies, they are deemed to be at high risk of performance bias.

It is recognised that all studies used survey measures to gather data. A disadvantage of self-report measures, in particular those which use Likert scales, as many of the papers did, is the tendency for participants to use the middle of the scale potentially in an attempt not appear to have extreme views towards people with LD, thus seeking social desirability (Edwards, 1957). A possibility of recall bias must also be considered given that participants were basing their responses on previous limited experiences of delivering care to people with LD. Across all studies, the level of performance bias was deemed to be high, suggesting that the results need to be considered with caution.

Incomplete outcome data

This domain considers the risk of bias from inadequate administration of incomplete participant data. For example, not reporting on how incomplete questionnaires were managed. Three studies declared they excluded incomplete questionnaire data and thus were deemed to have a low risk of bias (3, 8, 11) in this respect.

Eleven studies did not note their management of incomplete data thus the risk of bias was scored as medium (studies 1, 2, 4-7, 9, 10, 12-14). The response rate across the studies was varied, ranging from 16% to 75%. In the case of low response rate, a sampling bias may have influenced the results, as the attitudes of those who did not respond remain unknown and may have differed to those who participated. Studies with low response rates (<54%) are said to lower 'population representation' (Holbrook et al., 2005) thus the findings of the included studies with low response rates need to be considered with caution. Evaluating the studies as a whole in terms of bias from the inclusion of incomplete outcome data, the level of risk was deemed to be medium.

Selective outcome reporting

This domain considers reporting biases within a study due to selective reporting of outcomes. Six of the studies were assessed to have a low risk of reporting bias on the basis that they reported all of the predicted outcomes of the study. The reported outcomes of eight studies (4-7, 9, 10, 12, 13) were considered to have medium risk of bias because there was limited information on the measures used, some data were not clearly presented or it was difficult to ascertain which data some of the reported findings were based on. Across the studies, the level of risk of reporting bias was deemed to be medium.

Main findings of the studies

By summarising the results of the fourteen studies in Table 2 a number of key themes were identified. These themes are considered in turn below.

Training and education

The majority of the studies investigated the role of training and education on health professionals' attitudes towards providing care for people with LD. This was the most prominent theme within the literature reviewed and the focus for many of the studies' recommendations in improving health care for people with LD.

There was a common agreement across participants, both qualified and student, that they had not received adequate training and would be receptive to further information and that they had a lack of experience and knowledge of caring for people with LD, which was felt to have a significant impact on their confidence in treating people with LD and quality of healthcare delivered (2, 3, 5, 6, 8, 9, 10, 12, 13).

Almost all (93%) GPs in study 6 indicated that they would be willing to receive further LD training/ education, with only a third feeling adequately trained. Very few (18%) of registrars in study 5 felt adequately trained, with 98% willing to receive further LD information and 94% felt that healthcare for people with LD would be enhanced if they received further education. GPs in study 12 highlighted training needs in delivering healthcare for people with LD including common medical conditions, communication, and the role of specialist LD services. In study 9, GPs reported low satisfaction scores with the level of healthcare provided to people with LD and with their level of knowledge of LD issues. Conversely, GPs who had received LD training felt more satisfied with the healthcare they provided for people with LD.

Study 12 reported that although GPs acknowledged a need for further training and an apparent lack of confidence, there was little agreement regarding the value of training/ specialist skills or consistency in practice. These findings need to be interpreted with caution given the quality assessment indicating a high risk of bias for this study. Study 3 reported that

the level of GP training did not appear to affect attitudes towards people with LD; however, GPs generally reported a low level of LD training.

Impact of professional experience and confidence on the provision of healthcare for people with LD

Some studies explored the impact of health professionals' confidence on their attitude towards caring for people with LD. GPs in study 6 reported that people with LD constituted the minority of their caseload (0.7%). The majority of GPs recognised their limited experience, yet some also reported feeling confident in delivering healthcare for people with LD (5, 6, 13). Just over a third of GPs (36%) in study 12 who had no specific LD training reported having no confidence in meeting the healthcare needs of people with LD. It is important to note that these findings need to be interpreted with caution, due to the identified risk of bias of these studies during the quality assessment and they may not be generalisable.

Study 3 reported that GPs who indicated more experience of delivering healthcare for people with LD had more positive attitudes than GPs with limited experience.

Study 10 reported that the more contact nurses had with people with LD, the higher their confidence scores. Student nurses reported different levels of confidence depending upon their level of training (77% of second-year and 84% of fourth-year students agreed or strongly agreed they feel confident in caring for people with LD who have medical needs; study 14. Study 11 reported that student doctors who had clinical experience with people with LD and good supervision reported more positive attitudes towards people with LD than their colleagues with less experience and no or limited supervision.

Given the limited generalisability of the studies in this review and the issues with the use of self report measures, it would be important to further research professionals' attitudes utilising more robust research designs.

Health professionals' view of their role in providing healthcare for people with LD

Many of the studies explored how the participants viewed their role within the healthcare system for people with LD. The studies reviewed reported mixed results. The majority reported that GPs and nurses felt they had responsibility in providing healthcare and recognised the importance of their role (1, 6, 12, 14). Despite the recognition of their responsibility, professionals did not feel they held a lead role (5, 12, 14) and that specialist professionals were best placed to meet the healthcare needs of people with LD, in particular a nurse specialist (14). GPs also reported that they felt they had limited influence in the healthcare of people with LD (2).

Not all the studies involving GPs explored their view of their responsibility for health screening. For those that did (1, 4, 7, 12, 13), there was a lack of consensus, with views varying from it not being the GPs role as it would increase their workload unacceptably, to being willing to complete the screening. These mixed views were confounded by the findings that in practice GPs were not routinely offering screenings (12, 13) and the evident discrepancy between current care and intended future care (7). Again, it appears that the findings of the papers need to be interpreted with caution given the level of bias due to limited generalisability, questionable reliability and validity of the measures used and lack of consideration of confounding variables influence on reported attitudes.

Healthcare professionals' views of specialist services for people with LD

Some studies (1, 2, 4, 9, 12, 13, 14) investigated the health professionals' attitude towards support available from specialist services for people with LD, reporting that GPs valued support from specialist LD services (1, 2, 4), with some GPs reporting difficulties in accessing services (12). In practice, there appeared to be a lack of contact with specialist services (12, 13). Study 9 reported that GPs felt dissatisfied with multi-disciplinary and multi-agency working in relation to healthcare provision for people with LD, yet also felt this was an important factor in providing adequate healthcare for this population. There appears to be a mixed view of specialist services from GPs, however, these results should be interpreted cautiously due to the quality analysis suggesting the studies have a high to medium level of risk of bias and may not be generalisable to all GPs.

Barriers to providing health care for people with LD

Healthcare professionals recognised the limitations in healthcare for people with LD and cited a number of barriers affecting their ability to provide adequate care such as communication difficulties (2, 5, 6). Professionals felt communication issues affected the quality of information accessible to them during assessment, thus affecting the quality of care they could provide. Most (85%) of GPs in study 6 cited difficulties in communicating with the people with LD during consultations as a main barrier and 80% cited poor communication between GP and other professionals which significantly limited the healthcare provision for people with LD.

There appeared to be a consensus about the significant impact of limited consultation time available when seeing people with LD on the quality of assessment, examination and overall quality of healthcare (2, 5, 6).

Student doctors commented that remuneration levels needed to be reviewed when considering healthcare for people with LD (5). They also raised a lack of continuity of care reporting difficulties in establishing on-going doctor-patient relationships as a barrier in providing healthcare to people with LD (5).

Impact of professionals' characteristics on their attitude towards providing care for people with LD

Some of the research investigated differences in attitudes in relation to health professionals' characteristics. Studies 8 and 11 reported no significant associations between professionals' attitudes and demographic variables (e.g. gender, age). However, elsewhere it was reported that GPs practising for longer held less positive attitudes than newer qualified colleagues (1, 2, 3). Study 3 reported negative associations between age of the GP and their attitude towards people with LD whereby the older the GP the more negative the attitude, and females in this study had more positive attitudes than their male colleagues.

Study 9 reported that practice location (primary care or hospital based service) and training experience of GPs negatively correlated with their perception of satisfaction towards healthcare issues for people with LD. Those GPs working in primary healthcare had slightly higher level of satisfaction scores in relation to LD healthcare issues than those working in a hospital based service. GPs with LD experience also reported higher satisfaction scores than those with no experience. GPs' age was positively correlated with satisfaction, with the older the GP the higher their satisfaction score. GPs' gender and educational background positively correlated with their perception of the importance of healthcare for people with LD. Males scored slightly higher on perception of importance of LD healthcare issues than females. GPs' view of the importance of LD healthcare issues increased the higher the level of medical

education they had completed. There was a gender difference in study 2, with female GPs more likely to expect an increased workload as people with LD moved into the community.

Study 10 reported upon the impact of personal contact with people with LD upon willingness to have professional contact with patients with LD, with nurses who had regular personal contact being significantly more willing to have professional contact than those with no personal contact.

Views regarding community care

Study 2 reported a variation in the GPs attitudes towards people with LD from believing that behavioural disturbance was caused by psychiatric illness and that there was no benefit in taking a history from people with LD to stating that it was inappropriate to make a distinction between people with LD and other patients. Again in study 6, GPs showed a variation in their attitudes, with 15% noting that they would personally prefer not to deliver healthcare to people with LD and 43% strongly disagreeing with this statement.

In study 14, 96% of student nurses disagreed that people with LD should be a lower priority for healthcare compared to the general population, with 57% recognising that people with LD have more health needs than others. Student nurses reported feeling occasionally (42%) or rarely (39%) awkward and never (47%), rarely (39%) or occasionally (14%) frightened when meeting people with LD.

Studies 3 and 8 explored professionals' emotions in relation to their work with people with LD; there was a mix of emotions reported. In study 3, GPs reported a low prevalence of negative emotions and a moderate frequency of positive emotions when in contact with patients with LD. Feelings of frustration and relaxation were experienced the most, with feeling frightened or optimistic the least. Findings indicated that the more positive the GPs'

attitudes, the lower their negative emotion scores. Similarly nurses in study 8 reported limited positive emotional reactions when delivering healthcare provision for people with LD and less positive attitudes (e.g. people with LD were more likely to require segregation and were more difficult to deliver nursing care for) towards caring for this population than when caring for other patients.

Two studies (1, 13) explored the impact of the move of people with LD into community living and the closure of large institutions, with reports of GPs' concerns that the move would increase workload for GPs (1). Based on the quality assessment, these studies were deemed medium risk of bias and as such should be interpreted with caution, as they may not be representative of all GPs' views.

Discussion

In this discussion the papers included in this review will be considered in the context of Fishbein's (1998) IBM in order to develop an understanding of the findings and relevance to clinical practice. The findings of the current review will be compared with those of Fitzsimmons & Barr (1997) and suggestions for future research and clinical practice will be made.

Behavioural beliefs

IBM (Fishbein, 1998) suggests that professional' views regarding the consequences of providing care influence their attitude towards the provision of care (behavioural beliefs). GPs' considered multi-agency working to be an important area of their work, although also reporting low satisfaction scores in this area, which could be explained by their reported

difficulties in accessing specialist support. This could suggest that there is scope for effective multi-agency working; however, in accordance to IBM, GPs' actual intention to liaise with other services could depend upon their beliefs and potentially past experience of multi-agency working.

Some GPs reported that they felt they had limited influence over the healthcare of people with LD. Professionals' attitude and care delivered could be influenced by their underlying belief about the outcome of delivering care, leading to positive or negative outcomes for people with LD in terms of the quality of healthcare they receive. Thus it can be tentatively suggested that if GPs felt they had little influence over the healthcare of people with LD, they were more likely to hold negative attitudes as a result of the belief that the outcome of their work would have limited impact on the overall healthcare for people with LD.

There was a lack of consensus regarding the provision of health screenings. Views varied from this aspect of care not being a GPs' role, as it would increase their workload unacceptably, to being willing to complete the screening. These conflicting views were confounded by the findings that, in practice, GPs were not routinely offering screenings and a discrepancy between current care practices and intended future care. From these findings, it can be tentatively suggested that some GPs' beliefs that offering health screenings would increase their workload influenced the level of care given, with screenings not being routinely offered.

It was apparent that GPs were apprehensive regarding the move of people with LD from institutional care to community living and concerned with regards to the impact this would have on their workload. It can be suggested that these beliefs regarding the community

move could potentially influence both the GPs' attitude and behaviour (provision of healthcare) towards people with LD.

GPs and student doctors reported that there is a need to increase remuneration offered considering the increased amount of time and resource needed to provide good quality care for people with LD. This attitude could be a product of GPs' belief that providing healthcare for people with LD, due to the complex nature of their health needs and the barriers faced (e.g. communication), which would increase their workload and additional resources would be needed. Thus this should be considered in the planning of services to support professionals to deliver adequate care for people with LD.

Interestingly, although GPs recognised their limited experience and training in providing healthcare for people with LD, many reported feeling confident in this area of care. In contrast, most nurses' confidence scores varied depending upon their level of experience and training, suggesting that confidence in delivering healthcare for people with LD is influenced by experience and training in some professions but not in others.

Professionals' attitudes towards healthcare provision for people with LD may influence their level of confidence in delivering such care. A positive attitude is more likely to encourage professionals to play a role in healthcare for people with LD, thus building confidence in their skills and knowledge of this client group. Less positive attitudes may influence professionals' intention to deliver healthcare provision, resulting in a less likely chance of them gaining clinical experience.

Professionals' attitudes towards the provision of healthcare were reported to be associated with their emotional reaction to providing such care. Findings indicated that the more positive the GPs' attitudes, the lower their negative emotion scores. Likewise, student nurses who held less positive attitudes also reported fewer positive emotions. Ellis' (1962)

REBT model would also predict that one's emotional reaction to people with LD influences their behaviours (in this case providing healthcare).

Normative beliefs

IBM (Fishbein, 1998) would suggest that professionals' normative beliefs regarding the provision of care for people with LD can affect their intention to deliver care. Given that people with LD constitute the minority (0.7% as reported by Lennox, Diggins & Ugoni, 1997) of GPs' caseloads, GPs may hold a belief that providing healthcare for people with LD is outside of their day-to-day responsibilities. This is evidenced by some GPs reporting that specialist services are valued and best placed to meet the health needs of people with LD. However, some papers reported that in practice, awareness and use of specialist services were poor.

Professionals reported that further LD training could enhance the quality of their services, yet when explored further, there was little agreement regarding the value of training. Perhaps the view that people with LD constituted a minority of their case load and existing pressures on GPs led to the belief that the provision of LD care was not a normative duty and as such did not warrant additional skills when specialist services, which were deemed to be skilled in LD, were available.

Clinical experience and good supervision were reported to facilitate positive attitudes towards healthcare provision for people with LD in student doctors. It is possible that these attitudes were influenced by the student's normative beliefs regarding equal access to healthcare provision for people with LD, which may have developed through the opportunity to reflect upon clinical practice and issues relevant to ethics and patients' rights with colleagues and supervisors.

GPs with experience and frequent contact with people with LD were reported to have more positive attitudes than GPs with limited experience. Professionals with more experience may view caring for people with LD more favourably as a result of their experiences, possibly challenging stereotypical views and barriers associated with caring for this client group, which may have formed their normative beliefs in regards to healthcare provision for people with LD.

Efficacy beliefs concerning specific barriers

It is proposed that professionals' efficacy beliefs concerning specific barriers to care can affect their beliefs in their competence and abilities to provide such care (Fishbein, 1998). A lack of adequate training and knowledge of caring for people with LD was recognised by most professionals suggesting they held a belief that they did not have the skills and abilities to provide adequate healthcare for people with LD. Beliefs regarding limited self-efficacy may negatively influence their intentions to provide a service.

There appeared to be lack of consensus regarding the professional roles in healthcare provision for people with LD. Some professionals indicated that it is their responsibility to provide healthcare, with others feeling that they did not hold a lead role, as specialist services were considered best placed to meet people with LD's healthcare needs. The latter view may also be influenced by professionals' perceived low self-efficacy. It can be tentatively suggested that although professionals recognised their responsibilities, they did not feel skilled enough to take a lead role in the healthcare provision for people with LD, feeling that specialist services were better equipped in terms of skills and knowledge of LD.

Difficulties were reported in accessing and working alongside specialist services, yet in practice there appeared to be a lack of contact with specialist services. Professionals who

had positive experiences of accessing specialist LD support may be more likely to hold positive attitudes towards working with people with LD as their self-efficacy beliefs are reinforced through the knowledge that they can access effective specialist support.

