

**A thesis submitted in Partial Fulfilment of the Regulations for the degree of  
Doctor of Clinical Psychology**

**VOLUME I**

**RESEARCH COMPONENT**

**THE EXPERIENCES OF WOMEN OF SOUTH ASIAN ORIGIN  
WITH LEARNING DISABILITIES**

**By**

**Kulsoom Jawaid Malik**

**School of Psychology**

Department of Clinical Psychology

School of Psychology

The University of Birmingham

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## **Overview of Volume I and Volume II**

This thesis is submitted in partial fulfillment of the requirements for the degree of Doctorate of Clinical Psychology from the University of Birmingham.

The thesis comprises of two volumes. Volume I consists of three chapters which includes a literature review, and empirical paper and a public domain briefing document. Volume II comprises of four Clinical Practice reports and an abstract for an oral presentation of a Clinical Practice report. Each of the reports relate to clinical work undertaken during five different clinical placements.

### **Volume I**

Volume I consists of three chapters. The first chapter is a literature review synthesising whether it is possible to use Interpretative Phenomenological Analysis (IPA) in research with people who have learning disabilities. The review critically evaluates issues of assessing quality of IPA research. This chapter was prepared with the intention to submit to the Journal of Applied Research in Intellectual Disabilities (see appendix i for guidelines for authors). The second chapter is an empirical paper exploring the experiences of Women of South Asian origin in receipt of social services using an IPA methodology. This chapter was prepared with the intention to submit to the British Journal of Learning Disabilities (see appendix ii for guidelines for authors). Three super-ordinate themes are constructed relating to negotiating culture, independence and intersectionality regarding being a female.

### **Volume II**

Volume II consists of 4 clinical practice reports and a summary of a fifth oral report. The first report is a models essay on a 28 year old male with Downs Syndrome. The second report is a

service evaluation report about staff working with carers in a learning disability service. The third report is a single case experimental design report on the treatment of a lady with obsessive-compulsive disorder. The fourth report is a case study detailing the treatment of an older adult with dementia with regards to her displaying aggression towards her husband. The fifth report is an abstract of an oral presentation on a 15 year-old female with obsessive-compulsive disorder.

## **Dedication**

Dad and Mum, thank you for always believing in me. For giving me opportunities that you did not have yourself, for opening every door possible and guiding me to become the person I am today.

Jawaid, your love and support has been invaluable during every single phase of my training. Thanks for always being there for me and for persevering with me being a student throughout our whole married life thus far.

Hamza, my son, my everything. All my hard work is for you, so that your Dad and I can give you and your siblings the best start in life.

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Thank you Maa Ji and Daddy Ji for giving up your own personal life to support me to finish my studies.

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**VOLUME I**

**RESEARCH COMPONENT**

**CHAPTER ONE**

**IS IT POSSIBLE TO USE INTERPRETATIVE  
PHENOMENOLOGICAL ANALYSIS IN RESEARCH WITH  
PEOPLE WHO HAVE LEARNING DISABILITIES?**

Department of Clinical Psychology

School of Psychology

The University of Birmingham

April 2015

## **Abstract**

### **Background**

Researchers have tended not to recruit people with learning disabilities into research. This is now changing. This paper looks at the appropriateness of using Interpretative Phenomenological Analysis (IPA) in research with people who have learning disabilities particularly focussing on issues around the quality of such research.

### **Methods**

A comprehensive search strategy of three electronic databases was conducted by applying specific inclusion and exclusion criteria. A guide to assess the quality of IPA research was also developed for this review based on previous research

### **Results**

Seventeen papers met the inclusion criteria for this review. Quality assessment indicated that the included studies were of varying quality: 12% of the papers were rated as good quality, 59% as acceptable quality and 29% as poor quality. The papers in general were not transparent with regards to the ability levels of their participants.

### **Conclusions**

IPA is an appropriate methodology to use with people with learning disabilities. Future researchers interested in this methodology are urged to improve transparency around the intellectual abilities of the participants being recruited into the research

**Keywords:** Interpretative phenomenological analysis, quality guide, learning disabilities, qualitative research

# **Is it possible to use Interpretative Phenomenological Analysis in research with people who have learning disabilities?**

## **Introduction**

In a recent review, Beail and Williams (2014) compared the number of published research articles using qualitative methods in three major learning disability journals between 1991-2001 and then 2009-2011 and found that comparatively the numbers of published papers had doubled. Just under half of the more recently published papers involved people with learning disabilities as participants.

One of the reasons why researchers have avoided qualitative methodology in the past may be due to the view that people with learning disabilities present difficulties with “inarticulateness, unresponsiveness, a concrete frame of reference and problems with time” (Booth & Booth, 1996). They may also have concerns around whether the participants are able to give informed consent (Iacono, 2006). Research exploring the experiences of people with learning disabilities has therefore tended to rely on informant perspectives such as interviewing carers or staff (Dillenburger & McKerr, 2010; Hatton & Emerson, (2009). Gilbert (2004) argues that people with learning disabilities are not inappropriate participants for research but there is a lack of appropriate methodology to engage them in research. There have been many attempts by researchers to involve people with learning disabilities using a range of methodologies such as: narrative research (Booth & Booth, 1996); discourse analysis (Scoil, 2003); thematic analysis (Mitchel & Clegg, 2005) and grounded theory (Knox & Bigby, 2010).

Early work in this area by Atkinson (1998) advocates the importance of accessing the “consumer” experience of people with learning disabilities, helping them to think about their own circumstances and acknowledging that they are experts in their own experiences.

Given that the term “learning disabilities” can include people with varying intellectual and functional abilities (Scanlon, 2013) to avoid generalising, it is important that research recruits participants from well-defined homogenous samples. One qualitative methodology which aims to do this is Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). This review aims to explore whether this is an appropriate methodology to use with people with learning disabilities.

### **Interpretative phenomenological analysis (IPA)**

IPA attempts to gain an insider perspective with regards to individual experiences and is one of the most frequently used qualitative methodologies (Smith, 2011) In IPA, the researcher and the participants are jointly involved in making sense of the participant’s experiences through the researchers interpretative enquiry (Smith et al., 2009). This method allows the participants to have a voice (Larkin, Watts & Clifton, 2006) and takes into consideration three main theoretical stances: phenomenology, hermeneutics and idiography. In assessing whether IPA has been applied appropriately one would look at the implementation of these theoretical stances.

Phenomenology is a philosophical stance in which human experience is explored. In an IPA paper, one would be exploring to see whether a study is sufficiently grounded in what the experience is like for the participant rather than simply inferring what happened. With regards to hermeneutics, one would look at how the researcher supports and facilitates the participant making sense of their experience through interpretative analysis. Are the researchers going beyond what was merely said by the participants? Lastly one would explore if there has been an attention to detail with regards to context and the particular. One explores if there has been sufficient thought given to variation within a sample and also the contribution of each participant. In addition, thought on whether the

research sample is homogenous is also important. In IPA, the sample size tends to be small so that the research provides an in depth analysis of a clearly defined sample (Smith & Osbourne, 2003).

Brocki and Wearden (2006) examined the contribution of IPA in health psychology as the majority of IPA research has been conducted in this area and no one had looked at the methodology of papers in this area. They noted that the majority of the papers utilised semi-structured interviews. Very few of the 52 papers reviewed presented information about the interview schedule or prompts used during the interviews, thus resulting in a dilemma for the reader to assess the quality of the interview and if this had any effect on the data used for analysis. They also found that the sample sizes varied between 1 and 30. In addition, it was noted that the methods used to analyse the data were variable and subjective. Some authors employed audits and credibility checks, but it is not stated what proportion of papers did this. They concluded that IPA is an appropriate approach to use but they did not take into consideration the quality of these papers. However at the time there were no published guidelines on how to assess the quality of IPA research.

### **Quality of IPA research**

Ensuring that qualitative research is of good quality is increasingly an important issue for researchers and can be evidenced by the development of a number of quality checklists (e.g. Elliot, Fischer & Rennie, 1999; Morrow, 2005; Yardley, 2000). The application of these tools does pose a debate, with some researchers questioning their applicability to qualitative research (Smith, 2011). Smith argues that researchers should take issues of validity and reliability seriously but states that he is “sceptical” of checklists. He argues that generic qualitative checklists such as Yardley (2000) may be good for other qualitative methods, but appear too general for IPA.

In his paper, Smith (2011) also examined IPA papers published within health psychology between 2002-2008. He organised the papers into research categories such as “carers experience” or “client experience of therapy”. The largest category was “illness” and so he decided to assess the quality of 51 papers in this area. Smith (2011) defined the fundamental features of a high quality IPA paper: a clear focus, strong data, rigour, sufficient space to elaborate themes, interpretative analysis which is beyond descriptive, researcher points to both convergence and divergence of data and the paper must be carefully written. He states that he has deliberately not produced a checklist for researchers for fear of making the whole process too prescriptive. He rated the papers under three domains: good, acceptable and unacceptable. Each domain has its own criteria. He rated 27% of the papers as good, 55% as acceptable and 18% as unacceptable. He also produced guidelines as to what constitutes a good IPA paper. He concluded that he thought the results were “respectable” given that IPA is a relatively new methodology.

Larkin and Thompson (2012) explored what indicators researchers need to take into consideration when exploring the quality of IPA research. In addition to Smith (2011) they proposed that a “good” piece of IPA research will have the following features: “appropriate data from appropriate informants; ideographic focus; transparent data collection; focus on how things are understood; balance between phenomenological detail and interpretative detail; appropriate use of triangulation, audit and/or credibility checks; extracts to support commentary, contextual detail with regards to extracts, research and participants; attention of process and engagement with theory when presenting the analysis.”

To date, the above two references are the only attempts made by researchers to try and define what constitutes a good quality IPA research paper.



## **Aims**

Brocki and Wearden (2006) and Smith (2011) both focussed on the implementation of IPA within health psychology. Given that IPA is a new and increasingly popular research methodology (Smith, 2011) and that qualitative research using people with learning disabilities is increasing (Beail & Williams, 2014) it is of interest to explore the quality of IPA papers with this group of participants. This paper aims to answer the following questions:

- Is it possible to produce good quality research using Interpretative Phenomenological Analysis in research with people who have learning disabilities?
- Are there any additional challenges that researchers face whilst using this methodology with people with learning disabilities?

## **Methodology**

### **Search strategy**

Three electronic databases (MEDLINE, PsycINFO and CINAHL) were searched. A combination of subject heading searching and free text searching was used across the three databases. The advantage of subject heading searching is that under one umbrella term, any synonyms or spelling variations for a given term can be used in the search. All the terms were exploded (exp) to ensure that any more specific versions of the umbrella term were also included in the search. The disadvantage is that different search terms need to be used for different databases due to the databases indexing constructs in different ways.

Free text searching also known as keyword searching was also used because it allows for a given word to be searched irrespective of how the database has recorded that term. The different variations of the terms including truncations were combined using the

Boolean operator OR. They were then entered in parenthesis to the subject heading searching and combined using AND figure 1 to figure.3 below illustrate the different variations for the constructs as per database.

Figure 1: Variations of the key constructs for subject heading searching

		<b>Key constructs</b>	
		<b>Learning disability</b>	<b>IPA</b>
<b>Variations of main constructs according to database</b>	<b>MEDLINE</b> Exp Learning disabilities Exp Learning disorders Exp Mentally disabled person Exp Intellectual disability Exp Child development disorders	<b>AND</b>	IPA Interpretative phenomenological analysis Interpretive phenomenological analysis
	<b>PsycINFO</b> Exp Learning disabilities Exp Learning disorders Exp Pervasive developmental disorders Exp Intellectual development disorders		IPA Interpretative phenomenological analysis Interpretive phenomenological analysis
	<b>CINAHL</b> Exp Learning disabilities Exp Mental retardation Exp Learning disorders Exp Child developmental disorders Exp Mentally disabled person		IPA Interpretative phenomenological analysis Interpretive phenomenological analysis

Figure 2: Main constructs for free text searching in addition to subject heading searching for all three databases

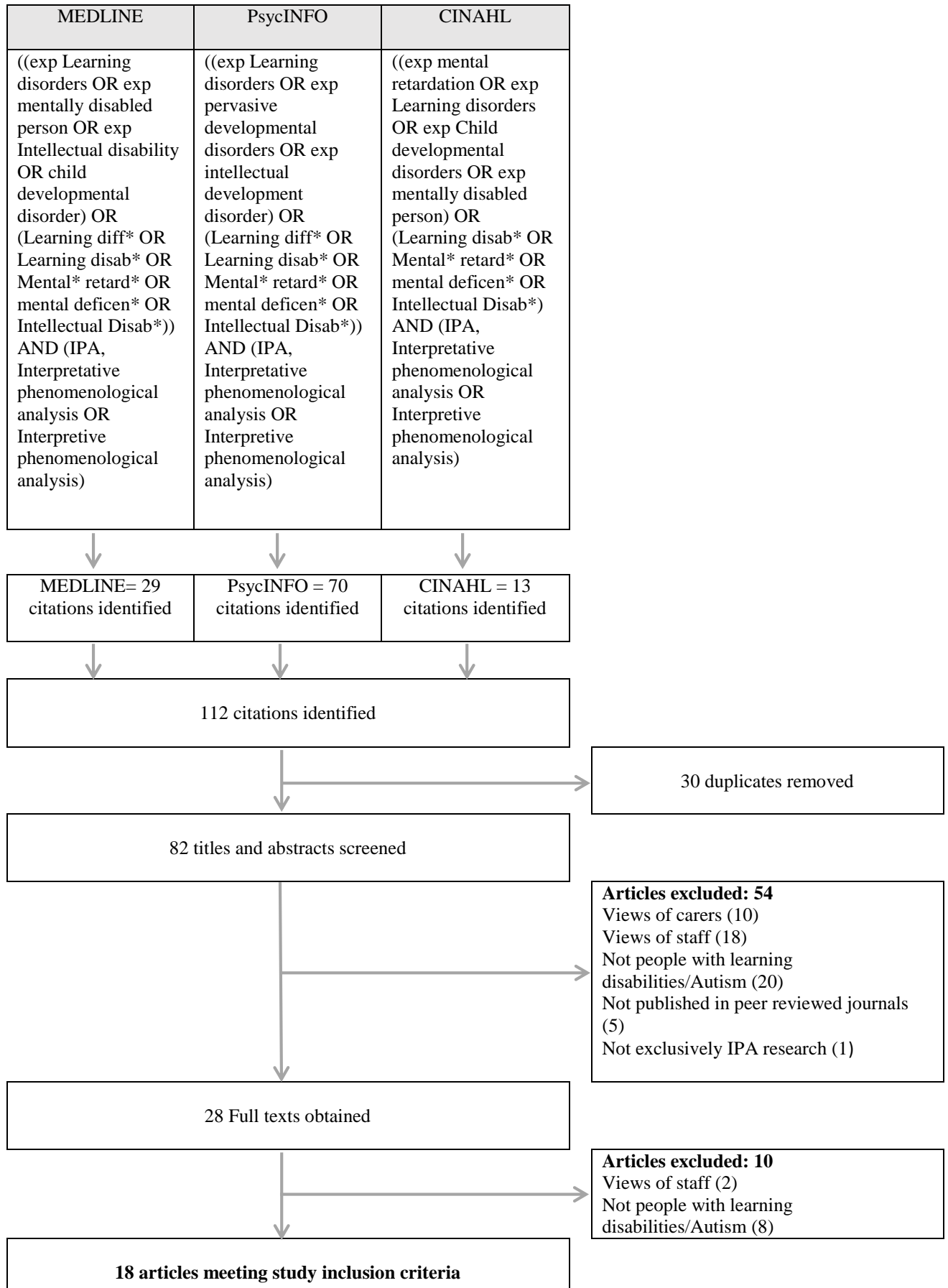
<b>Variations of main constructs including truncations</b>		
<b>Learning disability</b>		<b>IPA</b>
Learning diff* Mental retardation Learning disab* Mental deficien* Intellectual Disab*	<b>AND</b>	Interpretative phenomenological analysis Interpretive phenomenological analysis

The databases were searched with no date restriction and this was conducted on 1<sup>st</sup> September 2014. MEDLINE, PsycINFO and CINAHL generated a total of 112 papers. The inclusion and exclusion criteria (figure.3) were then applied to generate the final papers included in this review (figure.4).

Figure 3: Criteria for inclusion and exclusion

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<ul style="list-style-type: none"> <li>✓ Adults over the age of 18 with a learning disability</li> <li>✓ Explicit explanation as to how participants were assessed as having a learning disability</li> <li>✓ Data derived from individual interviews or group interviews</li> <li>✓ Published in English in a peer reviewed journal</li> <li>✓ Explicitly stated that IPA was used to interpret the data.</li> </ul>	<ul style="list-style-type: none"> <li>× Views of carers or staff</li> <li>× Views of people with learning disabilities in conjunction with views of people without learning disabilities such as staff views.</li> <li>× Data analysed using IPA and other research methods</li> </ul>

Figure 4: Search strategy



## **Descriptive summary of the papers included in this review**

In total 18 studies met the inclusion criteria for this review. Four of the papers investigated the experiences of parents with learning disabilities (Baum & Burns, 2007; Gould & Dodd, 2014; Shewan, McKenzie, Quayle & Crawley, 2014; Wilson, McKenzie, Quayle & Murray, 2013). Three of the studies explored the experience of receiving psychological therapy (Anslow, 2013; Merriman & Beail, 2009; MacDonald, Sinason & Hollins, 2003). Three studies looked at the experiences of people with learning disabilities as in-patients in hospital (Brown & Beail, 2009; Clarkson, Murphy, Coldwell & Dawson, 2009; Cookson & Dickson, 2010). Two further papers looked at the experience of diagnosis (Dysch, Chung & Fox, 2012; Kenyon, Beail & Jackson, 2014). The remaining papers explored the experience of: bereavement (McRitchie, McKenzie, Quayle, Harlin & Newman, 2014); retirement from daycentres (Judge, Walley, Anderson & Young, 2010); trauma (Mitchel, Clegg & Furniss, 2006); ethnic minorities (Pestana, 2011); self-concept (Pestana, 2015) and intimate relationships (Rushbrook, Murray & Townsend, 2014)

With the exception of three papers (Baum & Burns, 2007; MacDonald et al., 2003; Mitchel et al., 2006) all the remaining papers have been published in the last 5 years (2009-2014), suggesting using IPA with people with learning disabilities is a new method being used by researchers.

## **Recurrent sample**

Two of the papers had the same principal investigator and made references to using the same recruitment method and site (Pestana, 2011; Pestana 2014). To avoid exaggerating the results of this research in the review, it was decided that the earlier paper would be retained in the review and the newer one would not be included. This review therefore will be reviewing a total of 17 papers.

## Quality guide

The following steps describe the process of developing, populating and implementing the quality guide.

### *Developing the quality guide*

- 1) A review of existing literature revealed that to date, no specific IPA quality checklists have been developed (as previously discussed on page 4)
- 2) Two papers were identified to make recommendations around certain IPA quality markers ( Smith, 2011, Larkin & Thompson, 2012)
- 3) Initially, the section on “IPA quality evaluation guide” by Smith (2011) was examined. The specific focus was on the identifying features of what distinguished acceptable, unacceptable and good papers from each other (figure 5).
- 4) The Larkin and Thompson (2012) section on “quality issues” was also examined. This paper only makes recommendations for good papers in addition to Smith (2011) such as “collecting appropriate data, from appropriately selected informants” p.112. These are also presented in figure 5.
- 5) Yardley (2000), which is a general quality checklist for qualitative research was also examined. Yardley (2000) argues that there are four main areas to consider when evaluating qualitative research: sensitivity to context; commitment and rigour; transparency and coherence and impact and importance.
- 6) Lastly, Smith et al., (2009) was examined specifically focussing on the chapter “assessing validity” which proposes how to implement general qualitative quality markers in Yardley (2000) to IPA research. This source was not directly used to aid the development of the guide, but was important because it made

references to how important IPA issues could be considered using Yardley's (2000) checklist.

### *Populating the guide*

- 7) Taking into consideration quality issues raised by Smith (2011), Larkin and Thompson (2012) and Yardley (2009) the quality guide was populated detailed below.
- 8) Through consultations with Dr Larkin and Professor John Rose, it was decided that there were six main areas to consider when exploring quality issues in IPA research: theory, informants, transparency, coherence of analysis, focus and trustworthiness.
  - **Theory** relates specifically to Smith (2011) focus on whether a research paper adheres to the theoretical principles of IPA.
  - **Informants** relates to "sensitivity to context" in Yardley (2009), such as does the research take into consideration whether the research methodology is appropriate to the participants. This heading was also added as the specific focus of this paper is on using IPA with people with learning disabilities and so specific attention level of disability was added.
  - **Transparency** relates directly to Yardley (2009) with regards to "transparency and coherence". Transparency is especially important for those evaluating research to consider whether it is clear how the research was conducted and evaluated. It is worth noting that this guide has separated Yardley's criteria of "transparency and coherence" into transparency and coherence of analysis. The reason for this is because it was decided that

there are specific issues relating to IPA such as number of themes which could not be captured under transparency.

- **Coherence of analysis** takes into consideration specific IPA issues raised by Smith (2011) such as the evidence base for the themes.
- Focus maps onto Yardley’s criteria of “impact and importance” and also Smith (2011) recommendations that good papers are well focussed as well as Larkin and Thompsons ( 2012) guidance that a good quality research paper will be well focussed and engaged with theory.
- **Trustworthiness** was also added as quality marker as Larkin and Thompson (2012) suggest that it is important that IPA researchers demonstrate that they have taken the importance of reliability into consideration such as the appropriate use of triangulation.

9) The six main areas were used as headings for the structured tool designed for this study (figure 6). Details to consider when evaluating the research were posed as both quantitative questions (e.g., how many participants) and more open ended questions (how were the participants engaged in the research?). These details were developed as such questions were believed to be pertinent when making decisions about the overall rating of the paper.

