

SOCIAL SERVICE PROVISION TO PEOPLE WITH LEARNING DISABILITIES FROM
BLACK AND MINORITY ETHNIC COMMUNITIES: THE VIEW AND EXPERIENCES
OF SERVICE PROVIDERS

by

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Thesis Overview

My first placement was at Heartlands Hospital. After meeting with my clinical and academic supervisors, it was agreed that I would be conducting a systematic literature review. This was conducted to ascertain the research available on the quality of life of children with cystic fibrosis, in the hope of including a measure in the routine clinic assessments at Heartlands Hospital. As it was my first time conducting a systematic literature review, the guidance I received from the school librarian and my academic supervisor was highly useful. In this placement, I also had an opportunity to observe and assist the Multi-Disciplinary Team (MDT) in the routine clinical assessments. Overall this gave me an idea of a Clinical Psychologist's role in a MDT that has patients with a chronic illness such as cystic fibrosis. I had frequent supervision and that enabled me to clarify any doubts or questions I had regarding the systematic review.

Upon completion of the systematic review, the feedback I received was then incorporated into this thesis. Some of this feedback included having a separate table of the measures used across the studies, including the risk of bias assessment table in the review, and having more details of the papers in the table with the main characteristics of the papers included in the review. In addition to this, the implications for future research and clinical practice were also included as part of the feedback received.

Overall this placement, taught me the necessary skills required to conduct a systematic literature review from the search strategy to the actual write up of findings. These skills are valuable and will definitely be transferrable and applicable to any systematic literature reviews I will conduct in future. In addition, the time I spent at Heartlands Hospital with the Clinical Psychologist provided me with a clearer outlook on the clinical work conducted within the NHS and within a MDT.

At the end of the first placement I chose a placement on qualitative research on a project in learning disabilities (LD) for the spring term that I would carry on for the summer project. Therefore, in the spring term, one of my aims was to submit a university ethics form for the project which I would conduct in the summer. Working through the university ethics application process, I was able to get a clearer picture on what the research project would be about. In addition, I also learnt of some of the ethical issues that my project involved. In this placement as well I had to extensively read literature on qualitative research in general as I was a novice qualitative researcher. This prepared me for the project I conducted in the summer.

For the placement presentation, I chose to focus on the history of LD and also the current context of LD. This presentation pointed out the changes that have occurred in the field of LD in the United Kingdom (UK) to shape them into what they are in today. Since I am not originally from the UK, as an international student by familiarising myself with this literature helped me to understand the context of LD in the UK. The feedback from the presentation was mainly in the reflection section of the presentation, to include more reflection and also to include a section on eligibility criteria for services from Birmingham City Council. This was incorporated into the thesis.

As part of the summer project I had to conduct audio recorded interviews with social care providers to get their views and experiences of providing services to people with LD from the Black and Minority Ethnic community. In the analysis of the data I used Interpretative Phenomenological Analysis (IPA) which I had familiarised myself with in the spring placement while reading about qualitative research. Throughout the analysis and write up of the project I received supervision from my two supervisors and this guidance helped to accomplish my goal of writing up this report. I greatly appreciated the patience and the

feedback that they gave me in each supervision meeting because I know that without it, it would have been challenging to produce this written report. The main thing I learnt was how to conduct qualitative research effectively. Through data collection, my communication skills were sharpened as I interviewed social care staff according to the guidelines of IPA. The data analysis process, though it was time consuming, taught me to be patient. I also appreciated and learnt about the process of different levels of analysing data in IPA to get the participant's experiences. From the project I also found some areas that were of concern to service providers in the current climate and I do hope that these concerns and views may be used to inform service provision.

The feedback I received from my supervisors was mainly regarding the layout and write up of the results section. To incorporate this feedback I had to make separate tables for the quotes I used in each subtheme in order to make the report easy to read and follow through. Furthermore, in order to improve the write up in this section I had to consult the original analysis I had done on the transcripts to ensure that the reporting of the results was grounded in the data. As I continue on in my research career, since I am now more learned in qualitative research, I will continue to embark on more qualitative research projects.

Through three placements, the MRes Clinical Psychology course has equipped me with new knowledge and skills that have definitely increased my competence as a researcher.

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CHAPTER 1

Placement 1 report: Systematic literature review: Quality of life of children and adolescents with cystic fibrosis

Reflection

In this placement my main goals were:

- To gain knowledge about Cystic Fibrosis (CF)
- To know how to effectively search for literature
- To gain knowledge and skill in order to be able to write a systematic literature review
- To have an understanding of the role of the Clinical Psychologist working on the Multi-Disciplinary Team (MDT) in a National Health Service chronic illness department, in this case CF
- To gain an understanding of how the NHS functions
- To produce a systematic written literature review

My autumn placement was a systematic literature review on the quality of life (QOL) of children and adolescents with CF. The reason why this literature was conducted is because the CF MDT team at Heartlands Hospital wanted to introduce a QOL measure to children and young people with CF attending outpatient appointments. Therefore, this literature review was a first step in working towards eventually introducing QOL assessment in the routine clinic appointments by exploring the literature regarding CF and QOL in children and adolescents.

Prior to this placement I did not know what CF was and initially the thought of venturing into something new based in the medical field and that I was not familiar with seemed daunting. However, I took on the challenge and I was determined to understand and be equipped with knowledge about this condition. This process was made easier by my

clinical placement supervisor Dr Zoe Cross who gave me a book on the medical, social and psychological facts about CF explained in simple terms. I read it in the first week of the placement and after that I was more confident about reading articles based on CF and also even explaining it to my peers when asked about my placement and what exactly CF was.

I scheduled a meeting with the school librarian for a lesson on effectively searching for literature. I had not conducted a systematic literature review before and I definitely appreciated her sharing her knowledge and skills as she is highly experienced in this area. When I started searching for articles for the literature review I applied all she had taught me and after practicing it for a while I was more comfortable doing it myself. Two days of the week were spent literature searching and working on the write up of the report. Dr Gary Law my academic placement supervisor provided me with support throughout the write up of the report. I was privileged enough to meet up with him at some stages as often as once every week. This frequent supervision meant that I was able get any questions clarified and provided guidance for the write up. This was the first time I had conducted a systematic literature review and in every supervision meeting I learnt something new.

On Tuesdays, there is a CF clinic that runs at Heartlands Hospital where outpatients attend their routine check-ups. I attended these clinic sessions by shadowing Dr Zoe Cross who is the Clinical Psychologist in the CF MDT Team. The other members of the MDT team were the consultant medical doctors, clinical nurse specialist, dietician and physiotherapist. CF has a complex treatment regimen and each member of the MDT has a role related to the treatment regimen during the routine check-up. During the clinic sessions I was able to follow the patients through the check-up from one MDT member to the next. Each child or young person would start by seeing the dietician who would ask about their diet and the supplements they were taking. The clinical nurse specialist would ask them how they had been feeling

since the last appointment, if they had any physical complaints or problems with medication and organise home visits if need be. The physiotherapist would test their lung function and give suggestions on physiotherapy techniques that could be done at home. The consultant doctor would discuss the results from the lung function tests, changes in medication and any other problems the patient may have. As the patients were going through this check-up the clinical psychologist would build rapport with them and generally ask how they were coping at school and at home. Her role is based on a preventative model, because by being in clinic and talking to the outpatients during the routine assessment, if there were any problems that needed to be addressed they would be addressed in that clinic session reducing referrals and also dealing with problems before they were out of control. The clinical psychologist is also there to provide help for patients who may have psychological problems regarding treatment for example needle phobias.

I was able to attend a MDT meeting that is usually held before clinic commences and discuss about the inpatients, outpatients and research ideas. By attending this meeting and the clinic sessions I had a better understanding of how the different roles of the MDT work together and the most important for me was that it helped me a lot when reading articles. The articles on QOL that I was reading would describe the lung function tests, the routine clinic assessments and had some technical medical terms. Attending the clinic made what I reading in research articles come alive because I could observe what I was reading and I truly understood the applied aspect of research. In addition, I could ask any of the MDT members concepts I did not understand regarding CF and these were explained. The results from the literature review will initiate the process of introducing a QOL measure in the routine check-up.

Overall, during this placement I acquired knowledge and skill that I know will be applicable and beneficial not only in this course but in my career as well. Many thanks go to Dr Gary Law for the academic support and Dr Zoe Cross for the clinical support.

Introduction

Cystic Fibrosis (CF) is an inherited chronic disease that affects the respiratory and digestive system, specifically the lungs and the pancreas by clogging them with mucus resulting in difficulties in breathing and digesting food (Cystic Fibrosis Trust, 2012). It is common among the white population of European descent with one in every 2500 babies born in the United Kingdom being born with CF and over 9000 people are living with the disease (NHS Choices, 2012). In the 1950's people with CF died at a very young age but, today, because of advances in medical treatment children, adolescents and adults can expect to live up to about 40 years of age (Cystic Fibrosis Foundation, 2012). Effective management of CF consists of an expensive complex treatment regimen and regular contacts with healthcare teams (Palermo, 2006). These healthcare teams are usually multidisciplinary and, though it may vary across different healthcare centres, they usually consist of a physiotherapist, specialist nurse, dietician, clinical psychologist and medical consultant (Goździk, Majka-Sumner, Cofta, Nowicka, Piorunek & Batura-Gabryel, 2005).

CF poses a treatment burden and requires patients to regularly attend routine clinic assessments and also complete a complex treatment regimen at home, involving physiotherapy sessions and taking supplements and other medications (Stoppler, 2011). The complex treatment regimen may prevent children and adolescents from functioning well in their day to day activities. Patients with CF are living well into adulthood (Cystic Fibrosis Foundation, 2012) and it is important therefore to understand how the disease impacts on the quality of life of young people. In its broadest sense, quality of life (QOL) has been defined by the World Health Organization (1997) as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". However, in healthcare it is important to

differentiate between this broad QOL sometimes also referred to as well-being with health related quality of life (Spieth & Harris, 1996).

Health related quality of life (HRQOL) is a multidimensional construct that focuses on physical functioning and symptoms, and also psychological, emotional and social components (French, 1998). In addition, it is subjective because it relies on the patient's view instead of the physicians and it is a reflection of the individual's evaluation of their functioning (Quittner, 1998). This is vital as it provides more detailed information on how the patient feels and this can be incorporated into the treatment regimen. In children and adolescents with CF it is important to understand their HRQOL as it will help in determining the benefits and burdens of the therapeutic interventions (Quittner, 1998).

Abbott, Webb & Modd (1997) conducted a review on measurement of quality of life in CF in children and adults and, to the author's knowledge, there has been no systematic review since then on QOL in children and adolescents with CF. Therefore, the objective of this paper was to explore and review the literature on the research that has been conducted on HRQOL of children and adolescents with CF, since the Abbot et al., (1997) article.. There is a focus on factors associated with HRQOL and also measures used to assess different aspects of HRQOL in CF.

Method

Search strategy

The databases of PsycINFO, ISI Web of Science, Medline and Cumulative Index to Nursing and Allied Health Literature (CINAHL) were searched for articles from the timeline January 1996 to November 2012. The search started from 1996 in order to include all the papers that were published after the Abbot et al. (1997) review (which was actually conducted

in 1996). The following search terms were used: “cystic fibrosis”, “quality of life” and “health related quality of life”. The results were limited to those in the English language only and also those with the age groups from birth up to 18 years old. More information on the search strategy can be found in Appendix A. A hand search was also conducted on the reference lists of the final articles to identify any relevant articles that could also be included.

Inclusion and Exclusion Criteria

The inclusion criteria for the articles were as follows: 1) studies on children and adolescents from birth until 18 years old, 2) studies that included children, adolescents, and adults were only included if the data analysis was conducted separately for the different age groups, 3) studies measuring QOL or HQQOL, 4) published research, 4) studies in English only, and 5) studies from 1996 onwards.

Articles were excluded if they were studies on: 1) adults, 2) siblings, 3) other chronic illnesses or CF comorbid physical health conditions (in order to keep the focus on CF), 4) on other aspects of CF that did not relate to QOL or HRQOL, 5) validation and development of questionnaire studies only, 6) conference proceedings, magazines or dissertations, and 7) reviews with no QOL or HRQOL measures included.

Data Extraction

After duplicates were removed, the titles, abstracts and full texts were screened according to the inclusion and exclusion criteria. The data extracted (see Table 2) from the articles included in the review was author and publication year; objective of the study; study design, country of study, participants, measures, and findings.

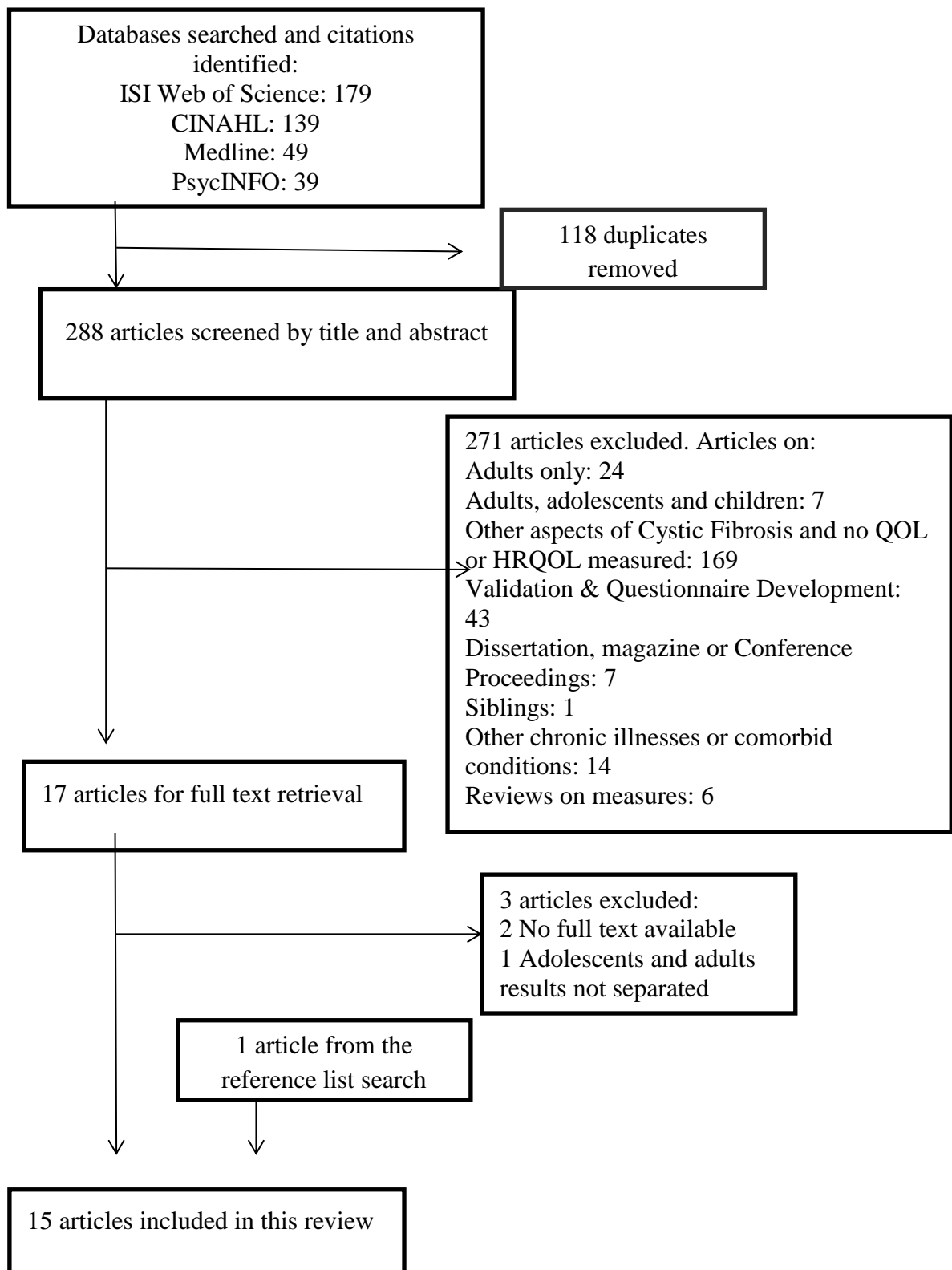
Risk of bias assessment

According to Higgins and Green (2011) the risk of bias is the extent to which the results in the studies included for the review should be believed. The TREND statement checklist (Des Jarlais et al., 2004) and the criteria by Ramos-Álvarezi et al., (2008) were adapted for the risk of bias assessment in this review and the articles were assessed according to that criteria. Two researchers independently rated a random sample (n=2) of the studies and there were very slight discrepancies in ratings, which were then discussed and it was relatively easy for the researchers to reach a consensus regarding the final scores. Therefore, since the quality criterion was clear and easy to follow, it is unlikely that there would have been major discrepancies in scoring across the remaining 13 articles.