Professionals recognised their limitations in delivering healthcare for people with LD and cited a number of barriers (e.g. communication difficulties, lack of continuity of care, lack of LD training and knowledge) affecting their ability to provide adequate care. These perceived barriers are likely to influence the care delivered to people with LD as professionals may or may not consider these barriers insurmountable which in turn will affect their intentions to engage in caregiving behaviours with this patient group.

External variables influencing attitudes and behaviour

Fishbein's (1998) model also proposes that individuals' demographics can be a factor in predicting their behaviour. In the studies reviewed here, time as qualified GP, age, gender, personal contact were found to be predicting factors of self-reported attitudes at least. Given the varied quality of the studies included in this review, in particular in relation to sampling bias, these findings should be interpreted with caution and warrant further investigation.

Comparison to Fitzsimmons & Barr (1997) review

Since the Fitzsimmons & Barr (1997) review, research has employed a number of different measures some of which have been shown to have better statistical properties than the ATDP (Yuker, Block & Campbell, 1960), the measure of choice before 1996. Thus the more recent papers have utilised a more accurate measurement of professionals' attitudes. A minority of studies used student samples, suggesting that research has attempted to overcome the sampling bias cited by the previous review. However, the generalisability of the findings

as a result of non-representative samples remains a weakness as well as risk of bias due to confounding variables and measurement of exposure, both rated as 'high' in the current review.

Since the Fitzsimmons & Barr (1997) review, healthcare professionals continue to report a lack in skills, knowledge and confidence in providing care for people with LD and cite communication as a main barrier to delivering care.

The 1996 review concluded that a shift in healthcare professionals' attitudes to a positive view of people with LD could support the provision of adequate healthcare for this population. The review of more recent papers suggests an attitudinal shift in professionals' view of healthcare provision for people with LD. For example, some GPs recognised their responsibilities in delivering health care for this patient group. However, this has only been a slight shift in attitude given the increased likelihood of general healthcare professionals being involved in the provision of healthcare for people with LD as a result of the move to community living and the promotion of equal access to health care.

Future research

The quality assessment of the papers in this review indicated that there are a number of methodological flaws in the current research, suggesting that findings are interpreted with caution. Thus this significant research area remains very much under-researched suggesting that further investigation with more robust methodologies is warranted.

A lack of LD knowledge was identified as a barrier for many professionals in delivering adequate healthcare for people with LD. Most held the belief that specific LD training would enhance the level of healthcare available for people with LD. Given the perceived high value of LD training, it is suggested that future research investigates the

efficacy of such training and influence on professionals' attitudes and provision of healthcare for this population. It may be possible to identify solutions to overcome the limited LD training available and provide healthcare professionals valuable information on caring for people with LD in an accessible format.

It is recommended that further research investigate the gap between professionals' intention to deliver healthcare and actual behaviour developing. Lennox, Diggins & Ugoni's (2000) study which explored the difference between what GPs' reported in terms of their current provision of care and intentions for future care provision for people with LD. This could identify beliefs, which influence GPs' intentions and solutions to enhance healthcare for people with LD.

A standardised attitude measure designed specifically to measure healthcare professionals' attitudes towards people with LD could tackle the methodological concerns identified in current research. Given the recent move to community living for people with LD, attitude measures need to reflect this significant change for people with LD and monitor the impact of the increasing demands on general healthcare services to deliver healthcare for people with LD. More exploratory study designs would enhance current literature on healthcare professionals' attitudes towards people with LD. Qualitative research would encourage participants to openly express their views rather than fitting in with pre-determined responses. Future research is encouraged to consider the use of vignettes when investigating attitudes. Lewis & Stenfert Kroese's (2010) study demonstrated the application of such a design and it would be helpful for future research to offer participants detailed information to base their responses on which could potentially increase the validation of participants' responses.

Clinical practice implications

Although people with LD are a minority group in terms of a GPs caseload, it is important that GPs are adequately skilled to recognise this population's specific health needs. It is a concern that a lack of specific training and clinical experience continue to appear to be barriers for people with LD in accessing equitable healthcare and having their health needs adequately met. This highlights the importance of both pre- and post-qualification training particularly on common medical conditions of people with LD, communication skills and liaison with specialist services when delivering healthcare provisions for people with LD.

Well-supported and planned clinical placements could facilitate healthcare students to reflect upon their experiences to both develop skills and explore any personal attitudes and views of caring for people with LD. As confidence and attitudes are likely to be influenced by previous experiences, it is important that clinical training placements provide positive experiences of working with patients with LD for students.

There was a lack of consensus in relation to GPs responsibility for health screening. Health screenings are essential in ensuring that the health needs of people with LD are met and that specific conditions are not overlooked through a lack of knowledge. Early intervention is key in this process suggesting that professionals need more information on specific conditions in LD and the importance of screening. Multi-agency working and an awareness of referral pathways to specialist LD services could also be beneficial.

Research has been conducted to identify ways to adapt the communication between healthcare services and people with LD to support accessible health care for people with LD (e.g. Dodd, 1999). However, it is clear from this review that communication issues continue to exist, highlighting the importance of investigating this barrier and promoting further ways to overcome communication difficulties.

The literature reviewed was worldwide, investigating healthcare professionals' attitudes from the UK, Ireland, Canada, New Zealand and Taiwan. However, country of origin did not appear to have an impact on the attitudes of healthcare professionals, with similar key themes arising across the studies; suggesting that the findings are generalisable across all cultures. Nevertheless, healthcare services do differ between cultures in terms of their service design, which needs to be considered when applying research recommendations to clinical practice.

Conclusions

Healthcare professionals' attitudes towards caring for people with LD varied both across and within the studies included in this review. There appear to be multiple cognitive and social factors that influence professionals' attitudes, affecting their intentions regarding care and subsequent care provision. At an organisational level attempts should be made to encourage professionals' confidence in their ability to provide adequate healthcare provision for people with LD and their motivation to engage with these patients in order to achieve equitable services for them. The findings of this review suggest that training, experience and supervision may achieve this in addition to establishing clear and accessible care pathways for patients with LD.

The findings of this review have identified gaps in the research which require attention, in particular the efficacy of available LD training as healthcare professionals pinpoint limited training as a significant barrier to LD healthcare provision which appears to create a gap between professionals' intentions for healthcare provision and actual care received.

There are a number of important clinical implications to consider in future planning of healthcare services to promote both accessible healthcare for people with LD and support for those professionals in delivering the care, including the importance of early intervention and the need to promote and implement health screenings for people with LD. Educational and health services are invited to recognise the importance of LD training and clinical experience throughout a healthcare professional's career and the significant impact this may have on the quality of healthcare provision for people with LD.

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Empirical paper

Midwives' experience of caring for women with Learning Disabilities

Midwives' experiences of caring for women with learning disabilities

Abstract

Background and Objective

People with learning disabilities (LD) are increasingly likely to become parents and are entitled to have access to the right support to be able to be suitable parents. However, access to such support is affected by limited resources, attitudes towards people with LD becoming parents, and lack of LD training. Little research has explored health professionals' experiences of their support of people with LD during their journey to become parents. Midwives are often the first professionals pregnant women come into contact with and therefore are key professionals in the support system for parents with LD. The principle objective is to develop an understanding of midwives' experiences of caring for women with a LD.

Design

The study explored midwives' experiences of providing midwifery provision for women with LD using an Interpretative Phenomenological Approach.

Participants

Nine qualified midwives' from a local midwifery service participated in the study.

Measurements and findings

A semi-structured interview schedule was utilised during one-to-one interviews with the midwives. The interview transcripts were analysed using IPA stages. Four superordinate themes were identified. 'Not being able to do my job', 'Delivering the best care', 'Support for midwife' and 'Safeguarding process'.

Key conclusions

The midwives reported receiving a lack of LD training and faced significant time constraints, which left them feeling out of their depth and guilty that they could not spend the necessary time with the women to meet their pregnancy needs. The midwives felt unsupported in their attempts to deliver adequate midwifery care, speaking about a lack of accessible support for pregnant women with LD. They were left feeling responsible to fill the gaps in service provision. The midwives were dedicated in delivering adequate care to help give women with LD a positive experience of childbearing. They felt a safeguarding process was an inevitable part of women with LD's pregnancy experience yet were aware that the right support at the right time could make a difference to the women and their parenting skills.

Implications for practice

It is recommended that training, on working with and providing services for people with LD, is made available to qualified and student midwives. It is important that accessible resources, professional support and supervision are made available to midwives. The inclusion of midwives in care planning meetings for women with LD is recommended to foster multi-agency working. Where there is a lack of local guidance for midwifery provision of women with LD, it is recommended that guidance is developed and implemented.

Highlights

- Midwives face a number of significant barriers in providing care for women with LD.
- Midwives reported a lack of LD training for both qualified and student midwives.
- Barriers to accessing support for women with LD impacted upon midwifery care.
- Support for women with LD can make a difference to their parenting skills.
- Midwives were dedicated in delivering adequate midwifery care to women with LD.

Key words: Learning Disabilities, midwives, Interpretative Phenomenological Analysis.

Introduction

Over recent decades, there has been a significant change in the design of services for people with learning disabilities (LD). Services are progressively supporting people with LD to live in the community and promoting their rights for community inclusion. As part of this movement, adults with LD are increasingly likely to form relationships and want to create their own families (WTPN, 2008). The UK government White Papers, 'Valuing People' and 'Valuing People Now' (2001, 2009) support this movement, advocating that people with LD should have the same rights and choices as other people, including the right to have a family.

It is difficult to confirm the prevalence of women with LD who are parents or are of childbearing age due to the possibility that women may not have their LD diagnosed (Beake et al, 2013); are only known to services when they become pregnant or are in need of support (WTPN, 2008); or hide their needs from services in fear of having their children removed (Tarleton, Ward & Howarth, 2006). However, it is acknowledged throughout the literature that the number of people with LD who are parents is rising (e.g. Mayes, Llewellyn & McConnell, 2006). This has been evidenced within health and social care settings through the increase in referrals of parents with LD (Guinea, 2001).

Support for parents with LD

The White Papers 'Valuing People' and 'Valuing People Now' (2001, 2009) advocate the need to ensure parents with LD have access to the right support to be able to be suitable parents. However, this is an area where there is significant shortfall in services. Becker et al (1997) and Parish & Huh (2006) report poor access to maternity services for women with LD, which is concerning given their additional needs, in particular their need for specialist social

support and health provision. Access to such support is affected by limited resources, attitudes towards people with LD becoming parents, and lack of specialist training (Booth & Booth 1993; Cooke 2005; Culley & Genders 1999). A high percentage of parents with LD face the prospect of having their child removed, often because of concerns about their capacity to parent effectively (Champion, 1995).

Following the 'Valuing People' (2001) statement that people with LD have the right to become parents, it is the responsibility of social and health services to offer, promote and make accessible, support for people with LD to enable them to become parents if they choose to do so. The Disability Discrimination Act (1995) and the Equality Act (2010) state that all people should have an equitable service. Accessible information on pregnancy, consent, childbirth and childcare is vital in supporting people with LD to have equal access to services and facilitate their abilities to meet their children's needs (NHS Executive, 1998; DoH Dfes, 2007; SCLD, 2009; RCN, 2007).

The 'Good Practice in Parenting Support for Parents with a Learning Disability' (2013) reports that parents with LD may require support from a range of services to meet both their health and social needs. Variations in policies across services in terms of their eligibility criteria for supporting people with LD may affect the consistency and support available to meet their needs. This document also reported that multi-agency working is scarce with professionals having limited awareness of other services available to support to parents, not enough sharing of assessment information and no consistent approach in the assessment of parenting skills of people with LD.

Barriers parents with LD face in accessing services

There appears to be a considerable dearth in specific LD training for healthcare professionals (Dovey & Webb, 2000; Gill, Stenfert Kroese & Rose, 2002; Lewis & Stenfert Kroese, 2010; McConkey & Truesdale, 2000). Stanley (1998) and Lennox, Diggins & Ugoni (1997) suggest that a lack of LD training has a detrimental impact on the quality of care people with LD receive, as professionals do not feel confident and lack experience in working with this client group, which in turn may reinforce negative attitudes and stereotypical views of people with LD.

Fitzsimmons & Barr's (1997) review of professionals' attitudes towards people with LD suggests that there appears to be a limited understanding of the nature, abilities and needs of people with LD, which may influence ability to deliver adequate care. Despite a generally positive attitude, there appears to be a stereotypical view of people with LD, regarding them as dependent, childlike and less able (May et al, 1994). Fitzsimmons & Barr (1997) suggest that some professionals hold low expectations for the health of people with LD, which can potentially have an impact on whether this client group will receive adequate healthcare. They recommend that services for people with LD should be led by an understanding of this population's specific needs and a respect for their human right to receive equitable access to health and social care (Fitzsimmons & Barr, 1997).

The lack of LD training, the subsequent widespread stereotyping and negative staff attitudes is particularly likely to have an impact on the level and quality of support available for parents with LD (e.g. Tarleton, Ward & Howarth 2006; McBrien & Power, 2002) which in turn has consequences for the parents' emotional health as well as that of the child's since a high percentage of children born to parents with a LD are subjected to custody proceedings.

McGaw (2000) and O'Hara & Martin (2003) suggest that a lack of LD training has a significant impact on services' abilities to provide adequate support for parents with LD which can have substantial consequences, with children being placed into care without their parents being given adequate opportunities to develop parenting skills.

Thus, despite a range of policies advocating adequate support for parents with LD (DoH, 2007; Valuing People, 2001; Valuing People Now, 2009) there are apparent barriers to them accessing services and the implementation of LD-friendly policies has been limited (Ward & Tarleton 2007). Parents with LD find contact with what are supposed to be support services stressful and are therefore less likely to seek support as a result of fear and worry of the outcome and of being de-skilled and disempowered (Gould and Dodd, 2014).

Midwifery services for people with LD

Most pregnant women will come into contact with a midwife. Magill-Cuerden (2006) and Hodnett et al., (2007) propose that midwives hold a principal role within the care system, supporting women during their pregnancy and providing specialist support and advice from the ante to post-natal stages.

Guidance is available for midwifery care for women with LD within guidelines for caring for women with disabilities ('Pregnancy and Disability', RCN, 2007) which aims to provide guidance for midwives to enable them to deliver high quality, person-centred care for disabled women during their pregnancy, birth and postnatal. Specific LD guidance on a national level is limited although some health trusts have produced their own local guidance (e.g. NHS Highlands, 2011; NHS Greater Glasgow and Clyde, 2006).

There is a distinct lack of research into women with LD's pregnancy experiences, from both the women's (Mayes, 2005; Mayes, Llewellyn & McConnell, 2006) and midwives'

view (Hoglund, Lindgren & Larsson, 2013). Begley et al's (2009) review concludes that provision of maternity services for women with LD is under-researched, with little known about women's experiences of midwifery care and a gap in the literature on knowledge, attitudes and behaviours of healthcare professionals towards women with LD.

The research evidence that does exist suggests negative attitudes regarding sexuality and sterilisation of people with LD. These attitudes are suggested to influence individuals, including professionals supporting people with LD, views' of women with LD becoming pregnant and parents (Stehlik, 2001; Cuskelly and Bride, 2004; Drummond, 2006).

Support available for midwives

It is estimated that only 7% of people with LD are parents (MENCAP, 2011). Thus parents with LD form a small percentage of a midwife's caseload. However the number of women with LD presenting to maternity services is increasing (Mayes, Llewellyn & McConnell, 2006). Leaviss et al (2011) report that since the early 1990s, people with LD becoming parents has increased by more than 40%. It is therefore becoming more important to ensure that midwives receive appropriate training and feel supported to work with this client group. Brown (2005) suggests a lack of awareness amongst midwives of parents with LD and their support needs, which has an impact on the services these parents receive. Moreover, women with mild LD's needs may go unrecognised within the context of a busy healthcare setting where finding the time to check women's understanding of information given is challenging and professionals, including midwives, have limited understanding of the communication needs of the LD population.

There appears to be limited literature exploring midwives' understandings and experiences of working with parents with LD with the exception of a MENCAP report (2011)

which suggests a significant deficit in the knowledge base of midwives caring for women with LD, highlighting the need for further training.

Current midwifery guidance (RCM, 2008; RCN, 2007) recommend that sharing good practice, alongside LD training and multi-agency working is essential when attempting to achieve equal access and efficient maternity services for parents with LD. Given the scarce literature regarding midwives' experiences, research into this area is needed to understand the psychological processes which determine the quality and thus outcomes of maternity services. This information could contribute to the promotion of good practice when working with prospective parents with LD.