10) It was noticed that Smith (2011) rated the lowest quality papers as “unacceptable”. The author for the current paper preferred to use the term poor. The guide is not intended to be used as a set of questions when exploring the quality of research but rather as a data gathering tool.



11) To aid more novice researchers, it was decided that it would be helpful for each heading to have some indicators as to what would constitute good, acceptable or poor application of each of the quality domains. For example, with regards to theory, good application of theory would be demonstrated through all theoretical principles of IPA being implemented appropriately, acceptable application would mean the researchers made a good attempt and poor application of theory would mean that the research is not consistent with the theoretical principles of IPA.

*Giving each paper an overall rating*

12) An overall rating of good, acceptable or poor quality based on figure 5 was systematically completed for each paper using a binary process.

- The quality guide was systematically completed for each paper, with the researcher “informally” assigning a rating for each domain.
- Each completed quality guide was assessed individually with figure 5. For example, if a paper was rated as “poor” for theory, then it is likely that the whole paper would be rated poor because it “was not consistent with the theoretical principles of IPA”. Each quality domain such as theory, informants etc. were considered when assigning an overall rating. This step in the rating process was deliberately not designed as a prescriptive process as rating papers in a complex and requires readers to consider all aspects of the research holistically. For this reason, a

point's based system ( such good for theory = 3 points, acceptable = 2, poor = 1 was deliberately not used, and then the same for informants etc.)

13) Each paper that was reviewed in turn and was assigned an overall rating, using the new synthesised criteria designed for this study. A selection of the papers were also blindly rated by the researchers supervisor and discussed with the researcher (especially where there were differences in the ratings) to ensure reliability and validity.

Figure 5: Key features of good, acceptable and poor IPA papers.

POOR PAPERS	<p><i>The paper fails on one of the four criteria for acceptable. It may be:</i></p> <ul style="list-style-type: none"> <li>• <i>Not consistent with theoretical principles of IPA;</i></li> <li>• <i>Insufficiently transparent for reader to see what was done;</i></li> <li>• <i>Not of sufficient interest; and</i></li> <li>• <i>Poorly evidenced</i></li> <li>• <i>Insufficient extracts from participants to support the themes being illustrated;</i></li> <li>• <i>No explanation for how prevalence of the themes was determined; and analysis is crude, lacks nuance</i></li> </ul> <p><i>Predominantly what lets a paper down is the poor evidence base. Typical ways this can occur:</i></p> <ul style="list-style-type: none"> <li>• <i>Large number of descriptive/superficial themes from a large number of participants;</i></li> <li>• <i>Each theme has short summary and one or two extracts without interpretation;</i></li> </ul> <p style="text-align: right;"><i>From Smith (2011) p. 17</i></p>
ACCEPTABLE PAPERS	<p><i>Must meet the following criteria:</i></p> <ul style="list-style-type: none"> <li>• <i>Clearly subscribes to the theoretical principles of IPA: it is phenomenological, hermeneutic and idiographic.</i></li> <li>• <i>Sufficiently transparent so reader can see what was done. Coherent, plausible and interesting analysis.</i></li> <li>• <i>Sufficient sampling from corpus to show density of evidence for each theme”</i></li> </ul> <p style="text-align: right;"><i>From Smith (2011) p. 17</i></p>
GOOD PAPERS	<p style="text-align: center;"><i>Paper must also clearly meet all the criteria for acceptable</i></p> <ul style="list-style-type: none"> <li>• <i>Well focused; offering an in-depth analysis of a specific topic;</i></li> <li>• <i>Data and interpretation are strong; and</i></li> <li>• <i>Reader is engaged and finds it particularly enlightening.”</i></li> </ul> <p style="text-align: right;"><i>From Smith (2011) p.17</i></p>
	<ul style="list-style-type: none"> <li>• <i>Collecting appropriate data from appropriately selected informants</i></li> <li>• <i>Some degree of idiographic focus balanced against what is shared within a sample</i></li> <li>• <i>An analysis that: transcends the structure of the data collection method ( e.g. the schedule for a semi-structured interview); focuses on how things are understood rather than what happened; incorporates and balances phenomenological and interpretative work to develop a psychologically relevant account of the participants engagement-in-the-world</i></li> <li>• <i>Appropriate use of triangulation (can be via methods, perspective’s, data, analysis, field world) or audit and/or credibility checking ( can be via respondents, supervisors, peers, parallel sample) to achieve trustworthiness</i></li> <li>• <i>Appropriate use of extracts and commentary to achieve transparency (claims should usually be substantive engagement with, and commentary on some longer extracts of data</i></li> <li>• <i>Appropriate level of contextual detail- for the excerpts, participants, researchers and study</i></li> <li>• <i>Attention to process: including analytic and reflexive components</i></li> <li>• <i>Appropriate pitch and engagement with theory ( in making sense of the analysis”</i></li> </ul> <p style="text-align: right;"><i>From Larkin and Thompson (2012) p.112</i></p>

Figure 6: Structured tool including quality criteria developed for this paper

<b>Research paper title</b>
<b>General notes and conclusions</b>
<b>Research question and research aims</b>

<p>1. <b>THEORY:</b> Good                      Acceptable                      Poor</p> <p><u>Good:</u> Clearly subscribes to all of the theoretical principles of IPA in a coherent fashion: it is phenomenological, hermeneutic and idiographic.  <u>Acceptable:</u> Attempts to subscribe to the theoretical principles of IPA but some areas are not clear. Some evidence of the research being phenomenological, hermeneutic and idiographic  <u>Poor:</u> Not consistent with theoretical principles of IPA</p> <p><b>Notes</b></p>		
<p><i>Phenomenological: is the study sufficiently grounded at looking at what the experience is like for the person? Or does it simply look at what happened. Is the question more than “what people talked about”. Are the researchers looking at the meaning?</i></p>	<p><i>Hermeneutic: How does the participant make sense of their experience? How does the researcher make sense of the participant making sense of their experience? Is there sufficient interpretation of meaning</i></p>	<p><i>Idiographic: concerned with the particular depth of analysis. How has an experience been understood from particular people in a particular context? Does it link to theory?</i></p>

**2.INFORMANTS:** Good

Acceptable

Poor

Good: Appropriate data from a homogenous sample of participants relevant to the research question

Acceptable: Appropriate data from participants which has enabled the researchers to make some attempts to answer the research questions.

Poor: Inconsistencies in data collection and lack of information on participant selection, unable to conclude if the participants are a homogenous sample.

Notes: Make references to the homogeneity of sample.

Number of participants: (*small and strict?*)

Age range of participants:

Gender of participants:

Sample:

**Additional contextual participant information**

Ethnicity of participants :

Mental health conditions:

Level of learning disability:

Additional information:

**3.TRANSPARENCY:** Good

Acceptable

Poor

*Good: Sufficiently transparent so that the reader can see the all the stages of the research process.*

*Acceptable: Appropriately transparent, lacks detail in some areas of research methodology*

*Poor: It is unclear what stages were undertaken, the majority of information is missing*

Notes:

**How were participants recruited to take part in the research?**

**How were the participants assessed as being suitable to take part in the research? (Was this done ethically)**

**How were the participants engaged in reflecting on the research topic?**

**How was the data analysed? Was it the most appropriate methodology? Does it fit with the data collection method?**

4. COHERENCE OF ANALYSIS: Good

Acceptable

Poor

*Good: Sufficient sampling from the corpus. There appropriate extracts from at least half the participants for each of the themes presented.*

*Acceptable: Appropriate sampling from corpus to show density. Most of themes have extracts from at least half of the sample.*

*Poor: the themes are not evidences well. Mostly large number of themes which may be superficial from a large number of participants. Analysis lacks interpretation and there is little or no commentary.*

Notes:

**How many themes were there and what were there? How many participant extracts are present with each theme? Are there extracts from at least half the sample?**

**Are the themes different from the main questions asked in the interview schedule?**

**Is there sufficient commentary with the extracts to explain how they link in with the themes? Appropriate commentary to make inferences?**

**Are there references to reflexivity?**



**5.FOCUS:** Good

Acceptable

Poor

*Good: The paper has a specific focus. The research question is interested in something that is of significance to the participant's life and is answered by the research?*

*Acceptable: The paper has some focus but it is not specific. The research question has some significance to the participant's life but is not specifically important.*

*Poor: The paper lacks a strong focus. It is questionable as to whether the research topic is of interest to the participant. Findings not related to question asked.*

Notes:

**Is the research question of significance to the participant's life?**

**Was the research question answered? Is it linked to theory?**

**6. TRUSTWORTHINESS:** Good

Acceptable

Poor

*Good: Appropriate use of triangulation or audit and/or credibility-checking to achieve trustworthiness.*

*Acceptable: Some attempt of using triangulation, audit or credibility*

*Poor: No use of triangulation, audit or credibility check*

*Notes:*

Triangulation

Audit

Credibility check

## Results

Table 1: a summary of the assessment of quality

Key: Criteria fulfilled Criteria not fulfilled

Quality criteria	Anslow (2013)	Baum and Burns (2007)	Brown and Beail (2009)	Clarkson et al. (2009)	Cookson and Dickson (2010)	Dysch et al. (2012)	Gould and Dodd (2014)	Judge et al. (2010)	Keynon et al.(2014)	MacDonald et al.(2003)	McRitchie et al. (2014)	Mirchel et al. (2006)	Merriman and Beail (2009)	Pestana (2011)	Rushbrooke et al.(2014)	Shewan et al. (2014)	Wilson et al. (2013)
<b>Theory</b>																	
Did the paper subscribe to the theoretical principles of IPA																	
<b>Informants</b>																	
Are the participants a homogenous sample?																	
Level of learning disability of the sample specified?																	
<b>Transparency</b>																	
Is it possible to follow all the stages of the research?																	
Is it clear how the interview schedule was developed and whether the questions are suited to IPA?																	
Was IPA the most appropriate methodology?																	
Are the stages of how IPA is implemented explained?																	
<b>Coherence of analysis</b>																	
Are there sufficient extracts for the themes																	
Is there appropriate commentary with the extracts to support the themes																	
<b>Focus</b>																	
Is the research question of significance to the participant's lives?																	
Was the research question answered? Was it appropriately linked to theory																	
<b>Trustworthiness</b>																	
Was there appropriate use of triangulation																	

The papers were then assigned a poor, acceptable or good label based the application of figure 5.

### **Data extraction and key characteristics of the 17 papers reviewed**

Data extraction was undertaken to extrapolate key characteristics for all the papers included in this review. Five papers were rated as poor (Baum & Burns, 2007; Judge et al., 2010; MacDonald et al., 2013; Merriman & Beail, 2009; Pestana,2011). All the poor papers did not implement IPA theory appropriately, this means that they did not adhere to phenomenology, hermeneutics and idiography. Secondly, all the papers lacked transparency with regards to the stages of the research. Thirdly, none of the papers explained the interview schedule and its development. Fourthly the papers lacked sufficient extracts to support the themes and lastly they did not employ any methods to demonstrate trustworthiness. The papers were also rated as being poor for the following additional issues: deriving themes that are not different from the interview questions (Baum & Burns, 2007; Merriman & Beail, 2009); descriptive commentary with little interpretative analysis (Baum & Burns, 2007; Judge et al., 2010); no commentary to support themes (MacDonald et al., 2003; Pestana, 2011) and a large sample which was not homogenous (Judge et al., 2010).

Ten papers were rated as acceptable (Anslow, 2013; Brown & Beail, 2009; Dysch et al., 2012; Gould & Dodd, 2014; Kenyon et al., 2014; McRitchie et al., 2014; Mitchel et al., 2006; Rushbrook et al., 2014; Shewan et a., 2014; Wilson et al., 2013). All of these papers were rated to subscribe to the theoretical principles of IPA and that IPA was the most appropriate methodology to be used. The papers varied in terms of whether they adhered to the other quality markers.

The remaining two papers were rated as good (Clarkson et al., 2009; Cookson & Dickson, 2010). With the exception of the researchers specifying the level of learning disability of the participants, the good papers met all of the other quality criteria.

Table 2: Summary of papers rated as Poor

<b>Study and aims/research question</b>	<b>Sample</b>	<b>Method</b>	<b>Results and trustworthiness</b>	<b>Discussion: specific issues relating to using IPA with people with learning disabilities</b>
<p><b>Baum and Burns (2007)</b> What are the experiences of mothers with learning disabilities losing custody of their children?</p>	<ul style="list-style-type: none"> <li>• N= 9, all white British</li> <li>• All female</li> <li>• Ages 22-45 (mean 35)</li> <li>• All the women had accessed learning disability services at some point in their lives</li> <li>• Participants level of learning disability unspecified</li> <li>• Homogenous sample as all the women had lost custody of at least one child.</li> </ul>	<ul style="list-style-type: none"> <li>• Recruited through staff working in the community learning disability service</li> <li>• Semi structured interviews lasting an hour each. No information on how the interview schedule was developed or examples of questions. Difficult to make assumptions on whether the questions asked were appropriate for IPA research</li> <li>• Lack of information regarding how IPA was implemented.</li> </ul>	<ul style="list-style-type: none"> <li>• Nine super-ordinate themes</li> <li>• Themes are illustrated as direct answers to the interview schedule</li> <li>• Commentary is descriptive</li> <li>• No references made to auditing, triangulation or credibility checks.</li> </ul>	<ul style="list-style-type: none"> <li>• Researcher stated that participants needed to be verbally articulate enough to take part in discussions</li> <li>• Researchers question level of learning disability of the participants?</li> </ul>

<p><b>Judge et al. ( 2010)</b> What are the perceptions of people with intellectual disabilities with respect to retirement: the mandatory transition from attending day centers in two Scottish localities?</p>	<ul style="list-style-type: none"> <li>• N= 16, unknown ethnicity</li> <li>• 11 female, 5 male</li> <li>• Ages 41-64</li> <li>• Participants not formally assessed but case records suggest mild-moderate range</li> <li>• The sample is not homogenous: all the participants were approaching retirement, but not necessarily experiencing it and there is huge variability in ages.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants recruited through the researcher approaching people attending two daycentres</li> <li>• No information regarding specific research questions or duration of interviews</li> <li>• Detailed information regarding how IPA was implemented.</li> </ul>	<ul style="list-style-type: none"> <li>• Five super-ordinate themes</li> <li>• Insufficient commentary to support themes due to large sample size.</li> <li>• Discussion explores each theme turn by turn but no attempt to link it to theory but some recommendations for service providers</li> <li>• No mention of triangulation, audit or credibility checking.</li> </ul>	<ul style="list-style-type: none"> <li>• Researcher states in the paper that they would encourage researchers to use qualitative methods with people with learning disabilities to empower them.</li> </ul>
<p><b>MacDonald et al. (2003)</b> To explore the experiences of people with learning disabilities in receipt of group analytic therapy.</p>	<ul style="list-style-type: none"> <li>• N= 9</li> <li>• 5 female, 4 male</li> <li>• Mean age 34</li> <li>• All the participants were accessing group therapy through the community learning disabilities service</li> <li>• Level of learning disability unknown</li> <li>• The participants were recruited from two groups: the women's group and the sex</li> </ul>	<ul style="list-style-type: none"> <li>• The participants were recruited through all group members being invited to take part in the research. Some group members declined</li> <li>• Semi structured interview schedule attached in the paper.</li> <li>• Many of the questions not suited to IPA: leading such as do you think..?</li> </ul>	<ul style="list-style-type: none"> <li>• Three super-ordinate positive themes with 17 sub-themes and four super-ordinate negative themes with 11 sub-themes emerged</li> <li>• Aimed to look at positive and negative aspects, hence the two types of themes.</li> <li>• There is no commentary to support the themes.</li> </ul>	<ul style="list-style-type: none"> <li>• Researchers followed guidelines provided by Booth and Booth (1996) suggests balancing questions which required open ended responses and concrete yes/no answers. These guidelines produced for narrative research and not IPA. Not discussed on the impact of this on IPA.</li> </ul>

	<p>offenders group</p> <ul style="list-style-type: none"> <li>The sample is not homogenous due to the different experiences from the different groups (this is reflected in the results). Differences in how long the group have been running for.</li> </ul>	<ul style="list-style-type: none"> <li>Some questions with deliberate yes/no answers to increase the interviewers understanding of the participants responses.</li> <li>Detailed step by step account of IPA stages adopted.</li> </ul>	<ul style="list-style-type: none"> <li>No mention of auditing, credibility checking or triangulation</li> </ul>	
<p><b>Merriman and Beail (2009)</b> What are the views of people with learning disabilities who are currently in receipt of individual psychodynamic therapy?</p>	<ul style="list-style-type: none"> <li>N= 6, ethnicity unknown</li> <li>All male</li> <li>Ages 25-45</li> <li>Homogenous sample as all the participants were receiving individual psychotherapy for at least two years</li> <li>Participants recruited from NHS learning disability services. Level of LD not specified.</li> </ul>	<ul style="list-style-type: none"> <li>Participants recruited through staff in health service clinic providing people with learning disabilities with individual psychodynamic psychotherapy to people who have learning disabilities</li> <li>Paper describes seven main areas explored in the interviews</li> <li>Interviews lasted between 15 – 35 minutes long and were designed to be as open as possible</li> <li>Some information regarding how IPA was implemented.</li> </ul>	<ul style="list-style-type: none"> <li>Results presented as themes emerging from the questions asked in the interview schedule. The results may have been better suited to an alternative qualitative analysis such as thematic analysis.</li> <li>Insufficient extracts of the sub-themes to support the commentary. In some places the extracts are descriptive.</li> </ul>	<ul style="list-style-type: none"> <li>No specific IPA/LD issues raised</li> </ul>



<p><b>Pestana (2011)</b> A qualitative exploration of the life experiences of adults diagnosed with mild learning disabilities from minority ethnic communities</p>	<ul style="list-style-type: none"> <li>• N= 4, Pakistani, Siberian, Irish and foster parents from India</li> <li>• 2 female, 2 male</li> <li>• Ages 22- 52</li> <li>• Mild learning disability as assessed using the ICD-10 criteria</li> <li>• Participants believed to be from ethnic communities. Sample is not homogenous</li> <li>• Detailed participant descriptions including information such as hobbies and employment status.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants were recruited through liaison with the manager of a charitable organisation</li> <li>• Semi structured interview with 17 open ended questions exploring a range of issues</li> <li>• Interviews lasted 60 minute in total</li> </ul>	<ul style="list-style-type: none"> <li>• 4 super-ordinate themes</li> <li>• Insufficient quotes to support the themes</li> <li>• The commentary with the themes are descriptive and lack interpretative element.</li> <li>• Unusual use of validation. Attempts to provide respondent validation by incorporating their comments into the final analysis.</li> </ul>	<ul style="list-style-type: none"> <li>• No specific IPA/LD issues raised</li> </ul>
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Table 3: Summary of papers rated as acceptable

<b>Study and aims/research question</b>	<b>Sample</b>	<b>Method</b>	<b>Results and trustworthiness</b>	<b>Discussion: specific issues relating to using IPA with people with learning disabilities</b>
<p><b>Anslow (2013)</b> What are adults with learning disabilities experiences of systemic family therapy using the reflecting team format?</p>	<ul style="list-style-type: none"> <li>• N= 5, all white British</li> <li>• 4 female, 1 male</li> <li>• Ages 18-44</li> <li>• All participants accessing NHS community learning disability services</li> <li>• Participants level of learning disability unspecified</li> <li>• Homogenous sample: all the participants were currently attending family therapy sessions with at least one family member.</li> </ul>	<ul style="list-style-type: none"> <li>• Recruited through a NHS service for people with learning disabilities that provides family therapy.</li> <li>• Semi structured interview developed based on previous research.</li> <li>• Author provides information on the topics explored by the researcher</li> <li>• Face to face interviews after watching a DVD of their latest family therapy session</li> <li>• Limited information on the stages of the analysis.</li> </ul>	<ul style="list-style-type: none"> <li>• Five super-ordinate themes and 12 sub-themes</li> <li>• Sub-themes are unclear and are not explicitly explained in the paper</li> <li>• At least 3 quotes per theme but not per sub-theme</li> <li>• Good interpretative commentary but the structure of the results section is not strong.</li> <li>• No discussion section in the paper to link paper to theory.</li> <li>• Post analysis, respondent feedback from three participants and a focus group with five professionals to validate the findings. Triangulation and credibility checking</li> </ul>	<ul style="list-style-type: none"> <li>• Three participants had their mothers present in research interview and acknowledge that people who support can add to the mix of the research data and IPA is not good at dealing with this.</li> <li>• Makaton used in the interview but it is not explained how this was incorporated into the analysis</li> </ul>

<p><b>Brown and Beail (2009)</b> What are the experiences of people with intellectual disabilities living in secure accommodation that self-harm?</p>	<ul style="list-style-type: none"> <li>• N =9, unknown ethnicity</li> <li>• 4 females, 4 males</li> <li>• Ages unknown</li> <li>• All participants who had self-harmed in last three months and were residents at secure accommodation specifically for people with learning disabilities.</li> <li>• Clinical impression that sample had mild learning disabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Participants recruited through the clinical team in the secure accommodation</li> <li>• Semi structured interviews, no information on how the interview schedule was developed or examples of questions. Difficult to make assumptions on whether the questions asked were appropriate for IPA research</li> <li>• Length of interviews unknown</li> <li>• Detailed information regarding how IPA was implemented.</li> </ul>	<ul style="list-style-type: none"> <li>• Three themes with extracts from at least half the participants</li> <li>• Good commentary with themes and references to reflexivity</li> <li>• An audit of the first authors themes was conducted by the second author.</li> </ul>	<ul style="list-style-type: none"> <li>• Authors wonder if IPA is an appropriate methodology to use with people with LD.</li> <li>• Researcher found participants talked openly and shared insights into their experiences</li> </ul>
<p><b>Dysch et al. (2012)</b> What are the experiences and perceptions of people with intellectual disabilities and diabetes?</p>	<ul style="list-style-type: none"> <li>• N=4 , all white British</li> <li>• 3 females, one male</li> <li>• Ages 30-43, mean 35</li> <li>• All the participants had diabetes but type varied and time since diagnosis varied significantly</li> </ul>	<ul style="list-style-type: none"> <li>• Nurses in the local diabetes clinic and local community intellectual disability team identified appropriate participants to the research team</li> </ul>	<ul style="list-style-type: none"> <li>• 6 super-ordinate themes and 15 sub-themes</li> <li>• A good attempt at interpretative analysis but some sections appear to merely describe what was</li> </ul>	<ul style="list-style-type: none"> <li>• Participants reported physical consequences of their illness rather than emotional consequences. They were able</li> <li>• Participants engaged well with interview,</li> </ul>