Results

Figure 1 shows the results from the search strategy. Overall, 406 articles were identified from the search and 118 duplicates were removed. After screening the abstracts of the remaining 288 articles, 17 articles were identified for full text review. Two articles had no full text available, one article did not separate the analysis of the adult and adolescent results, and one article was derived from a hand search. Therefore, a total of 15 articles were included in the review.

Figure 1. Literature search results



From the risk of bias assessment of the 15 papers, according to the quality criteria, the papers ranged between 28 and 36 points out of a possible 40 (See Table 1). Therefore since there was an 8 point difference amongst the papers, no papers will be excluded from this literature review as all the 15 papers were considered to be of good quality.

The following risk of bias assessment scoring key was used:

2= Yes it was mentioned/ information reported,

1= partially mentioned/ partially reported

0= no/not mentioned/ not reported

Table 1.

Risk of bias assessment

	Abbot, et al., 2001	Arrington-Sanders et al., 2006	Modi, et al., 2010	Powers et al., 2001	Hegarty et al., 2008	Swisher et al., 2010	Quittner et al., 2009	Sawicki et al., 2010	Kosciński et al., 2005	Szyndler et al., 2005	Palermino et al., 2006	Havermans, et al. 2005	Britton et al., 2004	Thomas et al., 2006	Tluczek et al., 2011
<i>Paper Section</i>															
Title and abstract															
Is the abstract structured?	2	2	1	2	2	2	2	2	2	2	2	0	1	2	2
Is there information on the study	2	2	2	2	2	2	2	2	2	1	2	0	2	2	2

sample?															
Introduction															
Is there enough information on the background of the study?	2	2	2	2	2	2	1	1	2	2	2	2	2	1	2
Is there a clear explanation of the rationale	2	2	2	2	2	2	1	2	2	2	2	2	2	2	2
Are the objectives and hypotheses mentioned?	1	2	2	1	2	2	2	2	2	1	2	2	2	2	2
Methods															
Is the	1	2	2	1	2	2	1	1	1	2	2	2	2	2	2

adequately															
Discussion <i>(Interpretation of the results, taking into account)</i>															
study hypotheses and objectives	1	2	2	1	2	2	2	2	2	1	2	2	2	2	2
sources of potential bias, limitations or weaknesses of the study	2	2	2	2	1	2	2	2	2	1	2	2	2	2	2
Suggestions for future	1	2	0	2	2	2	1	1	2	1	2	1	2	2	1

research															
current evidence and current theory	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Total	28	36	35	31	34	32	30	30	34	28	32	29	35	34	33

Table 2.

The main characteristics of studies included in this review

Author (Year)	Summary of Main Objectives	Study design	Country of study	Participants recruited	QOL Questionnaires	Other Questionnaires	Summary of main findings
Abbott, J., Baumann, U., Conway, S., Etherington, C., Gee, L., Graf Von Der Schulenburg, J., & Webb, K. (2001)	Compare QOL between German and English adolescents	Cross Sectional	United Kingdom and Germany	1) English participants *58 patients attending outpatient clinics (19 male and 39 female). Age range= 14-18. (M= 17.4, SD=±0.8) *49 healthy controls (25 male, 24 female) Age range 16-18. (Mean=17.8, SD=±0.5). 2) German participants	Short Form (36) Health Survey (SF36)	N/A	Overall, English participants reported significantly lower QOL compared to the German participants

				<p>* 26 patients attending outpatient clinics (18 male and 8 female).). Age range= 13-17 (M= 15.8, SD=±1.2)</p> <p>*75 healthy controls. (36 male and 39 female). Age range= 14-17 (M= 15.6, SD=±1.1)</p>			
<p>Arrington-Sanders, R., Yi, M. S., Tsevat, J., Wilmott, R. W., Mrus, J. M., & Britto, M. (2006)</p>	<p>1) To determine if there are gender differences in HRQOL</p> <p>2) To determine the HRQOL domains in which the gender differences exist</p>	<p>Cross sectional</p>	<p>USA</p>	<p>98 adolescents at the routine clinic assessment</p> <p>Age range 10 -18 (Mean=14.6, SD=2.5)</p>	<p>CHQ</p>	<p>N/A</p>	<p>Females reported significantly lower HRQOL specifically in the domains of global health, mental health, and perceptions of general health</p>

<p>Britto, M. T., Kotagal, U. R., Chenier, T., Tsevat, J., Atherton, H. D., & Wilmott, R. W. (2004)</p>	<p>1) Determining the differences in adolescents and parent reports of HRQOL 2) exploring factors associated with differences in HRQOL reports</p>	<p>Cross Sectional</p>	<p>USA</p>	<p>62 adolescents: at the routine clinic assessment 10-17 years (M=13.7).</p>	<p>Child Health Questionnaire (CHQ)</p>	<p>N/A</p>	<p>1) Adolescents rated their HRQOL significantly better than their parents with the biggest difference being in the general health perceptions scale 2) There were no differences in the HRQOL reports between parent and child, if the child had just had pulmonary exacerbations</p>
<p>Havermans, T., Vreys, M., Proesmans, M., & De Boeck, C. (2005)</p>	<p>1) Examining agreement between parents and children when assessing HRQOL 2) Analysing relationships between HRQOL, demographics and FEV₁</p>	<p>Cross-sectional,</p>	<p>Belgium</p>	<p>36 children and adolescents: routine clinic visits. Age range 6-13 years. (Mean age=9.31, SD=2.24)</p>	<p>CFQ-R</p>	<p>CFQ-parent version</p>	<p>1) Moderate agreements in respiratory and digestive symptoms. Disagreements on body image, emotional functioning and treatment burden. 2) Significant positive correlation between FEV₁ and respiratory</p>

							<p>symptoms scores for both parents and children</p> <p>3) Significant gender differences in children's eating disturbances scores with girls scoring higher.</p>
<p>Hegarty, M., MacDonald J., Watter, P., & Wilson, C. (2008)</p>	<p>1) Investigating differences in QOL between:</p> <p>a) in outpatients and inpatients</p> <p>b) parents and children's perceptions</p> <p>c) children and young people</p> <p>d) males and females</p>	<p>Cross Sectional</p>	<p>Australia</p>	<p>35 adolescents and children outpatients and inpatients.</p> <p>Age range: 6 to 18 years</p> <p>Mean: 12 years</p>	<p>CFQ-Revised</p>	<p>CFQ-R parental version</p>	<p>a) Inpatients scored significantly lower than outpatients on emotional state, social, body image and respiratory symptoms</p> <p>b) Children aged 6-13 reported significantly higher QOL than young people aged 14-18</p> <p>c) Females perceived less treatment burden than males</p> <p>d) Parents of children 6-13 years perceived</p>

							greater treatment burden than their children
Koscik, R. L., Douglas, J. A., Zaremba, K., Rock, M. J., Splaingard, M. L., Laxova, A., & Farrell, P. M (2005)	1) Investigate the effect of New Born screening on QOL 2) Determining the sensitivity of the CHQ	Cross Sectional	USA	15 children and adolescents from the new-born screening project. 21 controls. Mean age 11.4 (S.D=0.9) and 21 control (14 male and 7 female. Mean age 12.1 (SD=1.3).	CHQ	N/A	1) No significant difference in QOL between controls and screened participants 2) CHQ has low sensitivity with regard to markers of illness severity
Modi, A.C., Lim, C. S., Driscoll, K. A. Piazza-Waggoner, C., Quittner A.L., Wooldridge, J (2010)	Examining general QOL and CF-specific HRQOL after pulmonary exacerbation treatment	Cross Sectional	USA	52 children and adolescents: inpatients and outpatients. Age Range: Mean age 13.6 years	PedsQL CFQ-R	N/A	Participants reported significant improvements in HRQOL after treatment and the CFQ-R was more sensitive to changes than the PedsQL

Palermo, T. M., Harrison, D., & Koh J.L. (2006)	Examining the relationship between pain and HRQOL	Cross Sectional	United States of America (USA)	46 children, at regular clinic visits. Age range: 8.1-17.8 (M 12.9 SD=3.0)	CFQ-R	Pain questionnaires	Significant negative correlation between pain and HRQOL
Powers, P. M., Gerstle, R., & Lapey, A. (2001)	Examining the relationship between adolescent, mother and father reports of HRQOL and health as measured by pulmonary function	Cross Sectional	USA	a) 24 adolescents from routine CF clinic visits b) 24 mothers c) 24 fathers (18 male and 6 female). Age range 11 to 18 (Mean=14.6; SD =2.2)	CHQ	Parent Child Health Questionnaire	a) low correlations in adolescent reports and parents report of HRQOL b) significant correlations between parent's perceptions of health and adolescent's pulmonary health
Quittner, A. L., Schechter,	Determine the relationship between HRQOL	Cross Sectional	USA	1719 children, 930 Adolescents	CFQ-R	N/A	Low SES and minority status is significantly correlated with low

M. S., Rasouliyan, L., Haselkorn, T., Pasta, D. J., & Wagner, S. (2010)	and socioeconomic (SES) status, race and ethnicity			2102 adults from the Epidemiologic Study of Cystic Fibrosis (ESCF) database Mean age= 9.6, S.D=2.4) 930 Adolescents (435 female, Mean age =15.4, SD=1.1)			HRQOL
Sawicki, G. S., Rasouliyan, L., McMullen, A. H., Wagener, J. S., McColley, S. A. Pasta, D. J., & Quittner, A.	Determine the relationship between changes in health status and CFQ-R status	Longitudinal: completed assessment at 9 months and at 15 months	USA	337 children(50% male; M=8.9; SD=2.0), 581 parents, 398 adolescents (Mean age=14.3, SD=1.1) and 631 adults (52% male, Mean age= 26.9, SD=9.7) from the ESCF	CFQ-R	Treatment Complexity CFQ-parent version	a) Decline in FEV ₁ for adolescents and an increase in FEV ₁ in children over time. b) Significant positive correlation in FEV ₁ % predicted and the respiratory symptoms and physical functioning scales

L. (2011)				database			
Swisher, A. K., & Moffett, K (2010)	Improving quality of life by increasing physical activity	Longitudinal: 2 nd assessment conducted after 3 months	USA	12 participants: scheduled clinic appointments (7 female, 5 male) Mean age =11.9years, SD=1)	CFQ	Physical Activity Questionnaire,	50% improved their physical activity, and quality of life improved in the subscales of vitality, emotional and respiratory
Szyndler, J. E., ., Towns, S. J., van Asperen, P. P., & McKay, O. K. (2005)	1) Examining the interrelationships between QOL, family functioning, psychopathology and optimism	Cross sectional	Australia	52 adolescents :Outpatients and Inpatients Age range (12-18 years) Mean=15.6(SD= 1.98).	CFQ	1) Family Environment Scale (FES) 2) Symptom Checklist-90-Revised (SCL-90-R) 3) The Hunter Opinions and Personal Expectations	a) Significant negative correlation between psychopathology and QOL b) Significant positive correlation between optimism for the future and QOL c) Significant correlations between family functioning and QOL

Thomas, T., Mitchell P., O'Rourke P., Wainwright, C (2006)	<p>1) Comparison of HRQOL in CF centres</p> <p>2) To compare HRQOL of children with CF in Queensland from those in the United States</p> <p>3) examining the relationship between HRQOL scores and pulmonary function</p>	Cross Sectional	Australia	<p>217 Children and adolescents from a tertiary CF centre and a CF Outreach service.</p> <p>Age Range: 2 to 19 years</p> <p>Mean: 10.5 years</p>	<p>1) Paediatric Quality of Life Inventory (PedsQL)</p> <p>2) Cystic Fibrosis Questionnaire (CFQ)</p>	N/A	<p>1) The outreach centre group scored slightly higher in the PedsQL and no significant differences in the CFQ scores</p> <p>2) The PedsQL scores were significantly lower than those in the US, and the CF scores were similar</p> <p>3) Positive correlation between declining lung function and CFQ scores</p>
Tluczek, A., et al. (2011)	Assessing the relationships between pulmonary health and HRQOL	Longitudinal: assessment completed at three scheduled visits. Mean time between 1 st and 2 nd visit =1.1	USA	<p>95 children and adolescents from regularly scheduled visits. Age range 8-18. (Mean age=13.5, SD= 2.8)</p> <p>50 in control</p>	CFQ	N/A	<p>1) Positive relationship between pulmonary health and some HRQOL domains</p> <p>2) No relationship between changes in pulmonary health and CFQ scores over 2 years</p>

		years SD=0.3 years. Mean time between second and third visits=1.0, SD=0.3 years).		group			
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Table 3.

Descriptions of the QOL and HRQOL measures used in the articles included in this review

Name of questionnaire	Brief description	Types	Subscales	Scoring
Cystic Fibrosis Questionnaire (CFQ) and Cystic Fibrosis Questionnaire Revised (CFQ-R)	The CFQ is a disease specific measure that was originally developed in France and it has been developed in English to measure how CF affects the QOL of children and adolescents (American Thoracic Society, 2002). The CFQ-R is an updated version of the CFQ.	1) child version for children aged between 6 and 13, 2) a parent version for those children aged 6 to 13 3) the adult version for people 14 years and older	CFQ: has 9 QOL domains: Physical Functioning, Vitality, Emotional state, Social limitations, Role Limitations/School Performance, Embarrassment, Body Image, Eating Disturbances, Treatment Constraints. 3 symptom scales: Respiratory, Digestive, Weight. 1 health perception scale: Health Status American Thoracic Society (2002) CFQ-R has 9 quality of life domain measures: Physical, role/school, vitality, emotion, social, body image, eating, treatment burden, health perceptions and three symptom scales of weight, respiratory and digestive measures	A four point Likert scale is used and Scores are standardized ranging from (0-100). Higher scores indicate better HRQOL. Cronbach alpha of .60 to .76 across the scales (Modi & Quittner, 2003).

			(American Thoracic Society, 2002).	
Child Health Questionnaire (CHQ)	A generic measure that has 14 different physical and psychosocial aspects related to quality of life in children and adolescents (HealthActCHQ, 2010).	a) Child Version for children aged 5-to-18 years b) Child Health Questionnaire Parent Form has two versions. One with 28 items and another with 50 items. (HealthActCHQ, 2010)	12 scales: physical functioning, role/social limitations-emotional, Role/social limitations-behavioural, change in health, family cohesion, general behaviour, mental health, family activities, bodily pain/discomfort, general health perceptions, self-esteem, general behaviour	Responses made from a choice of 4 to 6 ordinal response, and scores for each subscale range from 0 to 100. The higher the score, the better the HRQOL. Cronbach Alpha 0.80 in the child and parent versions
Paediatric Quality of Life Inventory (PedsQL)	Generic measure that measures HRQOL in healthy children and adolescents and also those with acute and chronic health conditions (Varni, 2013). Some of these chronic health conditions consist of asthma, cancer, and cardiac conditions and the scales measure, physical, social, emotional and school functioning (Varni, 2013).	a) Child version: for children aged 8 to 12 years old b) Parent version	Emotional, School and Social and Physical Functioning Scales (Varni, 2013)	Responses made on a 5 point Likert Scale and Scores are standardised to be in the range (0-100). Cronbach Alpha of above 0.70 in both parent and child version questionnaires (Upton, 2005)
Short Form 36 Health Survey	Generic measure that gives a summary of physical health and mental health scores and can be used to compare the burden of	Used for people aged 14 years and older	comprises of 36 questions that have eight scales: physical functioning, role-physical, social functioning, vitality,	In each subscale the scoring ranges from 0 to 100. Cronbach Alpha between 0.80 and 0.92 across the subscales (Abbott et

	diseases (Ware & Sherbourne, 1992).		mental health, emotional role functioning, bodily pain, social functioning, (Ware & Sherbourne, 1992)	al, 2001)
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Participants

The participants in the studies were children and or adolescents with CF. The majority of participants in the studies were recruited from routine clinic visits and outpatient or inpatient clinics. However, there were some participants in three of the studies who were recruited from large databases, for example epidemiological databases.

Design

Four studies were longitudinal designs (Sawicki et al., 2011; Swisher & Moffett, 2010; & Tluczek et al., 2001), with the remaining studies cross-sectional in nature, assessing HRQOL at just one point in time.

Aspects of HRQOL Research

Parents Haverman's et al. (2006) and Hegarty et al. (2008) both included parents in their HRQOL studies and found that parents rated the domain for treatment burden higher than their children. Overall parents HRQOL scores in this domain was lower than the children's scores. However, the demographic details of these parents are not provided and it would have been better if these were provided to put the various differences in HRQOL domains into perspective.

Pulmonary function and HRQOL Pulmonary function tests are common at the CF clinic visits and measure respiratory function and lung damage (Havermans et al., 2006). Some studies found strong associations between HRQOL scores in the respiratory and physical domain and lung function (Thomas et al., 2006; Tluczek et al., 2011), such that HRQOL was positively correlated to lung function, respiratory and physical domain.