Research aims

Researching midwives' subjective experiences and understanding may contribute to what is known currently about supporting parents with LD during pregnancy, birth and the post-natal period; and throw light on how current guidance and training are impacting on midwives' abilities to provide care for this client group.

Midwives are often the first professionals a woman with LD comes into contact with during her pregnancy. They are therefore likely to have key experiences and insight which may inform future care pathways, service development, contribute to relevant staff training in a drive to provide appropriate access to and support by midwifery services for people with LD.

This study aims to explore the experiences and understanding of midwives who have cared for women with LD.

Research objective

The principle objective of the current research is to develop an understanding of midwives' experiences of caring for women with a LD. The second objective is to explore how midwives describe the way they work with women with LD in order to understand how midwives make sense of their experiences with this client group. A third objective is to explore midwives' experiences and attitudes to the role of LD training in determining the quality of service delivery for this client group.

Materials and Method

Design

Interpretive Phenomenological Analysis (IPA) is the research method chosen for this study, as the aim is to explore the experiences and understanding of midwives who have cared for women with LD; and their opinions on this client group and the maternity services they receive. IPA is an idiographic approach, offering insight into how an individual, in a specific context, makes sense of a specific phenomenon (Smith, Flowers & Larkin, 2009). IPA aims to gain an understanding of *how* an individual experiences an event through interpreting their reflections on their experiences. Through the application of IPA, an experiential account of midwives' experiences and understanding of working with women with LD will be collected. IPA considers data at an individual and group level, identifying participants' shared and divergent understandings of a common experience.

IPA best suits a data collection method that facilitates an experiential and 'rich' account of a participant's experiences. Working with small samples sizes allows detailed

analysis of the data and identification of common themes. A method of data collection adequate for this purpose is individual semi-structured interviewing (Smith, Flowers & Larkin, 2009). To ensure the data collected were homogenous and provided a rich account of the midwives' experiences, interviews were conducted with a small sample of midwives. The interview schedule is discussed within the Materials section.

Ethical approval

Ethical approval for this study was granted from the University of Birmingham (Appendix A). Subsequently, approval was sought from the NHS Research and Development (R&D) department of the initial two NHS Trusts identified for recruitment. Due to limited participation in the study, two further NHS Trusts were consecutively contacted to extend the sample. R&D ethical approval was granted from all these four NHS Trusts (Appendix B).

Materials

A semi-structured interview schedule was developed by the researcher in consultation with a qualified midwife (Appendix C). The midwife was consulted to ensure the language used throughout the schedule was meaningful and appropriate for the participants and the questions asked would help support the participants to discuss their experiences openly. The midwife highlighted the importance of reassuring the participants that there was no right or wrong answer and how the aim of the interview was to explore their experiences, not to judge them or their skills as a midwife. The schedule comprised of five main questions to facilitate discussion with the participant about their experiences of providing maternity services for women with LD.

At the onset of the interview, the researcher used a screening tool (Appendix D) to clarify the definition of LD for the participant in order to ensure they were aware of the specific population the researcher was interested in. The tool also acted as an introduction to the interview and an opportunity for the midwife to seek clarification of the aims of the research.

The initial questions were designed to encourage the participant to think about their clinical work with women with LD and reflect upon their experiences. The remainder of the questions were focused on training and resources the participant had experience of. Hoglund, Lindgren & Larsson (2013), Leaviss et al (2011) and Ward & Tarleton (2007) concluded that there is a distinct need for further LD training for midwives, which was why it was deemed important to collect data regarding midwives' experiences of LD specific training. Additional prompts were included in the schedule (Appendix C) to enrich the midwives' responses to ensure sufficient data were collected for the purpose of IPA methodology. The question regarding the midwife's clinical case example was asked at the beginning of each interview after the screening tool was discussed. The remainder of the schedule was used flexibly, although the researcher ensured that all topics were covered.

Procedure

An opportunity sampling method was used to recruit participants. A multi-site strategy was employed for recruitment. Two NHS Trusts were identified and contacted; two further Trusts were contacted when after a 3-month recruitment period the sample size had not been fulfilled by participants from the original two Trusts. A poster describing the project and inviting midwives to participate was emailed to practice development midwives of the NHS Trusts involved in the project. An information sheet with more details of the project was also

included. The poster was then advertised in 'staff only' areas within the maternity services. Interested midwives subsequently contacted the researcher to discuss the project in more detail. Inclusion criteria were set to enable a homogenous sample to be recruited. That is, participants were required to be qualified midwives, working in a NHS service and have worked clinically with a woman with a LD. The inclusion criteria also stipulated that participants were English speaking. This was to support the use of IPA since this approach requires a rich data and in-depth discussion, which would be difficult to achieve if non-English speaking participants were recruited. Further, the study did not have the resources for interpreters and translators. Recruitment was closed when the target sample size was achieved, which was nine participants.

Following initial contact from interested participants and ascertaining that they met the inclusion criteria, the researcher discussed the project with the participant and sent them the information sheet (Appendix E). The participants were given two weeks to decide if they would like to take part and during this time could contact the researcher with any questions. If the participant verbally consented to being interviewed at point of initial contact, a mutually convenient date and place was arranged. The participant was contacted via email before the interview to ensure they still wanted to attend. Upon meeting with the participant on the agreed date, they were asked to sign a consent form (Appendix F) and the interview took place. A £10 gift voucher of the participant's choice was given to compensate for their time. Interviews were conducted as per the interview schedule, as detailed above. They lasted between 29 and 62 minutes (mean 42 minutes) and were audio-recorded.

Participants

Nine female midwives were recruited. Seven participants worked as community midwives, across four different teams. Two midwives worked at the hospital, one held a supervisory role, as well as working clinically; the other was a specialist midwife for safeguarding children and vulnerable adults. All participants had examples of caring for women with LD during pregnancy or childbirth and were able to discuss their experiences of providing maternity services for those women. Participants varied in terms of the number of years they had been working as a qualified midwife. All participants had a minimum of three years experience, with two having twenty years plus. Participant details are provided in Table 1.

Table 1: Participant information.

Pseudo-name	Current area of work	Approx. age	Approx. years of experience
Jo	Community	40s	10+
Jess	Community (previously hospital based)	20s	≤ 5
Helen	Hospital	40s	10+
Lisa	Community	50s	15+
Judy	Hospital	50s	15+
Kerry	Community	40s	10+
Charlotte	Community	30s	5 - 10
Dawn	Community	40s	10+
Sarah	Community	30s	5 - 10

Data analysis

The audio-recordings of the interviews were transcribed. These data were analysed using the stages identified by Smith, Flowers, & Larkin (2009). All transcripts were read and

re-read, with initial notes and researcher reflections made. Notes and exploratory comments were made. These comprised descriptive comments, notes on the use of the participant's language and interpretative, conceptual comments (see Appendix G for example of a 'worked' transcript). Emergent themes were then identified. These emergent themes were grouped together. Once all transcripts had been analysed as described above, they were reviewed as a whole to identify patterns across the transcripts. This enabled final themes to be established (see figure 2 for example of initial themes contributing to a sub-ordinate theme). Themes were dismissed if they were not present within the majority of the transcripts, or if there was a lack of quotes, which could evidence the theme.

Figure 1: Example of initial themes contributing to a sub-ordinate theme.

Initial themes	Sub-ordinate theme	Super-ordinate theme
<ul style="list-style-type: none"> • Pressures of caseload, can't give everyone the amount of time to meet their needs and to deliver 'best' level of midwifery care (Jo). • Haven't got the time to deliver additional support to make care comparable for all women. Lack of time affects decisions made regarding additional care offered (Helen). • Time is a barrier in any pregnancy (Jess). • Pressure to get support in place in timely manner – complicated by additional support needs (e.g. LD) (Helen). • Pressured to meet care standards – maternity services not designed for women with LD needs, need additional time to meet all their needs. E.g. time to explain and ensure understanding (Helen). 	Not enough time to do everything	Not being able to do my job

<ul style="list-style-type: none"> • Time limitations prevent midwife delivering care to ideal standard – additional needs require more time than allocated (e.g. time to build relationship and gain woman’s trust) (Helen). • Haven’t the time to provide practical support which women with LD need (Helen). • Could do better if had more time, may change outcome (Lisa). • Pregnancy as an unknown quantity for any woman, even more pressure to get things right and make a difference for women with LD (e.g. to reduce barriers they face during their pregnancy which could be avoided if had time to deliver level of care which meets their needs) (Lisa). • Time pressures make complex cases more complex – can’t do what would like to do or what needs to be done (Judy). • Torn between cases – not enough time to do everything for every woman (Sarah). • Frustrating can’t do everything would like to do for all women (Sarah). 		
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A peer IPA group and the research supervisor were consulted during the analysis process to strengthen the validity of the results. For example, samples of transcripts were shared to explore the emerging themes, discussing those, which could form sub-ordinate theme and ideas for super-ordinate themes based upon the emerging sub-ordinate themes.

The themes identified were also discussed with two midwives, independent to the study. Both midwives reviewed a draft version of the result section and were invited to comment upon the themes identified. The aim of this process was to help validate the

researcher's interpretation of the midwives' experiences and to reflect upon the themes identified and if they were an accurate representation of midwives' experiences of caring for women with LD. The midwives' comments were considered during the discussion of the results.

Personal reflections

I developed an interest in this area of research through my clinical work with adults with LD who had children. My experiences made me aware of the lack of support for parents with LD and the professionals who work with them. This encouraged me to research other professionals' experiences in the hope of being able to make recommendations, which would contribute to service development and ultimately support for professionals in their work with parents with LD. I have some insight into the pregnancy experience and midwifery care through friends who have either become mothers or work as midwives.

I felt honoured at how the midwives were open and honest with me, as they shared their stories of caring for women with LD. I was disheartened at how the midwives faced so many barriers. It was inspiring to hear their determination to maintain a high standard of care for these women despite the challenges they faced. I was astounded at the pride the midwives took in their practice and how they were eager for additional resources to develop their skills and knowledge of LD in order to do their utmost to support the woman under their care.

I was mindful of my personal views when analysing and interpreting the data. To help with the reflective process, I kept a diary during throughout the research. This enabled me to be aware of my thoughts and feelings during the process, being mindful upon the influence of my personal thoughts on the analysis process. Through reflecting upon the diary, I was able to fully appreciate the midwives' experiences.

To help minimise bias, I discussed the themes that arose from my analysis with others. I felt it important to reflect upon the themes identified with independent midwives to help ensure I presented an accurate representation of the midwives' experiences, as they appeared remarkably committed and passionate about their work.

Results

Four superordinate themes were identified following analysis (see Table 2). The first theme, 'Not being able to do my job' identifies the challenges the midwives faced in delivering care. The second theme, 'Delivering the best care' details how the midwives strived to deliver adequate care. The third theme 'Support for midwife' concerns the lack of support available as well as detailing the midwives' experiences where they felt supported in their care of the women with LD. The final theme, 'Safeguarding process' describes the midwives' view that this process was an inevitable part of a woman with LD's pregnancy experience although support in terms of social care (housing, finances), activities of daily living, pregnancy education and parenting could make a difference.

Most midwives discussed very similar experiences during their care for women with LD, regardless of their role (hospital or community based), age or length of time as a qualified midwife.

Table 2: Summary of themes identified.

Super-ordinate theme	Sub-ordinate themes (number of midwives who contributed to each theme)
1. Not being able to do my job	1. Support available but not accessible (9)
	2. Having to do other people's jobs (9)
	3. Not skilled enough – out of my depth (9)
	4. Not enough time to do everything (8)
	5. Lack of LD training (9)
2. Delivering the best care	6. Wanting to do your best (9)
	7. Gaining a woman's trust (9)
3. Support for midwife	8. Feeling alone and unsupported (9)
	9. We need to work together (5)
4. Safeguarding process	10. Inevitable (9)
	11. Support can make a difference (9)

Not being able to do my job

This super-ordinate theme appeared throughout the midwives' narratives as they talked about their experiences. A number of barriers were identified with the midwives being concerned that they were not delivering the care the woman should be receiving as a consequence. They felt frustrated and guilty that they were not meeting the women's needs as a result of the barriers, many of which were out of their control.

1. Support available but not accessible

All the midwives felt that the women required additional support to meet their varied needs during pregnancy, as part of their human right to have children. The midwives talked about how there was an apparent lack of services available for the woman and when they tried to access support, they faced many barriers.

The midwives talked about feeling frustrated that support for the women in terms of social care (housing, finances), activities of daily living, pregnancy education and parenting was available but not accessible for a range of reasons. There was a sense of frustration that services were letting women down by not getting support in place when it was needed.

'I felt like I was banging my head up against a brick wall, to try and find the help and support, the appropriate help and support for her.' (Jo)

Jo and Charlotte spoke about how they had a lack of awareness of services available for women with LD, which was an extra obstacle in accessing support for the women. This experience left the midwives feeling guilty that they did not have the knowledge in order to deliver the care the woman needed as well as frustrated that they were not given the information or support they desperately needed from the organisation.

'it's very difficult to try find out what other agencies are around locally that can help her and support her, so I did struggle, I found it really difficult.' (Jo)

'I didn't realise.. that there's actually an advocate that can actually help ... if I'd had known that, I would have tried... having one of those for her as well.' (Charlotte)

Several midwives spoke about the benefit, in terms of accessing support, that the diagnosis of LD brings.

'I think the most difficult thing is because there isn't any diagnosis or she hasn't had any type of assessment ... then its very difficult to go to ... places becausethey want a diagnosis.' (Jo)

'If it's documented and it's diagnosed, it's easier to refer them... To get the extra support.' (Charlotte)

The midwives spoke about how it was frustrating that there was a gap in services available to support pregnant women with LD. Their experiences suggested that the women fell between existing services and where support was available, women with LD were often not eligible. There was a sense that the midwives felt frustrated because they saw the benefit of specialist support for other women with additional needs (e.g. young mothers), yet they were aware of the gap in services for women with LD and felt specialist support would be of great benefit.

'we get family nurses but they'll take 20 and under... Family support workers, they didn't want to look after her because they felt she was way over their heads and she wasn't going to be able to take in anything they told them, she... she fell down this huge hole... that was really frustrating.' (Sarah)

2. Having to do other people's jobs – can't focus on midwifery care

The midwives felt they had a clear role to focus on supporting the woman through her pregnancy and labour. They expressed frustration at not being able to focus on their role due

to the lack of support in place for the woman, which left many feeling responsible and pressured to pick up the extra care needs, as they were aware they would otherwise go unmet.

'it's just frustrating because we still have to do what we have to do plus more... as carers you can't just say 'well that's not my job' and ignore that aspect you just have to get on and do it' (Lisa)

The midwives spoke about how they were unable to ignore the women's other needs as they all had a significant influence on them but at the same time felt unskilled in meeting those needs, highlighting the need for multi-agency working.

'when I am looking after somebody especially somebody with a learning disability ... you can't ignore that, you got to make sure things are in place to support that woman.' (Jo)

3. Not skilled enough – out of my depth

All the midwives talked about how they didn't feel skilled enough to care for women with LD. This left the midwives feeling frustrated that they couldn't deliver care to an adequate standard. They questioned their own skills, knowledge and experiences and did not feel confident.

'I would always go away thinking, worrying about that situation... I suppose it only comes with experience of looking after them ladies that you'd ever.. gain that confidence' (Jess)

'I felt completely out of my depth..' (Lisa)

'I had no idea and I'm not unexperienced, I'm experienced in my job... But I'm not experienced with this ... 'cause we don't get loads and loads of people with learning disabilities...' (Sarah)

The midwives felt guilty that they were not doing enough, that they did not have the time, support or training to develop their practice to meet the needs of women with LD. This feeling of guilt did not sit easy with the midwives; they wanted to adapt their practice and felt frustrated they had a lack of training, resources and support.

'I did wonder whether or not my care of her was possibly not.... what I'd given the other women ... it made me feel really guilty' (Helen)

'you just feel overwhelmed.. and guilty that you're not providing, something because you don't know about it, you don't know what's out there... you find out maybe too late that all of this might have been useful.' (Lisa)

4. Not enough time to do everything

The majority of the midwives' narratives focused on the lack of time and how this is an issue in any pregnancy but presents as a particularly significant barrier to caring for women with LD.

