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Attitudes of Support Workers in Learning Disability Services towards Counselling Psychology

Abigail Louise Goss

Portfolio submitted in fulfilment of the Professional Doctorate in Counselling Psychology

City University of London

Department of Psychology

November 2016

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**Section C: Publishable Paper**

**Appendix 8: Guidelines for Authors for the European Journal of  
Counselling Psychology**

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## **Declaration**

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## **Abstract**

The following portfolio seeks to view counselling psychology and people with learning disabilities from a pluralistic standpoint. The focus of the research is to understand the attitudes of support workers towards counselling psychology and this particular client group. It attempts to investigate through mixed methods the likelihood of support workers considering a referral for counselling and the factors that affect this while understanding the views and opinions of support staff. In addition, the portfolio includes a publishable paper based on this research which focuses on the role of counselling psychology in improving access to counselling for people with learning disabilities. Finally, a case study presents therapeutic work with someone who has a learning disability underpinned by a pluralistic framework.



## **Section A - Preface**

## **1. Preface**

This portfolio represents a significant part of my journey on the Professional Doctorate in Counselling Psychology. There are two key themes that run through the portfolio; learning disabilities and pluralism. My decisions within this course have given me the opportunity to engage within the complexity and multi-layered nature of what it means to be a counselling psychologist, within an ever changing and demanding modern world. I used the opportunities within placements to experience working with many different people from different contexts and parts of society. My passion though lies within the field of learning disabilities and working with a client group who are one of the most marginalised groups, who have struggled to have their voices heard (Department of Health, 2009).

### **1.1 Learning Disabilities**

Learning disabilities or intellectual disabilities, describe a group of people who meet three core criteria of significant impairment in intellectual functioning, significant impairment in adaptive behaviour/social functioning and an age of onset that is before adulthood (British Psychological Society, 2015). The terminology to describe this group has changed over time and there still exists debates around which term is most appropriate to use that remain respectful to the person but useful to professionals to describe the differences and difficulties that they have (British Psychological Society, 2015). Learning disabilities is the term that is mainly used in the portfolio to identify this group of people however the term intellectual disability has been used when it was felt to be appropriate due to the aim or audience of the writing.

Although people who have a diagnosis of learning disability all share this underlying difficulty, each person is of course unique and requires thinking about in that way. However, there are common themes and factors that many people who have this diagnosis share. The voice of the collective is also more likely to be heard than the voice of the individual and this portfolio aims to give some voice to both.

My interest in learning disabilities began before starting the Doctorate while completing a Masters course which specialised in understanding, assessing and working with people with learning disabilities. One area though that was relatively neglected in the Masters course was working therapeutically with this client group. Through the Doctorate there was not only the opportunity to work therapeutically with clients who have a diagnosis of a learning disability but in addition complete research into counselling psychology for this client group.

## 1.2 Pluralism

Rescher (1993) describes pluralism as meaning that any significant question can be answered in a variety of different ways with answers that can be in conflict with each other. It is a philosophy that is closely aligned with postmodern and poststructuralist thinking and seeks to find useful pragmatic answers to questions through embracing the complexity, multiplicity and diversity of the world (Cooper & McLeod, 2011). Rescher (1993) asserts that everyone understands things based on their personal experiences and because the world is complex and imperfect then there will be a range of different experiences, which leads to a range of possible perspectives and plausible answers to any question asked.

Kasket (2012) describes counselling psychology as

*"...a particularly honest, realistic, pluralistically orientated member of the family of applied psychologies, in that it is willing to expand its horizons to accommodate a plurality of viewpoints, a multitude of possibilities and an infinite variety of potential 'truths' " (p.65).*

The pluralistic nature of counselling psychology that is described above by Kasket (2012), means that there is the opportunity to explore the various dimensions of experience (Frost & Nolas, 2011), finding what works for different people. Pluralism runs through this portfolio in both the research in the form of mixed methods and through the client study using pluralism as an integrative framework, in order to provide psychological therapy to an individual who has learning disabilities. Frost and Nolas (2011) argue that pluralism is needed due to the multi-dimensional experiences that people have. They talk about how our own actions, thoughts and feelings interact with issues of power, identity, interpretation and practical issues all at the same time. This, I will argue, is particularly relevant when thinking about people with learning disabilities.

Pluralism creates its own tensions when trying to mix research methods or psychological theories which have traditionally been seen as dichotomous and incompatible (Howe, 1988). Psychological therapies and research have traditionally been made up of particular schools of thought, which have led to rivalry rather than respect (Cooper & McLeod, 2011). This can make mixing concepts, which have been viewed as polar opposites difficult as they can be open to criticism for being unclear in direction and purpose. Pluralism is in its infancy relative to other paradigms needing more theory to underpin it (Goertzen, 2010) and continued development and reflection through philosophical debate (Johnson & Onwuegbuzie, 2004). However as Cooper and McLeod (2011) point out, psychological theories are beginning to move more in this direction as for many questions it is now more accepted that there are likely

to be a multiplicity of factors such as with the nature/nurture debate and the Bio-Psycho-Social Model (Engel, 1980). Rather than the need for one truth, psychology is embracing the need for a more complex, multi-layered understanding of the world. In the current research, pluralism and pragmatism offered a way to choose a paradigm that would best fit the research aims which could lead to thoughts about action (Gelo, Braakmann & Benetka, 2008) and could make a difference to people with learning disabilities.

### **1.3 Context**

Adults with learning disabilities represent a group of people who are seen as being at increased vulnerability from abuse, have complex needs and yet have historically been excluded from psychological therapies (Bender, 1993). Indeed there are still issues with people with learning disabilities accessing appropriate services and there being available therapists with the suitable training and experience to work with these clients (Jones, 2013b). Although government policy points towards inclusion and the use of mainstream services (Department of Health, 2001), the responsibility has remained on specialised services such as Community Learning Disability Teams to meet the needs of this group (Bouras & Holt, 2004). The current agenda of evidence based practice (British Psychological Society (BPS), 2009) and cost effectiveness means that specialised learning disability service's criteria will become more stringent and there will likely be more emphasis on access to mainstream services which typically cost less.

I agree with the voices of those within our field that for too long learning disabilities has not been considered enough in counselling psychology, both in practice (Jones & Donati, 2009) and research (Kasket & Gil-Rodriguez, 2011). While being well placed to work therapeutically with this client group (Massie, 2004) due to the underpinning philosophy and values, counselling psychology as a profession has remained relatively quiet in the field. The British Psychological Society is attempting to push forward the agenda of counselling for people with learning disabilities with its most recent collaborative report on psychological therapies and people who have learning disabilities (Beail, 2015). The contribution though from counselling psychology as a profession appears to be limited.

## **1.4 Content of the Portfolio**

### **1.4.1 Research**

The research attempts to answer questions about the opinions of support workers on counselling for people with learning disabilities. My decision to focus on support workers rather than the views of people with learning disabilities is due to staff being in the unique position to help aid the voices of those that they support to be heard. Through understanding the views of support workers and the factors that affect their consideration of a referral or speaking with their line manager about a possible referral to counselling, it suggests possible opportunities to improve access. The terms support workers and support staff have been used interchangeably within the research and refers to people whose paid employment is to support people with learning disabilities within their daily lives. When referring to consideration of a referral to counselling, this also includes support workers speaking to their line manager about a possible referral, as depending on the level of responsibility that a member of staff holds, this will affect the possible action.

The mixed methods design enabled a comprehensive view of not only the predictive variables that might affect the likelihood of support workers considering a referral for counselling for someone with a learning disability, but also how staff have previously experienced supporting someone to access counselling, how staff view counselling for people with learning disabilities and what they perceive as the possible barriers which can prevent access. Using the vignette meant that staff could express what they might consider doing and their reaction in a particular situation when there is change in the behaviour of someone that they support.

### **1.4.2 Publishable Paper**

The publishable paper based on the original research highlights the features of the study which are particularly relevant for counselling psychologists. The pluralistic methodology created a view of the phenomena from different perspectives and created multiple ways of looking at staff views in order to create a more detailed picture of their views and what might affect their thinking. Through looking at how staff view counselling for people with learning disabilities and the factors that affect the likelihood of staff considering a referral or speaking to their line manager about a referral for counselling for this client group, it allows greater understanding of how access might be improved. It explores how counselling psychologists might be able to use the findings to improve access to psychological therapies for those with a learning disability. It also considers the role of counselling psychology within the learning disability field.

#### 1.4.3 Professional Practice

The client study reflects on a piece of therapeutic work completed with someone who has a learning disability. An integrative approach to counselling using a pluralistic framework (Cooper & McLeod, 2007) was used in working therapeutically with this client. The client study discusses the complexity that needs to be taken into account when working with someone who has both ordinary and extra-ordinary needs. It sets out the adaptations that need to be considered when entering into a therapeutic relationship with someone who has a learning disability (Hurley et al, 1998). The therapeutic process and progress is reflected on as well as my own learning and development.

## **Section B - Research**

## **1. Abstract**

Many people with learning disabilities rely on others including support workers to initiate and negotiate their access to healthcare services including mental health (Kroese et al, 2014). Psychological therapies have historically been seen as not suitable for people with learning disabilities (Bender, 1993) and although this is changing slowly there is still more to be done to improve access for this client group (Beail, 2015). Therefore support workers have a key role in improving access to counselling for the people they support. The study was interested in the views and attitudes of support workers of counselling for people who have learning disabilities. The study investigated the likelihood of support workers considering a referral for counselling for someone that they support and the factors that affected this. Factors considered included factors related to the person with learning disabilities (such as level of learning disability) and characteristics and experiences of the support workers (such as previous experience of supporting someone to access counselling). 115 members of staff who support people on a daily basis completed an online questionnaire. A mixed methods design was used which included a vignette, Attitudes to Disability Scale (Power et al, 2010), closed answer questions and open-ended questions. The data was analysed using various statistical analyses and Thematic Analysis (Braun & Clarke, 2006) to answer the research aims. The findings from the vignette indicated that although the level of learning disability (mild, moderate or severe) did not influence the likelihood of consideration of a referral for counselling, staff were more likely to speak to the person if they had mild or moderate learning disabilities. Counselling was not the first consideration by staff and instead the GP would be the initial source of support if there were behavioural changes. The results of the statistical analysis indicated that previous experience, role, the prospects aspect of attitude, level of education and type of service affected or were related to the likelihood of support workers considering a referral for counselling. Thematic Analysis (Braun & Clarke, 2006) indicates that support workers previous experiences have tended to be positive but that they are also aware of multiple barriers that potentially prevent access. The results are discussed in relation to the research literature, the possible implications for improving access and the role that counselling psychologists can play.



## **2. Literature Review**

### **2.1 Introduction**

The current provision for people with learning disabilities and mental health issues is being closely examined. The scandal at Winterbourne View revealed on the BBC Panorama programme (Kenyon, 2011) showed horrific abuse of vulnerable people with learning disabilities, mental health conditions and challenging behaviour which shocked the nation (Transforming Care and Commissioning Steering Group (TCCSG), 2014). Although the Department of Health (2012) investigated the scandal, laying out the lessons that had to be learnt and what actions needed to occur to improve services and outcomes for this vulnerable group of people, this was not enough to lead to dramatic change. As Bubb (TCCSG, 2014) succinctly puts it:

"Over the past few years people with learning disabilities and/or autism have heard much talk but seen too little action". (p. 7)

This most recent situation reflects the latest mistreatment in a long history of discrimination. Even in ancient Greece, in Sparta, new-born babies would be considered by the elders of the commonwealth and if it was felt that there was a disability, including learning disabilities, the child would be thrown into the river or abandoned (Richards, Brady & Taylor, 2015). This practice was also widespread in ancient Rome, although the decision there lay with the parents rather than the state (Richards et al, 2015). This in effect was a primitive form of eugenics which based on Darwinian theory, had the aim of improving the rate of desirable characteristics through controlled breeding (MacKenzie, 1976). Eugenics has had a major impact on the treatment of people with learning disabilities as disabilities were seen as an undesirable characteristic that meant people with learning disabilities should be discouraged from parenthood (MacKenzie, 1976). In comparison to ancient history in Sparta and Rome, in more recent history the implementation of eugenics has ranged from segregation, to sterilisation (in late 19<sup>th</sup> and early 20<sup>th</sup> centuries), to the alleged state sanctioned killing of people in Nazi Germany, to more modern methods of prevention, including prenatal screening and abortion of potentially disabled fetuses (Hollander, 1989).