Comparisons Gender differences have been observed in the life expectancies of patients with CF, with females having a lower life expectancy compared to males (Arrington-Sanders et al., 2006). These differences are also observed in HRQOL with males reporting higher HRQOL scores than females (Arrington-Sanders et al., 2006; Hegarty et al., 2008). Abbott et al. (2001) found differences between German and English adolescents, with the English adolescents reporting significantly poorer HRQOL.

Measures

Across the articles, four main measures of QOL or HRQOL were used (See Table 3), with the Cystic Fibrosis Questionnaire (CFQ) being the most frequently used measure. HRQOL measures used in this review can be classified into generic and disease specific measures. Generic measures were originally developed to explain health from the patient's perspectives and are applicable to a wide range of diseases (Abbott, Webb, & Dodd, 1997). The Paediatric Quality of Life Inventory (Thomas et al., 2006), Child Health Questionnaire (Arrington-Sanders et al., 2006; Kosciak et al., 2006; Powers et al., 2001;), and the Short Form 36 Health Survey (Abbot et al., 2001) are the generic measures of choice with patients with CF.

Discussion

This systematic review explored the research on HRQOL in children and adolescents with CF. After a systematic search of the literature, data extraction and assessment of risk of bias various key findings were identified.

Quittner, et al. (2010) and Sawicki et al. (2011) recruited participants from the Epidemiologic Study of Cystic Fibrosis database and their studies had the highest number of participants. The database has a collection of several CF centres in USA and Canada with

clinical and demographic data of patients who receive care from these centres (Morgan et al., 1999). It could be assumed that the participants in these studies are therefore representative of the children and adolescents with CF in the USA and Canada. Patients with CF regularly attend routine clinic assessments and this was the most common way of recruiting participants (Palermo et al., 2006; Arrington-Sanders et al., 2006; Powers et al., 2006; Tluczek et al., 2011; Havermans et al., 2005; Swisher, & Moffett, 2010). By recruiting participants in this way, it is convenient for both the researchers and the participants as the research is integrated into their regular routine. Though this may be a convenient sample, researchers are able to target the right sample for the studies.

Some of the papers included controls in their studies and although this provides a way of comparing of HRQOL results the comparability may not always be possible when using a disease specific measure such as the CFQ. However, when utilising a generic measure a comparison is possible as indicated in the study by Abbot et al. (2001). Therefore, in order to allow for comparisons, future studies on HRQOL can include healthy controls when using generic HRQOL measures. Thomas et al. (2005) included comparisons of HRQOL with samples from two different countries. However, in the article it is difficult to ascertain how comparable these two groups were and to establish the similarities or differences between the two groups. Additionally, understanding HRQOL for CF in terms of cultural contexts is important if comparisons are to be made because different cultures and may have different ways of coping with CF (Abbott et al., 2001).

The findings by Sawicki et al., (2011) and Tluczek et al., (2001) are particularly interesting because they found minimal changes in HRQOL over 1 year and no association between changes in pulmonary health and HRQOL. It has been suggested that these minimal HRQOL changes over time are because CF patients get used to their way of life of CF and

because they have lived with the illness their whole lives, to them it would have become a normal way of life (Tluczek et al., 2001). Therefore, even though CF may seem like a burden for them it has become a regular part of their life. This is consistent with Holmbeck, Bruno, & Jandasek (2006) who suggested that longitudinal designs are particularly useful when used in chronic health conditions at critical developmental transition stages for example from childhood to adolescence. This seems to suggest that cross sectional designs which are representative of the majority of studies in this review are just as powerful as the longitudinal designs when assessing HRQOL in defined developmental stages that have no transitions.

Generic and disease specific measures were used in this review. However, generic measures are not sensitive to the changes in HRQOL for CF patients (Abbott, Web & Dodd et al, 1997). This is consistent with the findings by Thomas et al., (2006) who used both a generic HRQOL measure and a disease specific measure for HRQOL and found that there was a correlation between pulmonary function and CFQ scores but no correlation between pulmonary function and the PedsQL.

The review from Abbott et al. (1997) identified the need for a disease specific measure to be designed and this current literature review has identified studies that have utilised this disease specific measure that has been developed since the Abbott et al, (1997) review. They suggested that disease specific measures would be able to detect changes in the HRQOL scores when the patient's condition has improved or deteriorated (Abbott et al., 1997). This is supported in this review by the studies by Modi et al. (2010) and Thomas et al. (2006) who found that the CFQ-R was more sensitive to changes in HRQOL than the generic PedsQL measure. Studies measuring HRQOL in patients with CF should therefore aim to always use the CFQ which is a disease specific questionnaire. The CFQ can be incorporated into the routine clinical assessments for CF patients. The results can be used to address specific QOL

concerns (Hegarty et al., 2008) leading to individualised treatment. The questionnaire can also aid in communication between the patient and the health professional by providing information on daily functioning and can be used to assess the efficacy of new treatments (University of Miami, 2008).

Incorporating other measures into HRQOL research can provide a more detailed view of HRQOL. Palermo et al. (2006) incorporated a pain measure into their study revealing a significant negative correlation between pain and HRQOL. However, the details of some of these pain measures used were not mentioned and it is therefore difficult to ascertain which pain measures are associated with HRQOL. In contrast, Szyndler et al. (2005) incorporated three different measures in addition to the CFQ and these are mentioned in detail. From this study, it can be concluded that looking at the CF patient in terms of a holistic view and not only in terms of how well they are functioning in relation to their disease but incorporating psychological and social variables is valuable.

It is useful to know the parent's perspective of the child's HRQOL as they are often part of the treatment regimen that patients with CF undertake. Powers et al. (2001) suggest that future studies should look into the specific roles of mothers and fathers and also the time spent doing parental activities. This is because these roles may affect the way that the parent answers the parent report of the questionnaires.

Implications for clinical practice

From this review it emerged that HRQOL is an important measure to be included in the regular assessments of CF patients. More specifically the CFQ-R measure should be used as it is a more sensitive measure than the other generic measures. It provides valuable information about CF from the patient's perspective and not the physician's (Abbott et al.,

1997). This brings the focus more on what would benefit the patient in terms of treatment options and also any support they may need. Additionally, as this HRQOL measurement has different domains it would assist the MDT to identify which aspects of the patient's life need to be addressed and the appropriate treatment or interventions are provided. Including parent reports in the HRQOL assessments would assist in clinical practice by exploring any disagreements or conflicts that exist within the family which may in turn have an influence on the complex treatment regimen for CF.

Implications for future research

As suggested by Thomas et al (2005), longitudinal studies over time in different developmental stages need to be researched to ascertain how HRQOL changes over time or if it remains the same. Studies would also need to identify how often the HRQOL measure needs to be administered. Future research could look into parental roles and existing family dynamics and how they are related to the parent's perception of children or adolescents HRQOL (Powers et al., 2001).

Strengths and limitations

The main strengths of this review is its stringent search process which enabled a focus on only children and adolescents with CF and also the incorporation of the quality checklist for the papers that were included. However, there are some papers which did not separate the adults and the young person's results and had to be excluded. This potentially excluded some good quality papers.

In conclusion, this review has highlighted the different types and areas of research in HRQOL in children and adolescents with CF. HRQOL measurement should be incorporated at the routine clinic assessments. It is also quite clear that the CFQ is a more sensitive

measure when it comes to HRQOL measurement in CF and this should be the measure of choice during the assessment. It is difficult to come up with a general conclusion on what the level of HRQOL is in children and adolescents with CF due to the variations in CF severity. However, overall, it can be assumed that they tend to have overall good HRQOL with males having better HRQOL than the females.

CHAPTER 2

Placement 2 presentation. Learning disability services: The past and present

Learning Disability Services: The Past and Present



By

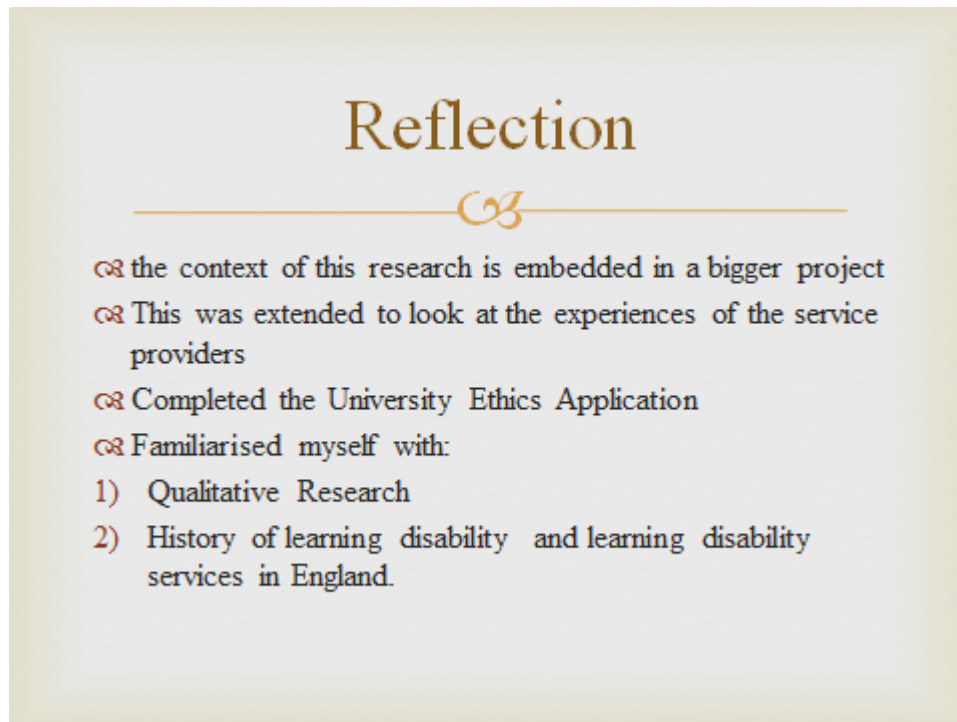
Primrose Nyamayaro
MRes Clinical Psychology Student
University of Birmingham

Aims of this presentation



- ☞ Reflection on the spring placement
- ☞ Brief introduction to my summer project
- ☞ Review of learning disability services: history and the present

Reflection



I started this placement by familiarising myself with literature on providing social care services to adults with learning disabilities (LD). This was because my placement was part of an on-going project entitled “People with learning disabilities from black and minority groups: An exploration of their experiences and views of services”. My supervisors aimed to extend the project to include the views of social service providers in providing services to adults with LD from the Black and Minority Ethnic (BME) communities to explore any barriers faced and inform service provision. After submitting the university ethics application form for the extension of the project, I started working on this presentation.

I decided to focus on the past and present context of LD service provision in the UK rather than on the ethics application process because focusing and outlining the historical and current context would assist me to better understand experiences faced by service providers which I will explore in my summer project. Therefore my main placement goals were to

understand the context of LD in the UK through this presentation, get university ethics approval for the project, reading literature about qualitative research and also gathering literature for the summer project. Furthermore, the preparations of consent forms, information sheets and letters of invitation for the research were also part of the goals. All these goals were met in this placement.

This placement enabled me to think more effectively on issues regarding ethics for qualitative research, for example, informed consent for recorded interviews and storage of participant's data. It also provided me with a holistic view on what my final project would be about.

Researching the history of LD and what used to happen to people with LD in the past enabled me to see the shift into social care and to understand some of the challenges faced in social care provision today. Consequently, one of the aspects of social care provision is to respond to and cater for the cultural differences amongst service users. Reflecting on where I am originally from which is Zimbabwe made me realise how different the UK context of LD is from my country's own. I appreciated the changes that have occurred over the years and how they have made a difference to the context of LD in the UK today.

Introduction



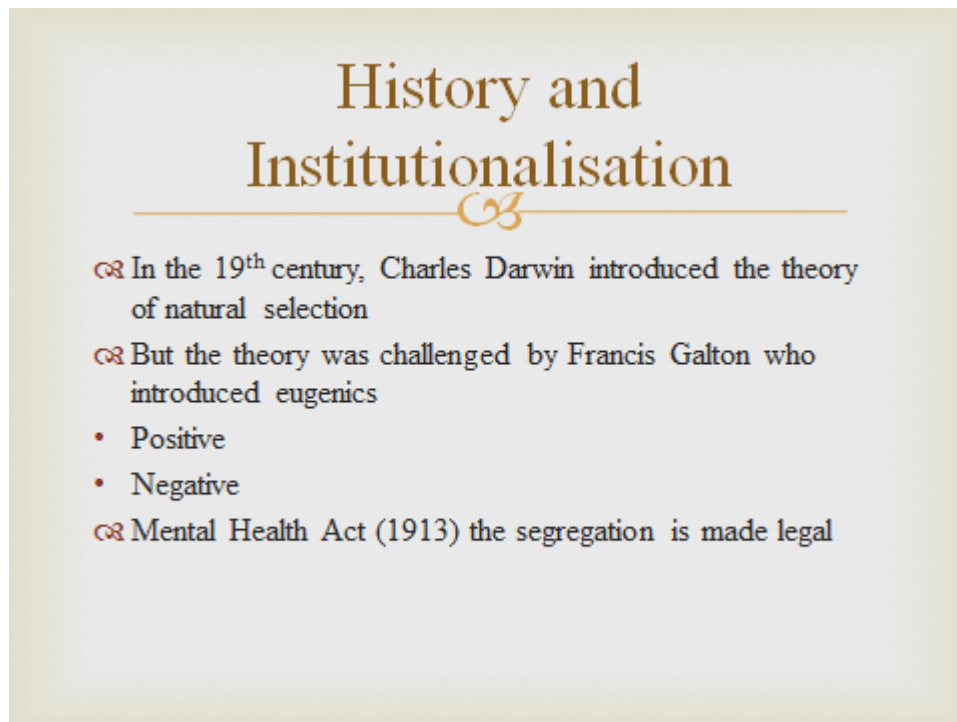
Introduction

- ⌘ Learning Disability
 - Reduced ability to understand complex information, cope independently, and has a lasting effect on development.
- ⌘ Estimated to affect 1.5 million people in the UK
- ⌘ It is different from learning difficulties
- ⌘ They can be classified into:

Type	IQ Range
Mild	50-70
Moderate	35-49
Severe	20-34
Profound	Below 20

LD is defined by the Department of Health (2001) as the “presence of a significantly reduced ability to understand new or complex information or to learn new skills, a reduced ability to cope independently, and an impairment that started before adulthood, with a lasting effect on development.” It is estimated that around 1.5 million people in the UK are affected (NHS, 2013). This should be differentiated from learning difficulties, a term usually used in education services to refer to specific difficulties such as dyslexia in which there is no significant impairment of intelligence (Emerson and Heslop, 2010). The National Health Service (NHS, 2013) classifies LD into mild, moderate, severe and profound. Many people with LD require assistance with day-to-day living. Such service provision has evolved over

time from early institutionalisation to care in the community, along with political and social development in Human Rights.



In the 19th century, Charles Darwin introduced the theory of natural selection. This theory suggested that nature could be relied upon to select the relevant characteristics that would aid survival of the human race (Atherton, 2003). Francis Galton challenged this theory, suggesting that survival should be maintained by artificial processes called eugenics. Positive eugenics referred to the process of promoting procreation within the intellectual classes whereas negative eugenics was inhibiting procreation amongst those who were “socially deviant” (Atherton, 2003). In Great Britain those classed under negative eugenics were segregated and separated from intellectuals, giving rise to institutions (Atherton, 2003). Following this, the Mental Health Act (1913) was introduced to legalise the detention of segregated individuals who were also seen as economically unproductive.

History and Institutionalisation

Reason for institutionalisation?

- So that they do not reproduce others who were like them

How did the institutionalisation happen?

- The local authorities had to identify them and if found to have a learning disability they were labeled as such and institutionalised

In Accordance with this Act, ‘mental defectives’ were segregated because they were seen as being a threat to society and in 1929 about 100 000 people were eligible for segregation (Farmer, Rhode, Sacks, 1993). The main reason for institutionalisation was because there was fear that “feeble minded” people would “repeat their type” resulting in the “propagation of a degenerate stock” (Atkinson, Jackson & Walmsley, 1997).

Furthermore, local authorities were required to identify and certify ‘mental defectives’ and special institutions were established to house them (Atkinson et al., 1997).