	<ul style="list-style-type: none"> <li>• Assessment of mild intellectual disability though clinical judgement</li> </ul>	<ul style="list-style-type: none"> <li>• Semi structured interviews between 45-90 minutes.</li> <li>• Author provides information on the topics explored by the researcher but not on the interview schedule and how it was developed</li> <li>• Some information regarding how IPA was implemented.</li> </ul>	<p>said.</p> <ul style="list-style-type: none"> <li>• Quotes from at least half the participants to support the themes</li> <li>• Triangulation used</li> </ul>	<p>discussed frustrations and challenges with regards to other people.</p>
<p><b>Gould and Dodd (2014)</b> What are the experiences of mothers with mild learning disabilities who have had their children removed?</p>	<ul style="list-style-type: none"> <li>• N=9, unknown ethnicity</li> <li>• All female</li> <li>• Ages 21- 29, one age unknown</li> <li>• Mild learning disability, assumed through eligibility for community learning disability services</li> <li>• Detailed table with information on participants and their children.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants recruited via health professionals</li> <li>• Semi structured interviews developed using previous research and peer reviewed and piloted using an experienced community nurse.</li> <li>• Detailed information regarding how IPA was implemented.</li> </ul>	<ul style="list-style-type: none"> <li>• 3 super-ordinate themes and 6 sub-themes</li> <li>• Insufficient extracts to support the themes</li> <li>• Interpretative commentary</li> <li>• No mention of triangulation, audit or credibility checking.</li> </ul>	<ul style="list-style-type: none"> <li>• No specific IPA/LD issues identified</li> </ul>

<p><b>Keynon et al. (2013)</b> How do people with learning disabilities may sense of the experience of being told they have a learning disability?</p>	<ul style="list-style-type: none"> <li>• N= 8, all white British</li> <li>• 1 female, 7 male</li> <li>• Ages 25-63 (mean 47)</li> <li>• IQ not assessed but clinical impression of mild learning disability</li> <li>• Deliberately selected participants from self-advocacy organisations, day services and newly diagnosed NHS patients.</li> <li>• The sample is not homogenous due to large variability between how people came to know about their learning disability diagnosis, mostly diagnosed whilst in school</li> </ul>	<ul style="list-style-type: none"> <li>• Participants recruited through a number of organisations</li> <li>• No details around how the interview schedule was developed but it was discussed with a reference group. The interview schedule is not shared but areas of what was explored in the interview is staged</li> <li>• Some information regarding how IPA was implemented.</li> </ul>	<ul style="list-style-type: none"> <li>• Three super-ordinate themes and 8 sub-themes</li> <li>• Insufficient extracts to support the themes</li> <li>• Commentary supporting the themes are short and whilst they attempt to be interpretative, they do this in a superficial manner.</li> <li>• A journal was used by the author and coding was checked by the other authors.</li> </ul>	<ul style="list-style-type: none"> <li>• No specific LD/IPA issues</li> </ul>
<p><b>McRitchie et al. (2014)</b> What is the experience of bereavement for adults with an intellectual disability?</p>	<ul style="list-style-type: none"> <li>• N= 13</li> <li>• 5 female, 8 male</li> <li>• Ages 20-72</li> <li>• Homogenous sample as all the participants had been bereaved in the last 3 years</li> <li>• Participants had a mild learning disability, not</li> </ul>	<ul style="list-style-type: none"> <li>• Participants recruited through day service providers in Scotland.</li> <li>• Semi structured interviews, no details on questions or how the schedule was developed</li> <li>• No information on the</li> </ul>	<ul style="list-style-type: none"> <li>• Four super-ordinate themes with many sub-themes that are not explicit.</li> <li>• Commentary is descriptive rather than interpretative in the majority of the results section. Some brief attempts at</li> </ul>	<ul style="list-style-type: none"> <li>• The results of the paper cannot be generalised beyond people with mild learning disabilities.</li> </ul>

	<p>stated how this was assessed.</p>	<p>length of the interviews</p> <ul style="list-style-type: none"> <li>Detailed information on how IPA was implemented using a computer programme.</li> </ul>	<p>interpretative commentary.</p> <ul style="list-style-type: none"> <li>Extracts from at least half the sample to support the themes</li> <li>Data analysis process assessed using Yardley (2000)</li> <li>Trustworthiness through triangulation and auditing</li> </ul>	
<p><b>Mitchel et al. (2006)</b></p> <p>What is the personal experience of trauma in people with learning disabilities?</p>	<ul style="list-style-type: none"> <li>N= 6</li> <li>2 female, 4 male</li> <li>Ages 23-57 years old</li> <li>Mild learning disability but it is not explained now how conclusion was made.</li> <li>All the participants were receiving on-going support from the local NHS learning disability service.</li> <li>Detailed information regarding type of trauma shared by the participants</li> </ul>	<ul style="list-style-type: none"> <li>Participants were recruited via staff in the local community learning disability service</li> <li>Focus group of staff regarding their views of LD and trauma used to develop a semi structured interview shared in the journal.</li> <li>Interviews lasted between 45-75 minutes. PDS used to collect data on the trauma.</li> <li>Detailed information regarding how IPA was implemented.</li> </ul>	<ul style="list-style-type: none"> <li>5 super-ordinate themes</li> <li>Sufficient extracts to support the data</li> <li>Some themes are explained through descriptive commentary such as theme 1. Other themes have more of an interpretative spin on them. References to themes relating to psychological theory but no further detail on the specific theory.</li> <li>A reflective diary was used but no additional mention of triangulation, audit or credibility checking.</li> </ul>	<ul style="list-style-type: none"> <li>Most participants struggled with self-reflective questions such as how do you think the event has affected your life. The participants were more likely to talk about their beliefs about trauma rather than the impact of it.</li> </ul>

<p><b>Rushbrooke et al. (2014)</b> What are the experiences of intimate relationships by people with Intellectual Disabilities?</p>	<ul style="list-style-type: none"> <li>• N= 9, ethnicity unknown</li> <li>• 5 female, 4 male</li> <li>• Ages 24-51 years olds</li> <li>• Participants currently in receipt of NHS services.</li> <li>• Level of learning disability not specified.</li> <li>• Detailed participant profiles including sexuality and relationship/marital status.</li> <li>• The sample is not homogenous as some participants were in relationships, others were not but this discussed in the paper. The homogeneity is based on the fact that all participants have a LD but the level of LD is unknown.</li> </ul>	<ul style="list-style-type: none"> <li>• NHS service providers identified potential participants</li> <li>• Semi structured interviews in which a local group of people with learning disabilities were consulted.</li> <li>• Interview piloted with a service user.</li> <li>• Types of interview questions shared in the paper.</li> <li>• Interviews ranged from 27-55 minutes.</li> </ul>	<ul style="list-style-type: none"> <li>• 4 super-ordinate themes</li> <li>• Quotes from at least half the sample for each theme.</li> <li>• Good interpretative commentary making references to commonalities between the participants and divergences.</li> <li>• Triangulation and auditing adopted.</li> <li>• Focus on exceeding criteria on “acceptable” for IPA by Smith (2010).</li> </ul>	<ul style="list-style-type: none"> <li>• Two participants chose to have their carers present. The impact of this on IPA is not discussed.</li> </ul>
<p><b>Shewan et al., (2012)</b> How do parents understand about their learning disability and how they perceive this to impact on them in their parenting role?</p>	<ul style="list-style-type: none"> <li>• N= 8, ethnicity unknown</li> <li>• 3 female, 5 male</li> <li>• Ages 23- 46</li> <li>• All participants parents</li> <li>• All participants eligible</li> </ul>	<ul style="list-style-type: none"> <li>• Participants recruited via an index worker in the local NHS learning disability service.</li> <li>• Examples of topics in</li> </ul>	<ul style="list-style-type: none"> <li>• One super-ordinate theme with three sub-themes</li> <li>• Themes are closely related to the questions asked and may be</li> </ul>	<ul style="list-style-type: none"> <li>• No specific IPA/LD issues.</li> </ul>

	<p>for services within a NHS learning disability service with a diagnosed learning disability</p> <ul style="list-style-type: none"> <li>• Level of learning disability not specified</li> <li>• Detailed participant summary</li> </ul>	<p>the interview schedule shared</p> <ul style="list-style-type: none"> <li>• Interview lengths between 22-67 minutes, with an average of 42 minutes</li> <li>• Summary of 6 states used during IPA</li> </ul>	<p>related to the researchers pre constructed ideas.</p> <ul style="list-style-type: none"> <li>• Sufficient extracts to support the themes</li> <li>• The commentary appropriate</li> <li>• Trustworthiness demonstrated through auditing, triangulation and reflective diary.</li> </ul>	
<p><b>Wilson et al. (2013)</b> To explore the postnatal care experiences of mothers with an intellectual disability.</p>	<ul style="list-style-type: none"> <li>• N= 6</li> <li>• All female</li> <li>• Ages 20-55</li> <li>• All women known to community learning disabilities team</li> <li>• No formal measure of LD but believed to have mild learning disability</li> <li>• Sample is not homogenous as some women had experienced losing custody of their children.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants recruited via staff in the community learning disabilities team</li> <li>• Semi structured interviews based on areas highlighted by previous research</li> <li>• Feedback from professionals on interview schedule</li> <li>• Interviews lasted between 57 minutes and 69 minutes</li> <li>• Detailed step by step account of how IPA was implemented.</li> </ul>	<ul style="list-style-type: none"> <li>• 2 super-ordinate themes and 7 sub-themes.</li> <li>• At least 3 extracts to support the themes</li> <li>• A good balance between descriptive and interpretative analysis.</li> <li>• Credibility check using an independent researcher</li> </ul>	<p>Acknowledges that IPA requires a homogenous sample and some participants had experiences of their children being taken away and some didn't and so researchers acknowledge variability.</p>



Table 4: Summary of papers rated as Good

Study and aims/research question	Sample	Method	Results and trustworthiness	Discussion: specific issues relating to using IPA with people with learning disabilities
<p><b>Clarkson et al. (2009)</b>            What are the perceptions of a group of adults with learning disabilities regarding direct support received in a forensic inpatient unit?</p>	<ul style="list-style-type: none"> <li>• N= 11 unknown ethnicity</li> <li>• 3 females, 8 males</li> <li>• Ages 20-53 (mean 33)</li> <li>• Eligibility to take part in the research though client being detained in an NHS hospital for people with learning disability.</li> <li>• No information regarding level of learning disability</li> <li>• Homogenous sample: the participants had resided in the hospital for an average of 4 years (range 1-10 years)</li> <li>• All participants had offended or were considering at high risk of offending.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants invited to take part in the research from across the whole forensic service including high secure units, low secure units and rehabilitation units.</li> <li>• Focus group (n=10) to develop interview schedule.</li> <li>• Author provides information on the topics explored by the researcher</li> <li>• Semi structured interviews lasting between 30 – 40 minutes.</li> <li>• Detailed information regarding how IPA was implemented.</li> </ul>	<ul style="list-style-type: none"> <li>• Two super-ordinate themes and seven sub-themes. With extracts from at least half the sample for each theme</li> <li>• The author has made a good attempt at interpretative commentary with some attempts at attempting convergence and divergence when explaining how the extracts support the themes.</li> <li>• Triangulation, auditing and credibility checking implemented by the researcher</li> <li>• Specific sections on the researchers own views and the impact of this on IPA.</li> </ul>	<p>No specific LD/IPA issues raised by researcher</p>

<p><b>Cookson and Dickson (2010)</b>          What are the experiences of people with intellectual disabilities, in secure care, with a diagnosis of schizophrenia?</p>	<ul style="list-style-type: none"> <li>• N= 11, unknown ethnicity</li> <li>• 4 females, 7 males</li> <li>• Ages between 19-44</li> <li>• Participants have a dual diagnosis of learning disability and schizophrenia as defined by ICD-10</li> <li>• Level of learning disability unknown</li> <li>• All participants detained in a medium secure unit and had a history of offending</li> </ul>	<ul style="list-style-type: none"> <li>• Participants recruited via the medical doctors in the medium secure unit.</li> <li>• Semi structured interviews developed in collaboration with two clinical psychologists who had previously used IPA.</li> <li>• Author provides information on the topics explored by the researcher</li> <li>• Interviews ranged between 20-65 minutes</li> </ul>	<ul style="list-style-type: none"> <li>• Three super-ordinate themes and 9 sub-themes</li> <li>• At least 5 extracts per theme</li> <li>• A good attempt to share interpretative analysis at the start and end of each theme</li> <li>• References made to divergence and commonalities between participant interviews.</li> <li>• During analysis stages, themes discussed with the research team and reviewed by an independent researcher</li> </ul>	<ul style="list-style-type: none"> <li>• Researchers passionate about using IPA with people with learning disabilities</li> <li>• Recognised that people with learning disabilities may not have the vocabulary to convey their experiences in the way that someone without a learning disability would articulate themselves.</li> <li>• People with severe disability or communication difficulties were excluded and so findings cannot be generalised to them.</li> </ul>
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## **Narrative synthesis**

A narrative synthesis provides an overview of all the papers that have been reviewed. The research outcomes are explored in relation to “key features of what makes a good IPA paper” highlighted by Smith (2011) which will be answered as the following questions:

- What was the focus of the papers?
- What was the quality of the data?
- Were the papers rigorous?
- Was there sufficient space given for the researchers to elaborate the themes?
- Was the analysis interpretative instead of just descriptive?
- Did the researchers refer to both convergence and divergence in the data?
- What processes were implemented to evidence reliability and validity?
- Was the paper carefully written?

In addition to the above, the literature review will explore what are the key issues to consider when using IPA with people with learning disabilities? Whilst it would be of interest to look at the results of these papers, this is beyond the scope of the current review.

## **Focus of the papers**

Smith (2011) argues that IPA research should have a clear focus: the topic should be specific and not broad. A specific topic requires a homogenous sample.

As summarised in the descriptive summary of the papers included in this review, the papers explored a variety of topics. Three of the poor papers did not have a specific focus. Judge et al. (2010) explored the experiences of people with learning disabilities in Scotland who have to “retire” from day service once they reach the age of 65. This paper lacked focus due to the sample not being homogenous. The sample included participants

between the ages of 41-64. This meant that some of the participants were approaching retirement but others were at least two decades away and so the participant's ability to reflect on their experiences of something which is far away is questionable. MacDonald et al., (2013) explored the experiences of people with learning disabilities in receipt of group analytic therapy. This paper pooled together the results of two different groups (a female only group and a group for sex offenders). The authors acknowledged that potential difficulties of pooling together the results of two different groups but still amalgamated the findings. Lastly, Pestana, (2011) attempted to explore the life experiences of people with learning disabilities from minority ethnic communities. A closer inspection of the sample revealed that the sample in the research included four people with different backgrounds: one participant was British Pakistan; another participant had emigrated from Siberia; another participant was labelled as an "ethnic minority" because their foster parents were Indian; the fourth participant was born and raised in Ireland". The definition of ethnic minority applied by the researcher as being from a ethnic minority was clearly very broad.

All good and acceptable papers were rated to have a clear research focus with the exception of Kenyon et al. (2014). This paper explored the experience of people being diagnosed with the learning disability. The majority of the participants in the sample had been "diagnosed" to have a learning disability whilst they were still in school. The mean age of the participants was 47. This raises the question of the importance of the diagnosis for many participants as well testing their ability to remember an experience that may have occurred over 30 years ago for them. If the research topic is not of immediate importance to the participant, it is likely to impact on their ability to engage with the research process and impact on the quality of the data.

Smith et al. (2009) do not advocate an ideal sample size to demonstrate homogeneity but suggest that 3-6 participants for novice researchers and 6-10 for those

with more experience using qualitative methods. The sample sizes for the papers in this review appeared in line with this recommendation with the exception of four papers. The two “good” papers (Clarkson et al., 2009; Cookson and Dickson, 2010) exceed this recommendation by 1. Judge et al. (2010) and McRithie (2012) recruited 16 and 13 participants respectively. Turner et al., (2012) suggested that large samples can lead to “data saturation” which means additional interviews do not result in additional themes.

Despite the requirements of small samples for IPA, 7 of the papers recruited a sample that was not homogenous (Dysch et al., 2012; Judge et al., 2010; Kenyon et al., 2014; MacDonald et al., 2013; Rushbrooke et al., 2014; Wilson et al., 2013). The details of the samples can be found in tables 1-3. Non homogenous samples not only violate the idiographic philosophy of IPA but may impact on the researcher’s ability to formulate theories (Smith, 1999).

All of the researchers overlooked the importance of homogeneity with regards to the participant’s level of learning disability. 15 of the studies assumed the participants to have a learning disability due to their eligibility to receive input from community learning disability services. Around half of the papers stated recruiting participants with mild learning disabilities which was based on impressions made by the clinical teams involved in the participants care or through the researchers own impressions and reviewing of case notes.

The remaining two papers (Cookson & Dickson, 2010; Pestana, 2011) recruited participants with an ICD-10 diagnosis of learning disabilities. The participants in Cookson and Dickson (2010) had an ICD-10 dual diagnosis of learning disability and schizophrenia.

## **Quality of the data**

Researchers tend to collect data through semi structured interviews as IPA requires a first person account in the form of a verbatim transcript for each participant (Smith et al., 2009). This method appears to be the default option for researchers (Smith & Osbourne, 2012) although IPA can be applied to other data collection methods such as written accounts (Smith, 1999) and focus groups (Palmer, Larkin, De Visser & Fadden, 2010). Smith (2011) argues that the quality of the interview will impact the data derived from it and will set a “cap” on the quality of the overall paper. All of the studies engaged their participants through face to face semi structured interviews which ranged between 20 and 69 minutes long.

Four of the five papers rated as poor gave no information about the interview schedule. The fifth paper (MacDonald et al., 2003) attached the interview schedule to the paper. This was particularly useful because it revealed that many of the questions were not suited to IPA for example, the questions “Do you think that...?” may have led participants to acquiesce, a particular difficulty for many people with learning disabilities (Booth & Booth, 1996).

Of the remaining papers rated as good or acceptable, four papers reported designing their interviews through focus groups involving staff and people with learning disabilities (Clarkson et al., 2009; Kenyon et al., 2014; Rushbrook et al., 2014; Cookson & Dickson, 2010). Three papers based their interviews on previous research (Anslow, 2013; Gould & Dodd, 2014; Wilson et al., 2013). One paper included their interview schedule (Mitchel et al., 2006) and the remaining three papers made no references to how the interview schedule was developed (Brown & Beail 2009; Dysch et al., 2012; McRitchie et al., 2014). Most of the papers made references to the interview topics only. Mitchel et al.

(2006) attached the interview schedule as an appendix and was strong in relation to the interview process. The advantage of attaching an interview schedule is that it improves the transparency of the research and it helps the reader to explore whether the interview has been adapted in any way to accommodate the needs of people with learning disabilities. In the case of this interview schedule, it appears very thorough and includes short questions using simple language.

### **Rigour**

In IPA, rigour refers to the analysis process, paying attention to both the breadth and the depth of the themes derived (Smith, 2011) and so the research process needs to be transparent.

With the exception of three papers (Anslow, 2013; Baum & Burns, 2007; Brown & Beail, 2009) the papers included detailed information regarding the procedure implemented during the analysis including details such as making notes in the margin to generate initial ideas. The papers followed the standard six stage method proposed in the IPA manual (Smith, Flowers & Larkin, 2009).

Smith and Osbourne (2003) argue that richness of data with an IPA context is not related to the participant's ability to recall detail (McVilly et al., 2008) but is related to the number of themes derived from the analysis. The number of themes varied between the papers from 1 super-ordinate theme and 3 sub-themes (Shewan et al., 2014) to 6 super-ordinate themes and 15 sub-themes (Dysch et al., 2012).

Rushbrook et al. (2014) is a good example of a rigorous paper and is particularly strong with regards to its interpretative commentary. One of the reasons for this may be that the authors had explicitly stated that quality was of importance to them and that they had attempted to apply the criteria proposed by Smith (2011) such as ensuring their data

had an appropriate evidence base by providing extracts for each themes for at least half the participants.

### **Elaboration of themes**

In qualitative research, the elaboration of themes is vital. Smith (2011) suggests that in some cases, researchers are better off elaborating a subsection of their themes in an elaborate fashion rather than presenting them all superficially. Smith (2011) recommends that for larger samples of greater than six participants, there should be extracts from at least half of the sample to demonstrate a theme. The poor papers all have a poor evidence base failing to support the themes derived from the analysis with sufficient extracts. Two of the acceptable papers also did not support their themes with sufficient extracts.

The quotes in all of the papers appeared distinctly different to other IPA papers. The extracts appeared short and snappy such as “makes me hot” (Dysch et al., 2012). Some of the papers had longer excerpts “All the babies were crying and I could not get to sleep. Kept moving me from one room to another I didn’t know where to put my face, when I saw them babies” (Mitchel et al., 2006). The quotes in the papers did not exceed two or three sentences.

The main features which differentiated the poor papers from the rest is that they had poorly developed analysis sections. All five poor papers did not have sufficient extracts to support the themes, as it is recommended that extracts from at least half the participants support the themes. All the “good” papers had strong analysis sections. Cookson and Dickson (2010) stood out from the other papers; there were extracts from at least half the participants for each theme.