This is a group of people whom are vulnerable and disadvantaged in modern day society and as such, need people to ensure that their voices are listened to, so that they are empowered to live the full and varied lives that they wish to (Department of Health, 2001). Counselling psychologists must play their part as professionals that are called to advocate and support people with learning disabilities to have their own voice. In particular, to ensure that those

with mental health difficulties have access to services and treatments that are appropriate and effective (TCCSG, 2014).

## **2.2 Chapter Outline**

The chapter will provide a contextualisation for the present research and provide a rationale for the research aims. The literature has been systematically reviewed in order to explore what is understood about counselling psychology and learning disabilities, and in particular the area of staff attitudes. Due to the multi-dimensional nature of learning disabilities the research that is being reviewed has been drawn from the allied disciplines. It will clarify the contemporary concept of learning disabilities itself and identify the prevalence of this population. Each of the explanatory models will be explored and the impact that these models have for the treatment and education of people with learning disabilities. The recent history of learning disabilities will be considered due to the legacy that this brings for people including deinstitutionalisation (Ericsson & Mansell, 1996; Mansell, 2005), Normalisation and Social Role Valorisation (Wolfensberger, 1983).

The health needs of people with learning disabilities will be identified, both physical and mental health, before looking at the prevalence of these. Factors that can affect psychological well-being and the identification of mental health conditions will also be explored. In addition, what is available in terms of mental health services for people with learning disabilities will be discussed before looking specifically at psychological therapies. A discussion will then be introduced of the various counselling interventions that have been used with people with learning disabilities.

Staff views and attitudes towards learning disabilities, mental health and counselling for this population will be explored, before lastly looking at the relationship between counselling psychology and people who have learning disabilities.

## **2.3 Terminology**

As well as the manner that services, attitudes and values towards people with this particular disability have changed, the terminology used has also gone through an evolutionary process of its own. Terms including 'idiot', 'imbecile', 'moron' and 'feeble minded' were later replaced with 'mental defective' and 'mental deficiency' (Richards et al, 2015). The term 'mental retardation' was introduced in 1961 by the American Association on Mental Retardation and was later assumed by the American Psychiatric Association, into its Diagnostic and Statistical Manual for Mental Disorders (DSM) (Harris, 2013).

Internationally there has been a more recent move away from the term 'mental retardation', to use of the term 'intellectual disability', both in the recently published DSM-5 (American Psychiatric Association (APA), 2013) and US law (Harris, 2013). This is said to be due to the pejorative nature of the term and because both professionals and advocacy groups have begun to abandon its use (Harris, 2013). Schalock et al (2007) discuss the general international move in research to using the term 'intellectual disability', and claims that this reflects the construct of disability having changed so that intellectual disability is considered less offensive and is more in accordance with international terminology.

The UK in contrast had favoured the term 'mental handicap' but the Department of Health replaced this with 'learning disability' in the 1990s (Bouras & Jacobson, 2002). This term has persisted and was used in the White Paper, Valuing People (Department of Health, 2001). However it can cause confusion with the terms, 'learning difficulties' and 'specific learning disabilities' such as dyslexia, due to the different essence of the term for the rest of the world (Bouras & Jacobson, 2002). The decision to use the term 'learning disabilities' within the current study reflects the common usage of this term not only by the UK government but also by UK advocacy groups, services, local authorities and the NHS. This is the term that support workers would be most familiar with and so was felt to be the most appropriate term to use.

These changes in the descriptive words used to label this particular group illustrate the rapidly changing attitudes and societal impact that this client group have. Interestingly these changes have come from professionals who struggle to find a term to identify the difference that can be identified within this group in an appropriate but respectful way (British Psychological Society, 2015). Using a label to describe the difference between groups fits more into the medical model than psychological model where psychologists would prefer to use continuums or descriptions rather than black and white diagnoses (BPS, 2015). The complex world though that we live in requires psychologists to collaborate and work alongside different professionals including medical professionals in a multidisciplinary way. This means that having a common language is helpful and means that reasonable adjustments can be made to ensure services are accessible.

However uncomfortable the use of these labels can make us feel, myself included, they can be useful to range of people including the person themselves. Taking a pluralistic and pragmatic standpoint means that although I adopt a relatively non-diagnostic approach towards the clients (Cooper & McLeod, 2011) I work with. It would be unethical though to not acknowledge the clear difficulties that this group of people face and find some term to be able to communicate with others and, in some cases the client themselves in order to have a shared

understanding. However, there needs to be awareness that through the application of these general labels professionals can fail to see the individuality and personality of the person. These terms and others dominate our society to identify difference and provide access to services. Holding both of these positions means that although the current labels of 'learning disabilities' (in the UK) and 'intellectual disabilities' (rest of the world) are flawed they are also useful in many ways and represent the only common language available at the moment. It is likely the terms used will continue to evolve as societal and scientific understanding expands.

## **2.4 Definition, Sub-Classification and Prevalence of Learning Disabilities**

### **2.4.1 Definition of Learning Disabilities**

The current understanding of the concept of learning disabilities is grounded most firmly within the construct of intelligence (Webb & Whitaker, 2012). The term does not refer to a homogeneous group (British Psychological Society, 2000), although it is often viewed as a discrete entity rather than the extreme of a continuum, where the dividing line has been arbitrarily placed by opinion (Whitaker, 2008).

The internationally accepted definition of learning disability contains three core criteria including:

- Significant impairment in intellectual functioning,
- Significant impairment in adaptive behaviour/social functioning and
- An age of onset that is before adulthood.

This definition has not only been laid out by the diagnostic manuals including the ICD-10 (WHO, 1992) and the DSM-5 (APA, 2013) but also by the British Psychological Society (BPS), (2015) and the British Government (DOH, 2001). The BPS (2015) sets out exactly how a diagnosis of a learning disability should be assessed for each of the three core criteria. Intellectual functioning is measured through the use of a general factor of intelligence that is summarised as a number called the 'intelligence quotient' (IQ), which is considered the standardised way to measure intellectual functioning in the general population (BPS, 2015). Adaptive behaviour is measured through looking at how somebody functions in their day to day lives and the level of independence they have in performing daily living activities in the three domains of conceptual, social and practical skills (BPS, 2015). The age of onset before adulthood means that there must be evidence of difficulties in intellectual functioning and

adaptive behaviour during the developmental period or prior to the age of 18 years (BPS, 2015).

The discussion below will focus on the intellectual functioning aspect of the core criteria due to adaptive behaviour being harder to objectively measure. Although the BPS (2015) recommend using assessments which are either, norm-referenced, criterion referenced or composed of a skills checklist, these have been criticised for adaptive behaviour due to poor concept definition, lacking predictive validity and being standardised on biased norms (Davidson & Baker, 2010).

#### 2.4.2 Impairment in Intellectual Functioning

What constitutes as significant impairment in intellectual functioning is generally accepted as being an IQ score at least 2 standard deviations below the mean, about 69 or less (BPS, 2015). IQ though does not tell the whole story, with the diagnostic manuals, ICD-10 and DSM-5 (WHO, 1992; APA, 2013), and the BPS (2015) warning that IQ should not be the only defining factor for diagnosing a learning disability. This reflects the complexity of interactions between factors including biological, psychological, social and the cultural environment (BPS, 2000). There is a drive towards assessments which assess each individual's unique needs and identify what supports may be needed (BPS, 2015).

Indeed the Wechsler intelligence tests (Wechsler, 2010) which are some of the most commonly used in the UK, contain error so that they are about 95% accurate to within about 3-5 IQ points (Whitaker, 2004) and it has been argued that this error is greater in the lower range of IQ scores (Webb and Whitaker, 2012). This presents issues of how certain you can be about someone's IQ especially when they may be near the cut off score of 69. This error is also exacerbated by the Flynn effect (Flynn, 2007), where IQ scores tend to rise in a population over time, which means that scores need be corrected depending what test is taken and when. However, when Whitaker (2010) looked at IQ subtests for Britain, he found that the Flynn effect may actually be reversing at the lower IQ range which causes even more concern about accuracy.

In fact there are even disagreements about what intelligence actually is and how best to measure it (Murphy, 1987). There is uncertainty about whether population IQ scores conform exactly to a normal distribution as in practice there seems to be a 'bump' leading to a relative over-representation of those scoring IQ levels below 50 (BPS, 2015). Questions have been raised whether the composition of the standardisation groups is appropriate and also how well you can generalise results over time, environment, testers and tasks (Murphy, 1987).

Some commentators have argued for alternative definitions and measures such as a functional criterion approach (Leyin, 2010), such as one based on how much support a person requires (American Association on Intellectual and Developmental Disabilities, 2004), or one that is explicitly based on clinical judgement (Whitaker, 2008). There does feel like there is potential within a functional criterion approach to address some of the inherent problems within the intelligence tests and this seems more standardised than clinical judgement which can vary widely between clinicians (Whitaker, 2008). These options however do not yet offer better alternatives to intelligence tests and due to clinical practice and research requiring a way to measure learning disabilities, the IQ test is likely to continue to be used as part of the diagnostic process (Murphy, 1987).

I agree with Davidson and Baker (2010), who have argued that IQ tests currently offer the greatest objectivity and impartiality. They are also at reduced risk of the existing recognised thresholds being changed due to political considerations such as budget constraints which would likely impact on a system regarding the amount of support required (Leyin, 2010). They offer a standardised way to measure intellectual functioning across different ages and offer another common language for professionals both in clinical practice and research. As long as assessments are completed and interpreted by trained psychologists, who understand and recognise the measures limitations (BPS, 2015), then there is a usefulness that can emerge through being able to identify someone's strengths and weaknesses so that you can advise and support people appropriately.

Although the permanency of the label of learning disability is questioned (BPS, 2000; Whitaker, 2004) due to it being a social construction where an arbitrary line was placed on the continuum of intellectual functioning and adaptive behaviour. It nonetheless is enshrined within our social and legal systems and is often used to gate-keep services so that only those with the diagnosis can access appropriate and specialised service (BPS, 2015). However, it has also enabled differentiation to occur so that people with autism who have average or higher IQ are not just pigeonholed into learning disability services but are provided with services that are developed for their particular needs (DOH, 2001).

#### 2.4.3 Sub-Classifications of Learning Disabilities

Learning disability has been further sub-divided by the diagnostic manuals, ICD-10 and DSM-5 (WHO, 1992; APA, 2013), into the sub-classifications of mild, moderate, severe and profound. Although the ICD-10 (WHO, 1992) explicitly says that these are arbitrary divisions of a continuum that is complex and can't be defined with complete precision, they do allocate IQ ranges to each sub-division (Table B2-1), although this is likely to be dropped from the

anticipated ICD-11 (BPS, 2015). The ICD-10 also specifies the profiles of need which may be seen at each level (WHO, 1992). The DSM-5 (APA, 2013) uses these sub-classifications but instead they are based upon adaptive functioning.

**Table B2-1: Sub-classifications of learning disability within the ICD-10 (WHO, 1992).**

Sub-Classification of Learning Disability	IQ Range
Mild	50-69
Moderate	35-49
Severe	20-34
Profound	< 20

The BPS (2000) in comparison advocated the use of two sub-classifications; significant and severe learning disabilities. This sub-classification has been maintained within the updated guidance on assessment and diagnosis published by BPS in 2015.

**Table B2-2: Sub-classifications of learning disability advocated by the British Psychological Society (2000).**

Sub-Classification of Learning Disability	IQ Range
Significant	55-69
Severe	<55

As can be seen in Table B2-2 the IQ ranges used to indicate cut offs for the sub-classifications are different to those used in the ICD-10 (WHO, 1992). Unfortunately this means that not only are there two slightly different systems using the term 'severe', but that these have completely different cut-offs which can lead to confusion in some contexts. However, most people tend to use the international system of mild, moderate, severe and profound, unfortunately though, this is not always made explicit (Leyin, 2010).

There are concerns that these international sub-classifications cannot be assessed reliably using the existing available measures of intelligence (Davidson & Baker, 2010), and that especially below 50 it is possibly more guessing due to the limitations of the IQ tests (Leyin, 2010). Davidson and Baker (2010) speak from personal experience of how important these sub-classifications are to referrers requesting assessments and how exasperating and unhelpful it can be to them for conclusions to be so tentative. As previously discussed, I agree with them that the results of an IQ test as an element of a comprehensive formulation is needed to inform and develop services, and shouldn't just be dismissed because of some of its limitations (Davidson & Baker, 2010).