The turn to social services and care in the community

The Turn to Social Services & Care in the Community



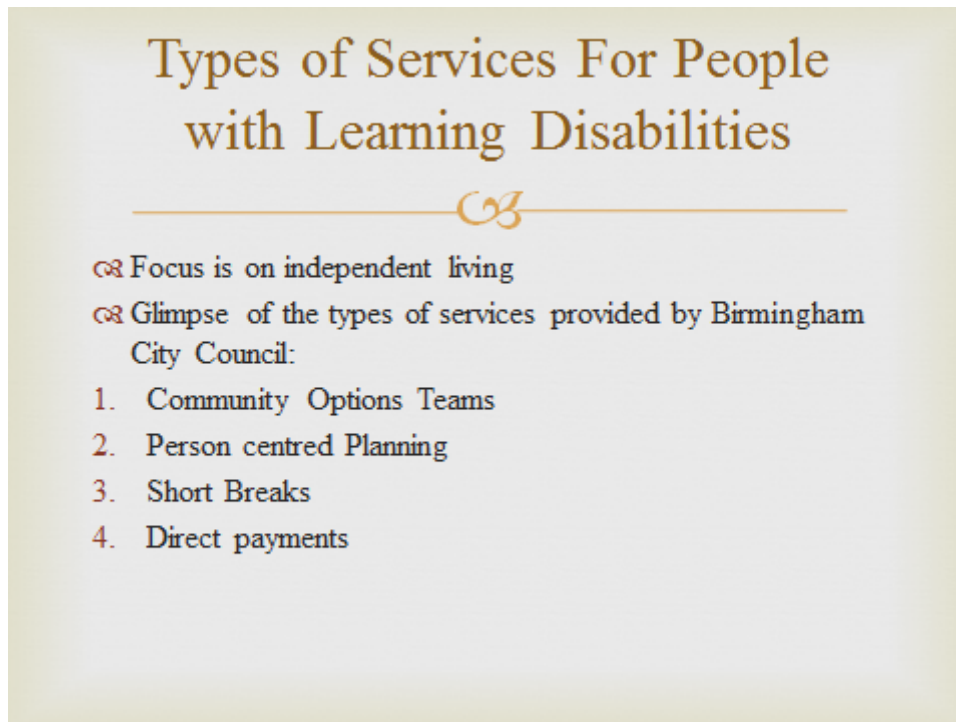
- ☞ Most of it started in the 1970's
- ☞ Example of turning point:
 - The white paper: "Better Services for the mentally handicapped"
- ☞ The Introduction of the Community Care Act (1990)
 - local authorities being given more responsibilities with regard to people with learning disabilities

There was a shift and change in ideology from institutionalisation to resettling in community residences. Large scale deinstitutionalisation occurred to promote inclusion and today segregation would be regarded as abhorrent.

In the 1970's a white paper entitled "Better Services for the Mentally Handicapped" (Farmer et al., 1993) was published. Suggestions from it included early diagnosis of LD, research into causes of LD, introduction of residential services, and avoiding segregation to encourage inclusion in the community.

The Community Care Act (1990) played a major role in shaping modern social services in the United Kingdom. The Community Care Act suggested changes to be made in social care (Swann, 1997). Local authorities became responsible for providing community care, planning the development of the service, and collaboration with health professionals to design and deliver services to people with LD (Swann, 1997).

Types of services for people with LD



Currently, social services help people with LD to live independent lives in the community. Birmingham City Council (chosen because of its locality) provides examples of services that are available (Birmingham City Council, 2013).

These are:

1. Community Options teams: Services provided focus on helping to determine and support adults in doing activities they enjoy, for example, going to the cinema.
2. Person centred planning: which focuses on helping people evaluate their life and talk about plans for their future, facilitating any changes they would want to make. This is also an opportunity to establish any particular support they would need. It is different from the medical models of disabilities that are set up to assess needs, allocate services and make

decisions for people (CareUK, 2013). Rather, it has the person at the centre and provides services based on what would best suit the individual (CareUK, 2013).

3. Short breaks: An opportunity to have a short break away from carers or home.
4. Direct Payments: A system whereby people are given the independence to be in charge of their social care budget and making decisions on the support they need

Overall, these services aim to promote independence and inclusion in the community.

Contemporary services for people with LD



In England the most common form of care comes from Community LD Teams which are often headed by social care services and have multi-disciplinary staff in charge of physical and mental health care, social care and resettlement (Bouras & Holt, 2004). People with LD often have poorer health and commonly experience respiratory, coronary and physical health problems (Royal College of Psychiatrists, 2012). Behavioural needs such as challenging

behaviour (CB) are also prevalent (Emerson, 1995). Emerson (1995) defines CB as “behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities” (page 44).

The MDT teams usually consist of a Social Worker, Community Nurse, Clinical Psychologist, Physiotherapist, Speech and language therapist, Psychiatrist, Dietician and Occupational therapist (Birmingham Community Healthcare, 2013). The Clinical Psychologist often plays a key role in providing interventions for CB by providing functional assessments and intervention, and also specialised therapy (British Psychological Society, 2011). However, not all people with CB may have access to a Clinical Psychologist due to lack of resources.

The move from institutions was characterised by a move to large group homes, however, group homes have reduced in size over the years (Mencap, 2009) to reflect typical community residences. Various types of residential services are available. This includes supported living where adults have the opportunity to live in a self-contained home but with support available from staff who are onsite 24 hours a day or from a support worker who provides a certain amount of support each week (KeyRing, 2013; Supported Living UK, 2013). Such service provision is currently increasing in popularity along with the political movement towards ensuring people with LD have equal rights and opportunities. Camphill is an example of a contemporary service that offers services such as schools for tertiary education, and residential communities (Camphil, 2013).

Issues in social service provision

Issues in Service Provision

⌘ Underutilisation of services:

⌘ 828000 are known to the services in UK but only 177000 use them

⌘ Why?

- Physical health related problems not looked into at social care services
- Services are too generic
- Limited employment opportunities
- Lack of awareness of services available (Hatton, 1998)

Emerson, Hatton, and Robertson (2011) state that many adults with LD do not use the services available to them. This is supported by Holland (2010) who found that more than 828,000 adults in England have LD and only 177 000 utilise LD services. Social care services are not freely available to everyone, after an assessment, predominantly by a social worker, a decision is made on whether the person is eligible for free care or has to pay (CareUK, 2013). Currently, there is a programme of reassessment of all adults with LD in relation to the social care provision. Birmingham City Council for example provides social care provision to people with substantial and critical needs only (National Audit Office, 2013). This means those with low to moderate needs do not have access to social services.

The Department of Health (2001) identified some issues in social service provision:

These included:

1. Healthcare needs of people with LD not being addressed. If this occurs then it may affect how they benefit from social care
2. Not tailoring day services to each individual. Each person has different needs and these should be addressed accordingly
3. Not having adequate employment opportunities. If this is addressed then it will contribute even more to the independence of people with LD.

In addition, Hatton, Azmi, Caine, and Emerson (1998) proposed a lack of awareness of the availability of services to be a problem within social care provision. This is mostly applicable to people from the BME communities. This indicates the potential for specific considerations to service provision to people from BME communities.

Issues in Service Provision

- Staff stress and burnout and in service providers
 - Leading to reduced quality of care
- Challenging behaviour (Baker, 2013)
 - Services need to be tailor made to address the complex needs
- Mental health problems in people with learning disability
 - Overshadowing usually occurs

Staff stress and burnout and in service providers

Stress is particularly high in staff providing services to people with LD (Alexander and Hegarty, 2000). Stress may result in burnout which is “a prolonged response to chronic emotional and interpersonal stressors on the job” (Maslach, 2003 p.189). Maslach and Johnson (1986), suggest that burnout and stress have consequences that affect both staff and service users because it results in a reduced quality of care, low morale, and high job turnover. One of the common factors that lead to increased levels of stress and burnout in service providers to people with LD is challenging behaviour (Raczka, 2005; Mills and Rose, 2011).

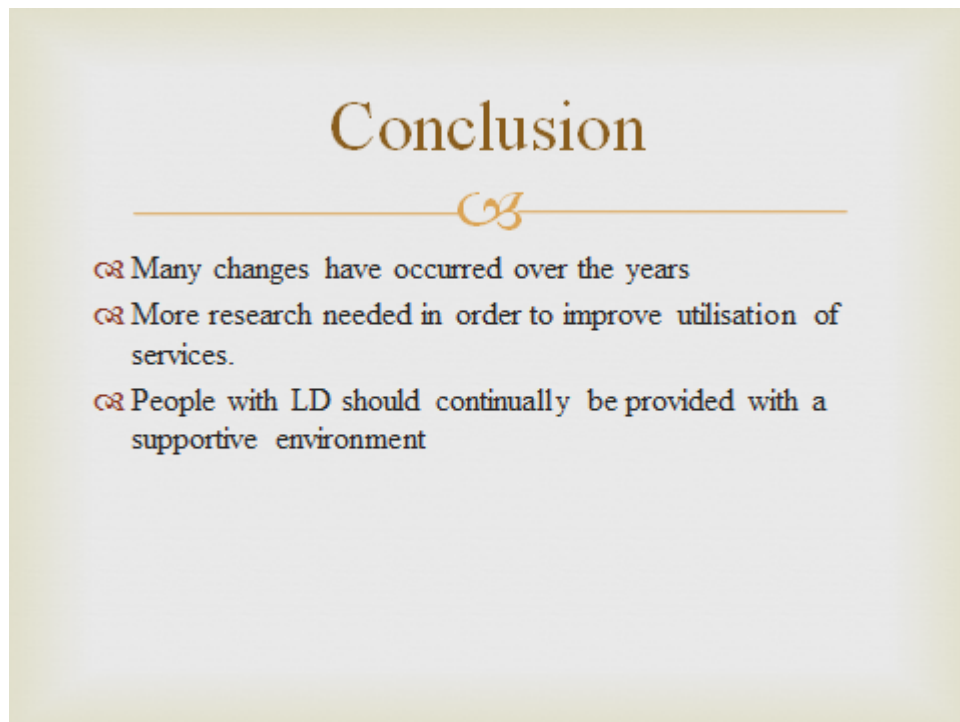
Challenging behaviour

CB is likely to impair personal development and family life and represents a challenge to services, families and to people with LD (Mental Health Foundation, 1997). CB such as aggression, destruction and self-injury are prevalent in 10%-15% of people with LD, and these peak between the ages of 20 and 49 (Emerson et al., 2001). However, prevalence has been reported to be as high as 60% (Zarkowska & Clements 1988). Services need to be adapted to address challenging behaviour (Baker, 2013) adding complexity to the climate of service provision.

Mental health problems in people with LD

The prevalence of mental health problems such as schizophrenia, anxiety and depression is estimated to be between 25% and 40% in people with LD (Foundations for People with Learning Disabilities, 2013). People with LD are less likely to seek help for mental health problems and when they do they are likely to be overshadowed with the mental health problem being attributed to LD (Giraud-Saunders, 2013). There are often disagreements between mental health services and specialist LD services with regards to who

should provide mental health services for people with mild to moderate LD as they do not appear to meet eligibility criteria for some services (Giraud-Saunders, 2013).



Conclusion

The approach to people with LD has changed over the last century from a stance of persecution to one of inclusion. As social care services continue to evolve and improve, the lives of people with LD are also likely to continue to improve as people become more independent and integrated into the communities they live in

CHAPTER 3

Summer project: Social service provision to people with learning disabilities from black and minority ethnic communities: The view and experiences of service providers

Abstract

People with learning disabilities (LD) from Black and Minority Ethnic (BME) communities report dissatisfaction with some of the services provided to them. This study aimed to explore the views and experiences of service providers in providing social care services to adults with LD from BME communities. Nine interviews were conducted and data analysis was carried out using Interpretative Phenomenological Analysis. The themes from these interviews centred on different complexities regarding service provision, the importance of being open minded as a service provider, looking out for the service user's best interests and the constraints of short term funding. The findings from this study indicated that service provision to BME communities was a challenging and complex process. Nevertheless, service providers still strove to be culturally competent. These findings may be utilised to inform guidelines for supporting social care service providers working with BME communities.

Introduction

There is increasing cultural and ethnic diversity in the UK. Social care providers are interacting with people from diverse backgrounds and cultures who may have different expectations and help seeking behaviours (Fulton & Richardson, 2010). There is increased concern expressed by family carers regarding service provision to people with learning disabilities (LD) from Black and Minority Ethnic (BME) groups because they consistently express dissatisfaction with some services (Hubert, 2006; Mir & Tovey 2003). It is therefore important to understand the views of the service providers regarding this dissatisfaction. This includes any barriers faced in providing services to people with LD from BME communities.

BME communities currently make up at least 14% of the population in England and Wales (Office for National Statistics, 2012). These minority groups can be categorised as Asian 7.5% (Pakistani, Indian, Bangladesh, Sri Lankan, Chinese), Black 3.3% (Black British, Black African, Black Caribbean), mixed or multiple ethnic group 2.2% and other minority groups 1%. The prevalence of LD in the Black and other minority groups is not well documented (Raghavan, 2009; Learning Disability Working Group, 2011) compared to the figures on prevalence rates in South Asian communities (Pakistani, Indian, Bangladeshi).

Prevalence of severe LD has been reported to be three times higher in South Asian communities compared to the White British population (Emerson, Azmi, Hatton, Caine, Parrott, & Wolstenholmed 1997). There are a number of reasons suggested to explain this increased prevalence and one that is of major concern is consanguinity, which is first cousin marriages that lead to poorer birth outcomes (Raghavan, 2009). However this should not be considered as the main causative factor (Raghavan, 2009).

A school based survey found increased prevalence of severe LD in the South Asian community compared to the Black, White and mixed race participants (Kerr, 2001). Moreover, Morton, Sharma, Nicholson, Broderick and Poyser (2002) found a higher prevalence in the Pakistani community compared to the Indian, Bengali, Chinese, Black African, Black Caribbean, and European populations. In contrast, a study conducted in Leicestershire compared the prevalence of LD in the White and South Asian population and found that they had similar prevalent rates (McGrother, Bhaumik, Thorp, Watson & Taub, 2002). The literature is therefore inconsistent in terms of reported prevalence rates. True prevalence rates are not known.

The Department of Health (2001) published a White Paper entitled *Valuing People*. That highlighted a number of issues to be addressed and made proposals to improve the lives of people with LD. These proposals covered four main areas, legal and civil rights for example the right to marry, independence in daily living, inclusion in community activities and choice for example in places to live. It is important that this White Paper is understood within the context of the Government at that time and the policies of that time (Burton & Kagan, 2006). An update entitled 'Valuing People Now' was published by the Department of Health (2009) and it emphasised among other things the inclusion of everyone with increased emphasis on people from BME communities and a person centred approach to providing services. However, in the current political and economic climate some of the equality, independence and inclusion agendas expressed in these two white papers may be hard to maintain due to the cuts in funding to local authorities (Learning Disability Today, 2013).

In order to explore service provision and the utilisation of services it is important to understand the views of the service users as well as carers or families. Service users are

people with LD and carers are people who provide support for the person with LD. Relatively few academic studies have explored service provider's perspectives.

Azmi et al., (1997) interviewed South Asian adolescents and adults comprising of Pakistani, Gujarati, Bengali, and Indian communities. Though they expressed satisfaction with their life and support from families, some of the participants were dissatisfied with culturally inappropriate services in terms of food and non-recognition of special religious or cultural occasions (Azmi, et al., 1997).

Differences have been found in the experiences of mental health service provision between White British adults and Black British, Black Caribbean and Black African adults with mild LD in a study of understanding service user experiences (Bonnell, Underwood, Radhakrishan, & McCarthy, 2012). White British adults had more positive experiences than Black adults who expressed concern in the languages spoken by staff and experiences of racial discrimination (Bonnell, et al., 2012). The main concern regarding language in the Black group was that there was no staff that could speak the service user's first language. This study is unique in that they used the Delphi consultation method for data collection and service users were encouraged to express their views. However, because of the nature of the Delphi method a consensus regarding experiences has to be reached and this may leave out some specific experiences which may be of importance.

Double discrimination (DD) has been cited as one of the concerns with regard to the use of services by those from the BME community (Department of Health, 2009; Midland Mencap, 2009). This refers to the discrimination experienced by people with LD from BME communities because of both LD and their ethnicity or religion (Midland Mencap, 2009). South Asian adults and adolescents who identify themselves strongly with their culture often

experience DD when accessing services (Azmi, Hatton, Emerson, Cain, 1997). This was evident in a study by Emerson and Robertson, (2001) as service users experienced stigma due to LD, their ethnicity and use of derogatory terms.

Family carers are very important in service provision because they usually have the role to facilitate access to services (Bignall & Butt 2000). There have been more studies exploring family experiences. Concerns have been expressed regarding services by family carers caring for adults who were mainly originally from India and the Caribbean (Hubert, 2006). These included lack of support from the social workers and inadequate support given to the family when the main carer is elderly or ill. Similarly, Burke and Cole (2012) conducted a study to explore families' perspectives of staff from statutory services. Families expressed that staff usually do not acknowledge important cultural beliefs that may assist in support and described lack of follow up on issues affecting the families. Similarly, in a study investigating South Asian family views of health and social care provision, Mir and Tovey (2003) found that family carers had difficulties expressing their needs because the services provided to them did not fully take into consideration their cultural needs, for example language.