### **Balance between descriptive and interpretative analysis**

IPA requires researchers to be “interpretative”, to go beyond what is said by the participant. All the acceptable and good papers had sufficient numbers of extracts and had attempted to provide both descriptive and interpretative analysis. For this reason, the themes did not have to “talk for themselves”.

The differences between the interview schedule and themes derived from analysis are likely to be closely related to how much interpretative analysis the researchers have done. Three papers in the review appeared to explore research topics that were closely related to the themes (Baum & Burns, 2007; Merriman & Beail, 2009; Shewan et al., 2014). For example, Baum and Burns (2007) explored the topic “What were the mothers’ experiences of support before and after their child/ren had been removed? Subsequent themes were: “relationship to support before children’s removal; relationship to support after children’s removal and relationship to support present support”. In the Merriman and Beail (2009) paper, the topics explored and the themes derived were closely related. For example they explored the topic of “the client’s experience of therapy” and derived the theme of “the participant’s experience of psychodynamic psychotherapy”. Such analysis does not appear to require any interpretative skills and appear to be more descriptive rather than interpretative.

### **Convergence and divergence in the data**

Where an IPA paper investigates the experiences of more than one participant, it is important for researchers to demonstrate both findings of individual participants but also to give a sense of shared experiences (Smith, 2011). This is a difficult skill to master and Smith (2011) believes that this is the “hallmark” of good IPA work. The distinct features of the “good” papers in comparison to the “acceptable” papers are that they were able to

demonstrate convergence and divergence effectively. Only the two good papers were able to demonstrate this.

For example, Clarkson et al. (2009) states “Six participants made reference to...” This suggests that approximately half of the participants shared this experience. The paper also demonstrates individual experiences. Similarly, Cookson and Dickson (2010) shared interpretative analysis both when introducing a theme and closing it. The authors took into consideration divergences and commonalities between the participant’s accounts. This in turn brings the paper to life and makes an interesting read.

### **Processes to evidence reliability and validity**

Holt and Slade (2003) believe that the validity of qualitative research can be based on the applicability of themes. It is important to note that within IPA, the aim is not to apply and generalise results. It is about capturing and making sense of an experience of a homogenous sample. Validity can be explored in terms triangulation (Patton, 1999), credibility checking (Patton, 1999) and reflexivity (Mays, 2000).

Triangulation was explicitly stated and adopted by six of the papers (Clarkson et al., 2009; Anslow, 2013; Dysch et al., 2012; McRitchie et al., 2014; Rushbrook et al., 2014; Shewan et al., 2014).

Auditing was practised by eight research teams (Clarkson et al., 2009; Cookson & Dickson, 2010; Anslow, 2013; Brown & Beail, 2009; Kenyon et al., 2014; McRitchie et al., 2014; Rushbrook et al., 2014; Shewan et al., 2014). 4 papers adopted credibility checking (Clarkson et al., 2009; Cookson and Dickson 2010., Anslow, 2013; Wilson et al., 2013).

Two papers made no references to any procedures to ensure valid and reliable results (Gould & Dodd, 2014; Michel et al., 2006).

## **Key issues relating to using IPA with people with learning disabilities**

It is a common approach for people with learning disabilities to have proxies present during research interviews to support them with communicating with researchers (Whitehurst, 2006). Two of the papers explicitly stated that carers were present in some of the interviews to support the person with a learning disability (Anslow, 2013; Rushbrook et al,2014). Anslow (2013) acknowledged that methodologically this was supportive in allowing people to take part in the research who might have otherwise struggled to do so. However, they noted that IPA does not provide any specific guidelines as to how to manage the additional complexity if a carer speaks in the interview to clarify or support an answer being given. Rushbrook et al. (2014) did not discuss the impact of carers being present in interviews.

Dysch et al. (2012) noticed that in relation to diabetes the participants in their sample struggled to talk about the emotional consequences of their illness and tended to answer such questions by focussing on the physical consequences. They questioned whether this was about having an appropriate vocabulary. Mitchel et al. (2006) noted that the participants struggled with questions about trauma in which they were required to self-reflect on questions such as the impact of trauma on them and discussed their beliefs around trauma instead. As the interview schedule is not provided it is hard to make inferences as to whether this is a reflection of the participant's abilities, the interview schedule, researchers ability to communicate in accessible language or the researcher ability to make interpretative enquiry?

Cookson and Dickson (2010) recognised that the participants in their study presented with limited vocabulary. Regardless of this observation, Cookson and Dickson (2010) adhered to the IPA theory and embedded IPA very well within the research process.

This suggests that if IPA is applied appropriately, verbal articulacy should not be a stumbling block for applying IPA. Similarly, Brown and Beail (2009) noted that one of the limitations of their paper is that there were concerns that the participants may struggle with the interview due to their limited verbal abilities and so the data would not be “rich” resulting in many themes. Despite these concerns, the authors went onto conclude that the participants were open and shared valuable insights into their experiences.

Anslow (2013) specified that some participants used additional communication methods such as Makaton. Whilst this is specified, the way in which Makaton has been incorporated into the analysis has not been recorded.

### **Discussion**

This review rated 2/17 (12%) papers to be of good quality, 10/17 (59%) as acceptable quality and 5/17 (29%) to be of poor quality. In comparison, Smith (2011) rated 27% of the papers he reviewed to be of good quality, 55% to be of acceptable quality and 18% to be of unacceptable quality. When comparing the quality of research using IPA with health psychology (Smith, 2011) and with a learning disability population (this paper), it appears that the proportion of “acceptable” papers are roughly equivalent. Differences lay with a larger proportion of poorer papers and a small proportion of good papers when the participants have learning disabilities. The difference in numbers could be accounted for by natural variation given the sample size of these reviews.

Given that just over half the papers both in this paper and in Smith (2011) are rated as “acceptable” suggests that researchers using IPA still have some way to go in terms of producing good quality research.

## **Sample**

As this paper examines people with learning disabilities as participants in IPA research, it is important to take into consideration how the researchers have conceptualised the term “learning disability”. The results suggest that most researchers pay little attention to the ability levels of their participants. One of the reasons for the lack of information may be related to the recruitment process, as the majority of the participants were recruited through staff in health services. The organisations therefore acted as gate-keepers and may have their own assumptions and judgements about whether people with learning disabilities are appropriate to take part in research or not. Lee (2003) found that “gate keeper” organisations can sometimes block access to participants when discussing sensitive topics. Another reason for this may be related to the inclusion and exclusion criteria for papers to be included in the review. During the initial search for papers, 82 papers were reviewed. Despite the term “learning disability” appearing in the keywords of the papers, a closer inspection of the papers revealed that in approximately 20 of the papers, the researchers were labelling their participants to have learning disability but the appropriateness of this label is questionable. For example some participants were recruited through self-advocacy services where a “diagnosis” of learning disability was not necessary to be a member.

In order for us to truly evaluate research in this area, it is vital that future researchers improve transparency regarding the characteristics of participants recruited into their research otherwise we may fall into the trap of either generalising from people with varying presentations or that we run the risk of recruiting people into research who may be in services but may not necessarily meet the definition of learning disability.

## **Methodology**

All the papers engaged the participants into the research using individual interviews. This is surprising as we know that focus groups are believed to help less able participants engage with research through peer support (Cambridge & McCarthy, 2001). This may be because IPA typically adopts one to one interviews (Brocki & Wearden, 2006). Given that IPA is still a relatively new methodology, researchers may not feel confident in applying IPA to focus groups despite guidelines to support researchers, such as Palmer et al. (2010).

The interview schedules were only available for two papers that were reviewed so it is difficult to comment on whether the researchers adapted their interview techniques or used any novel approach to engage the participants with the research. Whilst peer reviewed journals have stringent criteria with regards to word count to publish work which may impact on the way work is presented, the degree of detail regarding interviews varied significantly. The papers with the better analysis sections tended to have more transparency with regards to the topics covered in the interview. This may be because the reader could draw links between the questions asked and the types of responses given by the participants. The whole process was integrated and future researchers would be strongly encouraged to take into consideration the importance of sharing interview schedules. Without this information it makes it difficult to judge the quality of the interview and the impact this may have on the quality of the data.

Despite this, it is important to appreciate that all of the papers “produced data”. All the participants were able to engage with the interviews, while the papers did not present elaborate sections of prose it appears that the short prose did not have a large impact on the researcher’s ability to engage with the material. People with learning disabilities may require additional scaffolding through additional questions from the researchers to guide

and support them through the research which suggests that particular care needs to be taken when designing interview schedules.

To enhance the papers, if researchers share their interview schedules by publishing them, it would aid evaluation of IPA in the future to look at any technical adaptations that are made to accommodate the needs of people with learning disabilities (for example, have additional questions to prompt the participants been added to the interview schedule). Despite this, the proportion of “acceptable” papers was in line with research where participants did not have learning disabilities.

### **Data analysis**

It is important that IPA researchers produce themes that are thoroughly represented in the data (Jarman, Smith & Walsh, 1997) and that researcher bias is minimised (Smith et al., 1999). In some of the papers, the themes derived were very closely linked to the research questions asked. This may have led to the majority of the papers analysis sections being descriptive rather than interpretative because the level of analysis needed for a good IPA paper was not conducted by the researchers. It is possible that the researchers struggled with interpretative commentary on short prose. It requires the researcher to mentally join up the short answers and produce interpretative commentary across several answers rather than “line by line” as suggested by Smith et al. (2009). This may pose a difficulty for some researchers. Secondly, if the researchers were required to provide scaffolding to the interview by asking more questions to guide the participants through the interview it is possible that the researchers own preconceived ideas of their expectations of the findings may have lead them to ask leading questions.

## **Reliability and validity**

Issues of validity and reliability are not unique to IPA. The majority of the papers had some form of reliability or validity checking. Rushbrooke et al. (2014) explicitly stated they wanted to demonstrate reliability and validity suggested by Smith (2011). It is possible that the other papers may be following general guidelines around what constitutes as good practice in qualitative methodology. Yardley (2000) however points out that issues around reliability may not necessarily be a priority for qualitative researchers who aim to merely provide a possible interpretation amongst many others. IPA itself does not aim to generalise its results, but rather carefully selects a homogenous sample to present their story. What IPA is interested in is ideography: making sense of the particular and its interaction with relevant theories. Issues around reliability and validity do not appear to be related to the participants in the research having learning disabilities but rather to do with the importance researchers put on such issues.

## **Key issues using IPA with people with learning disabilities**

It is somewhat surprising that in the discussion sections of the papers, the researchers did not comment on the issues of using IPA with people with learning disabilities given that we know that participants with learning disabilities tend to acquiesce (Murphy & Clare, 1995), have difficulty understanding material that is presented verbally (White & Steen, 1995) and tend to have poor receptive skills and so are less likely to be aware of the implications of research (Arscott et al., 1998). Some of the researchers did raise concerns around interviewing a sample with limited vocabulary. Some researchers noted that the participants tended to focus on detail rather than their emotions (Dysch et al., 2012; Michel et al., 2006). For IPA, this should not present a difficulty, because IPA aims to go beyond what is being said and may reflect the researcher's ability to be "interpretative" rather than



the “data” produced by the participants. It is worth noting that none of the researchers stated in their discussions that the participant’s abilities impacted on the quality of their results. In addition, with the exception of one paper, which included participants using Makaton, no other communication aids such as pictures or activities were used by the researchers. It is possible that researchers may not feel such aids are congruent with IPA, or they may possibly not feel confident in adapting a fairly new research methodology.

### **Conclusions**

This paper set out to find out whether IPA is an appropriate methodology to use with people with learning disabilities. There is some good evidence that despite the interviews resulting in short sections of prose, 12/17 of the papers were of good or acceptable quality. We cannot ignore that research with people with learning disabilities is affected by many issues, however these issues do not appear to be significantly different to the issues raised with populations within health psychology. Future researchers are urged to improve the transparency of their research methodology especially with regards to their participant profile, which is likely to be impacted by issues such as whether the participants can give informed consent. On the whole, as Reid et al. (2005) suggests “the future of IPA research looks bright” (p.23) and this is certainly the case for people with learning disabilities contributing to IPA research.

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

**Doctor of Clinical Psychology**

**VOLUME I**

**RESEARCH COMPONENT**

**CHAPTER TWO**

**THE EXPERIENCES OF WOMEN OF SOUTH ASIAN**

**ORIGIN IN RECEIPT OF SOCIAL SERVICES**

Department of Clinical Psychology

School of Psychology

The University of Birmingham

April 2015

### **Accessible summary**

- We know that families of South Asian people with learning disabilities are not happy with Social services such as day centres and think they should be better
- This research interviewed South Asian Women with Learning disabilities and found that they think services are doing a good job.
- They are happy that their cultural needs are being met
- South Asian Women want services to help them learn new skills.

### **Summary**

This paper aims to reflect on the experiences of Women of South Asian origin with learning disabilities in the United Kingdom in receipt of social services as it has been reported that carers and service users have been dissatisfied with the services they receive. This paper focuses on the experiences of 10 women of South Asian origin with mild-moderate learning disabilities using opportunity sampling who were recruited through 5 gatekeeper organisations in the West Midlands. The women were interviewed using a semi structured interview either individually or as a group. The data was analysed using IPA. The analysis revealed three super-ordinate themes and eight sub-themes. The participants in the study were satisfied with services and expressed dissatisfaction when they were not seen to be learning or moving on. The results suggest that the participants managed complex issues such as acculturation and receiving different messages from services and families successfully.

**Keywords: Learning disabilities; Intellectual Disabilities; South Asian Women; Interpretative phenomenological analysis, social care services; Culture**

## **Introduction**

### **People of South Asian Origin with Learning Disabilities**

This paper aims to reflect on the experiences of Women of South Asian origin with learning disabilities living in the United Kingdom in receipt of social services and the way in which they make sense of the support that they are receiving taking into consideration their social and cultural context.

The term “South Asian” is used to describe people who identify themselves as originating from the following countries: Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka (World Bank, 2014).

Social services refers to services provided by the government with intention to benefit people living in the local community such as education, housing and leisure facilities. In the United Kingdom, social services are seen as separate to health care provided which is provided by the National Health Service (Leutz, 1999). Adult social care related to support provided by local social services for adults who need additional support. There is however no clear on definition due to historical and political dilemmas (Law Commission, 2011). This current project uses the definition of Leutz (1999) and in addition it also includes services such as educational establishments, day centres, accommodation (respite, supported living, independent living). Such services may be provided by local authorities such as councils, private service providers or charities (this definition was also used by the larger project as outlined under methodology on page 72).

The prevalence of severe learning disabilities is significantly higher in South Asian communities than any other ethnic community in the United Kingdom (Kerr, 2001). It is believed that between the ages of 5-34, the prevalence of severe learning disabilities is three times higher in South Asian families (Emerson, Azmi, Hatton, Caine, Parrott & Wolstenholme, 1997).

Emerson and Hatton (2008) estimated the need for social care for people with learning disabilities during 2009-2026 and concluded that Asian people represent the second largest group of new entrants after White British people. Although the term Asian also included people from Chinese backgrounds, the term was used to describe people from mainly Pakistani, Indian and Bangladeshi backgrounds.

It is therefore important to take into consideration the needs of people from this minority group. Chamba, Ahmad, Hirst, Lawston and Beresford (1999) found that South Asian families of people with learning disabilities experienced disadvantages with respects to housing, income, employment and health compared to their white counterparts. Despite this, they were still found to be receiving fewer benefits and support services. McGrother, Bhaumik, Thorp, Watson and Taub (2002) found that South Asian carers reported that the people they were caring for had greater skill deficits in areas such as washing, dressing, and toileting than reports from carers from white backgrounds

### **Poor uptake of Social Services**

Despite the high prevalence of people with learning disabilities of South Asian origin, it has been reported that in this minority group there is a low uptake of services and dissatisfaction with the services being received (Hatton et al., 1998, Azmi, Hatton, Emerson & Caine, 1997; Hensel, Krishan, Saunders, Durrani & Rose, 2005).

The majority of the research in this area has focussed on the views of carers (Hatton et al., 1998; McGrother et al., 2002; Raghavan & Waseem, 2007) who report a high level of awareness of health services such as the GP, dentist and Opticians and less awareness of specialist services such as community intellectual disability nurses (Hatton et al., 1998; Raghavan & Waseem, 2007).

Low uptake and dissatisfaction with services has been related to: language barriers and cultural inappropriateness of existing services in terms of diet, activities and staff provision, racial discrimination and preference of the Muslim community to use “faith healers” (Raghavan & Waseem, 2007); clash between South Asian values and Western values, such as the view that care should be provided by the family, and not through respite or long term care (Hensel et al., 2005).

Heer, Larkin, Burchess and Rose (2012) explored the experiences of Sikh and Muslim parents caring for their children with learning disabilities. The research highlighted three main areas of concern for the parents: making sense of the disability; feeling let down by services and looking into the future. With respect to feeling let down by services, the parents were particularly angry about GP’s unresponsiveness, whom they believed should diagnose and recommend appropriate interventions for their children. There appeared to be a mismatch between what the parents expected and what was being offered. In addition, the parents felt that services blamed them for having a child with a disability, believing the disability is the result of genetic causes due to cousins marrying. The parents often reported they preferred white service providers due to having negative experiences with Asian service providers such as feeling judged and them not being helpful.

## **Experiential-contextual framework**

Heer, Rose and Larkin (2012) have attempted to use an experiential-contextual framework to explain the interaction between families and services caring for a child with a learning disability in the United Kingdom in terms of three models of disability (minority, medical and social). Although this model attempts to explain the complex interaction South Asian families have with services it may also be useful in trying to understand the difficulties service users themselves may face. For example, families' responses to certain issues may be interpreted by services as not complying with services rather than looking at the beliefs they hold about people with learning disabilities. It is possible that service users may find themselves to be caught in the middle of the views of services and the view of their family.

## **Giving people with learning disabilities a voice**

If we want to understand the experiences of how service users interact with services, we need to interview them. Research in general has not always allowed people with learning disabilities to have a voice. This tendency is changing with an increase in qualitative research involving people with learning disabilities (Beail & Williams, 2014).

Azmi et al. (1997) pioneered research in this area by asking individuals with learning disabilities from South Asian backgrounds about their experiences of services. The research explored the views of 21 South Asian adolescents and adults with learning disabilities exploring eight main areas of their life: "accommodation, individual support, day services, service support, social and recreational activities, friendships and relationships, ethnic and racial identity and racism and stigma." The study found that the participants were generally using fewer services except for day



services. Young people tended to take part in home based social and recreational activities such as watching television and shopping and felt dependent on family members to take them out. This restricted the activities that they could take part in; as a result they reported feeling dissatisfied with this aspect of their life. Around 75 percent of the participants used day centres and reported being satisfied with this service but were dissatisfied with the services provided within the day centre setting. There was a lack of religiously appropriate food, and insufficient recognition of cultural and religious special occasions. The research paper concluded that pervasive racism and stigma were experienced in all aspects of these young people's lives, and that they experienced double discrimination: discrimination of having a disability and of being from a minority ethnic group. As a consequence, some services were seen as inappropriate. One of the main strengths of this paper is that it researched a group of people that had been neglected by research. This research is however almost 20 years old.

When interpreting the results, it is important to take into consideration that the sample amalgamated the views of South Asian males and females with learning disabilities. All the participants had a strong positive view of their cultural identity, which may have impacted on their dissatisfaction and sense of discrimination. Although the research suggests that there is a low uptake of services, unlike other studies, it is not clear whether the participants were aware of the services available to them. Given the small sample size, the results cannot be generalised and so more research is needed on sample that is more strictly defined. The interviews were also analyzed using content analysis and so there is some question on the transparency of the research process.

## **South Asian Women with learning disabilities**

Building on the findings of Azmi et al. (1997), Mir, Nocon, Ahmad and Jones (2001) suggested that South Asian women experience “triple jeopardy” with regards to their race, disability and gender and so their needs differ from the needs of South Asian males and white women with learning disabilities. For example, parents of Muslim daughters with learning disabilities preferred female staff to care for their daughters and recreational activities where alcohol might be served were seen as taboo so parents tended not to allow their daughters to attend (Raghavan & Pawson, 2009).

O’Hara and Martin (2003) found that Bangladeshi women were more likely to be married and living with an extended family than white women with learning disabilities in the United Kingdom. Bangladeshi parents saw it as their parental responsibility to see their child married regardless of whether their child is able to give informed consent to marriage and sexual relations. As a result, it is likely that services may experience difficulties in explaining issues around capacity and the implications of British Law to families.

## **Aims**

The current research aims to build on previous research on the experiences of carers of people with learning disabilities in receipt of social services to elicit views of service users. The researcher believes that people with learning disabilities are “experts” in their own experiences and so eliciting their view is very important. The aims of this paper are:

- To explore the experiences of Women of South Asian origin with learning disabilities living in the U.K. in receipt of social services.
- To explore how the participants make sense of their cultural identity

The paper aims to do this using interpretative phenomenological analysis (IPA)

Smith, Flowers and Larkin, (2009).

## **Methodology**

The research project contributed to the larger study “Adults with Learning Disabilities from Black and Minority ethnic groups: view of social services”. The larger project was funded by the National Institute for Health Research, School of Social Care and recruited approximately 40 participants including the participants from this study. This paper focussed on a subsection of Black and Minority ethnic groups: South Asian Women. The design and data collection process of the research study was subject to the rigorous evaluation of a steering group consisting of individuals from varying backgrounds such as clinical psychologists, academic tutors, advocacy services and service users from learning disability services. I contributed to the wider research project through inputting into the design of the project, particularly in relation to interviews with South Asian women, the interview schedule and associated materials. I independently: recruited my own participants; interviewed the participants and analysed the data using a different methodology to the larger project. I also attended the steering group meetings and my research was also subject to the evaluation by the steering group. Ethical approval for this project was granted as part of the wider research study “Adults with Learning Disabilities from Black and Minority ethnic groups: view of services” on October 22<sup>nd</sup> 2012. Kulsoom Malik was assigned as a named investigator for this project (see appendix 1 for final ethics approval letter).