#### 2.4.4 Prevalence of Learning Disabilities

Knowing how many people have a learning disability is important to be able to provide necessary supports and services. It is difficult to know the exact numbers of people with a learning disability as there is no definitive record (Emerson et al, 2011). The White Paper, Valuing People (DOH, 2001) estimated that in the UK there are approximately 145,000 adults with severe and profound learning disabilities and 25 per 1000 population or approximately 1.2 million adults with mild/moderate learning disabilities. They anticipated that in particular the prevalence of those with a severe/profound learning disability would increase each year due to increased life expectancy, children surviving into adulthood where it would previously have not been expected, a sharp rise in school children being diagnosed with both autism and learning disabilities and a greater prevalence of learning disabilities occurring in some ethnic minority populations.

Emerson and Hatton (2004) discuss two different ways to measure prevalence; administrative prevalence and true prevalence. Using learning disability registers and 2001 census data, they were able to calculate an administrative prevalence of 224,000 (0.46% of the population) adults with a learning disability in Britain. It must be noted that administrative prevalence's do tend to include more people with a severe or profound learning disability (Emerson & Hatton, 2004). Their true prevalence, which included an estimation of those not known to services, was estimated to be approximately 985,000 (2% of the population) adults. A more recently calculated true prevalence for England was estimated to be 900,000 adults with 191,000 of those being known to learning disability services (Emerson et al, 2011).

This means that there are a substantial number of adults with mainly a mild learning disability who are not known to services. Whitaker (2004) discusses the issues regarding this hidden population. It is not known whether everyone if tested would meet the 3 core criteria for a learning disability diagnosis and while there would be advantages in that they may gain access to services, there is also the stigma of the diagnosis to consider (Whitaker, 2004). It also raises questions about whether there are some people who would meet the criteria for a learning disability but are actually coping in the community without the need of services or who may be being excluded from services because of not having a diagnosis (Whitaker, 2004). There does however seem to be consensus that the numbers of adults with learning disabilities, especially those needing access to services, is rising.

#### 2.5 Different Perspectives of Disability

There are various different perspectives or models on disability and its possible origins. These have different influences on how people with learning disabilities are impacted by services,



policy and society. Llewellyn and Hogan (2000) describe a model as being a type of theory which can help to generate hypotheses but is not considered truth as it is not based in research driven data. It can aid explanation through presenting information in a systematic and representative way. Most literature does not differentiate between learning disabilities and disability in general so the models discussed are those in reference to disability but specific references will be made to learning disabilities where possible.

#### 2.5.1 Medical Model

The medical model has been seen as the dominant and most influential model of disability and has had a powerful influence on research, intervention and societal views of learning disabilities (Rioux, 1997). It originated from the disease model where it is seen that there is a condition that requires some treatment or intervention (Llewellyn & Hogan, 2000). The cognitive or physical impairments that arise are the result of underlying conditions or disease (Johnston, 1996). Indeed, medicine presents itself as the primary basis for diagnosing disability, influencing treatments and guiding access to societal services and benefits (Rioux, 1997).

The individual is seen as the aspect which needs to adapt and be flexible while society is viewed as fixed and unchangeable, therefore reducing the disability to an individual pathology (Llewellyn & Hogan, 2000). Rioux (1997) asserts that as the underlying condition itself is seen as the main issue, that there is the overall societal aim of reducing its prevalence within the general population and that the medical model places less importance on the role that society plays in limiting people with learning disabilities. Goodley (2001) agrees with this position claiming intellectual impairment itself remains a medical problem which is viewed as needing to be either eradicated or rehabilitated. Although learning disabilities are treated as discrete entities and as a medical condition by it being within the diagnostic manuals (Webb & Whitaker, 2012), it is not strictly a medical condition although it has very strong links with the medical tradition (Gillberg & Soderstrom, 2003). There is currently no single pharmacological intervention for the treatment of learning disabilities (Gillberg & Soderstrom, 2003) and so the focus has remained on prevention with varying amounts of success (Alexander, 1998).

#### 2.5.2 Psychological Model

The psychological model also views the disability as being routed within the person due to an individual pathology, in contrast however, it aims to treat the functional incapacity through strategies designed to enable people to reach their full potential (Rioux, 1997). It has been said that psychology has played an unintentional role in the development of the negative view of

disability as it has perpetuated the belief that a disability will have a negative impact not only on the person but their family, community and wider society (Supple, 2005). It helped to create the concept of individual differences and with that the idea of norms and abnormality. It linked the level of impairment with particular emotional and cognitive characteristics (Supple, 2005). Indeed Rioux (1997) warns that using a purely psychological model runs the risk of not taking into consideration enough of the environmental and situational factors as it can focus too much on the deficits in intelligence. However, it has also led to many strategies which have transformed people's lives through teaching, training and behaviour modification.

The psychological model has meant that many theories have been developed over time to explain the emotional and behavioural responses to disability rather than just thinking about the disability itself (Johnston, 1996). For instance, Johnston (1996) discusses Applied Behaviour Analysis, where disability is viewed as behaviour which means that disability is subject to the same explanations as other behaviours. These can therefore benefit from interventions which may be able to reduce the disability without a reduction in the underlying impairment.

The psychological model also led to the Systems Analysis Approach (Bronfenbrenner, 1989) and the Transactional Model (Sameroff, 1991). The Systems Analysis Approach involves examining the interactions between the person and the different environments that they interact with rather than objectively looking at behaviour in isolation (Llewellyn & Hogan, 2000). Application of this model means that assessments take into consideration the cultural aspects of a person's upbringing and gather information in multiple environments and from multiple people within the person's life (Llewellyn & Hogan, 2000). An example of this in practice would be a psychologist completing an assessment through interviewing the person, their support workers, their parents and job coach as well completing observations in each of these environments. The Transactional Model views disability as being created and maintained by many interacting variables including both the environment and social relationships (Llewellyn & Hogan, 2000). It emphasises the impact that interactions have on people where influence can be both positive and negative (Llewellyn & Hogan, 2000). Sameroff (1991) provides the example of the temperament style of a child evoking particular responses from the people they encounter and how this can enable a feedback loop, so that anxieties in a mother could lead to difficulties in feeding and sleeping, which then mean that the child is seen as having a difficult temperament and lead to the mother spending less time with the child.

However it is important to keep in mind how psychology has created to some degree what is known about behaviour and the mind, and when it has been applied to learning disabilities it

has meant that terms including 'syndromes' and 'mental impairments' have been created which have negative undertones (Goodley, 2001).

### 2.5.3 Social Model

The social model was created out of dissatisfaction with the medical model as people with disabilities rejected the idea of being defined as abnormal (Llewellyn & Hogan, 2000). It views people with disabilities as having been oppressed by the societal views of what is considered normal and places the collective responsibility for change onto society (Llewellyn & Hogan, 2000). Rioux (1997) agrees with this position arguing that there is the need to fix society due to disability being so inherent within the social structure. The social model places the explanation of disability on the dynamic interactions that occur between an individual's impairment and environmental disadvantages (Llewellyn & Hogan, 2000).

Rioux (1997) has proposed that there are two main approaches from a social model point of view; the Environmental Approach (Landesman-Dwyer, 1981) and the Rights-Outcome Approach (Roth, 1983). Rioux (1997) describes how the Environmental Approach places emphasis upon the interactions that occur between individuals and their immediate environment. It places the failure on ordinary environments to account for individual differences as to why some people are disabled by society. The Rights-Outcome Approach focuses on the relationship of the individual with that of society at large and how it is organised to create disability (Rioux, 1997). It focuses on justice being the required intervention.

Several examples have been used to emphasise how particularly the concept of learning disabilities is a socially constructed phenomenon. Goodey (2015) discusses how the term learning disability has not been a historically stable concept which means that even within living memory the criteria used for admissions to institutions would have little resemblance to the psychological assessments which are presently being used. Goodley (2001) argues that it can be easier to apply a social model to those with a mild learning disability rather than severe or profound learning disabilities. He uses three different ways of constructing disability which can give examples and illustrate the social model of disability being seen in action.

The first is the administrative construction where Goodley (2001) uses the example of how in 1973, the term 'borderline retardation' was removed from the American Association on Mental Deficiency's Manual of Terminology, which meant that some people lost services overnight. Their difficulties were still present but the construction was not. The second is institutional construction. Using bereavement as the example, Goodley (2001) explores how it

does not matter how the person with a learning disability reacts to bereavement. They can be diagnosed either with challenging behaviour or mental health problems. There also exists this double bind that often families want to protect the person by not telling them about a death, but then this can create further issues as the person will still be aware that something has changed or that their loved one is not around anymore. Thirdly, Goodley (2001) describes the relational construction, where unsociable behaviour is judged as being worse than if the same behaviour was seen in the general population and is instead attributed to the person's deficits.

It must be noted though that the more blatant forms of prejudice are slowly decreasing through the use of governmental policy (Equality Act, 2010) but Deal (2007) suggests that they are being replaced by more subtle forms of prejudice which can be equally as damaging. Deal (2007) coined the term 'aversive disablism' to recognise how government law may be modifying explicit behaviour but that prejudice attitudes may still remain. These attitudes may not even be recognised as prejudice as the person may recognise that disablism is bad so may not be anti-disabled but instead may support behaviour or policy that excludes disabled people (Deal, 2007). For instance, aversive disablism may support people with learning disabilities attending special schools as they are specifically set up to offer education to those with learning disabilities, rather than mainstream schools being expected to make changes and allowances to ensure children with learning disabilities can access appropriate education.

Goodley (2001) has questioned some of the assumptions that are made of the social model, such as the way that it does not pay enough attention to the definitional link of disability to the medical and psychological discourse and has proclaimed that there needs to be a refocus onto impairment through the re-socialising of impairment. Further focusing on the social model can lead to people's collective identities being weakened and lost as the impairment is at risk of being dismissed (Goodley, 2001). Critics also point out that the social model does not give enough consideration to the personal and emotional aspects of disability which can lead to internalised oppression (Watermeyer & Swartz, 2008).

#### 2.5.4 Bio-Psycho-Social Model

The Bio-Psycho-Social Model was developed to overcome the innate difficulties and missing dimensions which exist within each of the singular focussed models (Engel, 1980). Originally, it was proposed by Engel (1980), who described it as being based on a Systems Approach and discussed its application within the medical field to encourage a holistic analysis to health and treatment. It is an integrated model that when applied to disability, can explain how impairment and environment influence psychological representations which, would then

influence behavioural intentions and the resultant behavioural expression which is interpreted as disability (Johnston, 1996).

The utility of the model is felt to lie with the complexity that is apparent within disability and the many advocates of the model include the World Health Organisation (2002). Their interest in the model is due to diagnosis alone not predicting service needs or outcomes and so a model which can take into consideration the complexity of disability at different levels is required. Indeed Borrell-Carrió, Suchman and Epstein (2004) argues that the model does not only account for complexity but can help to account for causality although warns that practitioners may need to consider Complexity Theory rather than simplifying the causal components through a multi-dimensional linear approach.

What is clear is the value of any of these models lies with how useful they are rather than whether they are right or wrong (Engel, 1980). The bio-psycho-social model offers one such idea due to the current reality that there is no one single pharmacological, psychological, societal or educational treatment available to cure learning disabilities (Gillberg & Soderstrom, 2003). In practice, through the use of multi-disciplinary case formulation, it has shaped the way learning disability services think and develop to meet the needs of people with learning disabilities (Ingham, Clarke & James, 2008). It is common for services for people with learning disabilities to be multi-disciplinary in nature, which means that there will be multiple people or professionals working with someone with a learning disability on many different aspects of their life, whose approaches will be influenced by different models both historically and currently. The support that a person who has a learning disability receives will be as a result of the co-existence of these models and the relative influence that a particular model has at a particular time. This has principally been the case within learning disability services where the expectations and values of support staff have had to change to reflect the changes in influence of the various models (Bradshaw & McGill, 2015).