'we didn't have the time to get everything that we needed in place that we wanted to get in place... Which goes to show that if, as soon as you know there are any issues with

learning disabilities, let us know and we can try to get things in place... As soon as possible... And I think that's just hugely important...'. (Judy)

'I try to do it early enough, getting it all... Up and running, is the problem that I find that's obstructive to making sure that she gets the level of care... That she deserves'.
(Kerry)

The midwives felt there was a distinct lack of time available to meet the women's needs and these time pressures meant they might not receive the level of care they are entitled to. There was a sense that the midwives felt guilty about not being able to spend the time that the women clearly needed.

'a midwife who's really over worked and really stressed, thinking I haven't got time to make those phone calls, I don't know .. who to get in touch with.. she might not then get the appropriate support in place for that lady. And I'm not being judgmental against anybody, but.. it does happen'. (Jo)

'I think it gets lost, I think that women with learning disabilities probably still do lose the care they should have when they come to the hospital because we are too busy...'. (Helen)

Lisa and Charlotte talked about having to make adjustments to their routine practice to ensure women received the extra time they needed.

*'I had to.. give some of my work to other people... because it would take a long time.
So I had to, protect time to go and visit her'. (Lisa)*

*'I always tried to put her kind of at the end of the day or maybe try and see her at home...
So I'd have a bit more time to spend with her. ' (Charlotte)*

5. Lack of LD training

An evident theme throughout all the midwives' experiences was that they had a significant lack of LD training and information. They felt that specific LD training would be fundamental in their ability to provide midwifery services for women with LD. None of the midwives could remember having any specific LD training during their midwifery training. Charlotte and Dawn noted that it was still not a part of student midwives' training today.

*'as a student, we don't have training in it really. I've been qualified five years now, but
they still haven't got any specific training at the university. ' (Charlotte)*

Jess clearly valued the information she received yet felt the support could be developed to make it more accessible.

*'it's the first time I've ever had, anything regarding learning.. disabilities, as a student or
as a qualified midwife, so I think it is good but I think they could take it a bit further.. it's
just knowing who.. to go to'. (Jess)*

The midwives felt that LD training would be beneficial on many levels, suggesting that more midwives would benefit from specific training.

'it was very useful... And I'd recommend anyone to go on it... from a practical point of view and an emotional point of view, so practically, seeing the visual aid that they used to explain things... And emotionally, realising the impact Children's Services' involvement has with... families.' (Judy)

The midwives not only felt that training would be helpful but were keen to develop their skills and knowledge as they wanted to enhance the level of care they provide for women with LD.

'develop my knowledge and my skills so that it would enable me to manage things better.. so I can look after these ladies and give them the appropriate care....' (Jo)

'what would have helped me? ... a better understanding because there's so many.. learning disabilities, you'll never be able to have all the information in the world but.... a bit more specific to each.. learning.. disability as to.. what is good and what is bad practice.' (Jess)

Jess and Charlotte spoke about how it would be helpful to have LD specific training as a student and qualified midwife.

'I think you definitely need it in your training and then if you do come across it.. in practice, even as a student.. that's good experience for the future.' (Jess)

'I think more training... With students and the new midwives that come through, but even to like existing midwives, not just the new ones... Because if the experienced midwives have the training, they can pass on... The knowledge as they come through.'
(Charlotte)

Delivering the best care

This super-ordinate theme was evident throughout all the midwives' narratives. There was an exceptional sense that the midwives wanted to deliver the best care they could despite the countless barriers they faced. The midwives were focused on building a relationship with the women, as they felt it was essential to gain their trust to facilitate the midwifery care.

There was a covert assumption throughout the narratives that women with LD had the human right to become parents. The midwives never questioned the fact that the women were pregnant or that they were going to become parents. Although it was acknowledged that these women had additional needs that they required support with, there was a positive attitude throughout towards the women and a sense that the midwives strived to deliver the 'best' care they could within the circumstances.

6. Wanting to do your best

There was an overwhelming sense as the midwives' described their experiences that they strived to deliver the best midwifery care they could despite the challenges they faced, for example, time pressures and lack of skills. It was apparent they felt responsible for the

shortfall in the care provision and frustrated that they could not change the situation due to the challenges they faced in regards to time, resources and skills.

'we should all just try and do our best, for anybody ... it doesn't matter who they are what their circumstances are, I think that is part of our job To try and get the best for people'. (Jo)

'you try to do the job... the best way you can and if you feel in your heart that you have done as much as you possibly can to actually help that person... I don't think you can do any more really.' (Judy)

7. Gaining a woman's trust

All the midwives talked about the importance of continuity of care with any woman and how it was vital to build a relationship with a woman with LD to gain her trust.

'continuity of care in any given area was really important to her. It is to most women but certainly.. when you've got a disability I think it's pretty essential really.' (Lisa)

'they get to trust you and they open up to you more if they know your face.' (Charlotte)

'if you ask any woman, they prefer to see one face really... Than lots of different faces... for ladies who have got learning disabilities, I think it is important... for them to try and be able to see that same... person... So it's just, it doesn't make her feel uncomfortable then.' (Dawn)

Support for midwife

A super-ordinate theme relating to the support available for the midwife was woven throughout the narratives. The midwives reflected how the right support, for both the woman and the midwife, can make a significant difference in terms of the quality of care delivered and the woman's and the midwife's experiences. All the midwives felt that working in partnership with other services was key in order for the women to receive care that they were entitled to. The midwives who spoke of their experiences of multi-agency working reinforced the feeling that additional support for the midwife is needed and can make a significant difference in the quality of care delivered.

8. *Feeling alone and unsupported*

There was a strong sense that the midwives felt alone and unsupported in their care of women with LD. This feeling was emphasised by the lack of LD and highlighted the absence of specific LD training. The midwives felt out of their depth and had limited, if any, guidance to refer to. This led them to feel alone and unsupported by the organisation in their attempts to deliver care for women with LD.

'it's like the blind leading the blind I suppose, you literally just find your way through it...' (Jess)

'It was a bit like swimming around in the dark.'

'I was unsupported and everybody said, well just phone these people, it wasn't that easy...' (Sarah)

'there's loads of specialist people that deal with people with learning disabilities, help me, please tell me where I'm supposed to go with it, 'cause I didn't know... I tried, loads of times... But it just was falling on deaf ears... ... So it was really frustrating'
(Sarah)

All the midwives spoke about not receiving the right support. This was in relation to specific LD information as well as a significant absence in guidance from the organisation on policies for working with women with LD.

'it has been difficult and it's a shame it isn't a little bit more easier to To sort of be directed to other agencies where you can get the help and support' (Jo)

'I just don't feel there was ever .. anything explicitly said, or support from the trust itself to say ... this is what you should do in this situation ...' (Jess)

9. We need to work together

The midwives talked about their experiences of multi-disciplinary and multi-agency working and how it was vital for services to work together, supporting each other to ensure women were receiving the care and support they needed.

'I can't do everything... myself... and that's what it's supposed to be, it's multi-disciplinary... So we do need other people on board' (Kerry)

Lisa talked about how she was able to focus on the woman's midwifery needs through working as a team with other services.

'She did have carers... and a learning disabilities nurse... that was easier because she did have that support. ... I felt I could do my job without getting embroiled in trying to set up support networks that clearly weren't there for my other lady.' (Lisa)

The importance of sharing information across services was apparent throughout all the midwives' experiences.

'I have to say the family support worker, the health visitor, they've all been really good.. a multi agency approach.. is definitely the way to go because I think if it was just me, I would've struggled and perhaps not given her the.. best care I could've given her so, I think support from other agencies is important as well.' (Jo)

'working with Mencap have been amazing... I was really shocked, I've never had any involvement with them before, so all of that's been so positive and everything with my lady's been just so lovely and positive.' (Dawn)

The midwives felt that it was important to share information between community and hospital midwifery teams to support their colleagues to provide the level of care the women needed.

'we filled it all in (my maternity book) and I said, it's there and it makes all the healthcare professionals aware, when you go into hospital... Without you having to explain anything or them having to ask you, what is your difficulties... and I know she might not always speak out very well... If they've got that book, there's some things there... I think the book is more beneficial... for other healthcare professionals... to be more alerted to her needs.' (Dawn)

'I'll let the hospital know... a little bit about you... so at least the midwife that is going to look after you, can make sure they've got a student with them who can support you... And get a little bit of a... insider knowledge...' (Dawn)

Safeguarding

The safeguarding process featured in all the midwives' experiences. There was a sense that it was part of the pregnancy process for women with LD. The midwives felt under pressure during the process, worrying about how to do the best for the women and spoke about how support for the woman could make a difference during her pregnancy, suggesting that it could also have an impact on the safeguarding outcome, if it was in place and meet the woman's needs.

10. Inevitable process

There was a sense that the midwives felt a safeguarding process was inevitable in any pregnancy of a woman with LD and often felt guilty that there was no other option.

'if there are any concerns at all we have to do a referral and that can be hard as well because That's not the way I want it to go .. for her ... no body wants to do that ...but ...sometimes its necessary.' (Jo)

'I did refer her to the family support workers, but they felt that it was safeguarding because she had obvious disability... you don't want to necessarily go down the safeguarding route but I had to.' (Sarah)

11. Support can make a difference

It was evident that the midwives felt that support could make a difference in the pregnancy of a woman with LD and could be influential in the outcome of a safeguarding process.

'I think it really hit home for me because that makes you think hang on a minute ... these people deserve a chance and with a bit of help and support .. they can be good parents where as I think before that ... it's quite easy to just think .. social services ... which isn't giving them a chance and that's such a shame really'. (Jo)

'if you can give them enough support, if we do manage to get it right and give them the right support, it'll have a good ending...' (Charlotte)

'even if you did have to do a Social Services referral, could they provide any extra support as well... And it's not just that we don't want them to look after the children,

it's can we provide anything extra to help them in the transition and... even if it's for them being assessed to see, give them every chance they can.' (Charlotte)

'Just because they've got learning disabilities doesn't mean they can't be parents.

With the support, I think a lot of them can be.' (Charlotte)

Discussion

Summary

The midwives' narratives suggest that they are committed to their role and want to deliver the best care they can for women with LD. There is an underlying assumption that women with LD are entitled to become parents. The midwives highlight gaps in healthcare services and how they fall short in delivering the care these women are entitled to. This is due to a number of reasons, including limited resources, time and skills of the midwives and an absence of LD training and guidance. As the midwives discuss their experiences, there is a sense that they feel frustrated and guilty about the barriers that prevent them from delivering appropriate midwifery provision.

The integrated behavioural model (IBM, Fishbein, 1998) offers a theoretical explanation for the midwives' experiences. IBM (see Figure 2) proposes that multiple factors integrate to influence one's behaviour. Applying IBM to consider the cognitive and social factors determining midwives' provision of care, it would suggest that external variables (e.g. age, gender, education) affect their beliefs regarding the provision of care. Attitudes,

perceived norms and self-efficacy are, according to IBM, products of one's beliefs. Relevant beliefs include 1/ views regarding the consequences of providing care (*behavioural beliefs*) which influence one's attitude towards the provision of care; 2/ *normative beliefs* regarding the provision of care, which affects one's perception of what is deemed the norm in terms of care provision; and 3/ *efficacy beliefs* concerning specific barriers to care that affect one's belief in one's skills and abilities to provide care.

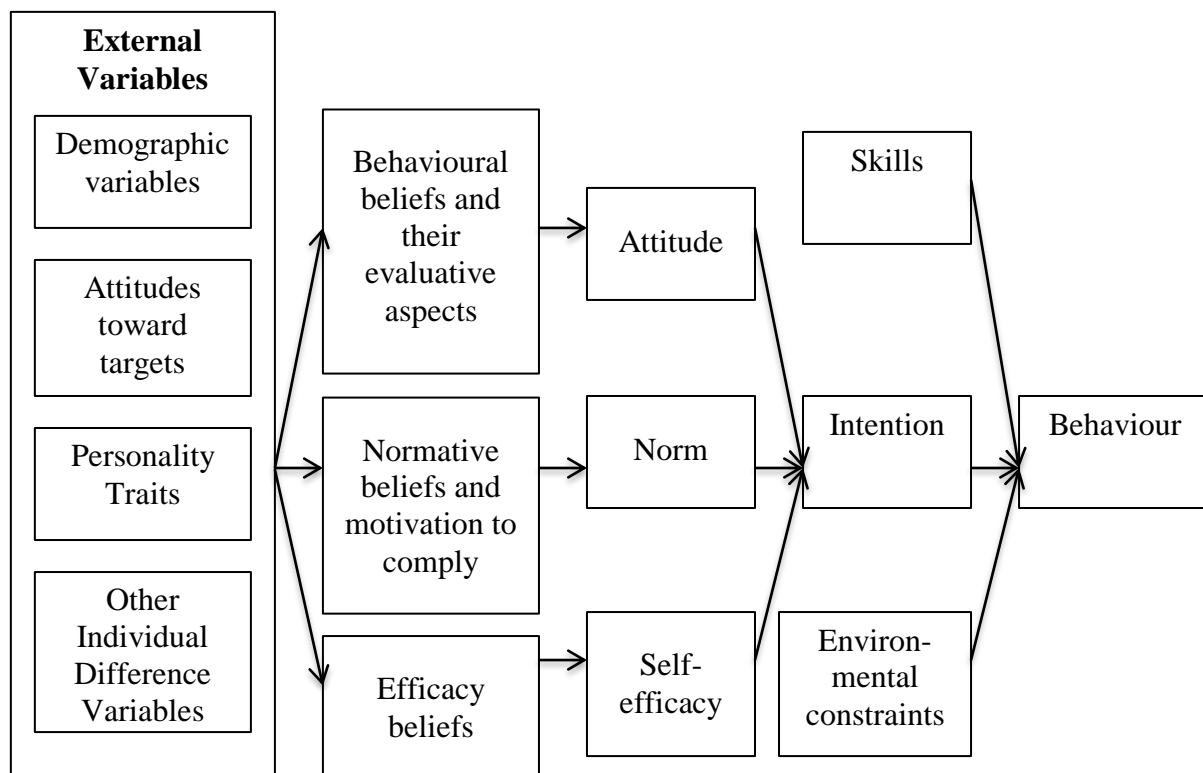


Figure 2: Fishbein's (1998) Integrated Behavioural Model (IBM).

The midwives cite a number of environmental constraints (e.g. limited resources, guidance and support), which IBM would suggest influenced their behaviour through the reinforcement of their belief that they did not have the skills and resources to deliver adequate midwifery provision. The midwives report positive attitudes towards women with LD becoming parents, with the belief that they could be good parents, with the right support. IBM would suggest that these positive normative beliefs and attitudes, along with a strong commitment to delivering adequate care had influenced the midwives' motivation to deliver the most adequate care they possibly could, against the challenges they faced.

The midwives' felt guilty that they could not offer the level of support that met the

women with LD needs, taking on other duties in addition to their responsibility as a midwife. Their efforts to meet the women's additional needs may be a product of a behavioural belief that the women deserved a chance to fulfil their right to become mothers. Likewise, their feelings of frustration regarding the limited specialist support available suggests a normative belief that women with LD should have access to adequate services to support them to become good parents. Such a belief may have influenced their behaviour, with the midwives trying to put in place additional support despite the many barriers they faced in accessing support.

It proposed that midwives' beliefs influence the care women with LD receive. The midwives' commitment to providing the best care possible despite the challenges faced and their willingness to undertake duties beyond their role to meet the needs of the women suggest they hold positive attitudes towards the women with LD.

Midwives' experiences of working with women with LD

The midwives felt they were not able to focus on delivering midwifery care in cases where the woman had unmet other needs (in particular social care) due to a lack of specialist support. There was a sense that they could not ignore those other needs despite the impact on their time. It has been acknowledged that early intervention and multi-agency working is needed to recognise and meet the needs of parents with LD (e.g. *The Same As You?*, 2000).

Midwives who worked with women supported by other agencies reflect on the positive difference this made, both in terms of the woman's experience and the midwife's ability to deliver adequate care. There was an apparent lack of services accessible to pregnant women with LD, frustrating the midwives as they were aware of the benefit specialist support

can offer for women with additional needs. This is similar to the experiences reported previously of women with LD (McGaw & Sturmey, 1994) and Doulas (McGarry, 2014) who felt that support appeared to be crisis-driven and provided by inexperienced mainstream services.

The midwives spoke about feeling alone, unsupported and unskilled in delivering care for women with LD. This appears to be a common theme across healthcare professionals (e.g. nurses, GPs) who also feel inadequately skilled and supported to deliver care for people with LD (Melville, Cooper & Morrison, 2006; Sowney & Barr, 2006). McGarry (2014) and Hoglund, Lindgren & Larsson (2013) highlight the need for more support for professionals working with women with LD during their pregnancy.