## **Design**

Research interviews were conducted with an opportunity sample of women with learning disabilities from South Asian backgrounds living in the West Midlands. The

project adopted an Interpretative Phenomenological Analysis (IPA) framework. Smith et al. (2009) suggest that IPA is informed through three main philosophical stances: phenomenology, hermeneutics and ideography. IPA aims to study experiences (phenomenology) through interpretation (hermeneutics) in the particular (ideography). IPA is therefore a methodology in which researchers make sense of the experience of a homogenous sample of participants through interpretative enquiry (Smith et al., 2009).

Figure 1: Eligibility criteria for participants to take part in the research

<b>Eligibility criteria</b>
✓ Women
✓ Over the age of 18
✓ Identified themselves as South Asian through the geography of their/parents origin.
✓ Able to give informed consent (assessed through a checklist based on the Mental Capacity Act 2005 and research by Arscott et al., (1998). See appendix 4 for consent form.
✓ Participants with mild/moderate learning disabilities (informed by current or previous support from learning disability services such as community NHS learning disability teams, history of attending a special school and through current support with regards to social and adaptive functioning such as support to travel, plan, financial skills based on ICD-10 criteria (figure 2)

Participants were given the option of conducting the interview in any language as there was funding for translation, as well as the researcher being able to fluently speak in

English, Urdu and Punjabi. All the participants opted to speak in English with the exception of one participant who opted to converse through a translator in Bengali. Despite the majority of the interviews being conducted in English, Urdu and Punjabi words were intermittently used with English words by the participants.

### **Selection of participants**

Seven “gatekeeper” organisations across the West Midlands were approached through telephone calls and emails. The organisations included education, social care, local authority, charities, private service providers and health services. Five organisations expressed interest and face to face meetings were arranged where details about the research and recruitment were explained. Potential research participants were approached by members of staff from the organisations explaining the research. The details of individuals who were interested in taking part in the research were forwarded to the researcher. A meeting between the research participant and the researcher was arranged to assess suitability for the research (appendix 2) and to gain informed consent. Two participants did not fit the eligibility criteria as they were unable to give informed consent were thanked for their time and offered a £5 gift voucher to compensate them for their time and contribution. The participants who were eligible for the research were also given a £5 gift voucher. The initial referrer was also informed of the initial meeting. A further meeting was arranged with participants who fulfilled the eligibility criteria and expressed interest in the research. A time was arranged for the interview at least one week after the initial screening meeting to allow the participants to have sufficient time to change their mind about taking part in the research. Details on how to cancel the interview were given to the research participant and those who support them.

Twelve participants were assessed as suitable and an interview was arranged with the participants from five organisations: community learning disability service (n=1), private day service provider for Asian women with learning disabilities 1 (n= 4), private day service provider for Asian women with learning disabilities 2 ( n=3), social care day service provider for Asian men and women with learning disabilities (n=1) and national charity for people with learning disabilities/mental health difficulties (n=3).

Two interviews were not included in the data analysis: the first interview was not included in the data analysis as it was conducted in Bengali with an interpreter and the interpreter did not adhere to the interview schedule and was asking her own questions. The second interview was not included due to concerns around safeguarding issues being raised in the interview by the participant. The interview was terminated after 10 minutes and the staff involved in the participants care were informed and the appropriate safe guarding procedures were followed with support from senior clinicians. A total of 10 participants were included in the analysis and deemed to be sufficient sample size for this research project, in line with recommendations by Smith, Flowers and Larkin (2009)

### **Assessment of learning disability**

All the participants were believed to present with “mild or moderate” learning disabilities as defined through the checklist designed for the wider study by Dr Gemma Unwin which was completed with participants and/or informants based on the ICD-10 criteria of learning disabilities (figure 2).

Figure 3 details a summary of the participant profile. All of the participants were born in the United Kingdom but identified themselves as South Asian due to their cultural heritage informed by where their parents were from.

Figure 2: Checklist for Assessing Degree of Learning Disability

<b>Checklist for Assessing Degree of Learning Disability</b>	
<u>Interviewer's Classification</u>	
<i>Circle most appropriate category</i>	
Scoring:	<i>A's = mild learning disability</i> <i>B's = moderate learning disability</i> <i>C's = severe learning disability</i> <i>D's = profound learning disability</i>
<b>Ask the potential participant or informants:</b>	
<ol style="list-style-type: none"> <li>1) Do you/does the person have/need help to do things like washing, eating, dressing and going to the toilet?               <ol style="list-style-type: none"> <li>a. No, fully independent in washing, eating dressing, with normal continence</li> <li>b. Yes, I need a bit of help – super vision may be required</li> <li>c. Yes, I need help to do these things</li> <li>d. Yes, I need a lot of help.</li> </ol> </li>   <li>2) Are you/is the person ever left on your/their own?               <ol style="list-style-type: none"> <li>a. Yes, I can look after myself – independent living may be possible</li> <li>b. Yes, but I do need some supervision</li> <li>c. No, I need support all the time</li> <li>d. No, I need support all the time</li> </ol> </li>   <li>3) Can you/the person read or write?               <ol style="list-style-type: none"> <li>a. Yes, I can read and write (a bit)</li> <li>b. I can possible read or write</li> <li>c. No, I have some visuospatial skills</li> <li>d. No, I have rudimentary visuospatial skills</li> <li>e.</li> </ol> </li>   <li>4) Do you/does the person need any help getting about?               <ol style="list-style-type: none"> <li>a. No, I am fully mobile</li> <li>b. No, I am fully mobile but my movement may be delayed</li> <li>c. Yes, I have some motor abnormalities, there may be a severe restriction in my movements</li> <li>d. Yes, I often have severe restrictions in my motor abilities, often immobile.</li> </ol> </li> </ol>	
<b>To be assessed by the interviewer through discussion</b>	
<ol style="list-style-type: none"> <li>1) Expressive language:               <ol style="list-style-type: none"> <li>a. Delayed, but everyday speech usual</li> <li>b. Delayed, but uses simple phrases only</li> <li>c. Severe delay, with few words or absent speech</li> <li>d. Severe delay, with speech usually absent</li> </ol> </li>   <li>2) Comprehension:               <ol style="list-style-type: none"> <li>a. Reasonable</li> <li>b. Limited to simple phrases/requests and concrete information</li> <li>c. Very limited understanding, limited to paired words or one stage commands</li> <li>d. Rudimentary understanding, if any</li> </ol> </li>   <li>3) Non-verbal communication:               <ol style="list-style-type: none"> <li>a. Good</li> <li>b. Limited</li> <li>c. Very limited</li> <li>d. Rudimentary</li> </ol> </li>   <li>4) Social development:               <ol style="list-style-type: none"> <li>a. Some immaturity, but otherwise normal</li> <li>b. Limited, but interaction usual</li> <li>c. May be very limited, autistic features common</li> <li>d. Extremely limited, autistic features very common</li> </ol> </li> </ol>	



Figure 3: A figure detailing information regarding the participants using pseudonyms

<b>Pseudonym</b>	<b>Age</b>	<b>Interview type</b>	<b>Organisation</b>	<b>Religion and Ethnicity</b>	<b>Ethnic group</b>	<b>Marital status and living arrangements</b>	<b>Additional information pertinent to the interview</b>
Nusrat Malik	35 years old	Group	Private ladies only, day service 1	Islam	Bangladeshi	Single Living with parents	
Nabiha Begum	43 years old	Group	Private ladies only, day service 1	Islam	Bangladeshi	Married to cousin living in Bangladesh Living with Parents	
Saddaf Akif	24 years old	Group	Private ladies only, day service 1	Islam	Pakistani	Single Living with Brother and Sister in-law	
Faiza Khan	34 years old	Individual	Private ladies only, day service 2	Islam	Pakistani	Married husband lives in Pakistan Living with parents	
Sophia Mughal	42 years old	Individual	Private ladies only, day service 2	Islam	Pakistani	Single Living with parents	Has Downs Syndrome
Wajeeha Shareef	39 years old	Individual	Private day service for Asian people	Islam	Pakistani	Single Living with parents	Answered some questions in Punjabi/Mirpuri
Aysha Aslam	33 years old	Individual	Charity 1	Islam	Indian	Single Lives in supported accommodation	Registered blind Lives in supported accommodation
Poonam Aggarwal	32 years old	Individual	Charity 1	Hinduism	Indian	Single Living with parents	Registered partially sighted
Meena Ralhan	48 years old	Individual	Charity 1	Sikhism	Indian	Single Lives alone in flat with support	Registered blind No contact with family
Kanwal Baig	46 years old	Individual	NHS	Islam	Pakistani	Divorced from husband living in Pakistan Lives in supported accommodation	Daughter 18 years old who was taken away from her as a baby
<b>Summary</b>	Mean age 33	7 individual interview 3 group	5 different service providers	8 Islam 1 Sikhism 1 Hinduism	5 Pakistani 3 Indian 2 Bangladeshi	7 single 3 married	

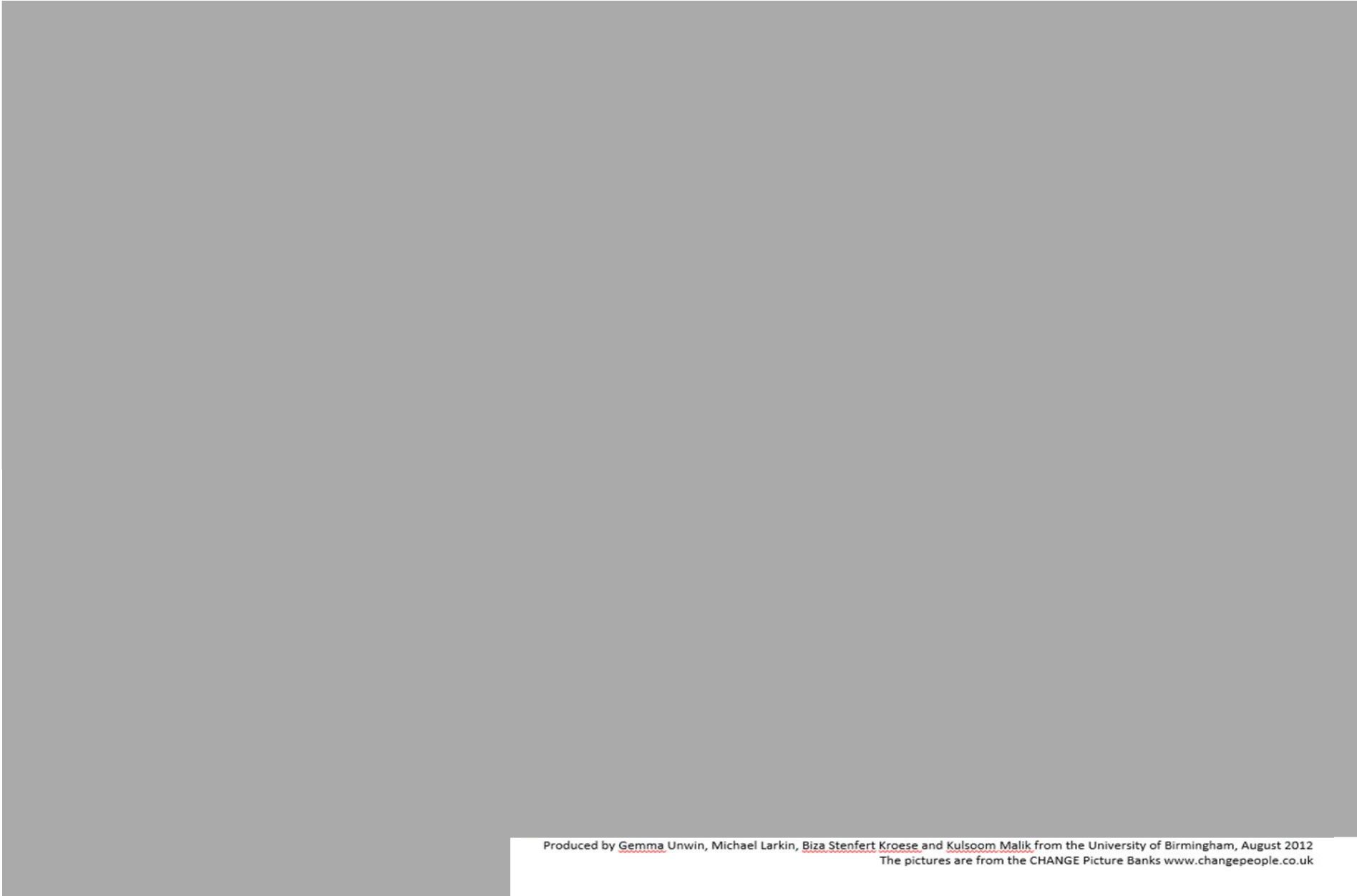
## **Interviews**

Individual semi structured interviews were conducted with 7 participants. One group interview with three participants was also conducted. Group interviews were considered to be advantageous in one circumstance where three participants attended a day centre together. The staff at the centre believed that they would otherwise struggle to contribute to discussions in an individual interview and that they could support each other through a group interview.

The interview consisted of two parts. The first part began with exploring a culturegram (figure 4) which was completed as an activity with the participant. It was designed by the wider research team including myself, based on a family assessment instrument developed by social workers to explore 10 main areas relating to cultural identity (Congress, 1994). The aim of the culturegram was to avoid making assumptions about an individual's culture and to focus research questions to include the participant's individual cultural practices. The questions were more closed and less demanding than the rest of the interview as it was felt it would help the participants to get comfortable with the interview process and give the researcher some initial concrete information to work with. The results from the culturegram were used to inform further prompts and were included in the general analysis.

The second part of the interview used open ended questions using an interview schedule also designed by the wider team and myself (figure 5). Research has suggested that open ended questions for people with mild learning disabilities can be advantageous as this methodology can reduce issues with acquiescence, inconsistency and social desirability (Shanly & Rose, 1993).

Figure 4: Culturegram



Produced by Gemma Unwin, Michael Larkin, Biza Stenfert Kroese and Kulsoom Malik from the University of Birmingham, August 2012  
The pictures are from the CHANGE Picture Banks [www.changepeople.co.uk](http://www.changepeople.co.uk)

## **Additional adaptations to the interview schedule to support participants with learning disabilities**

It was anticipated that some participants who struggle to communicate verbally may find it difficult to answer some of the interview questions. To support the participants, several adaptations were made. Prior to the interview, the researcher completed an information form with the referrer (appendix 3). This allowed the researcher to print off logos for services the person used prior to the interview as an aid memoir for the participant. The first section of the interview included pictorial prompts to support the participants to remind them about the types of activities services might support them with. The interview schedule was also designed to support participants with limited communication difficulties through simple language and additional questions to support the main questions.

Figure 5: Interview schedule designed by researcher for this researcher and main research team

<b>Interview schedule</b>
<p><b>Introductions</b></p> <p><i>[After settling in, arranging a drink and snack, getting agreement for recording, switching recorder on and checking it is working:]</i></p> <p>Hi my name is Kulsoom Malik and as you know I want to ask you what you think of services that are out there for you. When we met <i>[date/how long ago]</i> you said you wanted to help us with our project and you signed this <i>[show consent form]</i>. Are you still happy to take part? <b>[CHECK CONSENT]</b></p> <p><b>If yes:</b></p> <p>That's great. I'm really interested in what you think. Don't worry about speaking your mind. What you have to say is really important because you are the expert here!</p> <p>I won't keep you for too long today. I'd like to talk with you for about forty-five minutes. So, we will finish <i>[provide an anchor point such as, 'before lunch,' or show the finish time on a clock]</i>. If you would like to stop before then, just let me know. We can stop any time you would like to. <b>[EXPLAIN RIGHT TO WITHDRAW]</b></p> <p>I'm going to use this <i>[show recording device]</i> to record what we are saying. This will help me to remember everything you say to me today. When we have finished our meeting today, I will listen to the recording and type it up on my computer. When I type what you and other people have said, I won't use anyone's name, so nobody will know who said what. This makes it easier to be honest without worrying about hurting anyone's feelings.</p> <p style="text-align: center;"><b>Ground Rules for Group Interviews</b></p> <p>It is important that you do not tell other people what has been said today. Everyone in this group has the right to confidentiality. This means that we keep what they have said private and do not tell anyone else. It is also important that you think about what you say today and that you do not say anything that you do not want the other people in this group to hear. Do not say anything that might upset you.</p>

## Completion of Culturegram

OK, to start, I would like to do an activity with you.

*[Show culture map, use large poster map for group interviews or A3 version in individual interviews.]*

I would like us to talk about your culture and fill in this culture map. When we talk about culture, we mean things that make you, you. But, these things are often shared with your family, friends and other groups.

Culture often includes things like *[point to corresponding points in the culture map*

- The languages you speak
- Countries where you and your family might have lived
- Your religion
- The holidays and festivals you celebrate
- The church, faith groups or social groups you might go to
- Certain clothes you wear or don't wear

Or, certain foods you eat or don't eat

*[Complete the culture map by writing directly on it in individual interviews or sticking notes on in group interviews.]*

Can you please tell me about the language you normally speak?

What language do you speak at home?

What language do you speak outside the home?

Where have you and your family lived? [For example, have you always lived in England? Have your parents always lived in England? Where did your Grandparents live?]

Do you have a religion that you believe in? What religion do you believe in?

What holidays, festivals and special events do you celebrate?

What churches, faith groups or social groups do you go to?

Sometimes we do things because of our culture. We might wear certain clothes or pray at certain times. What things do you do because of your culture?

Sometimes we do not do things because of our culture. We might not eat certain foods or go to certain places. What things do you not do because of your culture?

*[Once culture map completed:]*

OK, thanks for telling me about your culture, I would now like to ask you some questions about the kinds of things people help you with and the people and services who might help you.

## Interview Questions for ALL Participants

### What sort of things do you like to get help with?

(Prompts: travelling, cooking, shopping, reading, using a phone, not getting bored, not getting angry etc.)

*[Use pictorial prompts.]*

**Who usually gives you help with these things?**

*[Use pictorial prompts*

**Outside your family and friends, do you get help from other people?**

***If yes, who?***

(Ask for as much detail as possible.)

*[Use logo map of services.]*

**Who do you find most helpful? Why are they helpful**

Clarify relationship to participant – paid carer, family member, friend etc.)

- ***If no service providers are mentioned: Outside your family and friends who do you find most helpful? Why are they helpful? What is it about them?***

(Prompt only if necessary: example of how someone can be helpful e.g. someone might help you to catch a bus to go to your social club, to go food shopping once a week or someone might help you around the house with washing clothes or making food.)

- **Who do you get on with best?**

(Prompt: who do you feel closest to?)

- **Why do you get on with them best?**

- ***If no service providers are mentioned: Outside your family and friends, with who do you get on best? Why do you get on best with them? What is it about them?***

(Prompt only if necessary: example of why you may feel close to someone e.g. you might feel close to a carer because you can talk to them about things or because you see them regularly.)

**For those who use services at present:**

*[Go through each service mentioned by participant, use pictorial prompts as an anchor when discussing each service. Use pictorial prompts for services they did not mention to see if they can recall and comment on them.]*

*[If available]* **Here's a logo for [service]. Tell me a bit about what it's like.**

- **Do you like [service and/or staff]? Why/why not?**
- **How did you access them? How did you start using the service?**

- **Where do you see them?**
- **What do they do?**
- **Do you think they are doing a good job? Why/why not?**
- **If a friend asked you if it's worth going to [names (if no longer available, use real or imaginary 'similar service')] what would you tell them?**
- **Can you think of anything that could be better about [names]?**
- **Do you feel that at [name of service] people treat you fairly?**
- **Do they respect your culture; that you are from a [name of minority group] family?**

(Prompt: Ask specifically about diet, gender mix, rituals and festivals, dress code, personal care as relevant to the minority group.)

*[Refer to culture map.]*

- **Are there any other things/services you'd like to do/attend?**
    - *If yes: what are they? What stops you from doing/going to them?*
    - *If no: why?*
  - **What are your plans for the future? Do you want your life to stay the same or do you want it to be different?**
    - *If different: how? How do you feel about that? Who can help you with that?*
    - *If the same: do you think it will stay the same?*
- If no: why*



## Analysis

The interviews ranged from 29- 52 minutes long and were audio recorded. They were then transcribed verbatim, pseudonyms were used for the participants and the data was stored using an encrypted data storage system. The data was then analysed using six stages proposed by Smith et al., (2009).

Figure 6: Six stages used during IPA analysis for the individual interviews

Stages	Process
1. Reading and re-reading	The researcher read the transcripts whilst listening to the audio file and then read the transcripts once more
2. Preliminary notes	Whilst listening and reading the transcripts line by line, interesting points or thoughts were noted, paying attention to the impact of the author and their own personal views/stance in the interview.
3. Development of the emerging themes	Connections between initial notes were collated to develop interpretative analysis and quotes were grouped together to produce themes (see appendix 5 for an example. This document relates to one participant only, and preliminary themes were derived for each individual participant as a way of exploring potential subordinate themes.
4. Case by case	Stages 1-3 were conducted for each of the transcripts.
5. Looking for patterns across the different participants	The different themes from each of the papers were listed and connections between the themes were clustered together to form super-ordinate themes and sub-themes. This was done by printing off key quotes for each participant on a different coloured paper and physically grouping them together for all the

participants to explore emerging themes. The potential themes derived at stage 3 were used to guide this process. This stage was refined several times through consultation with research colleagues Dr Larkin and Professor Rose.

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The group interview was analysed using an existing protocol developed for group interviews and IPA (Palmer, Larkin, de Visser & Fadden 2010).