#### 2.5.5 Applications of these Models

Indeed all the models described above have shaped learning disability services and been applied in various ways. Starting from the diagnostic process, the standardised measures of intelligence originated through the medical and psychological model (Llewellyn & Hogan, 2000). But even with diagnosis things are not clear cut, different services use the concept of learning disability slightly differently (Davidson & Baker, 2010). For instance, although the NHS utilises the diagnostic manuals only, social services in comparison undertake their own fair access to services assessment for eligibility for services and education services have completely different legal definitions for special educational needs (Davidson & Baker, 2010).

This can mean that someone who meets the criteria for one service may not meet it for another.

Some services have followed the psychological model through the use of a Functional Approach (Johnston, 1996). This approach has very much influenced adult education through the use of life skills training, job coaching and behavioural modification (Rioux, 1997). Coles (2001) also investigated whether the social model was influencing direct support from care staff. Although it was only a very small qualitative study of two people with learning disabilities, it did indicate some good examples of the application of a social model, to the support of people with severe and profound learning disabilities (Coles, 2001).

There have also been calls for traditionally medically dominated services such as mental health to include consideration of the social model. Indeed, Williams and Heslop (2005) have argued that the impact of the social model within learning disability services has led to improvements, such as improved use of alternative forms of communication such as easy read, which have not yet reached services designed for people with both learning disabilities and mental health problems. One thing is sure though, due to the dominance of a neo-conservative economic agenda, the focus of research and services is of a practical nature, where the utility and the need for cost savings, overshadow the empowerment and advocacy movements (Rioux, 1997).

## **2.6 History of Learning Disabilities**

Goodey (2015) discusses the importance of being aware of and understanding the history of people with learning disabilities. The thinking, views and attitudes towards this group have gone through their own particular development, which as Goodey (2015) asserts, means that what we understand to be the concept of learning disabilities today is different to how it would have been conceptualised in the past. Infanticide featured within the very early history of Sparta and Rome which was later overtaken by religious sympathy, charity and education (Scheerenberger, 1982). What is clear though is that these people were seen as different and as the eugenics movement gained popularity, they were seen as polluting the moral and intellectual integrity of society. Eugenics was seen as acceptable due to its scientific foundation based on Darwinian theory, it had the aim of improving the rate of desirable characteristics through controlled breeding (MacKenzie, 1976) and was felt to be morally and religiously acceptable (Hollander, 1989).

This meant that the late 19th century and early 20th century was characterised by segregation and sterilisation, although the latter was much more rarely used than the former (Hollander, 1989). Most institutions began as a more humane alternative to the workhouses but were

distorted by the ideas of eugenics (Mansell & Emerson, 1996). Indeed, eugenics played a key role in the development of psychological testing and psychometric theories which are so dominant today (MacKenzie, 1976). It declined in popularity following the end of World War II and the allegations that approximately 400,000 people with mental handicap or mental retardation had been selectively killed by the Nazi government (Hollander, 1989).

Deinstitutionalisation began at this time, although it was not until the series of public scandals in the 1960's when it emerged that people were being ill-treated, neglected and exposed to squalid conditions, that there was the drive to make it happen (Mansell & Emerson, 1996). Around this same time the Normalisation Principle was being developed by Nirje, which he explained as meaning, that the patterns of everyday life for people with learning disabilities should be made as similar as possible as the regular circumstances and ways of life in mainstream society (Nirje, 1985). Later Social Role Valorisation was developed as an extension to the Normalisation Principle and sought to support people with learning disabilities to hold socially valued roles such as an employee, husband or friend, which would lead to changes in perceptions of others of people with learning disabilities (Wolfensberger, 1983). Both of these principles played an influential theoretical role within deinstitutionalisation, shaping many visions and designs of services for people with learning disabilities (Wolfensberger, 1983).

Even so, the move towards care in the community was a slow one and it was not until the 1980's that deinstitutionalisation occurred on a larger scale (Mansell & Emerson, 1996). There is some evidence that these moves improved the quality of life for people with learning disabilities, as it improved the visibility of people and meant they were living in accommodation that was smaller and more typical of mainstream society (Felce, 1999). However it has been acknowledged that the move alone did not solve all of the problems, with it being common for people to still have limited opportunities for relationships, choices and engagement (Felce, 1999).

It has been argued that the negative view of disability has been ingrained within our society and now is part of 'family eugenics' (Hampton, 2005). Where the decision has instead moved from the Doctor or State, to the prospective parents who often hold onto the view of 'as long as it's healthy', often not fully realising that scans that they see as the opportunity to see their baby is preventative medicine to identify potential disabilities (Hampton, 2005).

As was illustrated by the recent abuse at Winterbourne View (Kenyon, 2011) this group is still very much at risk of mistreatment and negative attitudes towards them. The undercover footage shot as part of the Panorama investigation at the private hospital for people with

learning disabilities, mental health problems and challenging behaviour showed horrific abuse (Kenyon, 2011). This is included patients being poked in the eye, hair being pulled, being left outside in near zero temperatures and being restrained under chairs (Kenyon, 2011). Mencap in their 2012 report, 'out of sight', highlighted the failings of the Care Quality Commission inspections of Winterbourne View and other hospitals to discover the abuse and poor practice. There have been investigations and recommendations made following the scandal (Department of Health, 2012), but there are concerns that the reports will just join the other reports that have come before and barely gather dust before another scandal is uncovered (Mencap, 2012).

## **2.7 Health needs of People with Learning Disabilities**

The World Health Organisation (1948) defines health as *"a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity"* (p. 1). This focus on the holistic well-being of a person rather than the separate component parts as a definition has received much debate from commentators and critics (Üstün & Jakob, 2005). In practice and research the two have tended to be differentiated (British Medical Association, 2014). Current opinion however is turning more towards there being a bidirectional relationship, and research is beginning to support this (Kolappa, Henderson & Kishore, 2013). The importance of people with learning disabilities accessing appropriate services for both physical and mental health has recently been discussed in a report by the British Medical Association (2014), which also highlighted the relationships that exist between physical and mental health, the issues of diagnosis and barriers to accessing treatments in comparison to the general population.

### **2.7.1 Physical Health**

It has been well documented that people with learning disabilities have higher health needs to the general population (Cooper, Melville & Morrison, 2004; Emerson & Baines, 2011; Hames & Carlson, 2006) and often have physical disabilities that co-exist with their learning disabilities (Hollins & Sinason, 2000). However, in developed countries it has been shown that there are measurably poorer health outcomes for people who have learning disabilities compared to people without a learning disability (Evans et al, 2012). These health inequalities, which often begin at an early age, mean that people with learning disabilities have a shorter life expectancy, although this is improving (Emerson & Baines, 2011), and have health needs that are often unrecognised and unmet (Cooper et al, 2004; Melville et al, 2005).

Krahn, Hammond and Turner (2006) describe these health inequalities as a cascade of disparities where many factors compound together. They suggest that these include genetics, social circumstances, environment, poor access to preventative measures and medical



services. Other barriers that have been identified focus on personal attributes such as cognitive and communication difficulties (Lindsey, 2002), lack of knowledge and understanding of medical issues (Sowney & Barr, 2004) and a lack of opportunities to make healthcare related decisions (Ferguson, Jarrett & Terras, 2010). The knowledge, attitudes and negative stereotypes held by professionals have also been implicated as a barrier (Lindsey, 2002). For instance, Melville et al (2005), found that while only 8% of GP practice nurses had received learning disability training, some 86% had some difficulties during appointments while working with people with learning disabilities.

Some work has been done to improve communication and continuity of care, including the use of hospital passport tools which set out care plans and communication plans (Bell, 2012), but there is call for more work to occur across traditional boundaries to improve practice (Heslop, Marriott, Fleming, Houghton & Russ, 2012). One of the roles of the Community Learning Disability Teams is to enable access to mainstream services where possible (Bouras & Holt, 2004). However, Hames and Carlson (2006) found that many GP surgeries lacked knowledge of the role of these teams and were even confused about which professionals were within the team. This is concerning as GP's are often the most frequently accessed healthcare professionals for people with learning disabilities and often refer onto other services (Melville et al, 2005).

Support workers represent both a support and a barrier to accessing health services as often people with learning disabilities have to rely on them to negotiate their contact (Carlson, Hames, English & Wills, 2004) and identify that there is a health issue in the first place (Krahn et al, 2006). However this can mean that people with learning disabilities are not provided with enough of an opportunity to make healthcare decisions for themselves especially as the severity of the learning disability increases (Ferguson et al, 2010).

Finally administrative barriers have been identified including consent issues, familiarity of procedures, staff, environment and the flexibility of services (Lindsey, 2002). But as Sowney and Barr (2004) point out, equity of access is not just about being able to attend a service but also being able to benefit from it. Indeed it has been suggested that the health inequality gap is likely to widen as current health needs are based on the general population and although more research is needed, it seems that patterns and frequencies of illness are different for people with learning disabilities (Cooper et al, 2004; Emerson & Baines, 2011). Policy, tools and collaboration may help but surely working relationships that offer kindness, empathy and respect have got to be key (Bell, 2012).

### 2.7.2 Mental Health and Psychological Distress

Historically, there were some who argued that people with learning disabilities were not susceptible to mental health difficulties (Scheerenberger, 1982). While this view is no longer considered to be accurate, there is much debate around the psychological distress experienced and expressed by people with learning disabilities. The term 'dual diagnosis' is used to refer to the co-existence of a learning disability and a mental health problem (Sturmey, Lindsay & Didden, 2007). Unfortunately, much of the epidemiology of mental health problems in this client group is not known and what research exists is based on biased samples and inadequate methodology (Smiley, 2005).

There have been several arguments that people with learning disabilities are at greater risk of experiencing psychological distress (Eaton & Menolascino, 1982; Hollins & Sinason, 2000). The first argument relates to the high incidence of impairment in the central nervous system and the generally lower interpersonal coping skills (Eaton & Menolascino, 1982). In addition to this, there is emerging evidence that certain genetic disorders are linked with certain psychiatric diagnoses, for example, Down Syndrome is associated with increased incidence of Alzheimer's and affective disorders, while Fragile X is associated with anxiety (Matson & Sevin, 1994).

Psychodynamic thinking introduces the idea of there being psychic organising principles which are shared by most people with learning disabilities which include diagnostic process, issues in attachment, dependency, sexuality and mortality (Hollins & Sinason, 2000). It is well acknowledged that as soon as the learning disability is diagnosed, it can have profound effects on the family. While dissatisfaction with the diagnostic process is not inevitable (Cunningham, Morgan & McGucken, 1984), it can be difficult for parents having to deal with the multiple professionals that become involved (Todd & Jones, 2003) and the high levels of stress (Emerson, Robertson & Wood, 2004). Parents often have to go through a grieving process for the child that will never be and this can affect attachment (Hollins & Sinason, 2000). Indeed, studies seem to suggest that attachments when people are diagnosed quite early are more likely to be insecure (Esterhuyzen & Hollins, 1997). This disruption to attachment is likely to continue throughout life as the learning disability can be experienced as trauma which is re-enacted in the dynamics at various transition points as the emotional memory is triggered by the current situation and emotional state.

Hollins and Sinason (2000) identify this loss, plus dependency, sexuality and mortality as developmental issues that all people with learning disabilities will have to deal with. Often each of these areas presents difficulties both for the person with learning disabilities and those around them. For instance, people with learning disabilities may hear contradictory messages

about their sexuality while being more likely to experience sexual abuse and often have their grief pathologised even though their understanding of concepts around mortality develop later (Hollins & Sinason, 2000).

Maughan, Collishaw and Pickles (1999) looked at the self-reports of psychological distress by people with mild learning disabilities and found that they were markedly elevated in comparison to a group of people without learning disabilities. Bailey and Andrews (2003) however have argued that relying on self-reporting can be problematic, especially as the severity of the learning disability and communication difficulties increase. Bernal and Hollins (1995) feel that the presence of a learning disability can alter how psychological distress is expressed and that behavioural signs are more likely to be used for diagnostic purposes. This is supported by Bailey and Andrews (2003) who looked specifically at the literature on anxiety and learning disabilities finding that although it is well-recognised, it can be difficult for people with learning disabilities to meet all the criteria and the reliability is uncertain due to the reliance on behavioural symptoms. Cumella (2009) adds that people with learning disabilities may not fully understand that their experience is not normal.