The midwives felt their lack of skills and limited communication with other services negatively influenced the delivery of maternity care. Midwives' experiences suggest that services were not working together, which parents with LD report as a barrier to accessing effective services (MacIntyre & Stewart, 2012). McGarry (2014) reported individual supervision and peer group support was helpful for doulas working with women with LD. Such support could be beneficial for midwives also.

Despite a difference in roles of the hospital and community midwives, similar themes arose. There was good agreement throughout the narratives, irrespective of the midwives' role, age or time as a qualified midwife.

Midwives' view of their work with women with LD

Lack of time appears to be a frequent challenge midwives face during their clinical practice (Kennedy et al, 2010). Constraints on professionals' time are reported to significantly

influence support available for pregnant women with LD (e.g. Tarleton, Ward & Howarth, 2006, Crozier, Morris & Genders, 2013). The midwives felt guilty that they did not have the time to spend with the women to adequately meet their needs. They felt frustrated as they could see how to enhance the woman's care, yet unable to make adjustments due to time constraints.

There is a sense that the midwives did not treat women with LD any differently to other women. This appears to be a common working ethos of midwives; reporting they want to work towards delivering equitable services for all women (Lavender & Chapple, 2004). The midwives focus on developing a trusting relationship and highlighted the importance of continuity in their work with women with LD. These factors were felt to have a direct impact on the midwife's ability to provide adequate midwifery care (Hunter, 2006) and are known to be particularly important for women with LD (McGarry, 2014).

The midwives felt frustrated and guilty they could not do more and unconditionally aimed to do their utmost, going above and beyond their role, despite the barriers they faced. Kennedy et al (2010) also reported that midwives would 'go out on limbs' to deliver tailored care to meet women's needs, which were not part of standard midwifery guidance.

The midwives took pride in their work, wanting to give every woman adequate care and a positive experience of childbirth. They came across as committed and caring professionals. They felt frustrated that they could not provide a service for women with LD, mainly through the lack of support from other professionals and LD training. In contrast to previous health professional research (e.g. Hoglund, Lindgren & Larsson, 2013; Lewis & Stenfert Kroese, 2010), all the midwives held positive attitudes towards women with LD and it was never questioned that the women should have children. Although they acknowledged

support was needed, there was an assumption that the women had a right to have children, which the midwives acknowledged through their commitment to deliver adequate care, wanting to give the women a positive start to parenthood. It can be tentatively suggested that despite a lack of training in LD, the midwives held positive attitudes towards parents with LD, agreeing with the principles of 'Valuing People' (2001), which advocates for people with LD to have the right to become parents.

Safeguarding felt an inevitable process for the midwives. They often felt there was no other option due to a lack of support available to meet the woman's needs. McGarry (2014) found that doulas found the safeguarding processes stressful. Regular supervision and peer support did not always support the doulas resulting in burn out for some (Cherniss, 1980). Tarleton, Ward & Howarth (2006) recommend that training, supervision and support in safeguarding is needed for professionals who work in services for people with LD. Further attention needs to be given to how to support health professionals through the highly stressful safeguarding processes, which midwives are increasingly becoming part of.

Midwives' experiences and attitudes towards the role of LD training

The lack of LD training for healthcare professionals is well recognised. Crozier, Morris & Genders (2013) suggest that training can help professionals empathise with parents with LD, facilitating an understanding that people do not choose to be poor parents but require effective support to learn skills to become good parents. Hoglund, Lindgren & Larsson (2013) and Leaviss et al (2011) recommend LD training for midwives.

The midwives held a belief that LD training would be helpful to support their

provision of care for women with LD, with some reporting it should be included in mandatory training for qualified midwives. However, very limited, if any, post-qualification training had been attended. Those midwives, who had attended training, did so as they had an interest in developing their knowledge of caring for women with LD. They felt it had been influential in their work, giving them both insight into the women's needs as well as developing their own knowledge and skills. These midwives felt training helped on many levels, developing their awareness of LD needs, adapting their practice to meet these needs, and recognising how to seek specialist support. The dearth in LD training is recognised by the individual midwives, in this sample however the need for training is yet to be recognised at an organisational level.

Midwives could not remember any LD training as students and felt it was important this be made available to both students and qualified midwives. Michael (2008) recommends that LD training and experience features in undergraduate clinical education to develop both students' knowledge and experience of LD. It is suggested that clinical experience with people with LD can facilitate positive attitudes (Gill, Stenfert Kroese & Rose, 2002).

Research with student doctors (Ouellette-Kuntz et al., 2012) reported that role models and supervision could foster students' positive attitudes towards people with LD, reinforcing the importance of LD experience during education and on-going skill development for qualified professionals. The midwives reported a lack of confidence in delivering care for women with LD, linking with previous healthcare research (McConkey & Truesdale, 2000) which reported nurses from mainstream healthcare services had low confidence scores, reporting a lack of confidence and feeling unprepared when providing healthcare provision for people with LD. Professionals' (e.g. GPs, nurses) confidence is suggested to be affected by their level of training and experience in LD (McConkey & Truesdale, 2000; Stanley, 1998), highlighting

the importance of qualified midwives being skilled and hence confident in midwifery provision for women with LD.

In recognising their limited LD experience and knowledge, the midwives appeared motivated to develop their skills, feeling guilty they were not meeting the women's needs and frustrated that the level of midwifery care could be enhanced, if only they had the relevant skills and resources. Porter et al (2012) reported midwives were willing to utilise resources when accessible to support their clinical practice with people with LD. This suggests that other factors (e.g. organisational issues) besides the midwives' attitudes were acting as a barrier to their ability to develop their skills

Possible limitations

The themes identified in this study reflect the experiences of the nine midwives who participated in the study. Due to the idiographic characteristic of the research, the themes may not reflect all midwives' experiences of caring for women with LD and as such it is not possible to generalise the findings of this study accurately to all midwives who have worked with parents with LD.

It is possible that there was a selection bias since participation was voluntary. This may have led to a biased sample of midwives who wanted to discuss their experiences. Those midwives who did not choose to take part may possibly have more negative experiences and attitudes on providing maternity services for women with LD.

More than one recruitment site was included in the study, however all the participants were from one organisation. Organisational policies, support systems for midwives and

specialist services for parents with LD may vary regionally impacting on the generalisability of the findings.

Recommendations

Based on the findings, tentative recommendations can be made which may have a positive impact on the experiences of midwives and women with LD during midwifery care. It is recommended that training on working with and providing services for people with LD is made available to all midwives. Training and information on how to adapt care to support women with LD's level of understanding, the safeguarding process, and available support services would be beneficial. Given the increasing likelihood of midwives caring for women with LD, it would be useful to consider including LD teaching and clinical experience for student midwives. As participants had a positive view of hearing about service user experiences of services during LD training, it is recommended that service users are included in this teaching.

The midwives recognised their need for additional support, both resource and time-wise to make the reasonable adjustments (accessible information, effective communication) to their practice. Yet not all midwives were aware of accessible resources available for women with LD such as 'My pregnancy, My Choice', 'You and Your Baby' (CHANGE, 2012) or local advocacy services. It is important to raise awareness of accessible resources and professional support for midwives to assist in their provision of care for women with LD (Tarleton, Ward & Howarth, 2006). Resources available from CHANGE (www.changepeople.co.uk) and BILD (www.bild.org.uk), which were found beneficial in doula work with women with LD (McGarry, 2014) and the pregnancy support pack

specifically developed to support midwives in their care with women with LD (Porter et al, 2011) could be beneficial.

Supervision should be routinely offered to midwives caring for women with LD to support them in developing their skills and reflect upon their experiences. Where there is a lack of local guidance for midwifery provision for women with LD, it is recommended that guidance is developed and implemented. It would be helpful to invite local midwives to share their experiences of caring for women with LD, in particular the barriers they face, as well as making available specific guidance for midwives (e.g. NHS Highland, 2011) and national guidance (Guidance on Working with Parents with Learning Disabilities, DoH and DoE, 2007). Joint working, sharing information with colleagues through a specific LD forum and identifying a lead midwife for LD within a service are all ways of increasing the level of support for midwives, with minimal financial cost.

To foster multi-agency working, it is recommended that midwives are included in care planning meetings for women with LD from the start of pregnancy. It would be helpful for services for people with LD, especially those who are able to support pregnant women with LD, to continue to promote their services within healthcare settings. Liaison with LD nurse specialists, midwifery managers or the safeguarding lead for LD could be a practicable way of distributing information via safeguarding lead midwives.

The midwives acknowledged that the themes identified in this study are not unique to midwifery care for women with LD, with all current midwifery practice affected by the lack of staff, resources, time, continuity, supervision and training. This highlights the need for organisations to develop services, which match both the needs of pregnant women and the midwives who provide such a vital healthcare service.

Future research

Given the distinct lack of research on midwives' experiences of caring for women with LD and the poignant themes identified within this study, it is recommended that further research is conducted into midwives' experiences with this client group. It would be advantageous to study different geographical regions to identify if the themes, which emerged in this study, are consistent across midwifery services. The themes of particular interest are availability of training and support, support services available for pregnant women with LD, and multi-agency working. Such future research would allow good practices to be shared across midwifery services in an attempt to offer consistent and accessible care to women with LD. It could also identify potential solutions to the challenges midwives face, recognising and taking into consideration their experiences.

A lack of specific LD training was a key theme within this study, it is therefore important to investigate current LD training in terms of efficacy and develop a training programme, which would be accessible and effective for all midwives. It would be beneficial for an outcome measure to be developed in relation to the efficacy of LD training. This could ensure that any training delivered matched participants' needs, highlighting where further support would be helpful post-training.

All the midwives viewed a lack of training as a barrier to delivering midwifery services to women with LD. Fishbein (1998) proposes that one's skills and intention to perform the behaviour influences actual behaviour (e.g. midwifery provision for women with LD). Midwives' attitudes regarding women with LD are suggested to determine intention to deliver such care for these women, subsequently influencing midwives' behaviour and

therefore the care pregnant women with LD receive. It would therefore be beneficial to not only investigate the efficacy of LD training in terms of increased knowledge and skills but also the impact of training on midwives' attitudes towards people with LD and providing services for them.

Conclusion

This study aimed to explore midwives' experiences of caring for women with LD. The midwives, whether community or hospital based, reflected upon their frustration and guilt at not being able to do their job as they felt they did not have enough time or the skills to deliver the care the women were entitled to. They felt unsupported and alone in their attempts to deliver adequate midwifery care with limited, if any, LD training to support them. The midwives spoke of a lack of accessible support for pregnant women with LD and were left feeling that they were responsible to fill the gaps in service provision for these women. There was an agreement that the midwives were dedicated in delivering adequate care to help give women with LD a positive experience of childbearing. The midwives felt safeguarding was an inevitable as part of women with LD's pregnancy experience yet were aware that the right support at the right time could make a difference to women with LD and their parenting skills. The midwives requested more training and information on providing midwifery services for women with LD.

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Public domain briefing document

Introduction

This paper provides an overview of the thesis ‘Experiences and attitudes of health professionals who deliver services for adults with learning disabilities’ submitted in partial fulfilment for the Doctorate in Clinical Psychology at the School of Psychology, University of Birmingham.

A systematic review of the attitudes of healthcare professionals who provide care for people with learning disabilities

It has been recognised that people with learning disabilities (LD) are not receiving adequate healthcare, resulting in their health needs being inadequately cared for (Leeder & Dominello, 2005; Ouellette-Kuntz, 2005, ‘Valuing People’, 2001). Several contributory factors have been suggested to explain this inequality, from difficulties in accessing services (e.g. Alborz et al., 2005; Backer et al., 2009) to the attitudes of healthcare professionals’ delivering healthcare provision (e.g. Barker & Howells, 1990; Howells, 1996; Minihao et al, 1993; Scott & Routledge, 1997).

Fitzsimmons & Barr (1997) reviewed the research available at the time investigating health professional’s attitudes towards people with LD and the impact of this on the quality of healthcare provided. They concluded that given the aim of health services to deliver person-centred care, there needs to be an understanding of how negative stereotypes and attitudes towards people with LD can influence the services they are offered. Fitzsimmons & Barr

(1997) argued that such an understanding and respect for people with LD can improve current and future services to ensure people with LD receive the healthcare they both need and are entitled to.

The aim of this paper was to investigate how healthcare professionals' attitudes may have changed since Fitzsimmons & Barr's (1997) review and the impact, if any, on the quality of care available for people with LD.

Fourteen papers were identified following a systematic literature search and were evaluated in terms of their quality. Key themes were identified across the fourteen papers relevant to the healthcare provision for people with LD including a lack of LD training and education available, barriers which affect the provision of healthcare, how the professionals' viewed their role in the provision of community care for people with LD and their view of specialist services. The quality assessment suggested a medium level of bias across the literature.

Healthcare professionals' attitudes towards caring for people with LD varied both across and within the studies included in this review. In application of Fishbein's (1998) integrated behavioural model, there appears to be multiple cognitive and social factors that influence professionals' attitudes, affecting their intentions regarding care and subsequent care provision.

There are a number of important clinical implications to consider including the importance of LD training, supervision and clinical experience throughout a healthcare professional's career and the significant positive impact this may have on the quality of healthcare provision for people with LD. An identified gap in the research indicates the need to review the efficacy of available LD training, given limited training has been identified as a

barrier to delivering adequate LD healthcare provision for professionals.

Midwives' experiences of caring for women with Learning Disabilities

Background

People with LD are increasingly likely to become parents (WTPN, 2008). 'Valuing People' and 'Valuing People Now' (2001, 2009) advocate the need to ensure parents with LD have access to the right support to be able to be suitable parents. However, access to such support is affected by limited resources, attitudes towards people with LD becoming parents, and lack of specialist LD training (Booth & Booth 1993; Cooke 2005; Culley & Genders 1999). There is little research exploring health professionals' experiences of their care for people with LD during their journey to become parents. Midwives are often the first professional, pregnant women come into contact with and therefore are a key professional in the support system working with parents with LD. The main aim of the study was to develop an understanding of midwives' experiences of caring for women with a LD.

Method

Nine qualified midwives, from community and hospital-based teams of a local midwifery service participated in the study. Individual interviews were held to discuss the midwife's experiences of providing maternity services for women with LD. Interpretive Phenomenological Analysis (IPA) was the qualitative research method used to collect a first-hand and detailed account of the midwives' experiences of working with women with LD. The audio-recordings of the interviews were transcribed and were analysed using the stages

proposed by Smith, Flowers, & Larkin (2009); identifying four superordinate themes and eleven subordinate themes.

Summary of findings

Super-ordinate theme	Sub-ordinate themes
1. Not being able to do my job	1. Support available but not accessible
	2. Having to do other people's jobs
	3. Not skilled enough – out of my depth
	4. Not enough time to do everything
	5. Lack of LD training
2. Delivering the best care	6. Wanting to do your best
	7. Gaining a woman's trust
3. Support for midwife	8. Feeling alone and unsupported.
	9. We need to work together
4. Safeguarding (Child Protection) process	10. Inevitable
	11. Support can make a difference

Conclusions

The midwives reported receiving a lack of LD training and faced significant time constraints, which left them feeling out of their depth and guilty that they could not spend the time with the women that they required to meet their pregnancy needs. The midwives felt unsupported in their attempts to deliver adequate midwifery care, speaking about a lack of accessible support for pregnant women with LD. They were left feeling responsible to fill the gaps in service provision. The midwives were dedicated in delivering adequate care to help give women with LD a positive experience of childbearing. They felt undergoing a child

protection process, as a result of professionals' concerns regarding the wellbeing of the unborn child, was an inevitable part of women with LD's pregnancy experience. Yet the midwives were aware that the right support at the right time could make a difference to women with LD and their parenting skills.

Fishbein (1998) proposes that multiple influences, including cognitive and social factors, integrate to determine one's behaviour. Applying this model to the midwives' experiences, it can be proposed that the midwives' beliefs influence the care women with LD receive. The midwives' commitment to providing the best care possible despite the challenges faced and their willingness to undertake duties beyond their role to meet the needs of the women suggest they hold positive attitudes towards the women with LD.