### **Adaptations of IPA for people with learning disabilities**

IPA requires the researcher to conduct the analysis by reading the transcript line by line. The participant accounts however did not result in long sections of prose. The participants in most of the cases presented with short answers, or required additional prompts such as “can you tell me more”, “can you expand on that”. This resulted in the participants sharing more information but in small sections of dialogue rather than long sections. During the analysis stage, the analysis was completed as if the additional questions were not asked and so the answers had to be joined up without the additional scaffolding questions.

Due to some of the participants limited verbal abilities, the researcher struggled to decipher the responses to some of the questions and so asked for additional information such as “what do you mean by X” to help them decipher what was being said and to avoid making assumptions.

### **Quality check**

In order to ensure that the research adheres to the principles of IPA, several quality checks were implemented in line with the quality markers proposed by Smith (2011).

- *Triangulation* (Patton, 1999): two additional researchers were consulted throughout the analysis stage to discuss the development of the themes
- *Credibility checking* (Patton, 1999): the two additional researchers who supported the main researcher through supervision were experts in relation to the research question. One researcher specialises in research and clinical work with people who have learning disabilities and the second is a specialist in IPA.
- *Reflexivity* (Mays, 2000): through the use of a reflective diary, the researcher was aware that being a South Asian female herself may have impacted on her interpretative enquiry as some of the participants experiences may have resonated with her or were not congruent with the prejudices she may have held about South Asian women. In order to keep sight of this, the researcher regularly discussed this with her supervisors to ensure that this was acknowledged during the analysis

## **Results**

Three inter-related super-ordinate themes emerged from the analysis. The first theme relates to how “*services facilitate the development of more complex identities*”. This theme explores how the participants do not experience their cultural identities to be static, but experience it to be dynamic. They are able to use services as a medium in which they can push against and adhere to more traditional cultural values that are perceived to be dictated by their family and religion. The second theme relates to how the participants explore their sense of being “*stuck in the middle*”, *as they negotiate a journey towards independence with their families and services*. The participants attempt to make sense of how they manage the dilemma between the conflicting messages they receive from both services and their families about independence. For the participants receiving help this has both advantages and disadvantages. The third theme reflects the at idea that the

participant’s experience “triple intersectionality” as they notice disadvantages due being a woman, from a South Asian background and who has a learning disability. The prevalence for each of these themes in presented in appendix 5.

Figure 7: A table depicting three super-ordinate themes and eight sub-themes

Research question	The experiences of Women of South Asian Origin with Learning Disabilities in receipt of Social Services		
Super-ordinate Themes	Services facilitate the development of more complex identities	Stuck in the middle as they negotiate a journey towards independence with their families and services	Triple intersectionality
Sub themes	Being seen as a religious person	Families wanting to protect	Following rules
	Taking part in religious activities are up for negotiation	Moving forward: accepting some help, doing some things independently	Noticing differences between men and women
	Families provide the culture		
	Pushing against traditional values through culture		

**Theme one: Services facilitate the development of more complex cultural identities.**

All the participants in the study presented their cultural identities as a dynamic concept. In the interviews it became apparent that many of the participants experienced a push/pull effect between traditional values and more westernized/modern values. This theme included four sub-themes. The first sub-theme *being seen as a religious person: rules for living* relates to how some aspects of an individual's identity may be very strictly defined such as through what one eats and drinks. The second sub-theme is *taking part in religion: activities are up for negotiation*. The participants appear to have knowledge about religious/cultural values and customs but appeared to opt in and out of activities in negotiation with their families. The third sub-theme is that *families provide the "culture"*. The participants make references to how their families help them develop their cultural values and so there is not an expectation for services to facilitate this. The last sub-theme explores how the participants are able to *"reject traditional values through services"*, where attending services gave participants an outlet to make choices about what aspects of culture and religion they accept and which parts they reject.

Some of the extracts contain Urdu or Pujabi words. The translation of these words are provided in a glossary (page 121).

**Theme one (sub-theme one): Being seen as a religious person, rules for living**

For all of the participants, it appeared important for them to demonstrate that they were seen to be following their religion appropriately. Boundaries around food and drink appeared to be very clear, possibly because one might be making a statement about their religious orientation based on deciding to consume or reject particular food or drink. For other participants, religion provides rules for living and guides how one lives.

For Wajeeha, it was important for her to make a statement about having strict boundaries between what Muslim people eat and what non-Muslim people might consume, “*we can't have like Christian food; white people eat their own food*”. Similar discourse is evident when Sophia stated “*like normal meat, like English people have, we're not allowed to, to have these things*”. For Sophia, the term “normal” suggests that she is aware that her eating Halal meat is an exception, she is from the minority and that special provisions need to be made for her. The terms Christian and English describe a clear boundary that the participants use to demonstrate that their dietary needs are different. Such boundaries are not just restricted to the Muslim participants, for other participants such as Poonam, who is Hindu, what she eats and drinks is also clearly defined through religion “*I eat pork, but I don't eat beef and I don't eat lamb because of my religion*”. Similarly, Meena, a Sikh, felt that religion guided what she can and cannot eat “*because of religion the only meat I don't eat is beef, but I eat like chicken, pork and lamb.*” Faiza experiences her religion to provide stringent boundaries around what she can drink. “*We don't drink alcohol, can't have it, because it's forbidden*”. None of the participants stated that services were not fulfilling their dietary needs.

As suggested in the accounts above, the participants gave the sense that for them it was important for them to project an alliance to religion through knowledge of what they can and cannot eat and drink. Similarly, other participants felt like their religions provided them with rules for living around activities such as prayer, reading the Quran and fasting. Kanwal stated “*well you know I read namaaz<sup>A</sup> you have to be cleaned and you know covered properly*”. Saddam also believed her religion guided her in other aspects of her life, “*Not allowed to have boyfriends, No. (laughs quietly), because of our religion*”.

This sub-theme is particularly pertinent for Sophia who is clear about how as a Muslim person, she has to cover her body “*because some people, because some, some er*

*people or people like Muslims, you can't like show these things, can't show your body".*

She uses the framework of what you do on Hajj<sup>B</sup> and Umrah<sup>C</sup> to optimize what a perfect Muslim wears and compares this to wearing western clothing *"you can't do that because it's bad for law, because if you go to Umrah<sup>C</sup> or somewhere Hajj<sup>B</sup>, they're not, we're not taking part in this thing of."*

Sophia is very mindful that *"we are not allowed to copy them"*, then making references to non-Muslim people regarding differences in dressing and food. The term allowed suggests very strong non-negotiable boundaries.

#### **Theme one (sub-theme two): Taking part in religion, activities are up for negotiation**

Having knowledge about what is appropriate and not appropriate within religion did not necessarily mean that the participants actively engaged in such activities, for example in the group interview, Nusrat and Nabiha both stated that they prayed *"five days a week"* when they might have been referring to when Saddam<sup>A</sup> stated that she prays *"five times a day"*. On one hand, this suggests that both Nusrat and Nabiha may have both wanted to be seen to know about their religion, even if they did not engage in the activities themselves but may reflect the level of their learning disability. The desire to "prove" knowledge about Islamic values and principles may have been intensified due to the discussions happening in a group where all the participants were Muslim including the interviewer.

Demonstrating knowledge of religion appeared to be sufficient for participants to feel like they belonged to a particular faith and did not necessarily mean they took part in the activities. Poonam, discussed how *"my parents pray every morning; I only take part when it's special, but other days I don't"*. Whilst families may negotiate with their adult children about whether they adhere to activities such as fasting or praying, it appeared that families may want to educate their adult children on culture and religion. Faiza also stated

that she had knowledge of fasting, but did not feel the need to “have” to keep fasts, “*ramadan<sup>D</sup>, fasting, um my family do, I don't know (laughs)*”. Families may make exceptions for their children, despite them being adult women due to them having a learning disability. Ayshas’s reasons for not participating in activities appeared to be accompanied by practical reasons “*I don't fast, because of my medication.*” Similarly, Kanwal stated being unable to pray due to “being ill” “*I used to pray, now I, I'm ill and I don't do it, I have lots of tablets and I stopped*”.

### **Theme one (sub-theme three): Families provide the “culture”**

In general, with the exception of two accounts, the participants appeared satisfied with services and did not raised that they wanted services to support their cultural needs. One of the reasons for this may be because the majority of the participants lived with their families who appeared to provide modelling and education around and engaging in cultural activities. Poonam appeared satisfied that her family support her with her cultural activities. “*I celebrate Diwali with my parents. And all the family and friends*” When asked about what she celebrated with services, she replied “*Services? Oh, I don't ask them. I don't know if they do. I prefer it with my parents, not with anyone else*”. For Aysha , she attributes her parents living close to her to mean that she is able to attend Friday prayers “*Um er... Let me think, um Fridays. Well, um if I had a chance and because of, because of my parents live locally to um, locally and visits me all the time I can go to the mosque with them*”. When someone uses the word lucky, it tends to mean that they are in receipt of something special that may not be accessible to other people as she was the “lucky one”. This would suggest that she is aware that other people are not as “lucky” as her for their parents to be able to help them visit the mosque.



The importance of how families facilitate the development of cultural identity becomes evident in the accounts when families are no longer involved. In these interviews, the participants shared a sense of loss with regards to their cultural identity. Dissatisfaction was only expressed by the two participants that were no longer supported by their families. For example, Meena lives in supported accommodation, she no longer has contact with her family, yet she longs to speak Punjabi and to keep that part of her alive “*um when I used to live at home I thought it was important because at the end of the day it’s your parent’s language, so really you should speak it, but um I don’t really speak it.*” In Kanwal’s account, she similarly mourns both her parents and her desire to be supported to read the Quran “*I used to read it with my mum; they’ve died my mum and dad now. I, I can’t do, do it by myself*”. Kanwal suggests this is something that services could support her in, but felt that services wouldn’t know what to do.

**Theme one, (sub-theme four): Pushing against traditional values through services.**

The data suggest there is a desire from families for the participants to immerse themselves in religious and cultural values and activities as seen in the sub-theme above. It is important to note that all the participants were born and raised in the United Kingdom and they all seemed to experience a dilemma between how to manage the conflicting demands of traditional values with more modern western values. Wajeeha is caught in the middle between her family not wanting her to watch films balanced with her own desire to watch them. At the daycentre she attends, she talked about how “*sometimes they go to the cinema only I don’t go. Or like the other girls go, only I don’t go. I don’t- I don’t watch any movies like I love to go to the cinema only my dad and mum don’t let me go to the cinema. They said films are not good to watch*”. Much to her delight when movies are put on at the

daycentre, she is able to watch them. She is able to reject the rules imposed on her by her family and make choices about what she wants to do.

Similarly, Faiza states *“I like bowling; I don’t go with family”*. Despite Faiza enjoying bowling, this is not the norm for her family. Attending services means services allow her to participate in activities which her family may not encourage or give her permission to take part in.

Kanwal presents an interesting account of how she tries to make sense of her breaking a perceived rule of having a boyfriend. Kanwal’s experience of living in supported accommodations means that she has been able to have a secret boyfriend. She appears torn between positive interaction in her life and the expectations of her family *“it’s just, it’s boyfriend just eh, how can I explain to you? I go see him and come back, he, he makes me dinner and it doesn’t, he has cats as well, two cats, nice cats”* against her understanding that her family would not approve of this *“oh my G\*d, they won’t like it. Because if I tell them they might get upset or, although they’re already upset with me about with lots of things I don’t want them to get upset again ”*.

For Aysha, she has tried to talk about the facts of life with her parents, but has not had much luck. *“I’ve asked my mum about babies, she won’t answer me. At the centre we talk about sex, we talk about babies and we watch videos about babies”*. In South Asian culture, talking about sex is a taboo subject for many families and so Aysha was able to explore her interest through services.

### **Theme two: “Stuck in the middle” as they negotiate a journey towards independence.**

The second theme in this paper relates to how the participants see themselves on a journey towards independence. The service users appear to be stuck in the middle between

services who try and promote learning and independence and families who encourage their daughters to take a passive role. This theme has two sub-themes.

The first sub-theme relates to “*families wanting to protect*”. The families appear to keep their daughters “stuck” in the early stages of development, in the family home; they want to provide practical support. From the participant’s perspectives, the families appear to be happy to provide this.

The second sub-theme relates to *moving forward: accepting some help, doing some things independently*. This tends to reflect the support that the participants reflect on in their interviews: they do some things on their own and receive support to do other things. It explores the idea that support is not “black and white” in the sense that either carers/staff do everything for someone with a learning disability, or that the person takes care of themselves completely independently. The sub-theme also explores that for some participants, they experience a sense of injustice when others receive more support than them; they become concerned about their own abilities to do things without support.

### **Theme two (sub-theme one): Families wanting to protect.**

All the participants labelled themselves as having a learning disability. It appears that the families want to provide support for their daughters and may believe that the label “learning disability” means that they cannot do many things. For example, for Nusrat despite stating a desire to want to go to college, her mother encourages her to take a passive role with respect to learning “*I stopped going about a week now I don’t go to college. It’s too far for me and I need to have a taxi to take me there. And the taxi doesn’t come. I wait for the taxi and my Mummy says. She says go and sleep in bed. If the taxi doesn’t come, if, if the taxi isn’t early, early, doesn’t come to the door, ring the doorbell go*”

*back to sleep*". Nabiha also experiences a similar dilemma *"I used to go college. Yeah. I'm stopped now ((laughs)). I stopped my mummy says I should rest ((laughs))."*

The families desire to protect may mean that they slow down the participants desire to learn and move forward. For example, at the daycentre Sophia engages in activities such as *"like play a game or something, a jigsaw, or you can do knitting in there or sewing in there. Or you can play table tennis. Or you can go in the snooker or like bowling here"*. Yet at home, she is not "allowed" to take part in helping to wash her own clothes *"we do it home like that. My mum, my brother says you are not allowed to"*. This account suggests that at home, learning skills is not something she is encouraged to do. The families may feel that if they are around, a person with the learning disability doesn't have to do these things. Poonam appreciates the support she gets from her family and values this greatly *"I don't want to leave home. I like to be with my mum and dad"*.

Aysha noticed that she is not reaching the same milestones as other people and wants her family to support her in this, but her request is rejected *"I wanted a boyfriend once, yeah, and I kept on asking my mum when will I get married, when will I have a baby, um and um I know it's, I know it's taking so long, she said no"*.

**Theme two (sub-theme two): Moving forward: accepting some help, doing some things independently.**

When participants feel like they are helpless, services are viewed as being positive. This can be viewed in Poonam's account *"they're excellent, they help me with money, they help me with food, they help me with food hygiene, um they help me in lots of ways"*. Kanwal was aware of her limited abilities and valued being supported to do things *"No I can't do everything. The staff it helps me. They help me going out. Today I went shopping and they*

*help going shopping*". Nabiha also valued support when she felt helpless "*she helps in the toilet she does, washing me. Getting my supper ready*".

Saddaf acknowledges that without services she is restricted in what she can do on her own "*you'd have to do it by your own self. I wouldn't be able to*" and is therefore very positive about her experiences.

Whilst the families appear to provide most of the support inside the home, the accounts in the previous sub-theme do not make references to families encouraging the participants to learn new things. The facilitation of learning appears to be provided through services. For many of the participants, a sense of moving forward between the developmental milestones was important. For example, for Meena her experience of having support from services was invaluable "*when I left home I was near enough completely blind and I couldn't read or write or nothing or budget, they supported me with eye hospital appointments, spending hours and hours there, they help you, they encourage you actually to budget, to do your own shopping, but if you can't do it on your own the staff are there to support you.*" Meena recalls her journey in the sense of her experiencing rehabilitation. Staff supported Meena to learn how to do things and gain skills for independent living. It is interesting that Meena does not have contact with her family and so she appears to view services to be like a surrogate mother, helping her grow and develop "*it's like say when you're growing up and your mum's like teaching you like, you know, do this, do that, like saying I'm going shopping and the child's like putting stuff into a basket*"

Consistent with this, other participants valued support from services if they viewed themselves to be moving forward. Sophia states "*when you come here, like learn something*" similar discourse is evident in Saddaf's account "*I learn, I like for helping me making things*". Aysha is complimentary towards services because she can sense an

increased level of responsibility “*I like it because they let me do thing like cut salad. Well they didn’t before, but now my support worker has come into place, she lets me do the salads, chicken*”. Kanwal values that staff support her to take care of herself “*they done eh helping me ironing someday clothes, sometimes I do it sometimes they do it for me, some days I, I wash clothes um eh I put the, wash sheets and they put it in the dryer sometimes*”.

For other participants who are no longer living at home, they appear to notice differences between the support they receive and other people. Kanwal is resentful about her ability to be able to do things for herself. On one level, she longs to be independent she stated “*I want to move next door, and I, I want to go to the house really, having my own place really*”. In juxtaposition, she resents staff not doing things for her “*some other people they’re cooking for, they think she can do everything herself, why should we do it, that’s what I think*”. For Kanwal, her account represents the difficulties she faces living in supported accommodation. Most of the time, in her home, she is alone and main social interaction with staff is around receiving support. Yet Kanwal is an able person and appears confused between wanting to be supported and wanting to do things on her own.

Aysha talks about being “*travel trained*”. The word training has positive connotations, suggesting a gradual process and one which has support systems attached to it. It promotes a journey towards becoming independent but not in an overwhelming sense, “*they travel train me. They just show me how to get the bus. And then, if I’m working in a different place, they travel train me, and they cross check me and sign me off if I pass*”.

Poonam is partially sighted and has recently moved to a place which she believes will be supported and help her to live independently. She appears particularly dissatisfied when she notices another service user is “*more independent*” than her. She was asked whether she does her own shopping to which she replied by re-enacting a dialogue

between her and staff “*Um go to places by myself, like go shops ((agitated)) no.... and this girl who I live with, she can, she can just go bye! I’m going! I’m going to the shops to buy milk. And in my house, I’m going out to buy milk, no you can’t! ”*

Aysha has a similar experience “*Can other people go by themselves, yes, yes, but I can’t. And that makes me very angry. I thought I was here to learn um independence, independent travelling, but it doesn’t look like it does it?”*

### **Triple intersectionality: The impact of having a learning disability, being South Asian and being a woman**

This theme explores how the participants make sense of three parts of their identity: their gender (female), their ethnicity (South Asian) and their disability. Whilst this paper is not advocating that the participants felt like they were discriminated against by services, this last theme looks at how the participants notice experiences of where they might have been disadvantaged. This section suggests that the participants in this study noticed that their gender, ethnicity and disability intertwined with each other and that they experienced disadvantages due to this. This sense of overall disadvantage is explored through two sub-themes: *following rules* and *noticing the difference between men and women*.

The sub-theme *families wanting to protect* from the previous theme also links with this. The theme suggests that families wanting to protect could be related to all three aspects of the participant’s identity. The families may want to protect the participants in the study because of the triple intersectionality but it is difficult to tease out the impact of each of these dimensions individually as it is believed they are all closely related and interlinked.

### **Theme three (sub-theme one): Following rules.**

The participants in this research make references to following rules in different aspects of their lives. The dilemmas around making choices and about following rules tend to mirror the experiences that are perhaps experienced by adolescents who explore pushing boundaries to help them think about whether to follow parental rules or not. It is important to appreciate that all the participants in the study were adults, yet the theme of following rules and sometimes breaking them may lead to people to make assumptions that the participants are younger. The rules appear to be related to the other themes, that the families may worry that the participants may become too “westernized” which may conflict with their cultural identity, or that the participants may become too independent and that the families counter balance this by wanting to protect.

All the participants that are still living with their families make references to following rules imposed by the participant’s families. For example, Saddam would like to wear jeans but she does not have permission from her family *“I could wear like jeans but I don't, my family, they won't let me though”*. She believes that *“you have to wear big clothes”*. We can view the rules in terms of each three components of triple intersectionality. Firstly, disadvantage due to culture and religion. The rule around wearing western clothing could be based on Islamic principles or cultural/Pakistani values. Islamic values promote that both men and women should dress modestly. In terms of gender, Islamic values also stipulate the women should cover their bodies and guard their modesty from men. The same rules do not apply for men. In the interview, Saddam was dressed in shalwar kameez which is a loose long flowing top with baggy trousers. It is important to note that shalwar kameez is not an Islamic dress. It is Pakistani clothing and in many traditional families, wearing western clothing can be viewed as disrespectful if worn by women. In terms of disability, Saddam may not have the resources to make choices



around her clothing due not being able to drive or have money of her own as she is unemployed and so this restricts her ability to “follow” this rule or not. Modest clothing is also apparent in the account of Wajeeha who believes she has to be “*covered by a scarf, a dubatta<sup>E</sup>. Don’t fashion, don’t do make up*”. We may be able to make the assumption that someone with a disability has fewer resources to “rebel” against these rules as they would not have ability to support themselves should their families not approve of their choices.

Rules around clothing are not restricted to the Muslim participants. Poonam appears to have rules about wearing clothing that her mother finds appropriate “*my mum helps me with clothes shopping. I can't buy my own clothes because I'm always buying what she doesn't like, and then she doesn't let me keep it, so she has to buy for me, but she won't let me buy any more clothes*”. The term “doesn’t like” could be related to not being appropriate for a female to wear, not being appropriate for a South Asian person to wear and Poonam’s mother not believing that Poonam is “able” to make choices about her clothing herself.

Further examples of rules being imposed on the participants can be observed through further extracts. In Aysha’s house there are rules and rituals around personal hygiene; with references to New Year’s Day as she stated that “*my parents make me wash my hair on that day*”.

In addition to rules around clothing and personal hygiene, the participants also made reference to rules around activities that they are able to take part in. Despite living in supported accommodation, Kanwal is aware of what is acceptable and unacceptable to her family. She experiences a dilemma as to whether she should go dancing even though her family do not approve of her going “*I used to go pub, you know I go disco because eh like a pub. My brothers don’t like me dancing. I stop it.*” In this case, Kanwal may not go to the pub because it is not an appropriate place for a South Asian person to go, specifically a

female. As someone with a disability, her brothers may want to “protect her” and so they have rules around where she is and isn’t allowed to go. In some traditional families, brothers in the same way as fathers and so it appears Kanwals brother has taken on a parental role around where she is allowed to go, despite her stating that she enjoys dancing.