Others have argued though that the emphasis on difference is not accurate, for instance, Lovell (2007) looked at the distinctions between self-injury, typically used in reference to people with learning disabilities and self-harm which is typically used in reference to the general population. When he compared the two concepts he found more evidence that they are similar rather than different, and that the choice of behaviours exhibited could be due to the restrictiveness of the disability and what the easiest, most accessible method is. Lovell (2007) argued that self-injurious behaviour could be seen as rational in the context of the person's life.

### 2.7.3 Prevalence of Mental Health in People with Learning Disabilities

This raises questions regarding the possible prevalence of mental health in the learning disability population and the calculation of this. Similarly to the calculations of prevalence of learning disabilities there is much variance in the literature. Cooper et al (2007) reported that previous studies had ranged from 7% to an unbelievable 97% while Whitaker and Read's (2006) review, which covered studies published between 1979 and 2003, reported a range of 3.9%-54.3%. Interpreting these is very difficult though as there can be much variance depending on the diagnostic criteria used and what is included as mental health diagnoses (Cooper et al, 2007). Other issues that Cooper et al (2007) reported with these studies included biased sampling, lack of information regarding methodology, small cohort sizes and combining the rates for children and adults. Indeed, most clinicians rely on identifying signs

through observation and third party reports rather than self-reported symptoms due to the poor communication skills associated with having a learning disability (Woodward & Halls, 2009).

Even in the more recent studies that have tried to take into account some of these issues large ranges are reported. Cooper et al (2007) reported point prevalence of 15.7% (using DSM 4), 16.6% (using the ICD-10, WHO, 1996), 35.2% (using DC-LD, Royal College of Psychiatrists, 2001) and 40.9% (using Clinical diagnosis). There is also the issue about whether problem behaviour and Autistic Spectrum Disorder is included as they are the most prevalent diagnoses and excluding them means that the prevalence range drops to 13.9%-22.4% (Cooper et al, 2007). Bailey (2007) looked specifically at the prevalence of mental health for people with severe and profound learning disabilities finding a range of 13.2%-61.2%, again it depended on the diagnostic criteria and problem behaviour was the most common diagnosis. Indeed, Cooper et al (2009), report a point prevalence of 9.8% for aggressive behaviour alone.

Most of the research regarding prevalence seems to conclude that mental health is more prevalent in the learning disability population than the general population and when compared to the Department of Health's (2003) figure of 16% this appears to be true. But the picture is very complicated and some believe that these may even be underestimations, for instance there is evidence that diagnostic overshadowing occurs amongst psychologists and psychiatrists (Mason & Scior, 2004). Diagnostic overshadowing is a phenomenon where professionals are more likely to attribute a person's difficulties and symptoms to the learning disability or environmental factors rather than reasonably considering an underlying mental health issue as causing the changes in behaviour (Mason & Scior, 2004). Also the studies mentioned above did not include the 'hidden learning disability population' (Cooper et al, 2007). Whitaker and Read (2006) nonetheless feel that there is not enough convincing evidence to say for sure that there is a greater prevalence of mental health in the learning disability population in comparison to the general population.

#### 2.7.4 Factors that affect Well-being and Quality of Life

Although there are issues with the research that has investigated the epidemiology of mental health problems for people with learning disabilities, the research into behavioural phenotypes is promising (Smiley, 2005). There are also some other factors that can be tentatively proposed as being potentially influential. The effect of the environment has been identified as a key factor in the mental health of the general population with factors including institutional rearing, neglect, rejection, social exclusion, attachment and personal experiences being implicated (Rutter, 2005). Cumella (2009) feels that the factors that are typically

associated with mental health for the general population are similar for people with learning disabilities including social isolation, poverty and membership of a disadvantaged ethnic minority. In fact, the government white paper, *Valuing People Now* (Department of Health, 2009) suggests the people with learning disabilities represent the most excluded group in society. The negative social stigma that is attached to this group of people means that they can experience limited opportunities in areas such as employment (Handley et al, 2012) and this being on-going can result by impacting on self-evaluations and judgements (Dagnan & Waring, 2004).

Lindsay (2000) actually postulates that people with learning disabilities are often brought up in much more protected environments and that they may not have had the same opportunities to develop coping skills to deal with their emotions and difficult social situations. Maughan et al (1999) found that childhood social disadvantage and early adversity could account for between 20%-30% of variance when comparing mental health in people with mild learning disabilities and a non-learning disability population. They also tend to experience frequent occasions of failure which can impact on their locus of control and create learned helplessness (Jahoda et al, 2006). This is likely to have an impact when for many people with learning disabilities their living environments are poor, both socially and materially, and potential stressors are high (Maughan et al, 1999).

The picture is complicated and contradictory though, as illustrated by the cohort studies on mild learning disabilities and affective disorders completed by Richards et al (2001) and Collishaw et al (2004). Richards et al's (2001) data seemed to illustrate that although there was an increased risk of having an affective disorder, this could not be accounted for by social disadvantage, material disadvantage or physical health but for Collishaw et al's (2004) data those aspects seemed to contribute strongly to the increased risk. This theme is common; while one study mentions that mental health problems were associated with recent life events and not having employment (Reid, Smiley & Cooper, 2011), another agrees with the life events but discounts the employment and introduces other elements such as the type of support and incontinence (Cooper et al, 2007).

All this shows that there is much complexity in regards to why people with learning disabilities experience mental health problems, but the above mentioned studies can give some suggestion as to what may be helpful to both treat and prevent mental health problems from developing.

### 2.7.5 Available Mental Health Services

Unfortunately intervention for people with learning disabilities only tends to happen once the conditions are well established and more resistant to change (Allen et al, 2013). Even when services are accessed it is unlikely to be the full range (Prout & Strohmer, 1998). Allen et al (2013) have argued for more primary and secondary level interventions through the improvement of developmental environments and research so that people at risk can be screened and identified earlier.

The two main treatments for mental health problems in people with learning disabilities are psychopharmacology and Positive Behaviour Support (Allen et al, 2013). There are particular concerns about prescribing in this population particularly in relation to anti-psychotic medication (Clarke, 1997). The number of people with learning disabilities who are prescribed anti-psychotics far outweighs the numbers who have been diagnosed with psychosis (Crossley & Withers, 2009). They unfortunately seem to be used as a last resort when all other medication or other options have been exhausted (Clarke, 1997). However, as Crossley and Withers (2009) study illustrated, people with learning disabilities are often put on this medication for a prolonged period without much knowledge as to why and comply to taking it even though these medications have been found in the general population to have side-effects that can be difficult to cope with.

Positive Behaviour Support in contrast takes a more Systemic Approach by looking to change the systems in which the person lives that maintain the behaviours (Allen et al, 2013). Lindsey (2000) argues that the most effective services for people with learning disabilities take a multi-disciplinary approach that includes social, psychological and psychiatric knowledge and skills. However, those with a dual diagnosis often fall through the gaps of services (Dorn & Prout, 1993) as they fail to meet the criteria for mainstream learning disability or mainstream mental health services (Lindsey, 2000). There is a government rhetoric towards people with learning disabilities accessing general mental health services (Cumella, 2009), and this is supposed to be enabled where ever possible through specialised services such as Community Learning Disability Teams (Bouras & Holt, 2004).

The debate about whether people with learning disabilities should have specialised services or should access mainstream services continues (Simpson, 1997). It centres on whether mainstream services can provide the special expertise that is required by this population (Bouras & Holt, 2004). Indeed some specialised services have been positively evaluated such as an inpatient unit (Trower, Treadwell & Bhaumik, 1998) and a Community Learning Disability Psychology Team (Jackson, 2009).

Conversely, advocates of the use of mainstream services (Dagnan, 2007) argue that it can reduce stigmatisation, labelling and negative professional attitudes (Bouras & Holt, 2004).

There are issues with people with learning disabilities accessing mainstream services though. Although there are similarities in regards to need compared to the general population, there are also differences. These include communication issues, the presentation of mental illness and the environment needed (Cumella, 2009). Indeed Leyin (2011) looks at Improving Access to Psychological Therapies (IAPT) services in respect to people with learning disabilities. He acknowledges that there is no reliable evidence about how well IAPT is working for people with learning disabilities, but that it should be able to effectively support people with mild learning disabilities. He also identifies many barriers including people with learning disabilities not necessarily being able to refer themselves, diagnostic overshadowing, practitioners not having enough knowledge or confidence and commissioners not understanding the needs of people with learning disabilities.

One thing does seem to be evident though, whether it is mainstream or specialist services, a small number of users can take up a large amount of resources. Spiller et al (2007) looked specifically at schizophrenia and found that a small proportion of people with learning disabilities were consuming almost half of the service resources. Trower et al (1998) found that in a 12 bedded unit, 4 beds were occupied for over a year. Cumella (2009) agrees with this issue saying that often effectiveness of specialist services is compromised by bed-blocking due to the lack of suitable long term placements for people with dual diagnosis.

Different approaches to mental health services for people with learning disabilities have been considered including a Recovery Approach (Handley et al, 2012), and a Human-Rights Approach (Evans et al, 2012). The Recovery Approach applied to people with learning disabilities has led to use of person centred planning, but there are difficulties in understanding exactly what recovery might mean for this client group (Handley et al, 2012). The Human Rights Approach has recognised the division between learning disability and mental health services and there have been calls for improvement in policy, access, collaboration and training (Evans et al, 2012). These do present additional factors for consideration but do not solve the issues within the current systems.

Any treatment for people who have learning disabilities and mental health problems is likely to need to consider the bio-psycho-social model and intervene at multiple levels. Treating the symptoms of mental health without addressing the underlying factors that affect well-being and quality of life or possible undetected physical health issues will not lead to good health

outcomes and is likely to mean relapse. There are advocates within the British Medical Association (2014) of working in this way but there are still many barriers that will need to be overcome in order for these ideas to come to fruition.

## **2.8 Counselling and People with Learning Disabilities**

### **2.8.1 Therapeutic Disdain**

One aspect of mental health treatment that has always been severely lacking for people with learning disabilities is psychotherapy. Bender (1993) uses the term therapeutic disdain to describe the barriers at multiple levels which have prevented the development and access of psychotherapy for people with learning disabilities. Bender (1993) discusses barriers that he saw as being institutionalised within the profession of psychology and included the attitudes of influential people, the lack of research and the lack of curiosity to work with this client group.

For a long time there was a prevailing myth that people with learning disabilities couldn't experience the full range of mental health problems (Sovner & Hurley, 1983). This was not helped by prominent figures in the therapeutic world including Sigmund Freud (1953) and Carl Rogers (1957) either discounting or not considering this group in their thinking (Bender, 1993). There has though been some advocates of therapy for people with learning disabilities arguing that they both can experience the full range of psychological distress and that they should be considered for all potential treatments (Sovner & Hurley, 1983; Sinason, 1992).

Bender (1993) proposes that there has been widespread historical therapeutic disdain towards this group, while O'Driscoll (2009) has added that there have been many lost opportunities to move forward and promote the Psychodynamic Approach for people with learning disabilities. The reasons for this disdain have prompted attempts of explanation with factors being implicated including professional boundaries (Prout & Strohmer, 1998), diagnostic overshadowing (Hollins & Sinason, 2000) and a lack of appropriate courses and training (O'Driscoll, 2009).

There is also the expertise and willingness of individual therapists, who feel able to work with this client group, to consider. Hollins (2000) emphasises the ability in the therapist to be able to recognise the importance of the non-verbal behaviour in expressing distress or illness as they often have few defences to protect them from disclosing their real feelings. Indeed, O'Driscoll (2009) feels that often therapists struggle to process the disability transference and counter-transference where the feelings of learned helplessness, failure and stigma affect the therapeutic relationship. As Bender (1993) says *"The giving of this intimacy is more difficult, aversive and more energy consuming when that person is seen as unattractive."* (p. 11) In



addition, Brown (2013) proposes that people with learning disabilities not only present with ordinary needs, but also that these interact with extra-ordinary needs. However, they are often offered less skilled support due to professionals finding it difficult to stay with these people who struggle to articulate emotions and are seen as harder to reach.

### 2.8.2 Research in Counselling and People with Learning Disabilities

In comparison to research with the general population there is only a small amount of research into counselling for people who have learning disabilities (Dagnan, 2007). It is generally felt that inferences can probably be made from research regarding the general population to borderline or mild learning disabilities, but it is likely to be less relevant for those with moderate or severe learning disabilities where verbal communication difficulties are more likely (Bhaumik, Gangadharan, Hiremath & Russell, 2011). What research has been completed has focused on borderline and mild learning disabilities (Mason, 2007).