When dealing with families and service users from BME communities, cultural issues are of paramount importance. This is often applied via the concept of cultural competence. Cultural competence is the provision of "culturally responsive services to a multicultural clientele" page 2 (Harrison & Turner, 2010). This is achieved both at the individual level and the organisational level by converting what professionals and organisations know about diversity into policies and practices and incorporating that knowledge into service provision (Mir, 2008). To achieve cultural competence staff from BME communities may need to be employed in services for the workforce to reflect the people service is provided to (Mir, 2008).

Research into working with adults with LD in BME communities has mostly focused on healthcare professionals such as clinical psychologists and other healthcare professionals working in multidisciplinary teams (Heer, 2012; Summers & Jones, 2004). However, it is important to differentiate between health care and social care. Health care is mainly commissioned by the National Health Service (NHS) and usually comprises physical and mental health care. On the other hand, social care is mainly from local authorities or third sector organisations and comprises of support with daily activities (Health Committee, 2012). Amongst the key findings from Heer (2012) was that language barriers are faced by healthcare professionals when working cross culturally. This resulted in having to use professional interpreters but also family members as interpreters. However, it has been found that even though families can act as interpreters, professional interpreters are usually better as they are able to provide interpretations even for technical terms (Alexander, et al. 2004). The difficulties faced by Clinical Psychologists when working cross culturally in the study by Summers and Jones (2004) were mainly regarding marriage. These were specifically regarding the capacity of the person with LD to consent to marriage that families wanted them to commit to.

There is a gap in research concerning social care providers utilising rigorous qualitative methodologies to establish the views and experiences of social care providers to service users from the BME communities. Some of the existing research and documents include the views of service providers but the methods of analysis of these views have not been meticulous or grounded in qualitative methods (Hammerton, 2006; Mir, Nocon, Ahmad & Jones, 2001). Nevertheless, Mir et al, (2001) found that service providers often were not adequately equipped with detailed knowledge of the BME communities in order to provide

culturally appropriate care. In addition, in the study by Hammerton (2006), social care providers were often unaware of the cultural and religious needs of the service users.

Social care providers are responsible for providing services to people with LD. In order for them to provide culturally competent services, their views and experiences have to be considered. Therefore, the aim of this project is to investigate views and experiences of social care service providers who have experience in providing services to people with LD from BME communities using formal qualitative methods. The views of this crucial stakeholder group will help to identify current gaps and barriers in service provision that might inform the generation practical solutions to improve service provision.

Method

Context

This project was linked to an on-going study funded by the National Institute of Health Research (NIHR) on adults with LD from BME communities. The main objective of that study is to understand their views and experiences of service users with LD from BME communities. Consequently, in order to have a holistic view of social care provision for adults with LD from BME communities, it is important to explore the views and issues involved in providing services, from the point of view of service providers. This project addresses that question.

Participants

A range of service-providers from across Birmingham were interviewed, representing the broad spectrum of individuals involved in providing services to adults with learning disabilities.. Further details of the participants are presented in Table 1.

Table 1

Participant details

Pseudonym	Ethnicity	Gender	Type of Service	Position in LD Service
Rachel	Black Caribbean	Female	Statutory	Social Worker
Mary	White British	Female	Third Sector Organisation for Asian women with LD	Chief Executive Officer
Becky	White British	Female	Third Sector Organisation for people with Cerebral Palsy	Manager
Emma	White British	Female	Third Sector Organisation for people with Cerebral Palsy	Manager
Eric	White British	Male	Third Sector Organisation for adults with LD	Support Worker
Claire	White British	Female	Third Sector Organisation for adults with LD	Manager
Farah	Pakistani	Female	Third Sector Organisation for people with LD	Support Worker
Amira	Pakistani	Female	Third Sector Organisation for Asian women with LD	Support Worker
Sharifah	Pakistani	Female	Third Sector Organisation for Asian women with LD	Support Worker
Zahira	Pakistani	Female	Third Sector Organisation for Asian women with LD	Coordinator
Hamza	Pakistani	Male	Statutory	Social Worker

Punita	Indian	Female	Third Sector Organisation for Asian women with LD	Manager
Ranjit	Indian	Male	Third Sector Organisation for people with LD	Coordinator

Sampling The following inclusion and exclusion criteria were used when recruiting participants:

Inclusion criteria:

- Working in an organisation that provides social care to people with LD
- Experience of working with people from BME communities with LD
- Experience of working with adults aged 18 and over

Exclusion criteria:

- Health professionals for example physiotherapists and psychologists

Health professionals were excluded from this study because existing research has focused on the health care sector.

Ethical Considerations

Having been granted ethical approval from the University of Birmingham (See Appendix B), potential participants were identified through contacts from the aforementioned study. They were then contacted primarily via email. The letter of invitation, research information sheet and consent form, were sent to the potential participants (See Appendix C to E). Interviews were conducted at the participant's workplace. Before the interview, a brief overview and introduction to the study was given as stated in the information sheet. The participants were informed of their right to withdraw from the interview and were informed of confidentiality and that all data would be anonymised. They were also informed that confidentiality will be breached only if there was disclosure of poor practice for example harm or managed risk to others. Once they agreed to participate in the interview they signed

the consent form and with their permission the interview was audio recorded. The interviews lasted between 30 minutes to approximately 1 hour.

Reflection

In designing the methodology and process of data collection it was acknowledged that due to the nature of the topic under discussion it may have been difficult for the participants to talk openly about BME communities. This was especially the case in terms of referring to terms like “Black” or “White” or “Asian” due to the stereotypes and racial connotations that society has sometimes put to these terms. As an interviewer who is from a BME community, I did let the participants know they could feel free to talk openly and use any terms they felt necessary. I did prompt them if they had difficulties in articulating these concepts. In terms of the reliability of the information from participants who were managers, it was acknowledged that information provided may be presented in a more “we already do this manner” and from the perspective of the company rather than the manager’s own experiences. However, during the interview when this happened, I always tried to bring it back to their personal experiences.

Data Collection

A total of 9 interviews were conducted. Six interviews were conducted individually and 3 interviews were conducted in pairs. An interview schedule containing semi-structured questions and prompts to elicit the views and experiences of the service providers were used (See Appendix F). The audio recordings were transcribed verbatim and transcripts were analysed.

Analysis

The analysis of the transcripts focused on the verbal and semantic content of the data using Interpretative Phenomenological Analysis (IPA). IPA is an approach in qualitative research. Its main objective is to understand what personal and social experiences mean to people who experience them (Shaw, 2010). The guidance from Smith, Flowers and Larkin (2009) was used for the analysis. This enabled the extraction of meaningful information from transcribed data in the form of themes revealing the perceptions, views and experiences of the participants.

The process of the data analysis started by reading and re-reading of the transcripts and making some exploratory notes comprising of descriptive comments, linguistic comments and conceptual comments (Smith et al., 2009). These comments were then combined into the emergent themes for each of the different sections of the transcript. Following this, the emergent themes in each transcript were clustered together. Each section of these clustered emergent themes was denoted a general theme or superordinate theme and under each superordinate theme there was a subtheme with the line and page number of the transcript containing the quote relating to that subtheme and further interpretative comments (See example in Appendix G).

In order to develop the common themes or objects of concern across the participants using the transcripts, the themes for each transcript were printed on different coloured paper. These different coloured papers were spread out across a floor and objects of concern that were ‘‘similar’ across the transcripts were then clustered together (See Appendix H). Following this, abstraction took place, which is a way of combining common objects of

concern together and establishing a name for that cluster called a superordinate theme (Smith, et al., 2009).

During the process of analysis I received supervision from my two supervisors. In these supervision meetings, the discussions and guidance I received ensured transparency and that interpretations made were grounded in the participant's responses in the transcripts.

Results

The main themes across transcripts are displayed in Table 2. Four superordinate themes emerged from the analysis and these will be described in more detail.

Table 2.

Main themes and number of participants representing each subtheme

Super Ordinate Theme	Sub theme	Number of Participants Representing Each Subtheme
Service provision to BME communities is a multifaceted and complex process	<i>Family influence service provision</i>	3
	<i>Fine line between cultural threshold and advocacy?</i>	3
	<i>Understanding culture, language, families</i>	10
	<i>Negative Emotions</i>	7
Looking out for the best interests of the service users and families	<i>Vulnerability of Service Users</i>	5
	<i>Vulnerability of families</i>	6
It is important to be open minded as a service provider	<i>Focusing on what the service user wants</i>	7
	<i>Avoiding stereotypes in service provision</i>	4

Loss of control in service provision: services are controlled and determined by funding	<i>Reactive model of service provision</i>	4
	<i>Funding as a barrier for both service user and service provider</i>	4

1. Service provision to BME communities is a multifaceted and complex process

This superordinate theme focuses on factors unique to service provision to the BME community and the complexity of service provision because of those factors. Staff described a need to understand the service users' family along with how they influence service provision. As part of understanding the families and service users, service providers also talked about the importance of considering the cultural aspects of certain BME communities for example marriage. When staff provides services, there are language difficulties that are encountered and also negative emotions. In understanding the families and the cultural aspects of the BME communities staff indicated that there may need to be a balance between respecting culture and being an advocate for the service user. However, this may mean confronting cultural beliefs. Combining all these factors portrays the complexities that service providers are faced with.

Families influence service provision

For some participants, family structures posed a challenge to service provision. Service providers described how service users were not given opportunities to make independent decisions regarding service provision and how their perceptions were not always considered by families. From Becky's experiences, when providing services to service users from BME communities, service uptake may not occur because of what the families want. This is illustrated in the quote by Becky in Table 3. Families were often represented as having ultimate control over service provision and there was a sense of helplessness in Becky's account. What the family says is what will stand. There is only so much that service providers can do to challenge the family's decisions as sometimes they may need to "walk away". This may be an implication that she feels she has to abandon the service user in such cases. The

influence of families is also portrayed in the quote from Eric. He emphasised that families may have their own perception of service provision. This may mean that Eric as the service provider ought to respect these perceptions and not take offense when asked by a family to stop supporting a service user.

Table 3.

Quotes for subtheme: Families influence service provision

Main Illustrative Quotes

Becky: “We wanted the young lady to come because she very much wanted to come but the family said no (...) Sometimes we have to walk away from a person that really wants to come to us but the family is saying no”

Eric: “I have been moved a couple of times like I said over small things like that which were not my fault or the member's fault, it was just an interpretation from the family once again. It's never the member, (...) It's always the family. Always, that's what I've experienced, never the individual, they're not bothered. They're happy to see different people, oh that's interesting, you know what I mean, it's the family who are engrained in what they want.”

Fine line between cultural threshold and advocacy

The service providers discussed how they often encountered cultural issues that need to be respected and considered in service provision. There was a challenge in maintaining a balance between offering support and advocacy for service users but at the same time respecting culture and cultural norms. An example of an aspect where this challenge was

faced is marriage. When dealing with issues regarding marriage, service providers were faced with difficulties regarding the extent to which they should be involved.

Hamza and Rachel, who were both social workers emphasised the sensitivity of the marriage issue particularly focusing on forced marriages (see quote in Table 4). Hamza who is Pakistani finds it difficult to differentiate between what is a forced marriage and what is not forced. Especially when assessing the capacity of the service user, he states that he would need to always remember that the parents are looking out for the best interests of their son or daughter, and culturally he can relate to that. However, though he may understand them culturally, as a service provider he may still have the responsibility to advocate on behalf of the service user if he or she does not have capacity. The process of balancing these two aspects is a challenging task. Hamza mentions the need to be “culturally sensitive” and as he belongs to the Pakistani culture it may be facilitative but conversely it can make it difficult.

Participants stated that marriage is a cultural and social norm which parents may feel that their child with LD has a right to. As a service provider, the complexity comes in because it seems as though staff are preventing the service user from taking part in a common norm. If the service user does not have capacity then the service provider is therefore faced with a challenge of explaining why they should not take part in this norm. This may not always be acceptable to families.

Table 4.

Quotes for subtheme: Fine line between cultural threshold and advocacy

Main Illustrative Quotes

Rachel: “There’s this drive about erm forced marriages isn’t there? Hamza: But the thing is right, you’ve gotta look at it in a very culturally sensitive way right. Rachel: Exactly. Hamza: Now what is forced and what they feel is not forced but is supporting their loved one? Rachel: Exactly. Hamza: How they perceive it to be. Rachel: It’s maintaining a cultural norm and they could say why coz they have disabilities? Why can they not take part in the norms of...Hamza: society. Rachel: yeah what we all do”

Hamza: “They wanted him to get married. Take him back to Pakistan and get him married, and they said yeah we know somebody who can provide support for him and look after him and so on and his wife is going to come over and everything is going to be okay. Well obviously we tried to support the service user to see if they’ve got capacity. It was that he didn’t have capacity and the family didn’t like that. Right so all of a sudden the doors where shut on us. (...) Everybody thought mum and dad were the evil ones. I understood their fears, immensely I understood their fears. I: you understand them because they’re from a similar culture as you. Yeah I understand them yeah (...) it does become difficult at times”

Understanding culture, language, families

Culture, language and families are factors often intertwined in service provision. There are contrasting views between Mary and Punita regarding cultural similarity in service provision. Punita, who is Indian, emphasises that cultural similarity between service user and service provider is facilitative because she knows the beliefs that exist in the Indian

communities regarding LD (see Table 5). This puts her in a favourable position to challenge irrational beliefs. She implies that there is more credibility and success if beliefs are challenged by someone from the same culture. She also states the difficulty that a “white colleague” may face difficulties when working cross culturally. This seems to add additional complexities when working across cultures. From Mary’s experiences in working with BME communities she has experienced that being from the same culture as the family or service provider can be unhelpful. From her experiences, cultural sensitivity is the most important aspect when providing services and not cultural similarity between service provider and the service user. She states that this may be because families may not want service providers from their own community to be involved in issues that families perceive as awkward.

Based on cultural or religious beliefs, some families will not want their daughter to attend services that have both male and female service users. This statement is illustrated in Table 5 by Zahira’s experiences of working with families and individuals from the Asian community (Bangladeshi, Indian and Pakistan). This also reinforces the influence that families have in service provision as portrayed in the first subtheme. Though the service users may not necessarily share the same views as their families, their families’ views take precedence. It is important therefore, for her to ensure that the services provided meet the communities’ or families expectations.

Language was recognised as being a barrier to service provision by almost half of the participants. Hamza and Rachel acknowledge that though they may not have experienced any barriers thus far, it definitely is something that is of huge concern in service provision. The importance of language is also portrayed in the quote from Claire (see Table 5) as that may determine whether a service will be provided or not. Mary emphasises that language barriers may usually be with families of service users and not necessarily the service users. According

to Mary this may mean that service provision may still occur since the service user speaks English.

According to the service providers knowing the families' first languages helps in building relationships with families, resulting in successful service provision. The quote from Farah highlights that knowledge of first languages is of great importance for the mothers of service users. Shared language helps build relationships and was felt to give families clarity and understanding of what services are being offered. As indicated in the first subtheme, "families influence service provision" and language barriers need to be addressed in order to have successful service provision.

The changing cultural dynamics in Birmingham were implicated as another challenge. There are "new" BME communities that are settling in the UK. As stated by Ranjit describes (see quote in Table 5) how some service providers are not equipped with language skills spoken by these emerging communities. Therefore, because the demographics are changing, this adds further complexity.

It was the experience of some service providers that within the Asian community even though families may need support, they may not take up the services because it is unacceptable in their culture to admit that they need help. This is illustrated in the quote from Hamza (see Table 5). The culture being referred to in the quote is specifically the Pakistani culture, which Hamza belongs to. From his experiences it seems as though being from the same culture makes it more difficult to offer and provide support and he ought to take care not to offend. For Hamza, in order to do this he may need to encourage them that it is acceptable to seek support. This may help families to not feel guilty (as stated in the quote from Rachel)

but instead to understand and work through the tension of the belief that they need to cope but they cannot.

The norms and beliefs of the families play an important role in service provision. Service providers gave contradictory views regarding their experiences of extended family support in BME communities. Whilst Eric believes that “they have extended families that still function and work” the quote from Zahira in Table 5 contradicts this view. Zahira states that family dynamics are changing with time and the extended family may not be available to help like they used to. For Zahira, this seems to suggest that as a service provider it is important to understand the dynamics of the family that you are working with. In the families as well there is denial that they need support and there also exists an adherence to cultural norms that transcends reality, i.e. not coping.

Table 5.

Quotes for subtheme: Understanding culture, language, families

Main Illustrative Quotes

Punita: “we can understand where they might be coming from and it's almost like you agree with it initially because you know you can work on it and educate the parents to say you know let's look at it this way, this is what the condition is but if somebody, say it's a white colleague went in and they heard black magic they won't understand that that is a cultural thing and immediately they'll say no it's not, it's a medical condition it's never gonna happen you know and straight away erm the family will think well you don't understand and the doors are closed”

Mary: “I think quite often they don't want people from their own community to be within

their family dealing with sometimes quite awkward issues and they prefer to have someone from outside their culture so long as they're culturally sensitive in the way they deliver care (...). But they often say I don't want someone from my own community. Which is really, it is not what people expect.''