Aysha appears to struggle to make sense of how her family might see as part of “English culture” *“I don’t go club. I’m not allowed. I don’t go clubbing. Because people drink, and then they vomit. And then they take drugs and then they fight, they kiss, it’s really bad.”* For Aysha, drinking may not be appropriate in her family because she is a Muslim. Going to pubs and clubs may be viewed by some families as not being an appropriate place for women to attend due to them seeing things like “kissing and fighting”. This extract suggests that Ayshas family do not want her exposed to such things, which could also be related to her having a learning disability and the belief that she should be protected from such environments, as we would protect children.

Poonam also shares her thoughts around leaving home. During this section of the interview, Poonam initially began by explaining that her sister is getting married and she keeps asking her mother when she will get married and have babies. She then goes on to explain *“I don’t want to leave home. I like to be with my mum and dad. I miss them so much. And they do so much for me, they make my food and drink, they take me out, they buy me clothes. So my parents do everything. So I don’t need to go out with friends, or leave home, or be on my own or anything. I don’t want to have a boyfriend or a girlfriend, wife or husband or get married or have children or kids. Just my mum and dad is enough”*. On a superficial level, this account would suggest that Poonam does not want to leave home. A more detailed recall of this excerpt would reveal that Poonam became agitated and spoke very fast, she raised her voice and made facial expressions to suggest she is

angry. Her satirical references to not wanting a wife or girlfriend would further suggest she is angry. This suggests that she would like to experience all the things her sister is experiencing, but there is a sense that she understands she is different to her sister. It appears that she knows she will not be able to experience life's milestones such as marriage and pregnancy. For Poonam, comparing herself to her sister may lead her to assume that because she has a learning disability, she is disadvantaged. Possibly because her family believe it is not appropriate for her to marry and have children. It is possible had Poonam been a South Asian man with learning disabilities, her families' view of marriage may have been different. Whilst part of her desires to have these, part of her has learnt to accept that her parents do most things for her.

### **Theme three (sub-theme two): Noticing differences between Men and Women.**

This sub-theme is closely related to the previous sub-theme of following rules. In order to notice differences between men and women, one may notice that there are different rules for males and different rules for females.

Nusrat noticed rules around how a woman should behave through observing her mother *“you should have a scarf around your head. Every time. Yeah. When you're going out you should wear a scarf as well. My Mummy wears a scarf going to my uncle's house”*. The word “should” connotes rules. The fact that her mother wears it at her uncle's house may relate again to Islamic principles around modesty but it can also be seen as a way of showing respect to elders or males. Nusrat is aware that males do not “have” to wear a scarf, which is pertinent in some Muslim families.

Nabiha stated that she does not wear English clothes *“no, the man, the man don't like it”*. The “man” may mean her brother or her father but also could mean men in

general. She may have got the message from her family that you do not wear English clothes in front of men because it is not respectful and so men in general would not like it. Sophia notices that there are subtle differences between her families' perception of her brother getting married and their perception of her getting married "*my brother said it's not allowed. Mum won't like this, my dad said can't like that, my brother can if he wants to do okay, but she can't*". It is possible that she is not "allowed" to marry due to her having a learning disability. Noticing disadvantages whether it is due to having a learning disability, being a South Asian or a female is a consistent theme for Sophia. When Sophia is asked what days she celebrates she stated "*birthdays, my brothers birthday*". Sophia does not state that she celebrates her own birthday or a females birthday but her brothers. It is possible that Sophia may notice her family placing a greater emphasis on her brother.

Kanwal also experiences a similar dilemma as expressed anger when comparing Pakistani men and women "*Pakistani man or whoever I would say they can do anything wrong or whatever*". It appears that in her view Pakistani men can do wrong with no consequences yet Kanwal goes on to explain that if her white boyfriend wanted to marry her she would "*if he want to do he says first I want to get married then I will, I will do whatever you want me to do, I won't do nothing wrong*". There is a sense that Kanwal will follow the rules if her boyfriend wants to marry her, but the decisions around marrying appear to be with him. In the interview Kanwal did not state if her boyfriend had a learning disability or not but stated that he was not South Asian and so he does not experience the same disadvantage as her.

Faiza Khan expresses that "*Pakistani women not allowed er staying out late at night because it's dark and um erm the time its night*" when asked if she would like to stay out till late, she stated "*....er yeah, but not too long (laughs)*". Interestingly Faiza uses the term

Pakistani women and not Pakistani people, which would suggest that these “rules” are related to women and not men.

### **Discussion**

The aim of this study was to explore the experiences of women of South Asian origin in receipt of social services. The analysis identified three super-ordinate themes relating to their participants experiences of accessing such services and their perceptions of the cultural identities. Given that IPA was used to analyse the data, it is important to take into consideration the researchers views and the impact this may have had on the analysis.

### **Reflexivity**

Similar to the participants in the research, I am a South Asian woman, born and raised in the United Kingdom. In contrast to the participants I do not have a learning disability. I kept a reflective diary throughout the process to help me separate my own views and to think about how my views might impact on the research. Based on previous research and my own opinion. I came into the research with the hypothesis that the participants would be dissatisfied with the services that they were experiencing due their cultural needs not being met. I was surprised when this was not the case. At times, I found myself feeling frustrated with some participant’s “inability” to engage with the culturegram. I wanted to understand their culture so I could help them think about their dissatisfaction. Through reflection, I realised that culture may not be important to everyone. For example Aysha replied “I can do anything, it’s a free world, it is” when I asked her if there was anything she could not do because of her culture.

I found applying IPA to the data to be an interesting experience. Some of the participants had limited verbal abilities. I did not find this to be challenging as I have experience of working clinically with people with limited communication abilities. I

noticed that in my routine clinical practice, I may have to at times interpret what a client has said to be in therapy as they may struggle to articulate their thoughts and feelings in a coherent manner. For this reason, the interpretative element of IPA appeared to come as second nature as I believe clinicians have to do this anyway when participants are not verbally articulate. In clinical work, it may raise issues around reliability and validity. Given that this paper looked at the experiences of ten people, one may be more confident around their interpretation.

### **Acculturation: The dilemmas associated with managing two cultural identities**

The first super-ordinate theme explores the development of complex cultural identities. The participants appeared to have some aspects of their culture which were well defined such as what they eat and drink, as this may be a simple concept to understand. Whilst other aspects appear to be negotiable (such as whether they pray or fast) with their families supporting them to develop their cultural identity.

The participants' accounts detail the difficulties that the participants experienced in integrating western values with more traditional South Asian values. Models of acculturation are particularly relevant when making sense of this dilemma. Acculturation as defined by Berry (1997) is the process that occurs when a person is exposed to two different cultures. Berry (1997) argues that there are four acculturation strategies: integration, assimilation, separation/segregation and marginalisation. Integration is when an individual adopts both the cultural values and customs of both the host country and the country of origin. In the case of the participants in this research, participants who have integrated would take on both the values and customs of United Kingdom but also those that are related to their South Asian origins. Assimilation is when some had adopted the value of the host country and rejected the values of their country of origin.

Separation/segregation is when one rejects the host country and adopts the customs and values of their country of origin. Marginalisation is when they reject both the host country and country of origin due to passage of time.

The findings from the current research would argue that Berry's (1997) model of acculturation is too simplistic. The participants do not fit neatly into any of these acculturation strategies but rather experienced an amalgamation of elements of these strategies.

It is worth thinking about what it means for service providers if the participants in this study are struggling with acculturation. The participants believed services were fulfilling their cultural needs. In addition, with the exception of two participants who were no longer living at home, none of the participant accounts would suggest their cultural needs were not being fulfilled or that they were dissatisfied with services. This is in contrast with the views of parents who appeared dissatisfied with services (Hatton et al, 1998, Hensel et al, 2005 and Raghavan & Waseem, 2007).

Issues around acculturation for South Asian women are not unique to women with learning disabilities. The findings echo the literature on South Asian women without learning disabilities who also appear to struggle with negotiating conflicting identities of managing being South Asian also living in the United Kingdom (Gilbert, Gilbert & Sanghera. 2004).

The results from this study appear to be in contrast with Azmi et al. (1997). In Azmi et al. (1997) all the participants had a strong ethnic and racial identity and were dissatisfied with services. The participants in this study had dynamic cultural and racial identities and appeared satisfied with services in general. The participants from Azmi et al, (1997) and this study were all born in the UK. There are several tentative hypotheses that may explain the differences. Firstly, Azmi et al's (1997) research was conducted almost twenty

years ago. The passage of time may suggest that services have responded to the dissatisfaction expressed by the participants in Azmi et al. (1997) and consequently the many policies produced by services on engaging ethnic minorities with learning disabilities. The participants in the two studies are also different. The participants in Azmi et al. (1997) included male and female adults and adolescents between the ages 14-44, mean age 22. The participants in this study were all females aged between 24-46, mean age 33. It is possible that older females feel more able to get their needs met both from services and their families.

IPA research does not aim to generalise findings but it is useful to think of potential clinical implications. Firstly, we know that the small sample of people in this study were satisfied with services meeting their cultural needs as they have the option to “opt in” or “opt out” of cultural activities despite the views of their families. It raises the dilemma around to what extent do services “have” to listen to families. Is the satisfaction of service users more important or the satisfaction of families? Perhaps attention to cultural needs is more pertinent for people not living within the family home. Services need to appreciate it is not sufficient to describe someone’s cultural identity as “integrated” or “assimilated” but to appreciate this is a far more complex entity.

### **The dilemmas of conflicting views of services and families**

The second super-ordinate theme in this paper explores how the participants in this study were “struck in the middle” as they noticed differences between their expressed wishes to participate in activities provided by services and the wishes of their families with regards to independence. The participants were encouraged to “learn” by services which they appeared to want to embrace against the views of their families to be more “passive”.



Despite noticing these differences, the participants were successfully able to manage the differing views.

There are three parties involved in explaining this interaction: service users; families and service providers. Previous research informs us that service users are dissatisfied (Azmi et al, 1997), families are dissatisfied (Hatton et al., 1998) and that service providers experience conflicts with families on issues such as promoting choice and individuality (Heer et al., 2014).

The experiential contextual framework by Heer et al. (2012) attempts to try and explain the tension between service providers and families.

The findings for this paper suggest that although the participants in this study noticed differences between their own preferences and preferences of their family they were happy to have the “best of both”. All the participants expressed dissatisfaction when they felt services were not “helping them”. In the majority of cases, the participants were unhappy when services did not facilitate their learning and independence. The participants noticed that their families did not encourage them to learn but did not express dissatisfaction. Is it possible that they believe it is the role of services to help them learn and not their families? The families’ view of not encouraging learning may be based on their views of disability. For example, if families have the view that someone has a learning disability for theological reasons such as karma (Fatimilehin & Nadrishaw, 1994), they may also have the view that people with learning disabilities cannot learn and progress because their fate is somewhat predetermined and not something that is in their control.

The implications of this suggests that services may want to focus on promoting learning and the development of skills rather than encouraging cultural identity. This again may cause tensions with families who may worry about their daughters becoming too “westernized” and independent (Chesler, 2009).

## **Intersectionality**

The third super-ordinate theme relates to “triple intersectionality”. Intersectionality is a feminist sociological theory developed by Kimberlé Crenshaw (1991). It is the methodology of studying "the relationships among multiple dimensions and modalities of social relationships and subject formations" (McCall 2014). The theory looks at how various cultural and social categories such as gender, disability and culture interact with each other on varying levels to create a sense of injustice or inequality (Knudsen, 2006). In the case of this research, I am arguing that the participants experience triple intersectionality: looking at the intersections of the participants lives in terms of having a learning disability, being women and coming from a South Asian background. These elements cannot be thought of as separate but these intersections interrelate with each other. It has been suggested that at present there is a lack of research that integrates both feminist approaches with learning disability research and ethnicity (Traustadottir & ,Johnson 2000). This theory would support the view that South Asian women experience “triple jeopardy” (Mir et al. 2001).

In the study of women of South Asian origin who do not have learning disabilities, research also suggests that women experience a double disadvantage, having to negotiate issues of honour and shame, subordination and entrapment (Gilbert et al. 2006). This echoes some of the findings of this research, with participants having to follow rules and experiencing that male members of their families have different experiences to them. If we add to the complexity of having a learning disability such as needing to ask for help, concerns of not meeting milestones such as getting married as well as limited access to resources, the participants in this study noticed that they did not have access to the same experiences as other people.

For service users it is important to take into consideration that South Asian Women with learning disabilities may not have as many opportunities available to them in comparison to other people and that not only do they experience difficulties in terms of their disability and ethnicity as suggested by Azmi et al. (1997) but that their gender also limits them in their opportunities.

### **Limitations and Clinical implications**

The main limitation of this study is that the sample is not entirely homogenous. Due to time constraints and recruitment difficulties, the participant's ethnicity had to include women from all parts of South Asia. Despite this, the sample does have some similarities in terms of a small range for their ages and were all born and raised in the United Kingdom. Appropriate themes were derived from the sample in this research and there were many similarities between the participants across the sample.

One may argue that the sample size was small in this research study, however it is in line with the recommendations for IPA. IPA does not aim to generalise its results. We can take some recommendations around the kinds of issues women of South Asian origin with learning disabilities may be experiencing but are not advocating this is the case for all women.

It is worth noting that 6 out of the 10 of the participants in this study were recruited from "South Asian women's only" services, mainly run by South Asian service providers. There appears to be a shift in service provision as the parents in Hatton et al. (1998) suggested that increasing South Asian staff would increase their satisfaction with services and this appears to be the case with current service provisions.

The findings of the research are particularly interesting because they provide a different picture to the views of carers who are generally dissatisfied with services. The participants were satisfied with services including fulfilling their cultural needs.

The findings demonstrate how people with learning disabilities are not exempt from the experiences of South Asian females in the United Kingdom, as they also have to manage issues such as acculturation, independence and they notice additional disadvantage with regards to having a learning disability. The participants in this research discussed complex concepts and which could be used to help families and service provider's think about some of the difficulties service users experience when they are "stuck in the middle".

### **Further research**

IPA papers tend not to make generalizable statements with regards to findings. The research does however give insight into the experiences of a subset of people which may help us reflect on the experiences of other people in similar situations. This paper did not look at service utilisation, all the participants were recruited through services. This may have impacted on the positive view of services. Further research to build on this would involve recruiting "non-service users" to look at the experiences of people not in receipt of services.

In addition, further research could interview Women of South Asian origin and their families separately and then look at the impact of families of the experiences of the person with a learning disability.

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## **Glossary**

### **Namaaz<sup>A</sup>**

Islamic prayer offered five times a day.

### **Hajj<sup>B</sup>**

An intense Islamic pilgrimage which is a religious duty for all Muslims once in their lifetime.

### **Umrah<sup>c</sup>**

Islamic which involves some aspects of Hajj but is not a religious duty on Muslims.

### **Ramadan<sup>D</sup>**

Islamic religious festival where able bodied Muslims fast from Dawn to Dusk for one calender month.

### **Dubatta<sup>E</sup>**

A long piece of cloth shaped like a scarf designed to be worn over a female's bosom to cover herself in front of men.

**A thesis submitted in Partial Fulfilment of the Regulations for the degree of  
Doctor of Clinical Psychology**

**VOLUME I**

**RESEARCH COMPONENT**

**CHAPTER THREE**

**PUBLIC DOMAIN BRIEFING PAPER**

Department of Clinical Psychology

School of Psychology

The University of Birmingham

April 2015

## **Executive Summary**

This document is a summary of the two research components that were submitted in Partial Fulfilment of the Regulations for the degree of Doctor of Clinical Psychology at the University of Birmingham.

### **Key terms used in the papers**

The term “Interpretative phenomenological analysis” or “IPA” refers to a specific qualitative analysis method. It is a method by which a researcher interprets what a participant says in research and goes beyond merely what has been said by the participant. This is a relatively new methodology and some researchers are cautious about using this method with people with learning disabilities as participants.

The term “learning disability” refers to someone who has an IQ below 70, struggles to complete day to day activities such as washing and dressing and has had difficulties with learning since childhood.

## **A review of the literature**

### **Is it possible to use Interpretative Phenomenological Analysis in research with people who have learning disabilities?**

The aim of this paper was to explore whether it is possible to use IPA with people with learning disabilities, as researchers have tended to avoid using qualitative methods with people with learning disabilities. The reviewed concentrated on issues around quality of research in this area.

A search of the literature was completed in September 2014 which identified 17 papers suitable to be reviewed. All of these papers utilised IPA with people with learning disabilities.

The quality of papers was assessed by using a guide developed for this review. The guide was informed by previous researchers who are experts in IPA. The findings of the quality assessment revealed that 12% of the papers were of good quality, 59% as acceptable quality and 29% as poor quality. The proportion of acceptable papers were similar to the quality of research using IPA with health psychology. The literature review found more papers to be of poor quality and less of good quality within the learning disability field.

The review found that all the researchers underestimated the importance of sharing the profile of their participants' abilities. The papers tended not to share their interview schedule making it hard to assess the quality of the data collection method. The researchers generally did not express any difficulties in interviewing people with learning disabilities using IPA.

Overall the papers all produced "data" in the form of short snappy sentences up to a maximum of a few sentences which is different to long sections of prose for typical IPA papers. Future researchers are urged to increase the transparency of their research.

## **Empirical paper**

### **The experiences of Women of South Asian origin with learning disabilities in receipt of social services.**

This research was part of a bigger research project looking at the experiences of social services by people with learning disabilities from ethnic minorities. This research paper focussed on the experiences of a subsection of this population: South Asian women using IPA. To understand the experiences 10 participants were invited to take part in interviews either individually or in a group.

The research was conducted because families have expressed that they are unhappy with the services currently being provided because they are not culturally appropriate. Service providers have noticed that families and service providers differ in what they think is appropriate to deliver. This research aims to find out the views of service users as the last research paper in this area was almost 20 years ago.

In total, 3 main themes emerged from the analysis and revealed that South Asian Women with learning disabilities have to manage many complex issues.

The first theme “Services facilitate the development of more complex identities” related to the participants in the study see their identity as a complex entity. The theme had a further four subtheme relating to “Being seen as a religious person; Taking part in religious activities are up for negotiation; Families provide the culture and Pushing against traditional values through culture”. This paper found that cultural identity is not static and the participants in this paper adhered to some traditional value and some more modern values even if their families disagreed.

The second theme “Stuck in the middle as they negotiate a journey towards independence with their families and services” relates to how families tend to encourage their daughters to take a passive role in learning whilst services try to promote learning and independence. This theme had a further two subthemes “Families wanting to protect and moving forward: accepting some help, doing some things independently”.

The third theme related to “triple intersectionality” relates to how the participants make sense of their parts of their identity and how they experience disadvantage due to the impact of all three: their gender (female), their ethnicity (South Asian) and their disability. This theme has a further 2 sub themes “following rules and Noticing differences between men and women”

Overall the participants were satisfied with services, especially with regards to their cultural needs. They expressed dissatisfaction when they believed that they were not learning and developing skills. The participants were aware that they miss out on opportunities such their gender, ethnicity and disability such as having to follow rules.

The recommendations of this study are for service providers to be aware that people with learning disabilities are currently satisfied with services and their satisfaction would be improved if serviced aimed to support them in learning new skills.

**A thesis submitted in Partial Fulfilment of the Regulations for the degree of  
Doctor of Clinical Psychology**

**VOLUME I**

**Appendices**

**Kulsoom Jawaid Malik**

**School of Psychology**

Department of Clinical Psychology

School of Psychology

The University of Birmingham

April 2015



## **Appendix 1**

**Consent taken out due to confidentiality**

**Appendix 2:** assessment of suitability for the research prior to gaining informed consent designed for the wider study.

**Pre-Screen Questionnaire for Eligibility to take part in the Study**

*To be used with potential participants or informants to check whether potential participants are eligible to take part in the research.*

Name of potential participant:

Date: .....

**Answer YES to all four questions – the person is eligible to take part**

**Answer NO to any question – the person is not eligible to take part**

- 1) **Age**  
Is the person aged 18 years or over? Yes    
No
- 2) **Demographic background/ethnicity**  
Is the person from a black or minority ethnic community? Yes    
No  
*Prompt: What is the person's demographic category?*
- 3) **Learning disabilities**  
Does the person have learning disabilities? Yes    
No
- 4) **Capacity**  
Does the person have capacity to consent? Yes    
No

*Use the assessing capacity to consent flow chart and checklist for assessing degree of learning disability to inform this.*

*(Use the following checklist to determine whether learning disability is present.)*

**Use history question an initial screen, if this is present, the person is probably eligible and there is no need to ask the other questions.**

**If the answer is not known, ask the subsequent questions.**

**If at least three criteria are present, and you suspect these difficulties are primarily the result of learning disabilities (rather than mental health, language or cultural issues), then the person is probably eligible.**

**HISTORY:** Is there historical information documenting learning disabilities such as

- a) Self-report e.g. that they went to a special school, or had extra support within mainstream school. Did they have a statement of special educational needs
- b) Information from a family member about special education, developmental delay, needing help etc
- c) Such information from other agencies?

**LEVEL OF SUPPORT:** Specialist support provided through day services, a key worker, attendance at specialist learning disability health services etc; central role of another person providing help, not normally expected for an adult e.g. coming to appointments and speaking for

them, help with using public transport, doing the shopping, help with budgeting and other daily routines.

**TRAVEL** inability or difficulties using public transport independently.

**LITERACY:** Inability or difficulties reading or writing in their first language, writing minimal information only, reading words but limited understanding of what is read.

**PLANNING:** Overwhelmed by routine demands, inability to keep track of grocery needs, difficulty sequencing tasks or prioritising demands and activities.

**FINANCES:** Problems managing money e.g. trouble giving change from a pound, poor budgeting skills, and difficulty estimating costs.