Hurley, Tomasulo and Pfadt (1998) identified 9 adaptations that they felt were required when working therapeutically with people with learning disabilities. These included simplification, use of language, activities, taking into consideration the developmental level, directive methods, flexibility in method, the involvement of carers, the use of the transference and counter-transference and disability/rehabilitation approaches. When Whitehouse, Tudway, Look and Stenfort Kroese (2006) reviewed the research in Psychodynamic and Cognitive Behavioural Approach for use of these, they found that all were given consideration although as expected the emphasis of the importance of each variable was different in each approach.

Randomised Controlled Trials (RCT) are considered to be the gold standard when completing outcome studies but there are very few of these for counselling and people with learning disabilities (Beail, 2010). Most research tends to have small sample sizes, poor design and often lack control groups (Bhaumik et al, 2011). Beail (2010) explains that there is currently an emerging practice based evidence base that is being developed and that this creates a tension for researchers who must balance scientific rigour with external validity. There are also ethical issues to consider with research and people with learning disabilities due to mental capacity and consent (Bhaumik et al, 2011). There seems to be the dilemma that without robust research, there is a lack of confidence of using counselling as a treatment option, but that without therapists working in this way there is unlikely to be an evidence base that develops.

Mason (2007) examined the factors that affect the available provision of counselling for people with learning disabilities and found that there were three main factors. These were the perceived competence of clinicians, the level of learning disability and the influence of

diagnostic overshadowing. Knowledge and expertise on learning disabilities is not just needed though for those who decide to specialise in learning disabilities. Bihm and Leonard (1992) surveyed general mental health counsellors and found that 87% had worked with people with learning disabilities. Mason (2007) identifies that one of the major challenges is not just providing counselling but identifying suitable people. This is very true for research where studies need large homogeneous samples using manualised approaches and outcome measures which are very difficult to achieve in this client group (Beail, 2010). Research that does exist has centred on Cognitive Behaviour Therapy (CBT) and Psychodynamic Approaches but more recently other models are beginning to be explored with this client group.

#### *2.8.2.1 Cognitive Behaviour Therapy*

Applied Behaviour Analysis, which has developed into Positive Behaviour Support (Nagel & Leiper, 1999), has always been popular with professionals working with people with learning disabilities due to its ease of adaptation for all levels of disability (Bhaumik et al, 2011). Even relaxation training has been shown objectively through physiological changes and postural variables to be of benefit to people with profound and multiple learning disabilities (Hegarty & Last, 1997). It has nonetheless been acknowledged that it doesn't take into account enough of the emotional context and intrapersonal experience (Bhaumik et al, 2011). Although Sturmey (2006) feels that Applied Behaviour Analysis is often misrepresented, arguing that through various interventions it can address the emotional side.

Interest in Cognitive Behaviour Therapy for people with learning disabilities increased once it had been evidenced that they could accurately report on their emotions through self-report measures (Lindsay et al, 1994). But there was still concern about whether people with learning disabilities had the pre-requisite skills needed to engage with the model. These included recognising emotions and being able to link emotions, situations and beliefs. The general conclusions of research into these cognitive tasks revealed that performance was associated with higher IQ's and good receptive vocabulary (Sams, Collins & Reynolds, 2006; Joyce, Globe & Moody, 2006; Oathamshaw & Haddock, 2006), and that beliefs were the more difficult concept for people to understand, especially if the belief and emotion were incongruent with the situation. It was concluded that many may need preparatory training before engaging in therapy (Dagnan, Chadwick & Proudlove, 2000).

This aspect of readiness has been further explored by Willner (2006) and Taylor, Lindsay and Willner (2008) who both suggest additional factors other than intellectual functioning that could influence readiness including confidence, motivation and external factors such as carer involvement and therapist skills. Willner (2006) believes that assessment should guide but not

determine decision making regarding suitability for CBT, and that there are many things that therapists can do to increase readiness including psycho-educational work and pre-therapy preparation. Indeed Jahoda et al's (2009) research using Interactional Analysis on transcripts suggests that collaboration can occur and clients can actively take part in CBT. Although the number of sessions needed has been suggested to be higher than the general population, with Lindsay (1999) describing treatment lasting an average of 23 sessions (range 15-47).

Although there are many case studies looking into a wide variety of issues including interpersonal relationships (Creswell, 2001), nightmares and post traumatic ruminations (Willner, 2004), self-esteem (Whelan, Haywood & Galloway, 2007), Obsessive Compulsive Disorder (OCD) (Willner & Goodey, 2006) and theoretical discussions for anxiety and social phobia (Dagnan & Jahoda, 2006), the evidence base for anger management is the strongest (Bhaumik et al, 2011). This research has included both individualised (Taylor, Novaco & Johnson, 2009) and group treatments (Rose, Loftus, Flint & Carey, 2005). Willner's (2007) review of 9 studies indicated that level of verbal ability was a determining factor in the success of therapy, however Taylor et al's (2009) more recent study called this into question. What is clear is that it is difficult to unpick the cognitive from the behavioural components (Willner, 2007) and this confounds the evidence for CBT over the Behavioural Approach (Sturme, 2004). In addition, comparison is extremely difficult due to the adaptations that are often made to individualise the therapy (Whitehouse et al, 2006) which means that standardised manuals are so difficult to create (Willner, 2007; Bhaumik et al, 2011).

#### *2.8.2.2 Psychodynamic Approach*

Although Neville Symington's work at the Tavistock in 1978 is considered critical in using the Psychodynamic Approach with people with learning disabilities (Frankish, 2009), there were some therapists from the 1930's onwards who showed an interest but didn't develop their ideas (O'Driscoll, 2009). Without a doubt O'Driscoll's (2009) view of a history of opportunities lost seems very appropriate where there were many therapists well placed to develop the Psychodynamic Approach as a valuable treatment but didn't.

The research that exists on the Psychodynamic Approach for people with learning disabilities is extremely limited. James and Stacey (2013) reviewed research from 1980 to 2011 and only identified 13 studies. These were mainly case studies or case series and while they provided some support for the effectiveness of therapy with these individuals, the research was mired with issues. These included the inability to control for extraneous factors, key information being missing including the social context and very few using standardised outcome measures (James & Stacey, 2013). Bhaumik et al (2011) found similar results and also argued that

assessing the effectiveness of this approach is extremely difficult as it can be very hard to differentiate between the benefits of a Psychodynamic Approach from the intrinsic humanistic elements of therapy.

Again adaptations are often used in the therapy including flexibility and involving carers (Whitehouse et al, 2006) and there are calls for therapists to take into account the importance of context and the other people involved in the lives of people with learning disabilities (Brown, 2013).

There is also limited research regarding the experiences of the people with learning disabilities who have accessed Psychodynamic Therapy. Merriman and Beail (2009) explored this with 6 clients with learning disabilities and the themes that emerged suggested that they saw the space as somewhere to talk about problems and difficulties and found talking helpful. They felt that there were positive outcomes for them but there was a distinct lack of negative comments or criticisms. The authors wondered whether this could be due to a fear that the service could be taken away if they spoke negatively about it or their therapist (Merriman & Beail, 2009).

#### *2.8.2.3 Other Therapeutic Approaches*

More recently other therapies have been discussed in regards to people with learning disabilities. Systemic or Family Therapy was proposed by Fidell (2000) as having a lot to offer people with learning disabilities and their families. This sentiment was later echoed by Rikberg Smyly, Elsworth, Mann and Coates (2008) who also noted that it is still a very much developing area. Fidell (2000) provided advice to those considering using Systemic Therapy with this client group including ensuring collaboration, creative working, being aware of the pace and power dynamics.

Adaptations for Solution Focused Brief Therapy have been proposed for when working with people with learning disabilities (Roeden, Bannink, Maaskant & Curfs, 2009) so there is emerging interest in working therapeutically with this group. Actual research in Systemic Therapy is slowly emerging for instance, Rhodes et al (2011) evaluated a Systemic Consultation Model using a reflective team applied to challenging behaviour. The literature though remains scarce or has methodological issues (Roeden et al, 2009).

There have been thoughts about whether more Integrative Approaches would be more appropriate due to the lifelong nature of the disability (Fidell, 2000). Cognitive Analytic Therapy (CAT) has been discussed, in particular whether the reciprocal roles are relevant for this client group, with initial research showing promise (Psaila & Crowley, 2005). Indeed

practitioners are starting to think more specifically for people with learning disabilities, with models being developed such as Munro's (2011) Model of Couple Intervention.

Indeed the BPS (Beail, 2015) has published a report that discusses how the other various therapeutic approaches can be adapted including Cognitive Analytic Therapy, Mindfulness, Dialectical Behaviour Therapy, Systemic Therapy, Solution focused Brief Therapy and alternative therapies including Art, Drama and Music Therapy. The report outlines each approach, discusses appropriate adjustments for people with learning disabilities, and provides an overview of the available evidence and the views of people with learning disabilities (Beail, 2015). The majority of the available research that is discussed within the report are case studies and case series which leads Beail (2015) to conclude that most models indicate effectiveness although it is not always clear what would work for whom. Beail (2015) hopes that the report will encourage clinicians to provide a range of psychological therapies for people with learning disabilities, and engage further with research including evaluating routine clinical practice and using appropriate standardised outcome measures.

## **2.9 Support Workers Views and Attitudes**

Support worker refers to people whose paid employment is to support people with learning disabilities within their daily lives. The level of support provided to a person will tend to depend on the level of learning disability and other physical or medical issues. Indeed support workers could be supporting someone with almost any part of their life including personal care, health, activities of daily living, money management, appointments, maintenance of relationships and engagement with the environment. The variety of tasks that staff have to be competent in as part of a support worker role are complex and both emotionally and physically demanding (Woodward & Halls, 2009).

Staff attitudes and views are important when thinking about people with learning disabilities, their health and their quality of life. The Department of Health (2001) estimated that in 2000 there were 147,400 people with learning disabilities being supported in either NHS, residential care or community-based services. Support workers have faced a unique challenge within their role. The concept of learning disability and the societal policies that affect this population have evolved, so staff practice has had to develop in line with these (Bradshaw & McGill, 2015). While previously the agenda was safety and care there has been a shift over the last couple of decades towards empowerment and Active Support (Mansell et al, 2002). Although different factors interact, there is no doubt that staff have both a direct and indirect impact on the people that they support (Bradshaw & McGill, 2015).

Despite the important role that support workers play, they are often poorly paid and often services have to deal with high staff turnover and inexperienced, untrained staff (Woodward & Halls, 2009). The high level of dependency that people with learning disabilities have on these staff (Dagnan, 2007) means that they are key to improving access to psychological treatment. Therefore understanding their views and attitudes are central to be able to gain a holistic picture of the situation and develop possible interventions.

#### 2.9.1 Attitudes towards Learning Disabilities and Mental Health

It is well recognised that many people with learning disabilities have to rely on others to negotiate contact with health services including mental health services (Carlson et al, 2004). Therefore it is absolutely paramount that support workers have good working knowledge and understanding of mental health (Crossley & Withers, 2009). If staff can recognise and identify mental health issues early, they can play a significant role in referring and ensuring that the people they are supporting receive appropriate assessment and treatment (Tsiantis et al, 2004). They also hold a key role through assisting in the assessment process and implementing and monitoring treatment (Woodward & Halls, 2009). Unfortunately there is limited research which examines the knowledge and attitudes of staff working within the learning disability field on mental health and learning disabilities (Dagnan, 2007).

One study (Henry, Keys, Balcazar & Jopp, 1996) has looked at the attitudes of support staff through the Community Living Attitudes Scale (Henry, Keys, Jopp & Balcazar, 1996). The scale contains 4 sub-scales including empowerment, exclusion, sheltering and similarity. Henry, Keys, Balcazar and Jopp (1996) compared completed scales for 340 community living staff (including managers, supervisors and support staff) with those completed by 152 people from the general population. They found that managers and supervisors held more favourable views of learning disability, mental health patients and dual diagnosis than support staff. Overall, people with learning disabilities were seen as more different but also staff were less likely to endorse exclusion than the comparison group. Mental health patients were seen as more similar but participants were more likely to endorse exclusion. Those with a dual diagnosis were seen as between these two groups. The conclusions can only give basic overarching attitudes due to the limited information that that scale provides.