Zahira: "...some of the ladies used to go to College and they were fine in a mixed group but some of them Moslem or the Sikh families come from very very strict backgrounds(...) there has always been an issue with the Asian community erm on mixed services''

Hamza: "oh yeah language is a barrier and although for me and Rachel it hasn't been. Of course it's a huge barrier''

Claire: "we had to say no to two people because we don't have anyone who speaks their language''

Farah: "when they heard that I speak Punjabi or Urdu automatically the barriers used to come down (...) I can communicate with mum and she can ask me questions of any questions she has but when that language barrier is there, they find it difficult to communicate openly because they can't ask the questions they want they don't get the answers they want so the barriers is going to stay there whereas obviously if she can openly have a two way conversation any doubts she has in her''

Mary: "But in fact quite often it's the families who have trouble speaking English. We find quite a lot of our learning disabled service users actually speak pretty good English through school and so they've picked up a reasonable command of English so the language thing isn't such a biggie as everyone seems to think it is.''

Ranjit: " we have got Somalian, we've got Eastern European, further, a few who are from Africa. So we have new communities settling here all the time, we have the dialect, the

language problems, the languages being spoken in schools. You couldn't get your head around some of the language spoken in certain schools. The demographics are changing''

Hamza: ''the culture is such that if I had a child with a learning disability it's my responsibility to take care of that child. Why do I need to take up support of anybody else? (...) they need to understand that obviously because there are certain things especially in like you know critical and really really substantial amount of learning disability. They're hard to manage. And when carers are young they may be able to manage them, but when the children are older, physically...I keep referring to these service users as children but the person they're looking after them physically they're grown but mentally they haven't got the capacity to deal with stuff. So they still probably think, you're still supposed to be able to manage them but they're not able to and that's where the guilt comes in. (...) Rachel: the guilt would be from saying, I can't cope, I need help''

Zahira: ''usually families do help, external families will help erm but unfortunately as time's gone, you know the external family is sort of moving away, you know grandparents are passing away (...) and maybe grandparents don't want to take that responsibility as well (...) would never admit to saying I'm struggling and with the Asian community, they do not like to admit that they are struggling''

Negative Emotions

For the service providers, the experiences of negative emotions are characterized by the feeling of helplessness of the situations that they encounter with families and service users. An example of this is portrayed in the quote from Mary (see Table 6). Mary's negative emotions arise from having no control over cultural norms influencing certain things in this case, cousin marriages and families' refusal to go for genetic counselling in the Pakistani

community. Mary herself is not from the Pakistani community. Mary's helplessness and "depressing" emotions were amplified because she did try all she could to help a family even by including the Imam who was from the same culture as the family but nothing changed. For her, as a service provider she is faced with the difficulty of advocating whilst also trying to work in a culturally sensitive way. This is a complex process as she is faced with differences between cultural norms (cousin marriages) and acceptable practices which in this case, the acceptable practice would have been to "limit their family".

Farah illustrates how as a service provider, close relationships may be formed with families. As such, bereavement is a negative emotion that is experienced by service providers in service provision.

Table 6.

Quotes for subtheme: Negative emotions

Main Illustrative Quotes

Mary: "some of them negative experiences have been around families not going to genetic counselling erm with cousin marriages.. and we have had... one.. one... There is one family where there were 5 sons with profound learning disabilities....and everybody, we tried to we tried to get the Imam to persuade them to go for genetic counselling and limit their family and they just kept on and on trying to have 1 son who wasn't learning disabledOur staff was inside the family we were actually very concerned but to no avail.....nothing changed at all and that is very depressing"

Farah: "negative experiences...the emotional side of it I think because I think obviously when you lose parent carers, when you're providing services, that can be quite emotional"

This superordinate theme highlighted the complexities that service providers encounter in providing services to people with LD from BME communities. The complexities were encountered in a wide range of aspects including families, culture, language and negative emotions.

2. Looking out for the best interests of the service users and families

This superordinate theme recognises the provision of services to people with LD from BME communities as being to both service users and families. In addition, it is the service provider's responsibility to ensure that service user's best interests are at the heart of service provision. This theme portrays the vulnerability of both service users and families. Service users' vulnerabilities relate to aspects of marriage and funding. For families it was mostly regarding their experiences of service provision.

Vulnerability of Service Users

As highlighted earlier, there is complexity in LD services due to families' views not always being the same as service users'. In this subtheme the service user's vulnerability seems often in relation to family and what the family wants for the service user, in this case marriage. The quote from Punita (see Table 7) illustrates that in relation to marriage issues, the person with LD may have a lack of understanding of the whole concept of marriage.

Lack of understanding puts service users in a vulnerable state as Punita states that service users may be enticed to get married. The service user's spouses may leave the service user after becoming citizens. To Punita, service provision to the person with LD after they have been abandoned by their spouses is challenging. Service provision becomes complicated and challenging due to "mental deterioration" and also the introduction of children into the dynamic of service provision.

The vulnerability of the person with LD may leave them open to abuse even within the family when it comes to funding. This is illustrated in the quote from Rachel in Table 7. This is a concern for Rachel because service users may have their funding abused by their own families. In the quote in Table 7, Becky illustrates that the needs of the service user may be suppressed because families do not always utilise the funding appropriately according to what the service user wants. This may occur even though there is some understanding within the family that the person should have access to services. Becky highlights that it is a negative experience for her as a service provider, because she may not always be able to provide services to the person due to the misuse of funds.

Table 7.

Quotes for subtheme: Vulnerability of service users

Main Illustrative Quotes

Punita: “and I suppose working with the service users you know that they won't really comprehend what exactly is going on. Erm it's all very nice and they've all kind of you know they almost sometimes get enticed that you know you're gonna have all this lovely jewellery, clothing coz everybody loves that especially here they absolutely adore all that kind of stuff so it's almost they're kinda getting enticed by that erm but if to say "do they fully understand the whole commitment?" a lot of the women don't and that is a big concern, a massive concern (...) Erm and there are obviously you know in recent years, another big concern is as people obviously...because they do go abroad to get married as the husbands come in, the cycle that we tend to see is after the husband..tend to get their passport, you know a legal citizenship in the country they quite often would leave the service-users with children as well and we have seen that so it's almost like within you know if somebody doesn't come (to this

service) because they've got married you know within I think is it 3 years or 5 years when you become a legal citizen you see them back. But then within that time period you know obviously they've had children and they're mental state has deteriorated there's a lot you know. So you know you're going to have to pick up right from the beginning. I suppose quite often, you know to try and get that person's mental state back to where you might have...it's very difficult if we ever get them then. So again that is going to become quite difficult ''

Becky: ''Negative experiences are probably to do with finance and direct payments that are being paid to the family that a proportion of which could be used for day centre or day care or day activities, and in some cases it isn't it's kept within the family disregarding the person's needs and wishes. We have come across that''

Rachel: ''a lot of the financial abuse ones is a known person of a neighbour or family member is normally the alleged perpetrator in those kind of cases''

Vulnerability of families

Service providers acknowledged that some BME families have had bad experiences with service provision in the past and it is therefore important to build trust with them before work can commence. In the quote in Table 8, Punita suggests that owing to some families' previous bad experiences, additional work and effort has to be put into service provision. She also illustrates the importance of resilience and patience in service provision stating that building the trust with the family is a process that may take a long time.

In the subtheme ''understanding culture, language and families'' it was mentioned that cultural similarity may not always be helpful. There is a similar notion in this theme as illustrated in the quote from Hamza as there is a perceived increased vulnerability to gossip

within the BME community since it is a small community. The quote from Ranjit also states that some families perceive vulnerability to being judged if the service provider is from the same BME community as them.

Table 8.

Quotes for subtheme: Vulnerability of families

Main Illustrative Quotes

Punita: “well some parents have very bad experiences through social service day serv..you know social workers and they just presume well all day services are exactly the same, so a lot of them have very bad experiences, some of them just you know very much erm well "who are you? (...). It’s almost you’ve got to work with the parents before you can work with the women erm and again is because...it’s that trust thing (...).it took us a long time to gain the trust of parents an extremely long time really.

Hamza: “It’s a small community. You always see a lot of Asian people and somehow we all know each other and they don’t want their laundry washed or hanging outside”

Ranjit: “She goes, oh my gosh she’s Muslim she’s gonna judge me...(…) there could be some generalisation or assumptions placed because they are from the same faith”

This superordinate theme portrays the service provider as someone who would have to look at the best interests of both the service user and the family. Service providers may need to advocate for service users if necessary. With families, service providers may need to gain the families trust first before service provision commences.

3. It is important to be open minded as a service provider

When providing services to the BME communities, a wide range of different cultures are encountered. The service providers suggested the importance of being open minded regarding different cultures. There is also some flexibility needed in the planning of services for people with LD from BME communities.

Focusing on what the service user wants

This subtheme contrasts with the “Families influence service provision” subtheme. In this subtheme, participants spoke about their efforts to give control to the service user to suggest what they would want in their service provision. The quote from Punita in Table 9 illustrates that they can be given choice and freedom in the service provision process. Also that support is individualised to cater for that person’s needs. In her view, she would not assume that she knows what the service users want and instead would ask and listen to their views. The quote from Farah indicates that service providers try to listen and incorporate the views of the service user in service provision. Furthermore, Eric emphasises the importance of supporting what the service user wants. These illustrative quotes from Punita, Farah and Eric (see Table 9) indicate how the service providers do their best to provide the services that the service users want and suggest.

Table 9.

Quotes for subtheme: Focusing on what the service user wants

Main Illustrative Quotes

Punita: “Yeah so it’s very much mixed and what their needs are really as a group or as an individual, you know being a black male what is it that you actually, what is it that they want and that’s where the person centred plan really comes in I suppose”

Farah: “We don't tell them what they want, they tell us what they want and we try and support and provide that”

Eric: “well it would be like giving them option to support whatever they want to do”

Avoiding stereotypes in service provision

Person centred planning emerged to be of importance to the participants in this study. Service providers acknowledged that everyone is different. The quote from Becky suggests that in the past there were stereotypical attitudes of certain communities that were formed but in the present day these should not be applicable. Becky states the importance of being open minded when interacting with service users from BME communities. She also portrays an awareness of historical aspects. The importance of equal opportunities for activities and open access and choice, even when there are culture specific events is emphasised in the quote in Table 10 by Eric.

Table 10.

Quotes for subtheme: Avoiding stereotypes in service provision

 Main Illustrative Quotes

Becky: “you have got to be very non-judgemental. You can't go in with a white British attitude expecting the black erm stereotypical attitude because we've all moved on from...since the last what twenty thirty years”

Eric “you can't just label somebody because they're black, white, green, whatever and say that all that colour do are this....I wouldn't specifically only offer the Carnival to black people, I would offer it to everybody if I thought they were interested you know what I mean. I'm not saying you know, only cer...you know I'll only offer Asian culture things to Asian people I offer it to everybody”

Overall, the participants seem to be suggesting that in as much it is important to know the different cultures that are within the BME communities, there should be no pre-conceived ideas formed of what service provision should be like based on that person's culture. There should be individual choice and individualised support.

In summary, listening and giving freedom and choice to service users is emphasised in this theme. Furthermore, the importance of treating everyone as different and not having stereotypes of certain communities is reiterated.

4. Loss of control in service provision: services are controlled and determined by funding

In this superordinate theme the importance of funding in and how this affects service provision is explored. Funding is of concern both to the service user and service provider.

Reactive model of service provision

Service providers perceived themselves as not having control over services provided. The services provided are determined by the funding that is available and by funding authorities. This is illustrated in the quotes in Table 11 from Zahira and Farah. Therefore, service providers may often have to provide services based on expectations of the funding bodies and not necessarily according to what they think is important. Additionally, because funding bodies provide funding for specific communities or services, those are the services that will be provided. This seems to suggest that service providers cannot shape the services according to the known needs of service users without relying on the funding authorities.

Table 11.

Quotes for subtheme: Reactive model of service provision

Main Illustrative Quotes

Zahira: “there was a massive need for a service like this to be set up within (name of borough) erm obviously at the time due to funding it was only (name of borough)”

Farah: “Erm to be honest all of my families are from erm black minority ethnic families but we also have white British families now. Initially when our projects were funded they were funded just for that specific group of people”

Funding as a barrier for both service user and service provider

When funding is unavailable or limited it affects both service users and service providers. Service users will have limited access and likewise service providers will have limited provision. As a result of professionals losing the ability to provide support they may

become frustrated. Because of the close working relationship that is established they may know how much the service users need that funding in order to access the services. An example of this is illustrated in the quote in Table 12 by Farah. The frustration that Farah feels is a negative emotion that was portrayed as a part of service provision.

Other participants also stated that for service users, decreased funding or personal budget cuts for them mean that “they are not given the services they need” (Mary). There may also be a decrease in the service provision when service user’s funding is cut as illustrated in the quote from Punita. The service providers seem to suggest that when budgets are cut it is out of their control. If the service user does not have adequate funding to access the services then the service providers may be helpless. This is also one of the emotions in the “negative emotion” subtheme.

Table 12.

Quotes for subtheme: Funding as a barrier for both service user and service provider

Main Illustrative Quotes

Farah: “obviously sometimes it's quite frustrating as professionals when you are trying to help parent carers access services or get budgets or get the help they need because unfortunately losing...projects losing funding it's out of anybody's control but as professionals I think that was the...those two things are the main things that would affect er us as professionals really.”

Punita: “obviously cuts are happening big time. When people's personal budgets go through obviously quite often the criteria might be you need to cut people's budgets really and that is what's happening, from five days to they're being cut to three days or maybe 2”

This superordinate theme indicated the importance of funding in service provision and funding is portrayed as a major determinant in the uptake of services by service users and provision of services. The lack of control that service providers have in relation to funding is also highlighted.

Discussion

This study investigated the experiences of service providers who provide social care services to people with LD from BME communities. Perceived barriers to service provision were explored. The results highlighted the complexities related to service provision.

One of the main findings is that families are perceived to play a central role in service provision. Before working with the service user, service providers feel they need to work with families because “families influence service provision”. In order to work with families, there needs to be clear communication between service providers and families. However, in this study language was identified as being a barrier in service provision. This is consistent with the findings from Heer, (2012) who found language barriers amongst health care providers working cross culturally. Language was evidently a problem in this study because BME services users were turned away in some instances because the service providers could not speak their languages. The unavailability of internal staff who could act as interpreters was perceived as a barrier. Mir and Tovey (2003) also reported this finding. They found that family carers often had no language support for the services working with their children. In this study participants perceived language to be more of a barrier for families as the service users may speak English as they may have been through the UK education system.

At the initiation of service provision, families are very much involved and some of this involvement may make it difficult for service provision to even begin. However, the

participants emphasise focusing on the individual when providing services. This may be because people with LD are perceived as individuals who can make decisions that affect their lives and should be included in the decision making process (Mattingly, 2012.)

As mentioned in the previous chapter, person centred planning is at the heart of service provision in the UK and focuses on what the individual needs and the person with LD is in control of the service provision (CareUK, 2013). The Valuing People Now White paper (The Department of Health 2009) identified that few people had a person centred plan and individuals were not involved in planning their service provision.

The social care providers who were interviewed in this study highlighted the priority given to person centred plans and at the same time considering the individuals' cultural needs. This is in line with the suggestions of Valuing People Now and it is something that requires services to be tailored to meet the needs of the individual (CareUK, 2013). According to the participants in this study, who are from different social care services around Birmingham, this is something that they are currently doing. In the past, person centred planning has been shown to lead to better outcomes for the person with LD (Department of Health, 2005) and therefore it is something that is of benefit to implemented in social services.

From the superordinate themes "Service provision to BME communities is a multifaceted and complex process" and "Looking out for the best interests of the service users and families" there emerged some cultural aspects that are important to consider. For example, marriage was perceived to be an integral part of some BME communities specifically the Pakistani community. However, service providers, including social workers, indicated that it is a concern. They are faced with the difficulty of intervening when they

know that the person with LD does not have capacity to make a decision concerning marriage but also at the same time respecting the families' decision as it is a cultural norm.