**UNDERSTANDING:** Readily agreeing to everything said without commenting or contributing to the conversation, easily distracted inability to focus on topic or frequently changing topic, using complex words of which they do not seem to understand the meaning.

## Information about the research

### Title of the research

People with learning disabilities from black and minority groups: their views of services

We would like to invite you to take part in our research.  
We will go through this leaflet with you.

Research is a way we try to find out the answers to questions.

We want to talk to people from black and minority groups who have learning disabilities.

We would like to talk to you about services such as:

- day activities
- respite
- residential care
- help around the home

- support outside the home.

We want to know what good things happened.

We want to know what things could be better.

This is your chance to get your views heard.

Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you.

Please think about this leaflet carefully.

Talk about it with your family, friends, doctor or nurse if you want to.

Please ask if you want to know more.

Please ask if you do not understand something.

Please take time to decide whether or not you want to take part.

### **Why are we doing this research?**

People with learning disabilities who are from black and minority ethnic groups often say they are not happy with the services they receive.

We want to find out why people are unhappy.

We want to find out ways we can make things better.

## **Why have I been asked to take part?**

You have been asked to take part because

- you have a learning disability
- you are from a black or minority ethnic group
- you are aged 18 years or over.

We would like 30 to 40 people with learning disabilities to take part in this research.

## **Do I have to take part?**

No. It is up to you. You can decide whether or not you want to take part.

If you do want to take part, we will ask you to fill out a form saying you want to take part in the project.

You will be given a copy of this leaflet and your signed form to keep.

You can stop taking part at any time without giving a reason.

If you decide to stop, this will not affect the care or services you receive.

### **What will happen to me if I take part?**

We would like to ask you some questions, this is called an interview.

One of the research team will do the interview.

The interview will last about 1 hour.

We can split your interview over two sessions if you like.

You can talk to us on your own if you want.



You can choose to talk to us with your family, friends or carer.

We would like to talk to people on their own and in groups. It is up to you which you would prefer.

We can talk at a place you choose.

For example

- at your home
- day service
- church
- our office.

At a day and time to suit you.

We can get someone to help us talk to each other if you do not speak in English.

This person is called an interpreter.

They will have to be at the interview.

They will translate what we say to each other.

This means they will listen to what we say in English and then say it to you in your language. They will also listen to what you say in your language and then say it to us in English.

You might like to ask your friends or family to help with this too.

We will record everything we say and then type it out.

We will use a video recorder for group interviews. This will help us know who said what.

We will read what everyone has said during the interviews.

We will look to see what is the same and what is different.

We will use this to write a report. We hope the report will help to make services better.

During the interview, we will ask you questions like

- Who helps or supports you?
- What do they help you with?
- How do you feel about the support you get?
- What do you like?
- What don't you like?
- What could we do to make things better?

### **What are the possible benefits of taking part?**

We cannot promise the study will help you but we hope the information we get can help us improve things in the future.

To thank you for your time, we will give you a £5 voucher to be spent in a high street shop.

We will also pay you up to £10 for any travel costs.


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### **What if I get upset?**

The research should not upset you in anyway.

If you feel upset during the interview, you should tell someone. You can ask us to move onto a different question, you can decide not to answer a question or you can ask to stop the interview.

You can make a complaint if you are not happy about the research. You can make a complaint to Uta Noppeney at the University of Birmingham. Uta is not involved with the research.

	<p>Her contact details are: Dr. Uta Noppeney, University of Birmingham, Edgbaston, Birmingham, B15 2TT.</p>
	<p><b>Will anyone else know I'm taking part in this? Will anyone else know what I have said?</b></p> <p>We will keep your information in confidence. This means we will only tell those who have a need or right to know.</p> <p>In group interviews, it is important that you do not tell anyone else what has been said by others in the group. It is also important that you think about what you say and do not tell other people something that might upset you.</p> <p>Only the research team will have access to your name and address.</p> <p>When we type up the interview, we will use a different name for you.</p>

	<p>In any reports we write, we will use what you and others have said. This will help support what we write. However, we will make sure that no-one can identify you from what we write. This means that we will make sure that no-one can tell who has said what in the report.</p> <p>There are times where we might have to tell someone about what you have said. We will only tell someone what you have said when we think you or someone else is in danger or might get hurt. If this happens, we will only tell people who need to know to make sure everyone is safe.</p>
	<p><b>Who has reviewed the study? Did anyone else check the study is OK to do?</b></p> <p>Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research has been checked by a Research Ethics Committee.</p>

## **What happens after the interview?**

Any services you normally have will carry on. Your care will not be affected in any way.

If you decide you do not want us to use what you have said, tell the researcher. You will need to do this within a week of the interview.

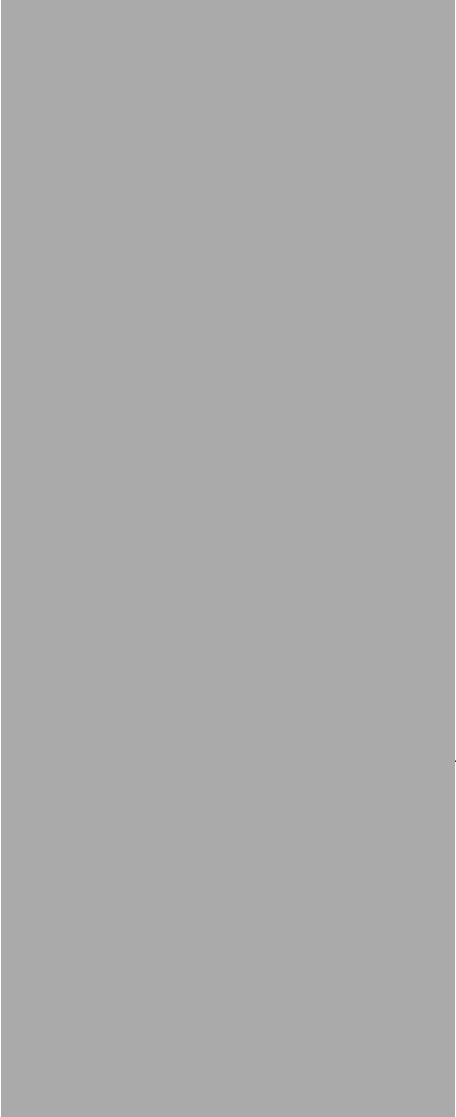
We are going to hold a meeting after we have done all the interviews. We are calling this the co-design event. We want to invite people to come and talk about what we have found out. We want to think about ways we can make things better.

Would you like to come to this meeting?

If you would like to come to this meeting, we will need to keep your name and address so that we can invite you.

We will also write a summary of the results. We can send you a copy of the easy read summary.

Would you like to get a summary of the results?

	<p><b>Contact details</b></p> <p>If you would like more information, please contact:</p> <p><b>Kulsoom Malik, Trainee Psychologist</b> <b>University of Birmingham</b> <b>School of Psychology</b> <b>Edgbaston</b> <b>Birmingham</b> <b>B15 2TT</b></p>
	<p>Thank you for reading this.</p> <p>Please ask any questions if you need to.</p>

Some of the pictures are from the CHANGE Health Picture Bank, CHANGE, Units 19/20, Unity Business Centre, 26 Roundhay Road, Leeds, LS7 1AB.



## Consent form for study

Your Name.....

The title of this study is

People with learning disabilities from black and minority ethnic groups: their views of services.

This means we want to find out about how you feel about services and support.

The names of the person who will be doing this study is Kulsoom Malik



Please go through this form carefully.

You may like to ask someone to help you go through this form.



If you do not understand anything, please ask.

If you would like to know more, please ask.

### **Agreement to take part in study**



I have read the information sheet or had it read to me.



I have been able to ask questions.

All my questions have been answered.




I have had the chance to talk to my friends, family and carers.



I know what this study is about.

I know how I will take part in the study.

I know that any information about me will be kept secret.



I know that relevant parts of my medical notes and information collected during the study may be looked at by people from the University of Birmingham. Other people may also look at this information, from regulatory authorities or the NHS Trust, where it is relevant to my taking part in the study.

I give permission for these people to have access to my records.

I know that no one will be able to identify me in any information that is presented.

I agree that the results about me can be published but only if my identity is kept secret.



I know that I do not have to take part in this study.

I know that I can stop taking part in this study whenever I want to.

If I leave this study, I know that my care will not be affected.

I understand what this form tells me

I agree to take part in this study

I would like to be invited to the co-design event

I would like to get a summary of the results of the research

Signed .....

Date .....

I have witnessed ..... giving consent to take part in the study.

Relationship with the person .....

Signed .....

Date .....

I ..... (person taking consent) have told this person about the study.

I have given them the information sheet.

I have answered their questions.

To the best of my belief, they have understood what I have told them and they are giving free and informed consent.

Signed .....

Date .....

**One copy to be kept by the participant and one to be kept in the researcher site file.**

The pictures on this sheet are from the CHANGE Health Picture Bank, CHANGE, Units 19/20, Unity Business Centre, 26 Roundhay Road, Leeds, LS7 1AB.

**Appendix 5:** Example of development of the emerging themes for one participant Aysha Aslam. Interesting quotes are presented with reflections.

These reflections are grouped together to explore the key issues/themes raised by this participant such as “independence” and the different layers of independence. Reflections are presented as highlighted text in the form of questions. This is an example, but this process was completed for each participant.

General information for Aysha Aslam

- Registered blind
- Can speak English and understand Gujarati , Kutchi
- Shia Muslim
- Celebrates Eid ul Fitr, Ramadhan, Mujlas
- Services used: independent living, X road, midland X, personal assistant
- Mother and Personal Assistant sat in the room during the interview.

**Stance**

Page no	Quote	
182 183	I: Yeah, exactly, Mum can tell me later. Um is it Mujlas you said?	There is a sense that when the participant made references to things such as Mujlas – that lead me to become more curious and to ask questions such as tell me more about that. Whereas other examples when she has mentioned fasting, I did not ask more questions because I knew what they were and maybe some of the richness of the data was lost because questions were closed down instead of opened up.
184	R1: Yeah.	
185	I: What’s that? Tell me about that.	
	R1: Um it’s for we say bungie. I: Okay, and what’s that?	

264	<p>I:Okay, all right. And are there certain places that you wouldn't go to because of your culture? Or certain things you wouldn't do?</p> <p>R1:Um no.</p> <p>I:No? Okay, all right.</p> <p>R1:<b>can do anything, it's a free world! It's a free world, it is.</b></p> <p>I:That's good.</p>	
433	<p>((assertively)) Yeah, they respect everybody's culture.</p>	<p>Because culture is not a big priority, may have got annoyed at the constant reference to culture.</p>

**Reflections: Independence? Something one strives for but is restricted due to disabilities. Are services seen as barrier in helping one achieve this, even though from a service perspective this is something they are trying to facilitate? How far can services really go if someone has a learning disability as well as a physical disability (blindness).**

Page no	Quote	
206	<p>Um er... Let me think, um Fridays. Well, um if I had a chance and because of, because of my parents live locally to um, locally and visits me all the time I can go to the mosque with them. I'm lucky in a way.</p>	<p>With reference to going to the mosque. Is independence only about when one is away from home? Is support from family members better received than support from staff. Is it about receiving support from people that one likes? Is support from family not seen as support?</p>
268	<p>I can do anything, it's a free world! It's a free world, it is</p>	<p>Making choices for oneself. Not wanting restrictions. Is this an ideal because actually she cant do everything? She is restricted due to her sight and LD?</p>
381	<p>Um I think so. I mean I just don't want to sit at, sit at home being a lemon or vegetable, yeah? Um yeah, I would like to go somewhere else.</p>	<p>How others will receive her? Is it the ethos of the services that she is accessing about striving for independence?</p>
527	<p>Um ((hesitates)) it would be good if I lived on my own.</p>	<p>Something to achieve</p>
735	<p>Or, or I could decide, okay, I'm going. Bye! In fact I would like to</p>	<p>Striving to be able to go out and be independent to do every day</p>



<p>742</p> <p>865</p>	<p>do that at some stage, like bye! I'm going. Okay, grab my coat, grab my bag, grab whatever I need, I'm off, I'm going, bye! I'm going to buy milk.</p> <p>There are no shops round the corner</p> <p>R1: Um go to places by myself, like go shops. ((agitated)) And this girl, who I was living with, [REDACTED] yeah, she can, she can just go bye! I'm going! I'm going to the shop to buy milk. And in my house, [REDACTED], I'm just going out to buy milk. No you can't</p> <p>Angry, frustrated and even here I thought it was independent living, but it's not, it's not, [REDACTED] and [REDACTED] can go out, bye, I'm going to college, [REDACTED] College. I need help.</p>	<p>things like go and buy milk.</p> <p>Feeling different to other people – also links in with services.</p> <p>What does independence mean....doing things on your own. Is it not independent if people help you even if you are making choices.</p>
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**Identity – a way of connecting with people. Either to feel close to them or to feel different.**

Page no	Quote	
258	Um ((hesitates)) well I don't know if I'm making the right choice or the wrong choice here because um my sister, Sana got married, got married in 2006...? Oh, 2002 um and I was a bit um, I was a bit jealous, well I was very jealous.	Aware that she had not reached the same milestones as other. Feeling inferior – wanting the same things as others. Limitations of having a LD or blindness? Can services/should services helps with this? Others are going through life events. Aware that she is different.
445	<p>Yeah. Um I know sometimes the words come out slowly in my brain.</p> <p>Yeah. But... Oh sorry, but then I'd have to give my answers straight away, I can't stop and think about it. Well, this is from my point of view. Because I might take so long thinking about it um by the time I've thought about it the time's up and you know the words don't come out as quickly of my mouth as it should be, not like other girls.</p>	<p>Some awareness of the LD</p> <p>Aware that it takes her longer to do things. May believe that it will take her longer to achieve the milestones in her life too .</p>
870	((assertively)) Angry! They can, they can just um get on the bus, yeah, number nine bus or whatever bus, I don't know, 11C, and then just go off.	Even though she has an awareness that her condition limits what she can do, there is an expectation that the service could help with the independence.
876	Um because of my condition.	Comparison to others makes it clear that she is different.
880	And it's making me very frustrated, very angry and um ((hesitates) um I came to Independence Plus, well Independent Living, um I thought I could do it but...	
919	Can [redacted] Can [redacted] go by himself, themselves? Yes, yes. But I can't. And that makes me very angry. I thought I was here to learn um independence, independent travelling, but it doesn't look like it does	Comparing herself to other people has made her become aware of her own limitations in terms of what she can access. Does not take into consideration that others may not have sight problems. "it's a free world" perhaps.

947	Not now. I'd, from my life and what I want I just want friends, yeah? Friends.	
953	Yeah, yeah I want, I want, I want local friends to go out.	
959	I would like people um with commonsense	

**Culture – way of living not something that is enforced through culture and religion but rather a choice based on practical reasons with a degree of flexibility. Solutions to problems should be practical.**

Page no	Quote	
96	Mother :It's only you understand, you don't speak them	With references to Kutchi
144	Um dal, rice...	Foods eaten.
146	Biryani.	
148	So that stuff, um... sambal.	
164/165	Very important, yeah. Because Eid, Eid and Chris...Christmas comes only once a year. And Eid-al-Fitr and...	See's Christmas as being part of her culture too and believes that it is important. Fitting in? Being the same as other people.
225	Um well we eat all meat except pork	Not eating pork is not a restriction that is imposed by the family in a literal sense. Practicalities ( which may have been a way for the family to deter precede reasons over religion/culture being an answer.
230	Um well um I want to try, I want to try it.	
234	Because I get itchiness.	
236	An itchy bum, like	
242	Um well when it's, weather permitting, um if the weather's nice and sunny and dry, a Punjabi dress Er well mm-mm, no. Well I think it's commonsense, if it's a nice day you can wear shorts and tee-shirts, if it's cold and wintery and snowing you can wear snow boots.	The types of clothes you wear seem to be decided by practical factors such as weather  What you wear is determined by practicalities. Does having a learning disability allow you to be more flexible?
172	I: Mm-mm. Do you fast?	Sees not being able to fast due to medication. No suggestion that it is something she would like to do. Practical solutions are important.
173	R1: Mm-mm no, because of my medication.	
174	I: Okay. And if you weren't on medication would you like to	
175	fast?	

	R1: Yes, I would. But my appetite is kind of low, I get hungry very quickly.	Solutions to problems should be practical.
709	Um we just saw one recently um Go Goa Go. Go Goa Gone	Watching indian films as a choice.



**Receiving support /services : Are services seen as being good when they allow one to be independent? Staff seen as barriers to this rather than acknowledging limitations such as blindness. Wants to be independent with respects to being outside the house ( just go and buy milk). An activity where staff input is minimal is seen as being of value. Services valued in terms of the amount of change this is seen, not necessarily about the amount of resources invested into people. Helping with money is helpful because it has an outcome.**

**Staff support is valued but the difficulty with mobility/going out and being independent taints the good things that they do.**

Page no	Quote	Comment
	Um er... Let me think, um Fridays. Well, um if I had a chance and because of, because of my parents live locally to um, locally and visits me all the time I can go to the mosque with them. I'm lucky in a way.	Im lucky in a way suggests that she is receiving support from her parents that other people might not receive. She attributes her parents as living close means that she can do things with them.  Is receiving some kind of support more stigmatised than others?
536	I: All right. Do you like it there? R1: Um yeah. I: Why is that? R1: Um because um they let me do things.	With references to where she is living.
562	Like cut salad. Well, they didn't before, but now [redacted] has come in the place and she lets me do salads, chicken...	Likes staff who let her do things and take her out – help her achieve her sense of independence that she is striving for.
565	Because um they take me out	
648	But now since [redacted] is on, yeah, I'm cooking dal and nan and rice	Services have helped her make cultural food which she enjoys. PA allows more freedom...maybe independence?
665	Um yeah. Um not that much, because when I come home the food was already made!	With reference to missing Asian food when not at home. Again culture can be flexible and adaptable based in practical reasons – can come home and eat daal.
674	((assertively)) Get rid of the staff! Get rid of the staff.	Services seen as the people in the service. Not in terms of what

815	Because you know they are, sorry, they are getting on my nerves now, yeah?	they do. The staff represent the service – personal qualities of the staff. May see them as a barrier to striving for independence because they put restrictions on her.
856	Um I was at, where was I at? Oh yeah, yeah I was there yeah, and I've had six mobility sessions or 12 and um I still can't do it.	Services should be able to help you move on and learn things...achieve milestones, strive for independence. Still cant-suggests that there is an expectation that the input should have been enough to facilitate the change. Not moving on and learning more is seen as the service not doing the right thing, not a limitation of the person with the LD.
903	Like for example like, let me give you an example, milk and sugar, yeah? Because we forgot sugar and milk, yeah, I would just like to go out and get it. But I can't because there's no local shops and...	The practical aspects of where a service is placed is important. This is seen to not facilitate independence.
908	Yeah, yeah. And, and bear in mind um you know um, um [REDACTED] um I was at before, the shops there were handy, very, very handy. When, when I came out, when we came out, I could smell chips.	Is she appropriately placed? In her new home she is away from local shops. Has this impacted on her sense of independence?
986	They're excellent, in that way they're excellent, yes. They help me with money, they help me with food, they help me with food hygiene, um they help me in lots of ways.	Difficulties with mobility taints the good work that the staff are seen to do.

**Milestones/developmental factors: services can provide support in moral and social development. When services are not seen to make a change that is viewed to helped one achieve milestones, then services are viewed as not being good.**

Page no	Quote	Comments
337	we talk about sex	Services allow her to learn about facts of life that one learns about as they grow up. Things you might learn at school – LD schools may have not made this available – learning about these things
341	we talk about condoms	



343	<p>yeah and we watch videos about babies</p> <p>Because they're making me um, they're making us learn about babies, condoms um yeah</p>	later in life. To make choices?
396	Er yeah, because um I wanted a boyfriend once, yeah, and I kept on asking my mum when will I get married, when will I have a baby, um and um I know it's, I know it's taking so long now but then I realised um babies are hard work	Learning about milestones in life is important. Coming to conclusions about making choices in life is important. Have an idea...find out some more....decide no longer wants to do that.
426	Um er yeah and because before um I was um being very serious um since um, since the staff at 128 um came, or [REDACTED] um tell jokes I'm getting a sense of humour and the service users, the service users um which is [REDACTED] nd [REDACTED] they um tell jokes as well. I'm getting used to it now.	Service providers provide more than what is seen superficially – such as educating about things or talking. But they can provide more holistic support – development of character. Helping people to go through developmental milestones?
582	Um I think the religious classes is okay, um it's... It's not that important to me, um because um, because I missed um er... because I missed a few years um at religious classes my mum's letting me catch up now.	As with culture...a degree of flexibility. Family trying to help her achieve milestones with the help of services who support her in taking her to religious classes.
604	And now um it's my time to catch up.	Not something she wants to do but important for mum. How much choice do people with learning disabilities get? Who's views are more important, service user, family or service?
926	Yeah. And, and I just um hope in the future I would, I would get to that stage, that would make my mum happy, um [REDACTED] happy, the staff happy, um but it's not me, it's not me. People say it's the cars, I'm on the road. And I thought it was me, me and my directions, but it's not, it's the cars outside.	Hoping to achieve milestones, not just for herself but for others. Limitations seen to be external to her  Pleasing others.
756	Er frustrated, um I would break things	Expression of emotions at different developmental stages.
758	I would, I would just cry.	
758	And I would just phone the manager.	

Independence – to make choices “ free world”

- In terms of making practical choices – what to wear
- Living away from home
- Wanting a husband and babies
- The ultimate milestone is to become independent. Is she striving to become and adult but the services are unable to facilitate this. Is it the LD or the blindness that is the barrier.

Milestones – getting married, having sex, having babies

- Catching up on religion from Mums perspective

Culture is a choice - it isn't enforced – eat dal out of preference. Can wear shorts, no restrictions. Watches Asian films.