Rose, O'Brien and Rose (2007) in contrast used focus groups to look at the attitudes and knowledge of staff working with people with learning disabilities and mental health difficulties. The focus groups included 29 staff from a range of services including mainstream mental health and specialist learning disability services. The participants were not just limited to support workers although the exact composition is not explicitly stated, but information

provided indicated that professional qualifications included those for nursing, psychology, occupational therapy, psychiatry and speech therapy. Themes from these focus groups indicated that there were concerns about what exactly constitutes a mental health problem for a person with learning disabilities, including whether or not to include challenging behaviour and diagnostic overshadowing (Rose et al, 2007). There were also concerns about expertise and having enough knowledge in both learning disability and mental health where traditionally these are viewed as different. The themes found through this study give an indication of the different views on learning disabilities and mental health issues held by mental health services staff compared to learning disability staff. However the conclusions that can be made are limited due to the participant's information indicating that more professionals than support workers were involved in the research.

The opinion within the literature is towards support staff not having enough expertise in mental health to be able to make informed decisions about mental health in people with learning disabilities (Tsiantis et al, 2004; Woodward & Halls, 2009). Research appears to support this view. Bates, Priest and Gibbs (2004) completed a study looking at the knowledge and training of learning disability staff on mental health. Using a quantitative survey which included vignettes, they asked 365 participants from the NHS and social services about their knowledge. Bates et al (2004) found that although 90% of staff in their study had worked with dual diagnosis, only 20% of the sample felt confident in their knowledge and skills of mental health. The analysis was limited though due to only frequency data being described. The generalisation of the sample is difficult as well due to the sample population not only including support workers but the majority (63%) were professionals such as nurses, social workers, occupational therapists and physiotherapy.

Costello, Bouras and Davis (2007) completed a pre-post study comparing support workers who attended a training workshop on learning disabilities and mental health with those who did not. They used a questionnaire that gave a score for the level of knowledge and awareness that support staff had while also asking them to complete the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) Checklist (Moss et al, 1996) for someone they supported and give an indication whether they felt that person had a mental health difficulty. Costello et al (2007) found that a third of the people with learning disabilities that were thought to not have a mental health problem by support staff, did meet criteria for having significant psychopathology on the PAS-ADD Checklist (Moss et al, 1996). The study also revealed that support workers' knowledge improved through attendance at the workshop compared with those who did not attend.

This view has led to more interest in the training for staff and the difference that this makes. Woodward and Halls (2009) criticise traditional training for support staff working with people with learning disabilities feeling that it concentrates on normalisation, social integration and mandatory health and safety. Although all these aspects are important it can miss the emotional and psychological needs of people and mean that staff focus on the practical tasks rather than seeing their important role in supporting people's lives (Woodward & Halls, 2009). Henry, Keys, Balcazar & Jopp (1996) did find that those with more training in inclusion philosophy held more inclusive and empowering attitudes, but their finding could also be due to more experience due to managers and supervisors holding the more liberal views. There are thoughts that actually staff understanding is improved further through experience than through theoretical concepts delivered in training (Bradshaw & McGill, 2015).

Costello et al (2007) did actually look at the real life effect of mental health training on the knowledge and behaviour of support staff working with people with learning disabilities. They did see greater knowledge and more positive views of mental health services for people with learning disabilities, which meant that staff felt they would be more likely to refer to mental health services. But just because knowledge is increased does not mean that it will make any difference to practice. As Tsiantis et al (2004) found (in a Greek sample) that even though staff knowledge had improved following training, there were no discernible differences in practice and staff commented that it was difficult to implement knowledge once back at work. Although there may be barriers to staff implementing training, I do feel that support staff knowledge remains key and maybe training should not be the only strategy employed. They are often considered major advocates and interpreters for people on a daily basis and if we can empower people from the bottom up, then maybe real change can occur.

### 2.9.2 Attitudes towards Counselling and People with Learning Disabilities

Staff represent both a support and barrier to accessing mental health services for people with learning disabilities (Costello & Bouras, 2006), influencing care and treatment consciously and unconsciously in a number of ways (Chaplin et al, 2009). Involving people with learning disabilities in their own health and well-being is vital, and while this can only be done through staff having the correct information to support the process this has to be balanced with confidentiality (Chaplin et al, 2009). In addition, Willner (2006) raises the issues of staff readiness to support the process. He looks at the involvement of staff to support engagement with people with learning disabilities in Cognitive Behaviour Therapy and raises 3 areas of concern. These include the IQ of staff which can vary greatly, the cognitive demands that CBT



can place on staff and concern about whether many staff share the therapeutic disdain that has been shown towards this client group by professionals.

There are two qualitative studies which have looked at staff views towards counselling and people with learning disabilities (Rikberg-Smyly et al, 2008; Stenfert Kroese et al, 2014). Unfortunately these studies do not look solely at support workers but look more generally at professionals and even family members. This makes it incredibly difficult to separate out only the views and attitudes of support workers. Rikberg-Smyly et al (2008) interviewed 64 participants following initial Systemic Consultations. Using Content Analysis to analyse the responses, they found generally positive views towards the intervention, with many finding it helpful and saying that they would choose to attend another if it was offered. Indeed 74% of support staff said that they had felt able to express their view and 56% felt it had broadened their perspectives. Interestingly professional staff had more negative views towards the intervention than support staff and family, often saying that they had not felt prepared. The authors wondered if professionals had felt more able to express negative views due to the power differential between the support staff and researchers (Rikberg-Smyly et al, 2008).

More recently Stenfert Kroese et al (2014) interviewed 11 support workers and professionals before, and 9 of these same participants after CBT had been provided to people with learning disabilities that they were involved in supporting. Thematic Analysis was used to analyse the responses. The results indicated that before the therapy, there was limited knowledge regarding the aims and process of CBT and that the outcomes hoped for centred on other people's wellbeing rather than the client with a learning disability. The interviews afterwards revealed that people became more client focussed and reported improvements in the wellbeing of the client. However those interviewed also felt that the changes would be short lived and that long term intervention would be needed to make a difference. Stenfert Kroese et al (2014) concluded that there was a lack of confidence in both knowledge and skills in mental health and they felt that training could lead to more appropriate and timely referrals for therapy for people with learning disabilities.

The conclusions that can be made from these two studies are limited due to the variety of people interviewed. Staff will be in a very different position from both the family carers and professionals. They are often low paid (Willner, 2006) and experience work environments where there may be poor communication, poor morale and conflicting attitudes and beliefs within staff teams (Stenfert Kroese et al, 2014). This is unlikely to encourage support workers to think therapeutically and reflectively about behaviour and the health needs of people with learning disabilities, when they can feel like the service priority is to provide 'care' especially

with severe and profound learning disabilities (Bigby, Clement, Mansell & Beadle-Brown, 2009).

Through personal experience and the research literature there are indications that self-referring for psychological therapy by people with learning disabilities is incredibly rare (Stenfert Kroese et al, 2014). This means that staff views and attitudes become paramount if access to therapies will be improved. Staff are used to referring people for Positive Behaviour Support and psychiatry but counselling is a relatively newer area for staff to consider when their mental health knowledge may not have been prioritised (Dagnan, 2007). Only by understanding the views of support staff can professionals working in the mental health field be able to ensure fair access and appropriate treatment.

## **2.10 Counselling Psychology and People with Learning Disabilities**

There is relatively little known about counselling psychologists working with people with learning disabilities in Community Learning Disability Teams (Jones, 2013b), and it is considered a relatively neglected area of research in comparison to clinical psychology (Kasket & Gil-Rodriguez, 2011). What is known is that in terms of the number of counselling psychologists working primarily with people with learning disabilities, we are in the minority. This can be seen from a survey of members of the division of counselling psychology where only 11 of the 73 respondents worked with people with learning disabilities in the NHS (Bor & Archilleoudes, 1999). In comparison, Nagel and Leiper (1999) were able to contact 291 clinical psychologists working in Community Learning Disability Teams for their survey looking into the provision of psychotherapy for people with learning disabilities.

There are calls that counselling psychologists are well placed to work with this client group (Jones, 2013b) but as I discovered last year at the BPS Division of Counselling Psychology Conference 2014 not many counselling psychologists seem to be interested. The workshop presented by Massie (2014) on working with this client group attracted less than 10 people out of a conference of over 200. Jones (2013b) wonders if this could be due to the infancy of the profession or whether counselling psychologists do not yet have all the necessary competencies to engage therapeutically with this client group. It may be that there is a lack of interest in working specifically with this group and therefore an assumption that knowledge of how to therapeutically work with people with learning disabilities is not relevant. However, with the current opinion and policy it is highly likely that mainstream services will be increasingly expected to provide mental health services for this client group (Bouras & Holt, 2004), which means that counselling psychologists are likely to need to have the skills and awareness to work effectively with clients. Indeed Kanellakis (2010) warns that counselling

psychologists need to be mindful of the wider disability issues, especially when the disabilities are not obvious such as in the case of mild learning disabilities and people with hidden learning disabilities, which counselling psychologists are likely to be coming across now.

The values of the profession do position us in a perfect place to contribute to improving services and intervention options (Massie, 2014) but also to take disability outside of the 1:1 therapeutic room to intervene at the organisational and societal level (Kanellakis, 2010). One key consideration in counselling psychology is the therapeutic relationship. Jones and Donati (2009) reviewed the literature on the therapeutic relationship and people with learning disabilities and found only 2 American studies on the subject (Bihm & Leonard, 1992; Strauser, Lustig & Donnell, 2004). Although these did regard the therapeutic relationship as an important variable, they could only conclude that the empirical and theoretical knowledge of the therapeutic relationship and people with learning disabilities remains poor. Jones (2013a) did later publish a qualitative study in which eight counselling psychologists working Community Learning Disability Teams in the NHS with adults with learning disabilities were interviewed about their experience and understanding of the therapeutic relationship in relation to this client group. The analysis used Interpretative Phenomenological Analysis and indicated that the therapeutic relationship for these psychologists is both fundamental and influential. It was highlighted that working with this client group can be complex and difficult requiring flexibility, creativity and effective supervision and knowledge in order to provide effective therapy.

### **2.11 The Focus of the Research**

The continued call for research into counselling and people with learning disabilities (Kasket and Gil-Rodriguez, 2011; Jones, 2014b) is a justified endeavour. Only through research can the 'therapeutic disdain' (Bender, 1993) be challenged and more appropriate treatment and interventions be offered to this client group. There is no reason why therapeutic input with people with learning disabilities should be the main domain of clinical psychologists when the philosophy and underpinnings of counselling psychology have much to offer to people with learning disabilities (Massie, 2014) and the research literature.

The profession is faced with a dilemma. If people with learning disabilities are not referred to services for consideration for counselling, then psychologists and in particular counselling psychologists will not have the awareness and need to gain the knowledge and skills to work with them. But also if counselling psychologists do not have enough awareness of learning disabilities and their presentation, then they are at risk of not identifying this client group and not providing appropriate interventions using adaptations that have been indicated through

research (Hurley et al, 1998). Through understanding the role and views of support workers who are often involved at all stages of the process, it may be possible to improve access to psychological therapies for people who have learning disabilities.

My research is interested in the attitudes of support staff towards counselling for people with learning disabilities and the decision making process regarding referrals. As people with learning disabilities are rarely self-referrers (Stenfert Kroese et al, 2014) and require support to navigate services (Tsiantis et al, 2004) it is felt that staff are a valuable focus. Surely if as a profession we understand the factors that might affect referrals and the attitudes of support workers towards counselling for people with learning disabilities, then counselling psychologists have a much better chance of being able to assess and implement therapy effectively.

## **2.12 Research Objectives**

Discussions around counselling psychology research indicate that researchers should actively look to bridge the practice-research gap (Gil-Rodriguez & Hanley, 2011) and produce knowledge that professionals can use within their work (Kasket, 2012). It has already been presented that psychopharmacology and Positive Behaviour Support has dominated in the treatment of mental health within the field of learning disabilities (Rhodes et al, 2011). This is despite the increasing evidence of the potential benefit that counselling could offer (Beail, 2015). Little is known about counselling psychologists working with this client group (Jones, 2013b) and the research field has been dominated by clinical psychology (Kasket & Gil-Rodriguez, 2011), but it has been argued that counselling psychologists have much to offer and that the profession's values position us perfectly to contribute to improving services and intervention for people with learning disabilities (Massie, 2014). Support workers working with people with learning disabilities are in a critical position to support access to counselling and make referrals, due to the reliance people with learning disabilities can have on them (Stenfert Kroese et al, 2014). This research seeks to understand the attitudes of support workers in learning disability services towards counselling psychology.