Recommendations

It is recommended that training on working with and providing services for people with LD is made available to qualified and student midwives. It is important that accessible resources (e.g. from CHANGE, www.changepeople.co.uk and BILD, www.bild.org.uk), professional support and supervision are made available to midwives. The inclusion of midwives in care planning meetings for women with LD is recommended to foster multi-agency working. Where there is a lack of local guidance for midwifery provision of women with LD, it is recommended that guidance is developed and implemented. The midwives acknowledged that the themes identified in this study are not unique to midwifery care for women with LD. This highlights the need for organisations to develop services, which match both the needs of pregnant women and the midwives who underpin such a vital healthcare service.

It is recommended that further research be conducted into midwives' experiences with this client group. It would be interesting to compare the findings of this study with midwives' experiences from different geographical regions. Given that the midwives cite a lack of LD training as a barrier to delivering midwifery services for women with LD, it is important to investigate current LD training in terms of efficacy and develop a training programme for midwives to meet their LD training needs.

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APPENDICES VOLUME I

Appendices Literature Review

Appendix A

Description of RoBANS scoring

The RoBANS scoring guidance (Kim et al., 2013) was modified to assess the risk of bias of the studies included in this review. The original guidance (below) was considered with the following modifications –

Selection of participants

Low risk of bias

- The sample was representative of the population, and they gave a valid explanation upon which they based this decision.

Medium risk of bias

- It is uncertain whether the selection of participants resulted in a high risk or low risk of bias.

High risk of bias

- The participants were drawn from a limited sample i.e. one recruitment site.

Confounding variables

Low risk of bias

- The major confounding variables were adequately confirmed and considered.

Medium risk of bias

- It is uncertain whether the confounding variables resulted in a high risk or a low risk of bias.

High risk of bias

- The major confounding variables were not considered.

Measurement of exposure

Low risk of bias

- The study completed statistical analysis of the measures used reporting robust psychometric properties.

Medium risk of bias

- It is uncertain whether the measurement of exposure (the measures used) resulted in a high risk or a low risk of bias.

High risk of bias

- A lack of psychometric validation was reported.

Blinding of outcome assessments

This domain was not included in the quality assessment of the studies included in the review because no outcome assessments were used due to the non-experimental design of the studies.

Incomplete outcome data

Low risk of bias

- The study declared they excluded incomplete questionnaire data.

Medium risk of bias

- It is uncertain whether there was any missing data from the reported results (e.g. the study did not report upon their management of incomplete questionnaires).

High risk of bias

- It was clear missing data affected the study outcome.

Selective outcome reporting

Low risk of bias

- The study reported all of the predicted outcomes of the study.

Medium risk of bias

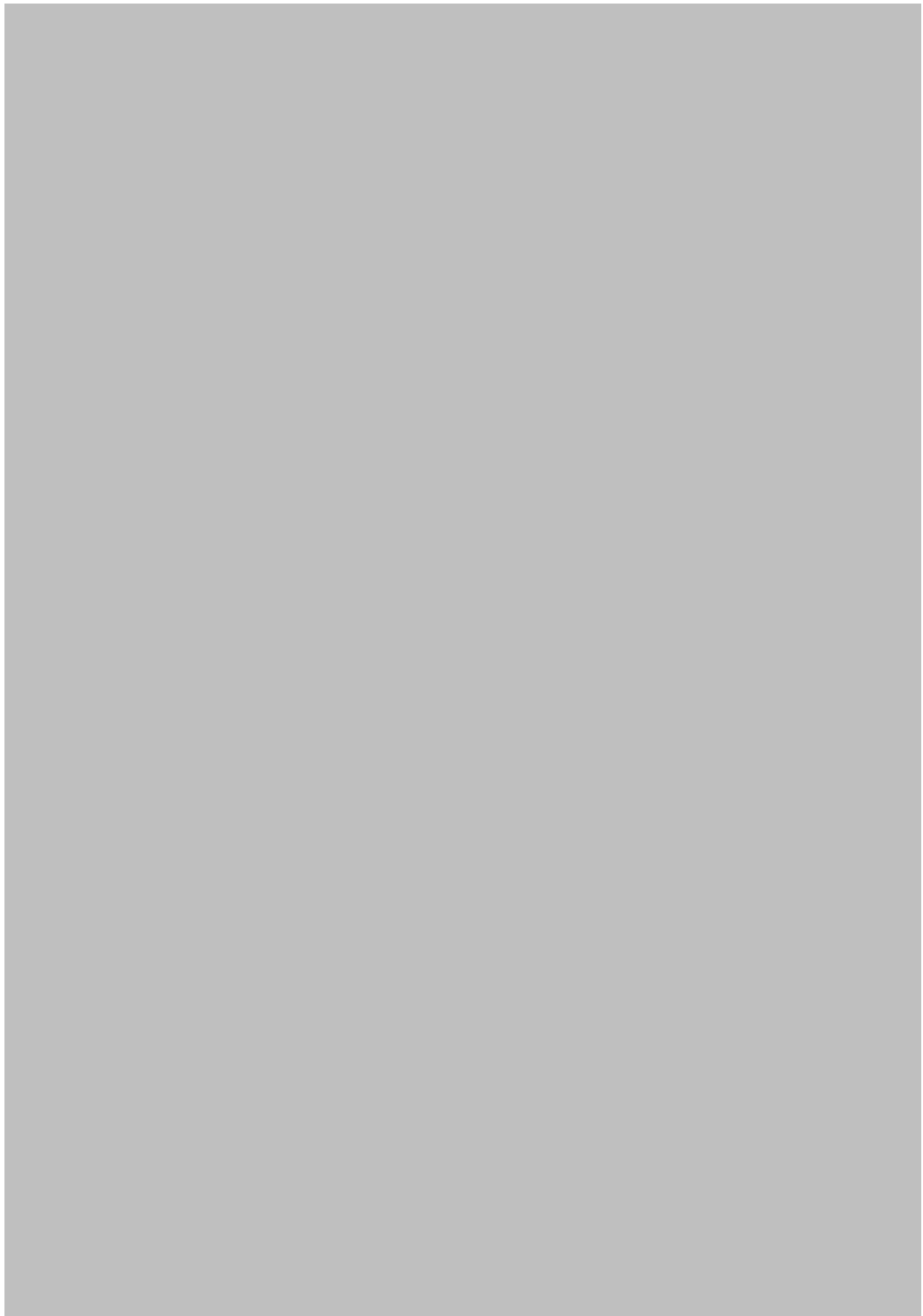
- It is uncertain whether the selective outcome reporting resulted in high risk or low risk of bias (e.g. there was limited information on the measures used, some data were not clearly presented or it was difficult to ascertain which data some of the reported findings were based on).

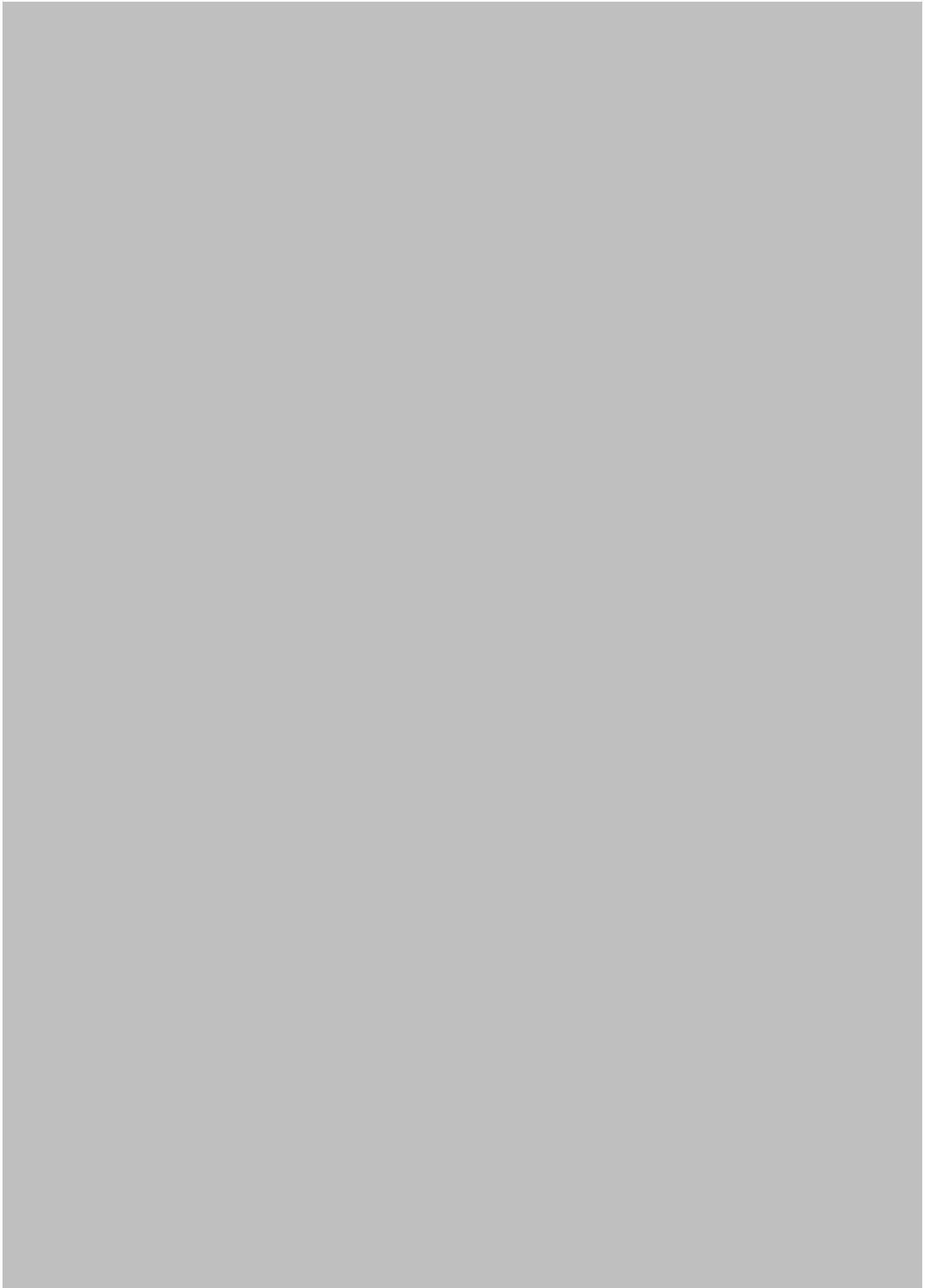
High risk of bias

- The pre-defined primary outcomes were not fully reported.
- The outcomes were not reported in accordance with the previously defined standards.
- Primary outcomes were not pre-specified in the study.
- The existence of incomplete reporting regarding the primary outcome of interest.
- The absence of reported on important outcomes that would be expected to be reported for studies in related fields.

Appendix 1. The Risk of Bias Assessment tool for Non-randomized Studies (RoBANS)









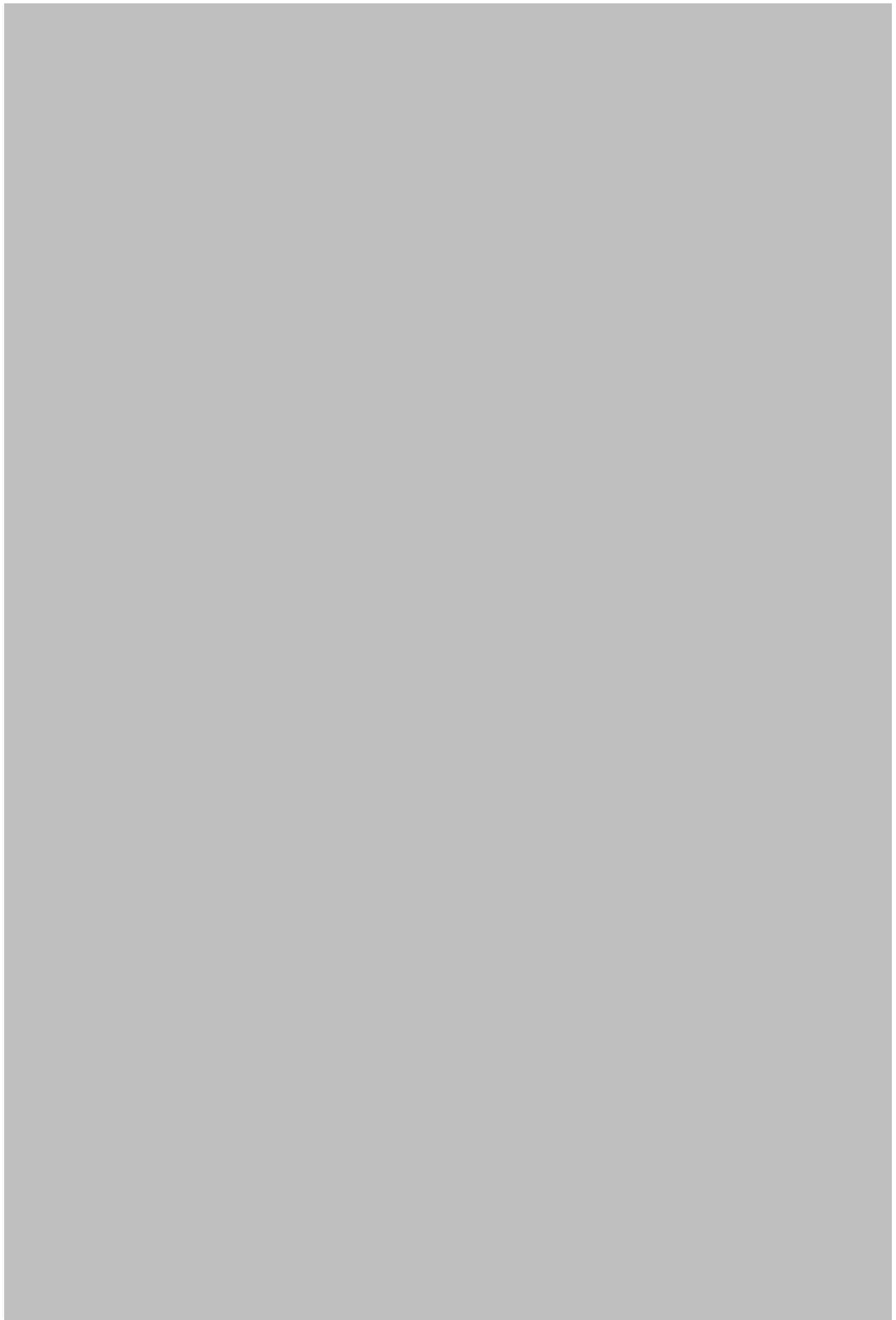


Appendix B
Journal of Applied Research in Intellectual Disabilities guidelines
For authors
(available from <http://onlinelibrary.wiley.com/journal/10.1111/%28ISSN%291468-3148/homepage/ForAuthors.html>)

Appendices Empirical Paper

Appendix A

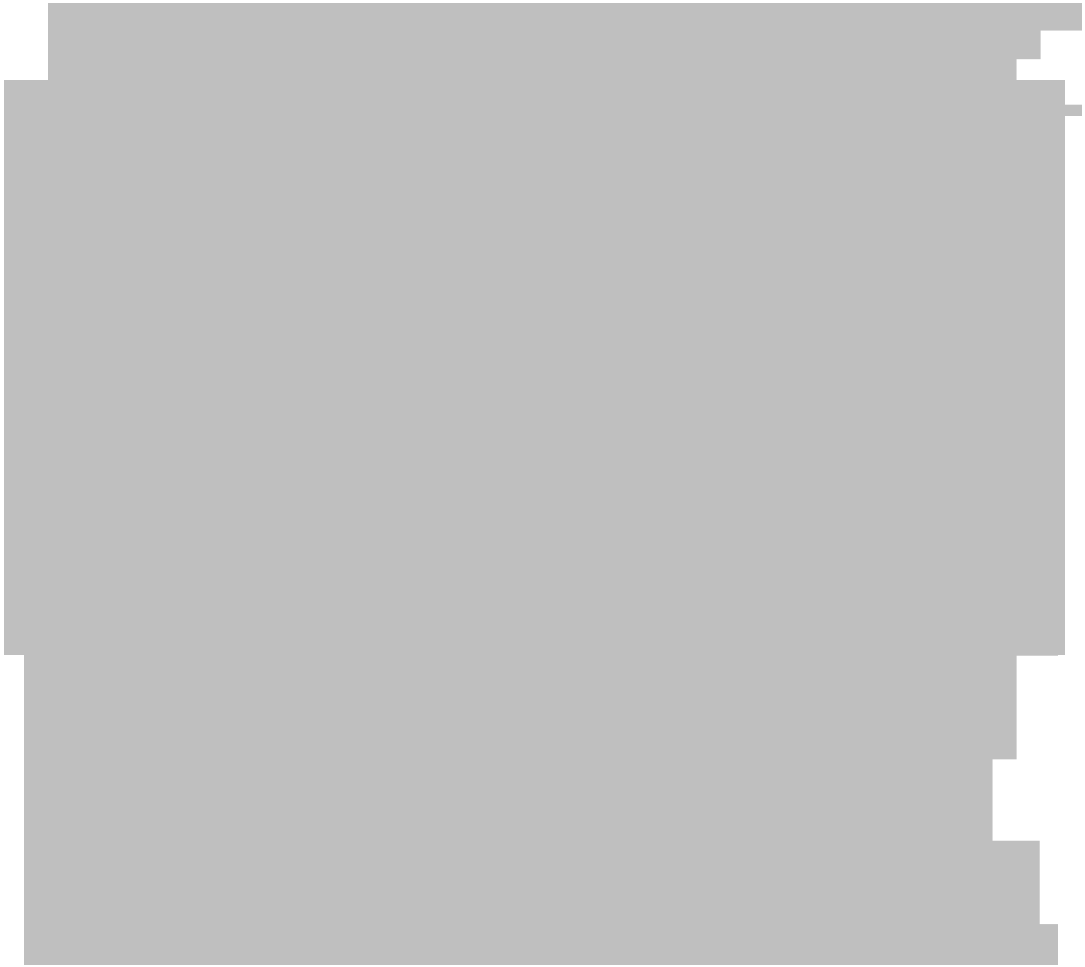
University of Birmingham Ethical Approval