Past research has also identified marriage as a concern in working cross culturally with adults with LD from BME communities (Summers & Jones 2004). Similar to the findings of this current study they found that the families of the person with LD valued marriage highly. Families wanted their son to get married as it would give the family prestige and also that the wife would take care of the son. Therefore, clearly this is a concern in these particular cultures because, as indicated by the participants the person with LD may lack the understanding of what marriage is. From some participant's experiences, the person with LD would go back to their home country to be married but may be abandoned by the spouses after they became British citizens. In such circumstance, the service provider may find it difficult as they become personally involved and have to advocate for the person. Even though it is something that may be considered as unacceptable culturally, it is important that it is done in the best interests of the person with LD. Advocacy for people with LD is a complex issue that needs sensitivity and their rights in the law should be considered. These rights should be in line with British Medical Association and The Law Society (2005) guidance. The guidance suggests that for people with LD, the marriage can be voided if the individual does not have the capacity to consent to the marriage. Implementation of this guidance may assist in reducing the number of forced marriages

According to Papadopoulos, Tilki, and Taylor (1998) cultural awareness is the first pre-requisite for cultural competence to occur. Service providers need to be aware of their own beliefs in order to avoid stereotypes, which is something that the participants in this study portrayed. They highlighted the importance of having an open mind regarding different BME communities and actively try to avoid stereotyping cultures. They also acknowledge the

changes that are occurring in certain cultures for example, the extended families from the Asian communities who are known to often help out with caring. It is important to note that service providers try and avoid stereotypes but are aware of cultural norms. This is a subtle but important difference.

There have been suggestions of having staff that represent or who are from the different BME communities to which services are being provided (Heer, 2012; Mir, 2008). From this study there are some advantages and disadvantages that emerge because of that. One of the main advantages is that there is increased cultural including religious understanding and some families are willing to take up services for their son or daughter when there are staff who are from the same culture as them because there is an increased likelihood that they will trust them and also there are no language barriers. Another advantage is that service providers may be in a better position to challenge any impeding cultural beliefs that the families may have.

However, some of the service providers stated that they have experienced families who do not want service providers from the same culture as them. This finding is consistent with the findings from Mir et al, (2001). This is because of the fear of being judged and fears of breach of confidentiality to the wider BME community that they belong to. Therefore, from this study it can be suggested that in order to achieve cultural competence in the social care services, the service providers need to still have the cultural knowledge and beliefs of the BME communities but need to always provide individualised support without making any assumptions.

The negative emotions experienced by the service providers are similar to those identified by Hassiotis (1996) working with BME communities in a psychiatric clinical

practice. Most of the negative emotions arose from not achieving the expected outcomes. From this study, an example would be the frustration of not being able to provide support to the service users due to lack of funding.

In this study, funding was identified as a major determinant in service provision. It is estimated that one in four people with LD do not have adequate funding to access services (Mencap, 2012) and because of funding cuts that are currently occurring they are not able to receive sufficient support (Sully & Bowen, 2012). This is not limited to just people with LD from BME communities. Another concern raised was service users' funding being kept within the families and not used appropriately for services. In light of this, families may need to be further educated and monitored to ensure funding is utilised appropriately and according to the service user's needs.

In the "reactive model of service provision" subtheme it was observed that participants may be restricted in terms of service provision because of funding. There is a reliance on funding authorities and what funding authorities fund is what is provided. However, service providers views regarding service provision should also be considered and included when identifying which services to fund because as it stands, from this study it is evident that service provision is indeed "reactive".

Implications for future research

This study provides information on service access primarily within the Asian community. It is important for future research to include the views of service providers that draw their experiences of working cross culturally in LD services from other BME groups besides South Asian communities, including emerging communities such as East European. This may provide findings that are more representative of the BME communities that are in

the UK. Further research is required on the prevalence of forced marriages and capacity to consent to marriage for people with LD. These findings may inform services that provide services to adults with LD who may want to get married. Language barriers in service provision may also need to be explored to find out why professional interpreters are not engaged in service provision. The prevalence of family influence on service provision may need to be researched further too.

Implications for practice

This study indicated the importance of working with families when providing services to people with LD from BME communities. In order to incorporate this in service provision an audit tool may be developed for services. The audit tool may be designed in such a way that families' views and the service user's views are recorded. Then service providers indicate how they incorporate both views in service provision. In order to reduce language barriers, professional interpreters may need to be included in service provision. This may facilitate improved communication between service providers and families of service users.

Reflection

In the process of data collection using interviews, I found that most of the service providers were happy to talk about their experiences openly and their concerns regarding providing services to BME communities. Even though the interviews focused on service provision to the person with LD, the participants indicated that the families play a very important role in service provision.

From the literature I appreciated the need to have culturally competent services for BME communities. However from the interviews I realised that this is not easy and may be a complicated process.

As the study commenced, I aimed to include the views of service providers who had specifically worked with Black British, Black Caribbean, Chinese, Black African as there is low service uptake amongst these groups. However, experiences were mainly in relation to Asian communities.

Social workers are a central part of the social care services. Due to availability time constraints I managed to include two social workers' views but it would have been better to include more social workers, in a focus group for example.

Conclusion

This study explored the experiences and views of service providers working with people with LD from BME communities. It identified the complexities of working cross-culturally and also the many concerns that are associated with working with people from BME communities. In a place like Birmingham which is a multicultural city with numerous different cultures and also some new emerging communities it is important to have cultural knowledge and cultural awareness in order to deliver culturally sensitive care. The findings from this study are useful in informing social care services particularly those in the third sector as they are the main sector represented in this study about the cultural issues that may need to be addressed and also in increasing service uptake in the BME communities

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Helm.

Appendix A: Literature search strategy



Wednesday, November 14, 2012 10:30:54

#	Query	Limiters/Expanders	Last Run Via	Results
S2	"Cystic fibrosis" AND "health related quality of life"	Limiters - Published Date from: 19960101-20121131; English Language; Language: English; Age Groups: Child, Preschool: 2-5 years, Child: 6-12 years, Adolescent: 13-18 years Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL Plus	20
S1	"cystic fibrosis" AND "quality of life"	Limiters - Published Date from: 19960101-20121131; English Language; Language: English; Age Groups: Child, Preschool: 2-5 years, Child: 6-12 years, Adolescent: 13-18 years Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL Plus	119

Database: PsycINFO <1996 to November Week 1 2012>

Search Strategy:

-
- 1 exp Cystic Fibrosis/ (564)
 - 2 health related quality of life.mp. (5278)
 - 3 exp "Quality of Life"/ (23154)
 - 4 1 and 2 (26)
 - 5 1 and 3 (52)
 - 6 limit 5 to (human and (childhood <birth to 12 years> or adolescence <13 to 17 years>) and 100 childhood <birth to age 12 yrs> and english) (22)
 - 7 limit 4 to (human and english language and (childhood <birth to 12 years> or adolescence <13 to 17 years>)) (19)
 - 8 limit 1 to (human and english language and (childhood <birth to 12 years> or adolescence <13 to 17 years>)) (314)

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ResultsTopic=("cystic fibrosis") AND Topic=("quality of life") AND Topic=("health related quality of life")

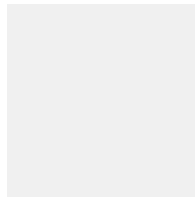
Refined by: Languages=(ENGLISH)

Timespan=1996-01-01 - 2012-11-14. Databases=SCI-EXPANDED, SSCI,

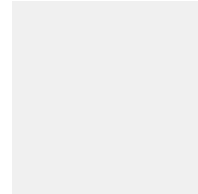
A&HCI, CPCI-S, CPCI-SSH.

Lemmatization=On

Results: 179



Page of



18

Database: Ovid MEDLINE(R) without Revisions <1996 to November Week 1 2012>

Search Strategy:

- 1 exp Cystic Fibrosis/px [Psychology] (465)
- 2 exp "Quality of Life"/px [Psychology] (11090)
- 3 1 and 2 (26)
- 4 health related quality of life.mp. (16144)
- 5 1 and 4 (42)
- 6 limit 1 to (english language and humans and "all child (0 to 18 years)") (305)
- 7 limit 3 to (english language and humans and "all child (0 to 18 years)") (17)
- 8 limit 5 to (english language and humans and "all child (0 to 18 years)") (32)

Appendix B: Ethics approval letter

Dear Dr Larkin

Re: “Social Service Provision to People with Learning Disabilities from Black and Minority Ethnic Communities: the view and experiences of service providers” Application for Ethical Review ERN_13-0149

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee. The study was granted conditional ethical approval on 9th April 2013.

On behalf of the Committee, I can confirm the conditions of approval for the study have now been met and this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee’s attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University’s Code of Practice for Research and the information and guidance provided on the University’s ethics webpages (available at <https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx>) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form

(<https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx>) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk <<mailto:healthandsafety@contacts.bham.ac.uk>> .

Thank you,

Deputy Research Ethics Officer

Research Support Group

Finance Office

Aston Webb, B Block

Edgbaston, Birmingham

B15 2TT

Tel: 0121 414 8101

Web: www.birmingham.ac.uk/researchsupportgroup

Appendix C: Informed consent form

Social Service Provision to People with Learning Disabilities from Black and Minority Ethnic Communities: The View and Experiences of Service Providers

Informed Consent

1. I have read and understood the information sheet and all my questions have been answered to my satisfaction
2. I agree to have my interview audio recorded
3. I understand that extracts of my responses may be used in theses, publications and conferences but will not include my name
4. I understand that my interview responses may be kept for up to 10 years
5. I understand that I can choose to withdraw from the interview at any time without repercussions
6. I understand that I can choose to withdraw my data within 2 weeks of the interview
7. I would want to be contacted to attend an event at the end of the project at which the results of this study will be reported
8. In the unlikely event that there is disclosure of poor practice (e.g. harm, or unmanaged risk to others) I understand that confidentiality may be breached

I _____ agree to participate in this study being conducted by Primrose Nyamayaro.

Signature

Date

Appendix D: Letter of invitation

University of Birmingham
School of Psychology
Frankland Building
Edgbaston
Birmingham,
B15 2TT

15 May 2013

Dear Sir/Madam

Thank you for your interest in participating in our research entitled “Social Service Provision to People with Learning Disabilities from Black and Minority Ethnic Communities: The View and Experiences of Service Providers”. As a participant in the research you will be asked to take part in an audio recorded interview. I have attached the information sheet with some important information about the study, the consent form for you to sign should you still be interested in participating.

Kind Regards

Primrose Nyamayaro

Appendix E: Information sheet

Social Service Provision to People with Learning Disabilities from Black and Minority Ethnic Communities: The View and Experiences of Service Providers

Invitation

You are being invited to take part in this research study on “Social Service Provision to People with Learning Disabilities from Black and Minority Ethnic Communities”. We aim to explore the views and issues involved in providing social care services for people with Learning Disabilities (LD) from Black and Minority Ethnic (BME) communities.

Why are the researchers doing this?

As well as being part of my (Primrose Nyamayaro) Postgraduate project at the University of Birmingham which has been approved by the University’s ethics committee: results from this will help us to identify current gaps and barriers in service provision and to generate practical solutions to improve service provision.

Why have you been invited to take part?

You have been invited to take part in the research because you are a Social Service Provider who has experience in providing services to adults with learning disabilities.

What will happen if I agree to participate?

We will interview you individually or ask you to attend a group interview. These are expected to last between 1 and 2 hours. These activities will take place at your workplace and we will need to arrange a time to meet, which is convenient for you. With your permission, the interview will be audio recorded and the data will be analysed. This data will be transcribed and some of the extracts from the interview may be used in the research report and as part of publications, for example in a journal.

Will my responses from the interviews remain confidential?

Your responses from interview will be audio recorded with a password protected recording device. The audio recorded data will be transferred to a password protected computer and deleted from the recording device. Only the named researchers will have access to the audio recordings. The researchers will then have printed transcripts of the interviews and all personal identifiable data will be removed from the transcripts. Participants will be given pseudonyms in the transcripts and written report and even though some of your extracts from the transcribed data will be used in the report, your name will be kept confidential. The data from this study may also be used in future studies, however only authorised researchers will have access to the audio recordings and confidentiality will be maintained. It is only in the

unlikely event of disclosure of poor practice (e.g. harm, or unmanaged risk to others) that confidentiality may be breached.

How long will my interview data be kept for?

The contact details will be kept in a locked filing cabinet and will be used to invite you to the event where results will be presented in November 2013. The interview responses transcripts will be kept for up to 10 years.

Do I have to take part?

Participating in this study is completely voluntary. Should you choose to withdraw from the study at any point during the individual interview or group interview there will be no consequences. However, the interviewer will ask you if your responses up to that point can be used in the analysis. If not, the recorded responses will be deleted. You will also have the opportunity to withdraw up to two weeks after the interview.

Who do I contact for further information?

1. Primrose Nyamayaro
MRes Clinical Psychology Student University of Birmingham
pcn242@bham.ac.uk
07549207772

2. Gemma Unwin
Research Fellow University of Birmingham
g.l.unwin@bham.ac.uk
0121 414 7225

3. Dr Michael Larkin
Senior Lecturer University of Birmingham
m.larkin@bham.ac.uk
0121 41 46036

Appendix F: Interview schedule

Interview questions

1. Can you tell me more about your role in this service?

Prompt: what do you do exactly?

2. How long have you been in the social services sector?

Prompts: different things done over the years

3. How often do you encounter people from Black and Minority Ethnic communities with learning disability?

Prompts: do they come for particular services?

4. What would you say are the distinctive needs of different populations that you have worked with

Prompts: Do you prepare any differently than you would with people from white backgrounds?

5. How do you develop relationships with service users from Black and Minority Ethnic Communities?

Prompts: How do you try to incorporate their cultural beliefs?

6. Can you tell me about some of your experiences of working with people from a range of cultures?

Prompts: positive experiences negative experiences

7. What do you think the best care and support for people with learning disabilities from BME communities would look like?

Prompts: What are your needs?

8. What do you perceive as barriers to providing services to people from BME communities with learning disabilities?

Prompts: what do you find difficult?

Appendix G: Example of analysis for interview transcript

Family influence on Service Provision	Page/line	Quote	Comments
Difficult to reach out to the BME community	2/15-17	BECKY “We have tried to search out really ethnic service users and you come across some barriers mainly with family”	<i>*earlier in the interview Becky emphasised that the service is completely inclusive. ‘search out’ suggests they are really trying their best to reach out to them to them. *the family makes the process difficult</i>
Service users put in difficult situations	8/124-127	BECKY “ and they are quite close knit as families so it does cause a lot of hurt so it does cause a lot of hurt for the actual service user you know to choose. Who do I choose? Do I choose the day centre or my family?”	<i>*being a tight knit family here seen as hindrance because it impedes independence *service user is faced with some hard choices *emphasises on the hurt it causes</i>
The families have the final say on service provision, not the service user	29/472-474	EMMA “Erm and difficulties in that sometimes we have to walk away from a person that really wants to come to us but the family is saying no, and we can only take it so far”	<i>*when the family says no, the service providers are left with no option but to leave *as Emma says this, there is a sense of helplessness being conveyed</i>
Challenging Families	11/176-177	EMMA “We wanted the young lady to come because she very much wanted to come but the family said no”	<i>*the families have great influence on the decisions and what the service user actually wants may be ignored</i>
	7/114-121	BECKY “...unable to leave the family. And we don’t like to have conflict in that area we will support individual offer advocacy or self-advocacy or completely independent advocacy but we had no, have	<i>*for the service providers the focus is on the individual and what the individual wants. *when families are confronted it does get challenging *even more difficult because Emma is not from their culture, so they may feel like she does not</i>

		no...We have been in situations where we have confronted the family's views EMMA: Erm but it has not worked well because it has caused so much conflict for the family and for the person with cerebral palsy and it has been very very difficult.”	<i>understand them</i>
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Gender Issues	Page/line	Quote	Comments
Parents do not want daughters attending mixed services	6/97-106	EMMA “We've encountered quite a few within our own outreach and we have had people attend here. Where it's been female and it's been the Sikh religion it can become very difficult because although the young ladies wish to attend, it can conflict with family because there is young man here. BECKY: Mmmhhh. EMMA: and obviously there can be relationships not physical relationships but emotional relationships” forged, whereby the parent's don't, they don't want that for their daughters. So they have been withdrawn.	<i>*do the young ladies still wish to attend regardless of the service provided and there being men there?</i> <i>*maybe the service users don't have as strong of a cultural identity compared to the parents so they don't mind?</i> <i>*the family influence is highlighted here too.</i> <i>*Disregarding what the service users want and the families always having the final say</i> <i>*even though relationships are a part of life and the daughters are adults, parents are still protective over them</i>
Parents want service users to ensure no relationships are formed and service providers cannot promise that	11/167-175	EMMA: “and said that unless this gentleman didn't come anymore then she'd have to withdraw her daughter. We tried to give her assurances that her daughter would be very safe within our community and that she wouldn't be left unattended. However, if she did want to stop and talk to the young man, she had human rights and she would, we wouldn't really stop that. Now mother then was... opposed she said	<i>*Conflict here: in saying they would do all they can to keep them apart-it's a statement to please the family, “but she has human rights” is a statement to look out for the service users' interests too.</i> <i>*both service user and family cannot be pleased</i> <i>*once again I see here that the family always</i>

		"well if you are not going to keep them completely separated well she can't come". So we then couldn't stop the young man coming because he was just here and talking to her."	<i>has the final say and the interests of the service user are put aside</i> <i>*in the end the whole situation is out of the service provider's control and there is nothing that can be done about it</i>
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Funding	Page/line	Quote	Comments
Families misuse service users' funding	24/393-397	EMMA "Negative experiences are probably to do with finance and direct payments that are being paid to the family that a proportion of which could be used for day centre or day care or day activities, and in some cases it isn't it's kept within the family disregarding the person's needs and wishes. We have come across that"	<i>*families do not consider what the Person with LD wants or needs. They decide for them and do what they think is best</i> <i>*maybe families may need more knowledge of what happens at the services?</i>
	25/400-401	EMMA: "It's not within the Black, Afro Caribbean, Black Africans, so much as the Indian, Pakistan community. That can be an issue	<i>*why is there that high prevalence in the Indian Pakistan community? could be issues arising from mixed services?</i>
Why families misuse the funding	25/405-408	EMMA: "It's probably that the family wish to take if that's the right phrase of their family members erm probably trust themselves more to look after their needs and cultural issues that they think we may not be able to"	<i>*The families do the care themselves so then they pay themselves instead of taking the Person with LD to other services?</i> <i>*parents have no confidence in the services and don't know if cultural beliefs will be respected</i>
Lack of funding makes it difficult to provide services	29/467-468	EMMA: "Well I think definitely restrictions in funding and that applies across the board it affects everyone"	<i>*generalisation of funding: affects even non-BME communities</i>
	29/476		<i>*mentions funding 3 times, emphasis on how important it is</i>

		“BECKY: Yeah, funding, definitely funding. Funding is a big thing”	
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Language	Page/line	Quote	Comments
Knowing the service users’ language helps	14/226-227	BECKY “definitely. and he has actually settled in because one of our staff here is Somalian, so she speaks Arabic”	<i>*having staff that speak the service user’s native language helps in service provision</i>
Speaking the same language is important when settling issues	20/328-333	EMMA “If we had a service user that did not speak English or had a problem speaking English then we would then have an interpreter obviously to come in and support and perhaps an advocate from their own culture so that they can you know put on the table the issues surrounding them you know, the problems they have”	<i>*advocacy in the first language is important *if there is someone who can interpret then at least the service user can express exactly what they want *it’s not enough to just understand the language but everything also needs to be understood in service users’ cultural context.</i>

Cultural beliefs	Page/line	Quote	Comments
Lack of independence due to cultural beliefs	7/110-114	EMMA “We've also got another young lady who would want to live independently and for many years we have had nominations to try and move her to sheltered housing which is next door and but unfortunately because of cultural restraints that young lady is unable to leave the family”	<i>*independence and living alone as an adult is part of societal norms *cultural norms trump societal norms in this matter *again the influence of the family is shown here</i>
Adapt services to			

incorporate cultural beliefs	19/297-300	EMMA: “Obviously yeah the food, we are very respectful of their cultural needs, that's vital. Erm so if they tell us they need to do something because of their culture or erm we will then bring it into the fabric as well of what we do every day”	<i>*the emphasis on inclusion is portrayed here *acknowledging and respecting cultural needs</i>
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Stereotypes	Page/line	Quote	Comments
Stereotypes should be avoided in service provision	17/265-268	EMMA “I think you have got to be very non-judgemental. You can't go in with a white British attitude expecting the black erm stereotypical attitude because we've all moved on from...since the last what twenty thirty years.”	<i>*stereotypes should be a thing of the past, things have changed and people should move with the changes</i>
People are not stereotypical anymore	18/289-292	“EMMA: and once they come here they will see just how multi-cultural and as I said it's Birmingham, and we have all moved on from the stereotypical black man, white man, Asian man, etc it's all a bit in the melting point and that's great.”	<i>*by living in Birmingham where there a lot of different communities coupled with the changes over the years regarding ethnicity/race stereotypes people should not have that stereotypical mind-set.</i>

Appendix H. Common Themes/objects of concern across participants

Marriage Present in Interview 2, 6, 8, 9			
Person with LD, Lack of understanding of the concept of marriage			
Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Hamza	“she couldn’t understand what marriage was”	29/633	Service Provider Experiences: Working With Complexity
Punita	“do they fully understand the whole commitment? A lot of the women don’t”	47/828-829	
Ranjit	“people have been married to an individual to become their support worker”		
Abandonment after spouses become British citizens/being used as a gateway to a “better future”			Looking out for the best interests of the service users and families
Ranjit	“when he gets a British passport or residential stay they leave”		
Punita	“after the husband, tend to get their passport, you know legal citizenship in the country quite often they would leave the service users with children as well”	47/833-835	
Fine line between respecting a culture and advocacy			Service Provider Experiences: Working With Complexity
Amira	“we don’t get too involved where it offends”; “it’s a sensitive issue	27/595-596	
Hamza	“now what is forced and what they feel is not forced but supporting their loved one?” “when you walk into a situation like that and you’re assessing capacity of somebody you have to be culturally sensitive”	30/663-664	
Rachel	“it’s maintaining a cultural norm and they could say why coz they have disabilities?”	27/599-600	

Language (present in all 9 interviews)			
<i>Knowing the families' native languages helps in building relationships with the families</i>			
Participant	Quote	Page/Line	Final Superordinate theme
Farah	“when they heard that I speak Punjabi or Urdu automatically the barriers used to come down”	15/261-263	Service Provider Experiences: Working With Complexity
	“I can communicate with mum and she can ask me questions of any questions she has but when the barrier is there they find it difficult to communicate”	16/277-279	
Sharifah	“we have a good relationship with the mums as well because they don't know how to speak English but we know how to communicate in Urdu so it's easy for them to speak”	8/141-143	
<i>Language as a barrier in service provision</i>			
Eric	“would choose sometimes because he could to communicate in his language that he would speak with his family. Now of course I could never understand so that was a barrier”	5/84-87	Service Provider Experiences: Working With Complexity
Punita	“Erm but when people especially within the Asian community, I think one there is a language barrier so they don't necessarily understand what is being asked”	44/767-768	
Ranjit	“language is definitely a barrier”	28/571	
Mary	“we don't have any Chinese speaking staff either. It would be a huge barrier I think	22/487-492	
Claire	“we had to say no to two people because we don't have anyone who speaks their language”	7/113-115	
Hamza	“oh yeah language is a barrier and although for me and Rachel it hasn't been. Of course it's a huge barrier”	16/349-350	
<i>Knowing a range of languages improves service provision for BME service users</i>			

Emma	“he has actually settled in because one of our staff here is Somali so she speaks Arabic”	14/226-227	Service Provider Experiences: Working With Complexity
Sharifah	“If somebody is referred to us (manager) will ask them what do language do you speak and if they can't speak English and they need somebody to speak in Urdu then either me and Amira will go”	9/152-154	
Hamza	“With the South Asian languages, I think I can manage. If I can't speak their language, they'll speak mine. And if they don't speak mine. I'd speak theirs.”	15/322-326	

Funding (present in interviews 1, 2,, 3, 5,6, 8, 9)			
<i>Families misusing service user's funding</i>			
Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Rachel	“a lot of the financial abuse ones is a known person of a neighbour or family member is normally the alleged perpetrator in those kind of cases”	26/582-584	Looking out for the best interests of the service users and families
Punita	“it's an additional income for the family and not the service user”	46/814-815	
Becky	“finance and direct payments that are being paid to the family that a proportion of which could be used for day centre or day activities, and in some cases it isn't it's kept within the family disregarding the person's needs and wishes.”	24/393-397	
<i>Funding cuts as a barrier for both service user and service provider</i>			
Punita	“from five days they are being cut to three days or maybe 2”	43/761-762	Loss of control in service provision: services are controlled and determined by funding
Mary	“things to do with funding where people are not given the services they need”	19/417-419	
Farah	“Sometimes it's quite frustrating as professionals when you're trying to	23/410-413	

Amira	help parent carers access services or get budgets or get the help they need because unfortunately projects (are losing funding)” “we’ve got a lady who pays for two days and comes in one day free and a lot of them want to come in five days but we just can’t meet their needs because you know funding is cutting down”	23/409-417	
<i>Funding is the determinant for the types of services provided</i>			
Ranjit	“And the funding crisis that the world is in at the moment, everything is underpinned by funding and resources”	3/64-66	Loss of control in service provision: services are controlled and determined by funding
Mary	“we focused on people from South East Asia but our new funding stream is asking us to open up to more people” “we are grant funded for that and it is for Asian women”	3/65-66 3/56	
Zahira	“there was a massive need for a service like this to be set up within Sandwell term obviously at the time due to funding it was only Sandwell”	5/75-79	
Farah	“Initially when our projects were funded they were funded for just that specific group of people”	9/149-150	

Trust present in interviews (6, 4, 7, 8,)			
<i>Building Trust is a process that takes a long time/patience needed to develop trust</i>			
Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Farah	“they wanted us to keep that distance but over years of building rapport and trust with the family”	6/90-91	Looking out for the best interests of the service users and

Punita	“it took us a long time to gain the trust of parents an extremely long time really”	18/311-312	families
<i>Trust from the family is important in service provision/Trust is a prerequisite in service provision</i>			
Punita	“it’s almost you’ve got to work with the parents before you can work with the women erm and again is because...it’s that trust thing”	19/321-322	Looking out for the best interests of the service users and families
Amira	“a lot of the parents, mothers, they trust us”	4/62	
Claire	“building trust really, Yeah going into that area so that they can get to know that you are not there as a threat , you just wanna be there as a help”	23/371	

Families (present in interviews 5, 3, 7,)			
Conflict/Tension in providing favourable support for the family and person with LD			
Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Farah	“obviously remain as sensitive as possible to obviously try to make the family happy and to keep the young person happy”	24/424	Service Provider Experiences: Working With Complexity
Becky	“It does cause quite a lot of hurt for the actual service user you know to choose? Who do I choose? Do I choose the day centre or my family?”	8/124-127	
Families have final say in service provision not the service user/service users not given opportunities to make own decisions			
Becky	“Sometimes we have to walk away from a person that really wants to come to us but the family is saying no”	29/472-474	Service Provider Working With Complexity Experiences:
Eric	“It’s always the family. Always, that’s what I’ve experienced, never the individual, they’re not bothered”	37/645-646	

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Cultural Similarity between Service User and Service Provider (present in interviews 1, 2, 4, 6, 8, 9,)			
Increased Vulnerability to Judgement and Gossip within BME community/Nervous of people from the same community			
Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Hamza	“It’s a small community. You always see a lot of Asian people and somehow we all know each other and they don’t want their laundry washed or hanging outside”	17/381-384	Looking out for the best interests of the service users and families
Ranjit	“She goes, oh my gosh she’s Muslim she’s gonna judge me”	22/444-455	
	“there could be some generalisation or assumptions placed because they are from the same faith”	15/312-313	
Mary	“they don’t want people from their own community to be within their family dealing with quite awkward issues”	9/183-188	
	“they often say, I don’t want someone from my own community”	8/176	
Cultural Understanding/Knowledge of appropriate culturally sensitive service provision			
Amira	“coz we are Asian as well so we have got the language, same culture we know if there’s time for prayer, staff do it themselves”	4/67-70	Service Provider Experiences: Working With Complexity
Hamza	“I would look at a south Asian differently than I would look at a non-South Asian person. Why I would do that is because I have been through very similar situations with my parents”	30/667	
Punita	“(if) it’s a white colleague who went in and they heard black magic they won’t understand it’s a cultural thing”, “the family will think, well you don’t understand and the doors are closed”	31/549	

Claire	“there must be things I completely miss because you know it’s a different culture, different mindset maybe?”	20/326-328	
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Cultural Norms and beliefs (present in interviews 1, 2, 3, 4, 5, 6, 9)			
Contradictory Views on Extended family support			
Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Zahira	“usually families do help, external families will help erm but unfortunately as time’s gone, you know the external family is sort of moving away, you know grandparents are passing away”; “and maybe grandparents don’t want to take that responsibility as well”	37/650-655	Service Provider Experiences: Working With Complexity
Eric	“they have extended families that still function and work”	25/441	
Hamza	“things are getting more expensive. Financially people are struggling so they tend to go out and find work a lot more”	6/118-120	
Denial that they need support/adherence to cultural norms more important than reality			
Zahira	“I would never admit to saying I’m struggling and with the Asian community, they do not like to admit that they are struggling”	37/648-650	Service Provider Experiences: Working With Complexity
Hamza	“the culture is such that if I had a child with a learning disability it’s my responsibility to take care of that child. Why do I need to take up support of anybody else?”	5/92-95	
Mary	“There is one family where there were 5 sons with profound learning disability....and they were trying to have one son who wasn’t learning disabled”	17/383-389	

	“the whole cultural stuff (sigh) around marrying close relatives, I mean there is clear evidence...that the incidence of learning disabled births in the Asian women community is higher”	27/594-597	
Eric	“that was part of her culture to work but as a result, that individual couldn’t be supported by her”	26/461-462	
Punita	“well the main carer who is mum can’t cope...but it’s almost expected that you will carry on coping”	45/790-797	
Ranjit	“sometimes they don’t want to accept that that child has a learning disability especially if it’s a son”	14/286-287	
Services Acknowledging and Respecting Cultural Needs			
Hamza	“so are they going to have halal meat? “ “we would make sure the person is provided with the right food”; “we take everybody’s needs quite, not quite, very seriously”	20/433-442	Service Provider Experiences: Working With Complexity
Becky	“if they tell us they need to do something because of their culture, or erm we will then bring it into the fabric of what we do everyday”	19/297-300	
Claire	“listening to what they want as an individual and adapting our service around what they want I think would be ideal really”	19/308-311	
Eric	“a Muslim would eat halal erm a Jewish person would eat only...Kosher...so those are quite significant when optioning venues or places to take them. That would be something that is considered”	10/166-171	

Individualised Support (present in interviews 2, 4, 5, 6, 7, 8)	
Focus is on what the individual wants	

Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Farah	“we don’t tell them what they want, they tell us what they want”	18/316-317	It is important to be open minded as a service provider
Punita	“what is it that you actually, what is it that they want and that’s where the person centred plan really comes in I suppose”	13/228-230	
Eric	“it would be like giving them an option to support whatever they want to do”	12/205-206	
Claire	“ listening to what they want as an individual and adapting our service around what they want”	12/205-207	
Amira and Sharifah	“we give them choice because we are not in a the ladies you know, Sharifah: they’re adults”	19/327-329	
Ranjit	“it depends on that person’s needs”	5/98	

Stereotypes (present in interviews 1, 3, 4, 5)			
Avoiding Stereotypes in service provision			
Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Becky	“ you have got to be very non-judgemental. You can't go in with a white British attitude expecting the black erm stereotypical attitude because we've all moved on from...since the last what twenty thirty years”	17/265-268	It is important to be open minded as a service provider
Mary	“everybody is different you know there is no template about how white people behave similarly there is not one about how Asian people behave”	20/433-435	
Claire	“it’s not sort of up to us to say well you’re black you’ve got to go. It’s very much a would you like to go?”	18/299-301	

Eric	“you can’t just label somebody because they’re black, white, green, whatever and say that all that colour do are this..”	18/318-320	
	“ “...I wouldn't specifically only offer the Carnival to black people, I would offer it to everybody if I thought they were interested you know what I mean. I'm not saying you know, only cer...you know I'll only offer Asian culture things to Asian people I offer it to everybody”	16/276-280	

Emotions associated with Service Provision (present in interviews 1, 7, 9)			
Negative feelings as part of service provision/negative emotions			
Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Farah	“negative experiences...the emotional side of it I think because I think obviously when you lose parent carers, when you’re providing services, that can be quite emotional”	23/405-407	Service Provider Experiences: Working With Complexity
Hamza	“we couldn’t do anything else”, I was worried about her. Wake up sometimes worrying”	14/307. 14/313-314	
Rachel	“the guilt would be from saying, “I can’t cope, I need help”	18/396	
Mary	“Our staff was inside the family we were actually very concerned but to no avail.....nothing changed at all and that is very depressing”	19/410-413	
Sharifah	“just seeing her state as well that was very upsetting”	21/362-365	

Gender (present in interviews 3, 4, 5, 8)			
Parents want daughters to attend all female services			
Participant	Quote	Page/ Line Number	Overall Final Superordinate Theme
Zahira	“Some of the ladies er used to go to College and they were fine in a mixed group erm but some of them Moslem or the Sikh ladies come from very very strict backgrounds”	22/376-378	Service Provider Experiences: Working With Complexity
Becky	“But there has always been an issue with the Asian community erm on mixed services”	20/438-439	
Eric	“Where it’s been female and it’s been the Sikh religion it can become very difficult because although the young ladies wish to attend it can conflict with family because there is a young man here”	6/98-101	
	“But it evolved behind the scenes that the father was very very very very angry because I’m a man and I’m escorting his learning disability daughter”	35/621-623	
Sharifah	“you have to remember they are like old school and they’re not as...they still have got their thinking so it’s very easy for them, peace of mind for them, putting them in all female environment and they like that”	5/84-86	