Appendix B

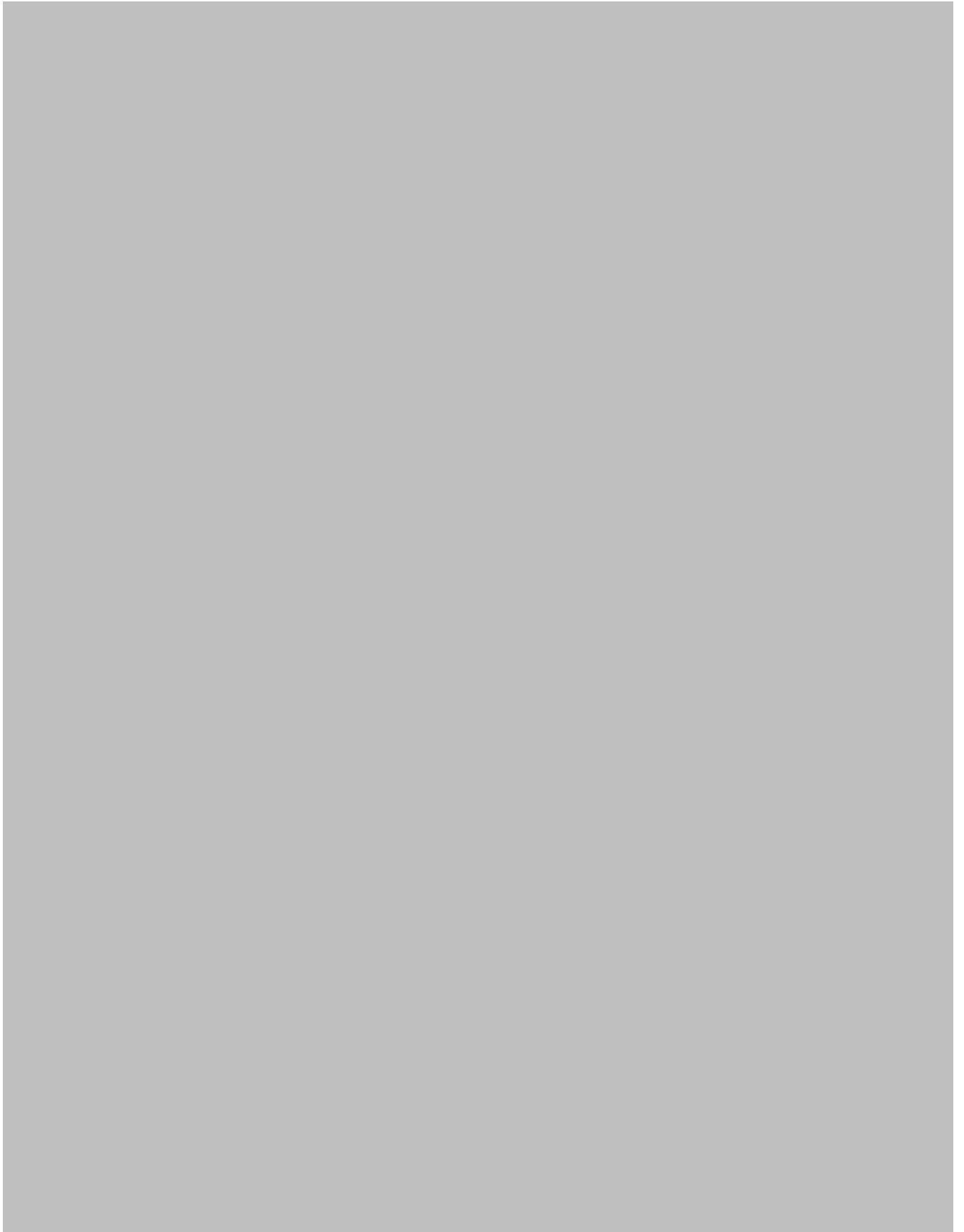
Letters of local ethical approval

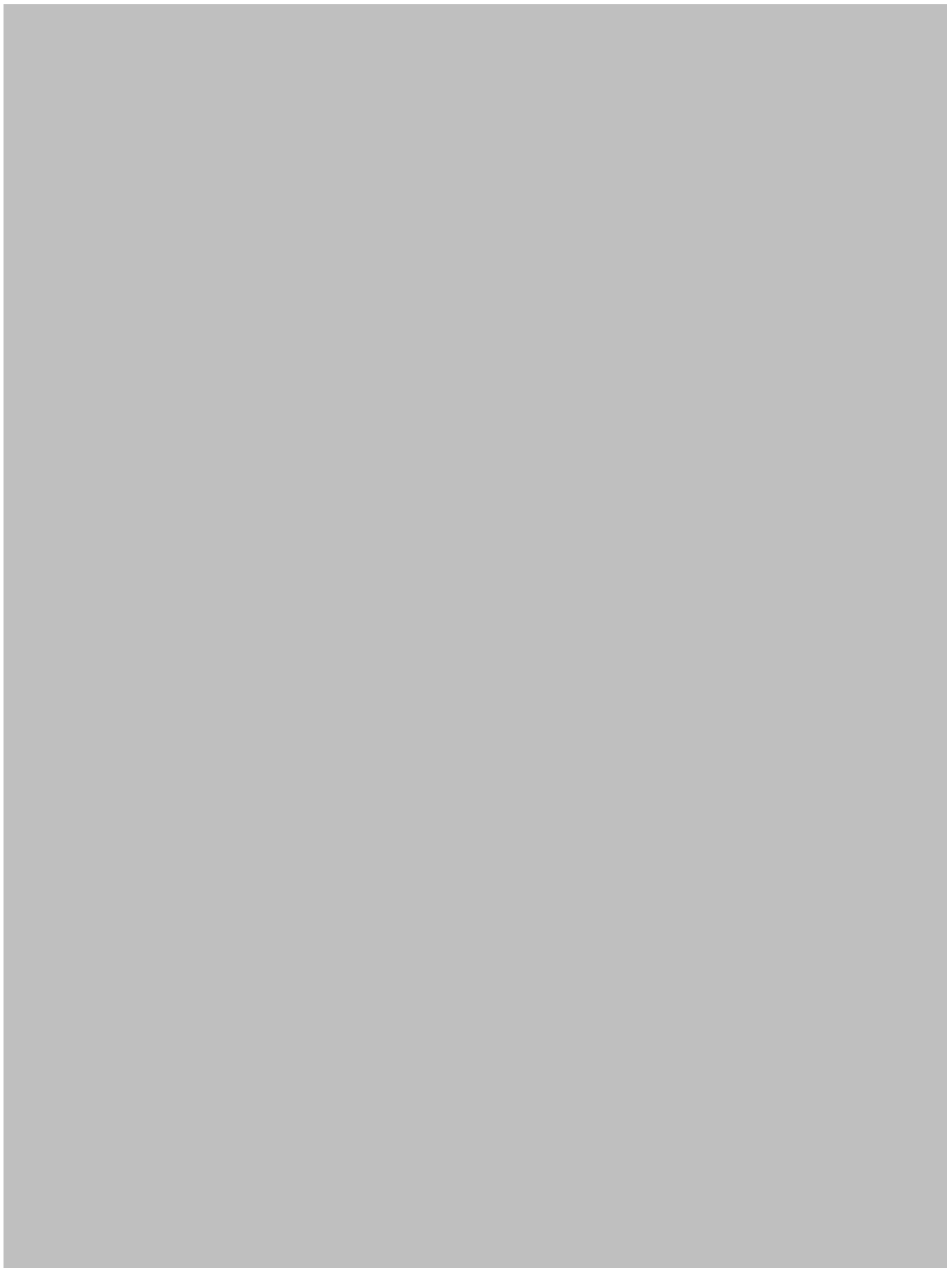


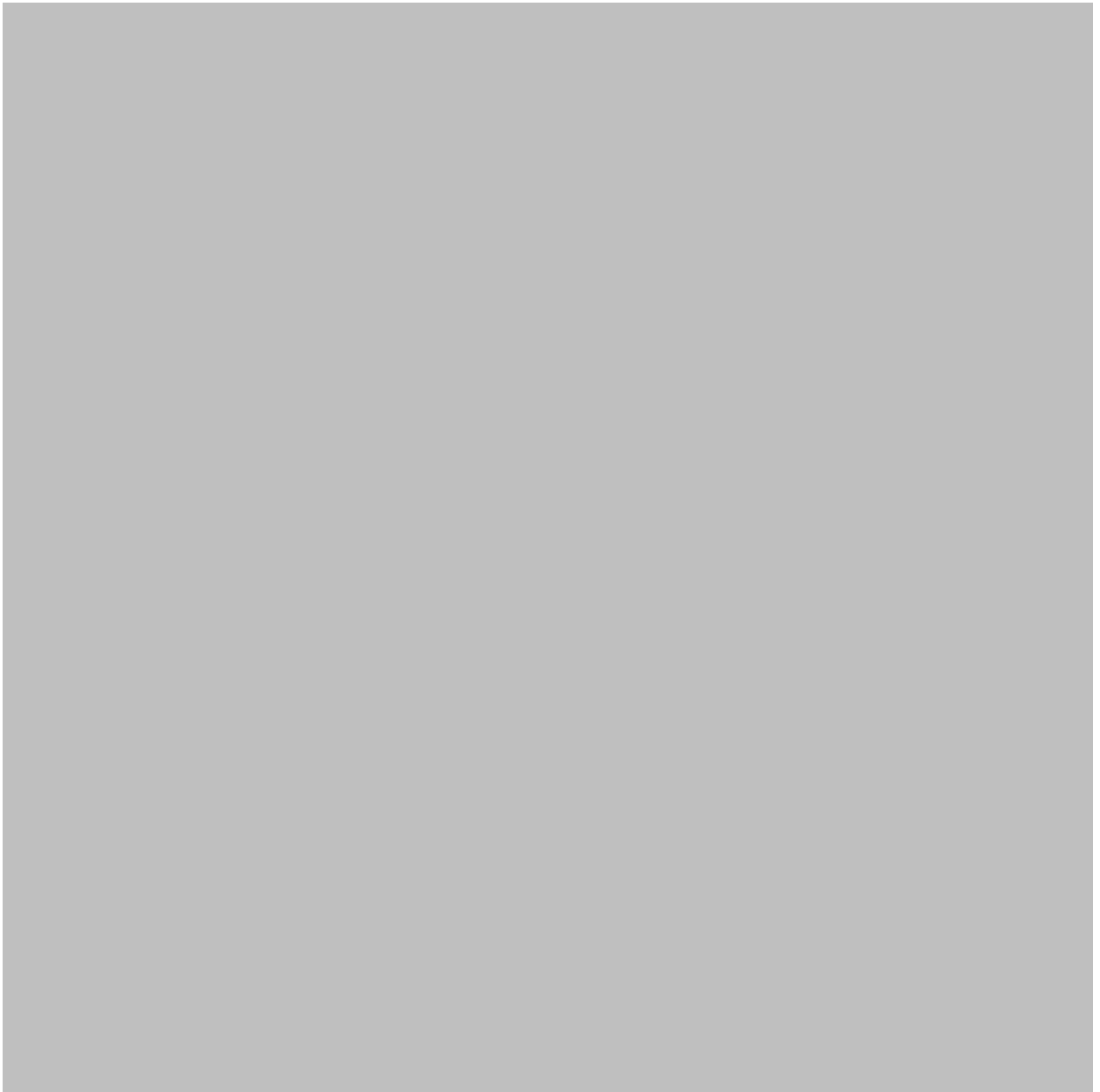














Appendix C

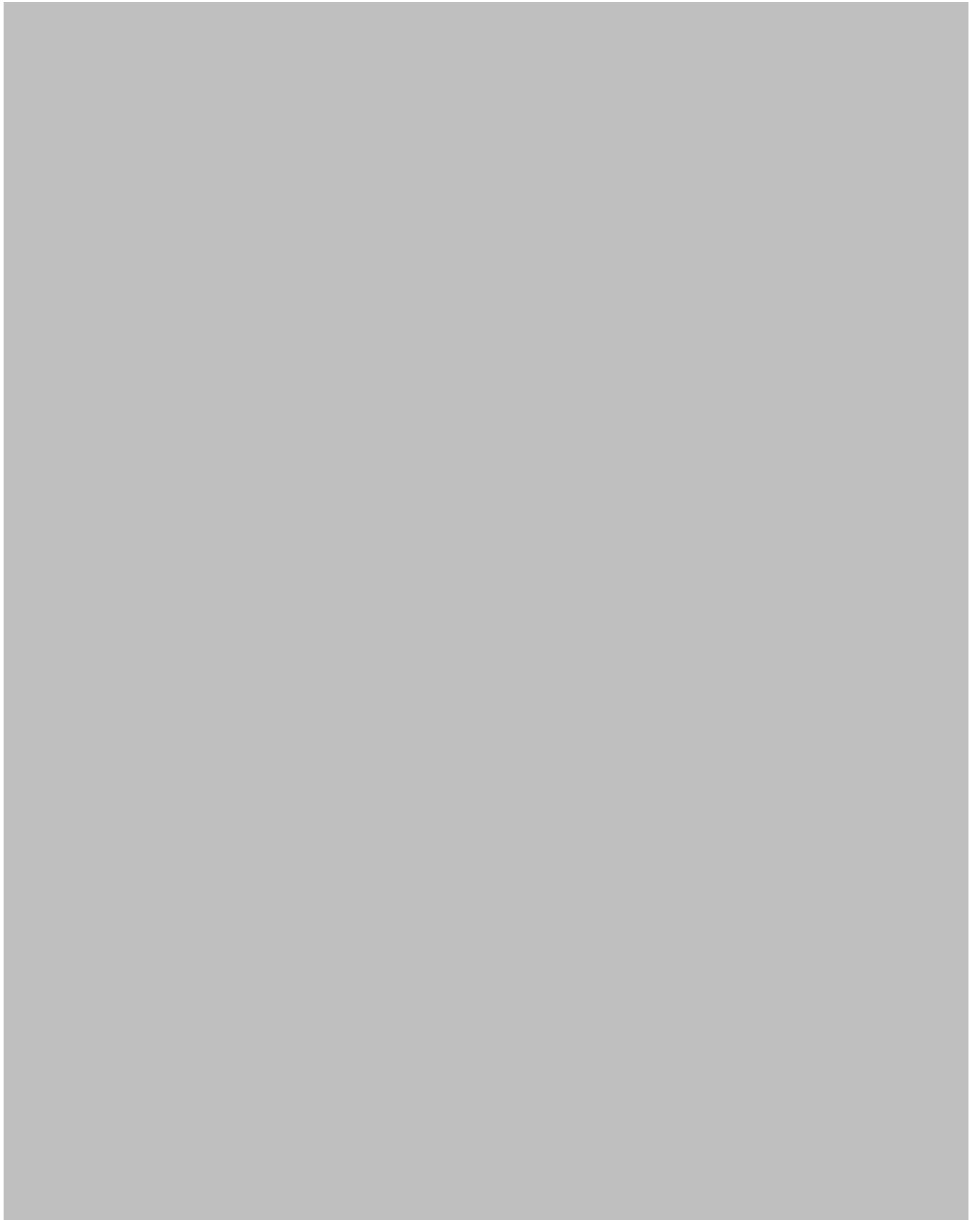
Semi-structured interview schedule

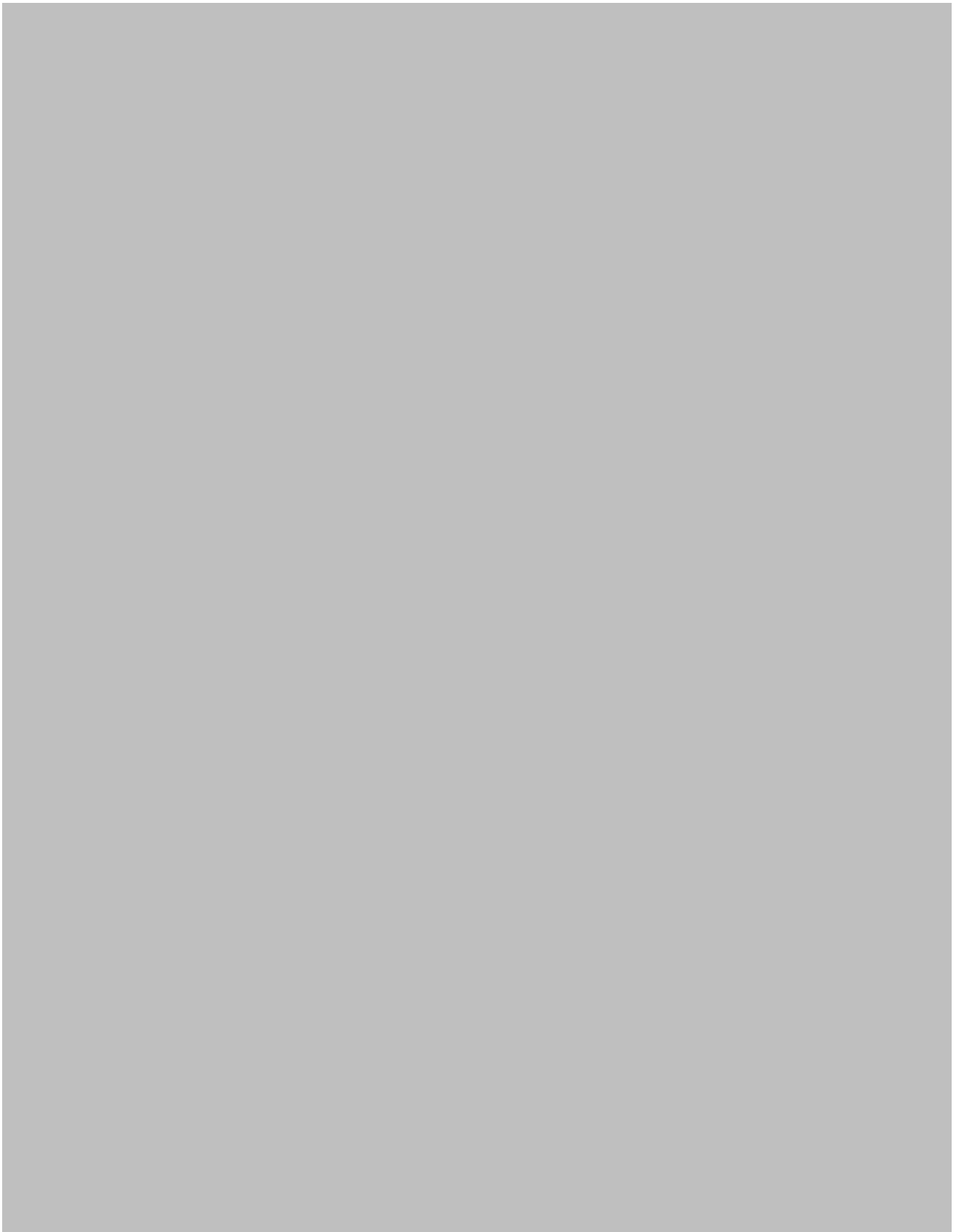
Interview Schedule
Version 1 October 2012

1. Definition of learning disability given.
2. Can you think of a specific time when you were caring for a woman with learning disabilities?
 - a. How did you feel about caring for this woman?
 - b. How did you recognise she had a learning disability?
 - c. Do you think she was given a good standard of care from you?
 - d. From the health service in general?
 - e. When thinking about this case, do you have any examples of good practice that helped you care for this woman?
 - f. When thinking about this case, what was difficult in providing care for this woman?
 - g. Where there any child protection issues when working with this case?
3. What do you think would help you to care for women with learning disabilities?
4. As a student midwife, did you have any learning disability specific training?
 - a. If you did, did you feel this was beneficial?
 - b. How has it helped you in your current clinical practice?
5. As a qualified midwife, have you received any learning disability specific training?
 - a. If you did, did you feel this was beneficial?
 - b. How has it helped you in your current clinical practice?
6. Would you be interested in taking undertaking learning disability training now?
 - a. If yes, how do you think it would benefit you?
 - b. If no, what are the reasons? Is there any other training you feel would support your ability to care for women with learning disabilities?

Appendix D

Definition of LD screening tool



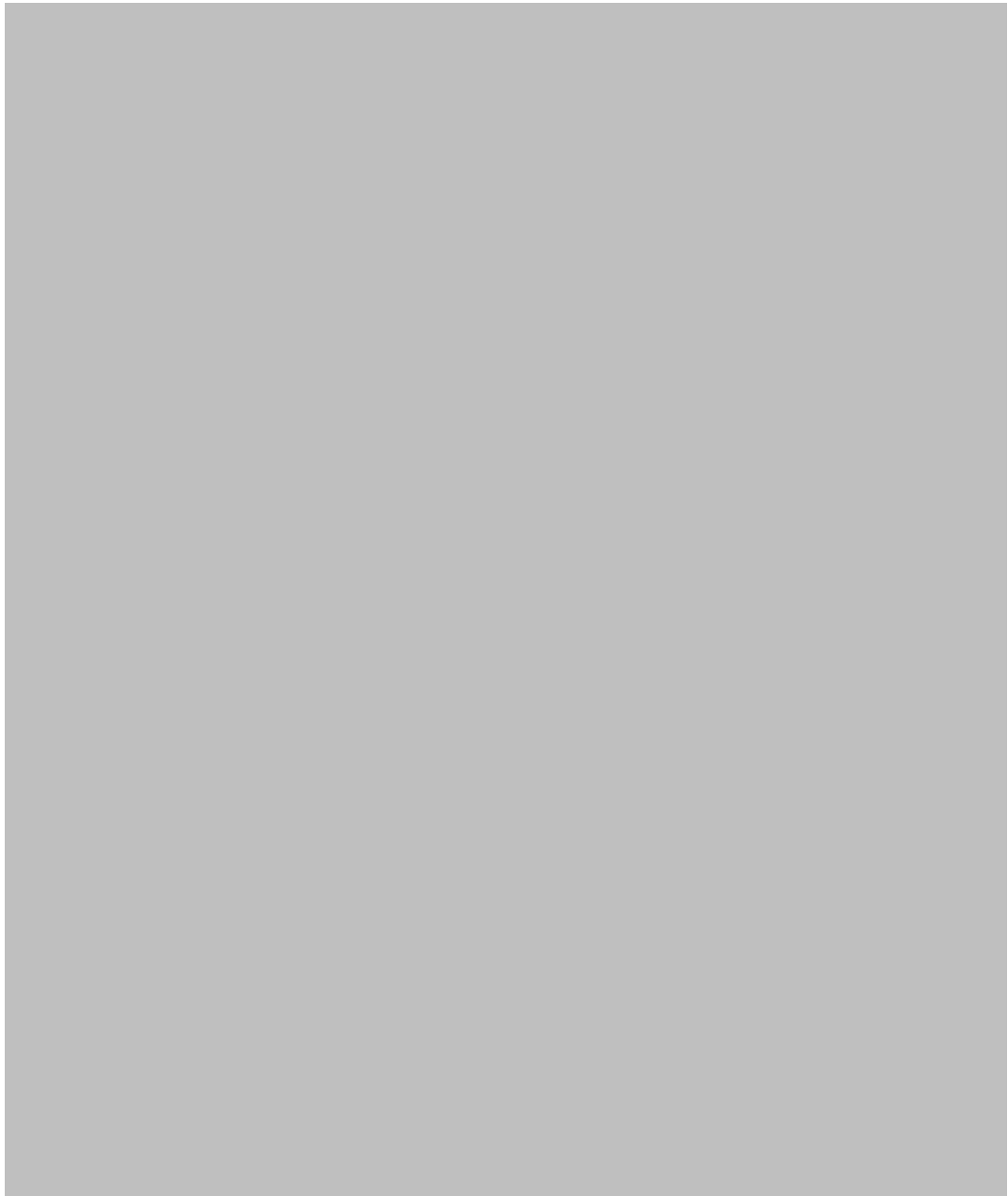


Appendix E

Participant information sheet







Appendix F
Participant consent form

CONSENT FORM
(Version 2, November 2012)

Title of Project:

Midwives' experiences and understandings of working with parents with learning disabilities

Researcher:

Emma Castell. Trainee Clinical Psychologist. University of Birmingham.

Research site:

Participant Identification Number:

Please read each statement detailed below. If you agree with the statement, please initial the box.

If you do not understand any of the statements, or have any questions, please speak to the researcher.

Once you have completed the form, please sign and date it at the bottom of the form, in the space provided.

1. I confirm that I have understood the information sheet dated November 2012 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time up until the analysis has commenced (01/03/2013). If my interview takes place after 01/03/2013, I understand I have a month post interview to withdraw. I understand that I may withdraw my interview entirely or in part, up until this point, without giving any reason, with no repercussions. To withdraw from the study I understand I need to contact the researcher via the contact details on the information sheet. ☐
3. I understand that the research interview will be audio-recorded and then transcribed (typed out) by the researcher. ☐
4. I understand that the researcher may use direct quotes (what I said) from my interview in the write up and possible publication. I understand that my name will not be attributed to any such quotes and that I will not be identifiable by my ☐

comments. I understand that I will be given a code name and that any reference to direct quotes will be linked to that code name.

5. I understand that the researcher and other members of the research team at the University of Birmingham may see parts of my interview transcript to ensure that the analysis is a fair and reasonable representation of the data. I understand that only my code name will be used in discussions about the research.

☐

6. I understand that parts of the data may also be made available to the NHS Trust with whom I am employed but only if any previously undisclosed issues of risk to me, patients or other's safety should be disclosed.

☐

7. I agree to take part in the above study.

☐

Please print, date and sign your name below

.....
Name of participant

.....
Date

.....
Signature

.....
Name of researcher

.....
Date

.....
Signature

Appendix G

Example of a 'worked' transcript

*emphasis on difficult - struggle - confusing
 *anything like that - not sure?
 *ums - uncomfortable? Anx? unsure?
 *nothing - extreme? Absolute.
 *honestly - felt unskilled - out of comfort zone?

Participant 2

35 first because there doesn't seem to be even though we've have got this
 36 new er pathway ...
 37 R: yeah
 38 P: that its very difficult to try find out what other agencies are around locally that
 39 can help her and support her,
 40 R: yeah
 41 P: so um, I did struggle, I found it really difficult. Um.... I spoke to the GP and I
 42 went through her medical records to see if there was a diagnosis
 43 R: Right
 44 P: or um if she had been statement-ed or anything like that. And there was, just,
 45 like you say, interchangeable, interchangeable, learning difficulty, learning
 46 disability, some said it was mild, some said it was moderate,
 47 R: yeah
 48 P: so it got really confusing, so I spoke to one of the GPs and um she was
 49 very There is nothing there, there is nothing out there for ladies with learning
 50 disabilities and she found it quite... difficult to, to find help and support So
 51 um As it happened The lady herself had said that she that she'd got this
 52 Um, um this lady who sees her and I was like well who is she, she didn't know
 53 who she was, she knew her first name but didn't know who she was, um so I took a
 54 contact number for her and invited her to the CAF meeting, and I um, through the
 55 conversation thought she was to do with housing, um and it turns out that she's
 56 from er from an organisation, I think its Bromford housing but they got a very
 57 small team
 58 R: ok
 59 P: that um look after anybody with learning disabilities
 60 R: oh
 61 P: and they, they'd offer quite a wide range of services ... so um,.... to be
 62 honest, if I hadn't had met her I wouldn't have known
 63 R: Yeah
 64 P: where to have gone to to be quite honest, so with her help Health
 65 visitor and I got her family support worker as well and she also has a
 66 pregnancy outreach worker
 67 R: ok

difficult to find out about services
 difficult to support
 personally found it difficult to look for diagnosis
 view of GP
 confusion in terms used
 even GP didn't know
 GP nothing avail. for ED
 also found it difficult
 confusion
 didn't know details
 even client confused
 small resource
 last chance
 only option to invite & see if help
 chance meeting

Helped by non-health professional
 didn't have name where to get help
 with having support
 resulted in health professionals involved

know what needs one but can't access support
 need to develop not only knowledge but access to services
 need to dev. skills
 lack of exp/ knowledge made it confusing
 how difficult it will be?
 view of GP as all knowing but didn't
 emphasises how difficult would be to care for
 perceived view of patient knowing
 confused situation
 view of LO as v. diff. to work with - scary
 wouldn't solve all problems
 not going to be easy even if get support in place?
 lack of knowledge
 due to special service
 should be special role?
 felt useless - out of options
 reflection of own skills (lack of)
 rel. services
 multi-professional working
 needs more the 1 service involved

Participant 2 Transcript

68 Participant: so ... amongst us We've managed to get quite a lot of support in
 69 place ... for her

70 Researcher: mmm sounds like it

71 Participant: so er yeah um so.... it but it has been difficult and it's a shame it isn't
 72 a little bit more easier to

73 Researcher: yeah

74 Participant: To sort of be directed to other agencies where you can get the help
 75 and support but the, I think the most difficult thing is because there isn't any
 76 diagnosis or she hasn't had any type of assessment ...

77 Researcher: yeah

78 Participant: then its very difficult to go to ... places because they want to know
 79

80 Researcher: they want a diagnosis

81 Participant: yeah, yeah

82 Researcher: Ok, and how did you, I mean you mentioned that you the first
 83 midwife, wasn't, she felt the learning disability was a mild level

84 Participant: yeah

85 Researcher: and you felt it was moderate,

86 Participant: yeah

87 Researcher: how did you recognise that, how did you sort of know?

88 Participant: just, just, I guess, just from speaking to her, it was obvious, it
 89 was obvious that some of the things, that I said, she didn't understand she kept
 90 asking me the same questions so I was repeating information so her understanding ...
 91 wasn't ... it wasn't great and and it worried me and I just thought well you know this
 92 is her second baby um and she had an awful lot of support from her family who
 93 were really really good Um and obviously before that she was living with her
 94 husband

95 Researcher: yeah

96 Participant: Um so I think he did a lot of.... you know.... a lot the bills, and the
 97 housekeeping side of things She actually wanted to, to move out of her parent's
 98 house

99 Researcher: ok

Handwritten notes and diagrams:

- Needed more than one person to get support in
- LD is too complex to manage on own → needs specialist service not midwife role?
- Need to share care amongst several professionals due to difficulties/needs
- could be made easier
- Difficult to manage LD as it is without extra barrier in getting support
- access to services
- need diagnosis to get services → Lack of understanding of LD = may misdiagnose not pick up on 4 view of labelling?
- look beyond the & focus on individual's needs & how best to care for them?
- lack of understanding is worrying & how would cope without family?
- Reflection on midwife's skills? Pressure to get it right?
- Pressure to get support - consequence on midwifery care? - ability to care for baby & self & other children?
- Consequence of moving out
- Pressure to get support - consequence on midwifery care? - ability to care for baby & self & other children?
- LD was obvious + didn't understand repeating info
- Worried about lack of understanding
- Had a lot of family support before
- Parent wanted to move out of parent's house
- LD is obvious & why need diagnosis to get support?
- Had support to move out - worried about consequences - impact on own
- need a lot of support & managed but wanted to move out - worried about consequences - impact on own
- Disbelief?
- uncomfortable? Anxious?

Appendix H
Midwifery guidelines for authors
(available from <http://www.midwiferyjournal.com/authorinfo#idp1153152>)