Therefore the research questions for the present study are:

- What are the views of support workers of counselling psychology for people with learning disabilities?
- How likely are support workers to consider referring someone they support for counselling?

- What are the factors that might affect support workers considering a referral for someone that they support for counselling?

### **3. Methodology**

#### **3.1 Outline**

This chapter discusses the chosen mixed methods design and how that methodology which includes Statistical Analysis and Thematic Analysis (Braun & Clarke, 2006) was selected and implemented. It lays out participant selection, recruitment and the procedures for data collection. It outlines how the data analysis was carried out and concludes by examining the ethical considerations and how rigour will be ensured within the study.

#### **3.2 Epistemological Stance**

The identity of counselling psychology has evolved over the years and as a profession, it continues to engage with the tensions within its identity (Woolfe & Strawbridge, 2010). Indeed Kasket (2012) describes the profession,

*“counselling psychology as a particularly honest, realistic, pluralistically orientated member of the family of applied psychologies, in that it is willing to expand its horizons to accommodate a plurality of viewpoints, a multitude of possibilities and an infinite variety of potential ‘truths’ ” (p.65).*

This description very much connected with my original attraction to the profession and links with my epistemological position.

It does not seem possible to have a piece of research that does not have a theoretical drive (Morse, Niehaus, Woolfe & Wilkins, 2006). The discussions and debates around epistemology seem endless and complex. My traditional background in psychology and particularly behaviourism meant that a hypothetico-deductive approach (Willig, 2001) previously fitted with my ideas of a theory of knowledge. My assumptions of what is real seemed to fit within scientific realism that the world is knowable and although fallible, science offers a good mode of inquiry into it (Madill, Jordan & Shirley, 2000). This has changed for various reasons related to my increased knowledge and experience with research but also my journey to become a counselling psychologist.

I would still describe myself as a realist but more of a critical realist, which acknowledges that our beliefs and expectations affect the way we perceive the world (Madill et al, 2000). Realism seeks an ideal truth or theory (Madill et al, 2000). However, through experience and further study it seems clear to me that research can never give a conclusive answer that can account for all the complexity that exists in the world. Critical realism recognises that our own personal experiences, beliefs and expectations affect how we perceive the world and thus will affect our

behaviours (Madill et al, 2000). Therefore I feel that knowledge that is gathered through scientific research should be viewed through this lens as no research is likely to be completely objective, which scientific realism aims to do (Madill et al, 2000). The impact of both the participants and the researcher is likely to affect the design of the study and the outcomes and thus I feel that this needs to be taken into account and acknowledged when research is being carried out.

In contrast, the ideas I hold of theory and knowledge seem to fit much more within pragmatism (Yardley & Bishop, 2008) and pluralism (Chamberlain, Cain, Sheridan & Dupuis, 2011). Yardley and Bishop (2008) define pragmatism as not seeking a truth that is independent from human experience. It allows for multiple worldviews and paradigms, which mean that pragmatists can align themselves with any paradigm that best fits with the research aims (Gelo, Braakmann & Benetka, 2008). It is also a paradigm, which prefers action to philosophizing and leads to not only induction and deduction, but also determines plausibility through abduction (Johnson & Onwuegbuzie, 2004). Pluralism features within the description of counselling psychology above (Kasket, 2012) and is multidimensional and also goes beyond the methods utilised per se (Chamberlain et al, 2011). When applying this attitude to research, it means that different methods can be seen as equally valid when exploring important issues and questions (McAteer, 2010). Indeed Camic, Rhodes and Yardley (2003) argue that the pluralistic approach can encourage scepticism and innovation while remaining rigorous, thorough and useful.

It must be noted however that much more work and debate is needed on both pragmatism and pluralism due to their relatively new application within psychology (Johnson & Onwuegbuzie, 2004). Howe (1988) proposes that pragmatism holds 'what works' above 'truth' and that it is too committed to relativism and irrationalism. Indeed Wertz (1999) warns that the decision of 'what works' is often a matter of opinion and that not all research needs to solve a practical problem. Johnson and Onwuegbuzie (2004) explore some of the weaknesses of pragmatism which include it promoting gradual change rather than revolutionary change, the theory finding it difficult to deal with useful but not true beliefs and its failure to put to rest many philosophical debates.

Pluralism is also a paradigm that needs more theory to underpin it and it has been warned that if taken too far could lead to fragmentation within psychology (Goertzen, 2010). Pragmatism at least does represent a middle ground, if the paradigms are considered to be on a continuum, it prevents the need for a forced choice in research paradigms (Howe, 1988). Advocates of both

pragmatism and pluralism feel that the philosophical debates around epistemology should continue to ensure the development of the paradigms (Johnson & Onwuegbuzie, 2004).

The research questions and the knowledge sought in the current study emerged through this theoretical position. There was felt to be different layers within the overall research questions which would need different methods and analysis in order to answer the questions adequately. Through understanding the view and attitudes of support workers to counselling as well as what affects the likelihood of considering a referral to counselling, it would give a more comprehensive picture of what counselling psychologists might need to be aware of. Consequently my design incorporated mixed methods to address my research objectives.

### **3.3 Design**

The research consisted of a survey approach with vignette analysis and included closed answer questions, rating scales and open ended questions, looking at the opinions of support staff on counselling psychology and people with learning disabilities. This study employed a mixed methodology using a variant on the triangulation design called a validating quantitative data model (Gelo et al, 2008). This meant that both the quantitative and qualitative data were collected concurrently but that the qualitative data was used to validate the findings of the quantitative data which had the dominant status (Leech & Onwuegbuzie, 2009).

In relation to the quantitative experimental aspect of the design, this used a 'between subjects' design using a vignette (Appendix 5). The dependent variable being the likelihood of staff's consideration of referring a person for counselling while the independent variable is the 3 levels of learning disability (mild, moderate, severe) of the person. Other possible variables were also collected including demographic information, experience of supporting people who have been for counselling and participant's own personal experience of counselling.

Open-ended questions exploring participant's views of counselling and people with learning disabilities were analysed using qualitative analysis.

#### **3.3.1 Mixed Methods**

##### **3.3.1.1 Methodology Selection**

Toomela (2010) argues that methods should not be chosen for their own sake or because of personal preference but that they should be selected to enable the researcher to answer the research question. When developing the research questions to investigate the attitudes of support workers towards counselling psychology and people with learning disabilities, the three particular questions mentioned in Section 2.12 appeared to be key.



Therefore selecting the methodology to investigate this meant that it needed to have predictive ability, produce relationships between the variables that affect the likelihood that a referral for counselling would be considered and enable a general understanding of support workers' views and attitudes on counselling for people with learning disabilities. Mixed methods seemed to offer the opportunity to explore this topic, not only from the practitioners point of view by having an understanding of factors affecting referrals, but to also understand the underlying assumptions and views of support workers of counselling psychology for people with learning disabilities.

#### *3.3.1.2 What are Mixed Methods?*

Mixed methods have been developing since the 1980's as an alternative to the 'Quantitative vs Qualitative debate' (Gelo et al, 2008). The debate though is much more than just whether words or numbers are better and instead involve deep fundamental questions about how we pursue and understand knowledge (McGrath & Johnson, 2003). The approaches are viewed as dichotomous rather than an interactive continuum that allows researchers to ask different and complimentary questions (Newman & Benz, 1998). This debate has been coined by Howe (1988) as the incompatibility thesis, which he goes on to dispute arguing that both qualitative and quantitative research share commonalities in areas such as both making assumptions, and both constructing interpretive arguments based on the evidence that they've collected.

Trafimow (2014) argues that mixed methods allows a third research goal beyond that which qualitative and quantitative each allow. It enables the establishment of unifying theories that are not causal so that relations can be made between abstract constructs rather than causation. In addition, mixed methods can help contextualise statistics, support associations to develop explanations, help identify additional variables and balance the inherent problems within each approach (Kelle, 2006). It can mean that by using evidence in various forms that non-linear relations can be thought about and explored (McGrath & Johnson, 2003).

Using mixed methods though, creates its own set of unique weaknesses which need to be carefully considered. Firstly, as the approach is relatively new there is a general lack of agreement regarding terms and definitions (Kelle, 2006). Researchers using mixed methods also have to be aware that by using them they are opening themselves to a litany of issues relating to epistemology and methodology (McGrath & Johnson, 2003). Certainly some researchers have been critiqued for not being explicit in their epistemological position or providing a clear rationale for the use of mixed methods (Kelle, 2006). Sale, Lohfeld and Brazil (2002) warn that because the qualitative and quantitative paradigms study different

phenomena that they can't be combined for cross-validation or triangulation purposes but can provide complementary evidence.

Bryman (2007) asks researchers to ponder the question whether the end product through the use of mixed methods is more than the sum of the individual quantitative and qualitative parts, while Greene and Caracelli (2003) propose four instances where using mixed methods is likely to be meaningful. These include when thinking dialectically about mixing paradigms, when using a new paradigm, being a pragmatist and wanting to put substantive understanding first.

These are all elements that I thought carefully about when selecting the methodology to meet the studies objectives. Mixed methodology enabled me to fulfil the different yet complimentary research objectives, which aligned with my pragmatist and pluralistic epistemological position. It did though require careful consideration as to which mixed methods to use.

Morse et al (2006) advise that it is not possible to have a fully equivalent design as one methodology must always fit into the other to ensure methodological congruence and reduce threats to validity. Through using a validating quantitative data model (Gelo et al, 2008), where the quantitative data was given dominant status (Leech & Onwuegbuzie, 2009), it assisted with alleviating these issues. The use of Thematic Analysis also provided cohesion as it is a method that is essentially independent of theory and epistemology (Braun & Clarke, 2006).

### 3.3.2 Quantitative Methods

Quantitative methods are useful to researchers as they enable generalisations to be made regarding the relationships between variables (Toomela, 2010). Gore-Felton (2005) feels that quantitative methods should be used within the counselling psychology profession, as it is just as important as the qualitative methods to ensure the validity of the new knowledge generated. The fact that human behaviour is so complex with many variables both internal and external affecting it means that analytic methods are required to explain these relationships in a way that can inform theoretical models (Gore-Felton, 2005).

Indeed Neville, Carter, Spengler and Hoffman (2006) ascertain that using quantitative methods within research sits within the remit of the scientist practitioner status of counselling psychologists. Although there are varying definitions which adds to the complexity and confusion of what the term 'scientist practitioner' exactly means in practice, Neville et al (2006) argue that the three inter-related roles identified by Hayes, Barlow and Nelson-Grey (1999) must be considered. These include, being consumers of researchers (integrating it into

their own practice), being evaluators of their own practice and being researchers themselves [Note: Hayes et al (1999) were thinking about the wider field of health rather than just counselling psychology].

Clark-Carter (1997) discusses three classifications of quantitative methods: experimentation, asking questions and observing. The current study utilised the first two of these. Experimentation is usually used when the researcher is attempting to discover causal relationships between phenomena (Clark-Carter, 1997). This occurs through the manipulation of variables and measuring the effect that this has.

Asking questions occurred through the use of the questionnaire and this was done in a variety of different formats. Clark-Carter (1997) feels that this method can be ideal when the researcher has a clear idea of the range of possible answers that they wish to produce. He advocates that there are strong advantages for the researcher of using this measure as it can save time, reduce the effect of the way questions are asked through the standard format used and leads to responses that can be immediately quantified. It does however also have weaknesses including the researcher missing out on phenomena and that the knowledge produced can be too abstract or general for direct application (Johnson & Onwuegbuzie, 2004).

### 3.3.3 Qualitative Methods - Thematic Analysis

Through the use of open ended questions it was hoped that an understanding could be gained of participants' views on counselling psychology and people with learning disabilities. It was also hoped that it would give participants the opportunity to put their quantitative answers into context. There were several qualitative approaches considered for the analysis of this data including Thematic Analysis (Braun & Clarke, 2006), Grounded Theory (Glaser & Strauss, 1999) and Content Analysis (Weber, 1990).

Any method needed to have the ability to be combined with quantitative approaches and have an epistemological underpinning that would not be in conflict with my own or that of mixed methods. Grounded Theory which seeks to generate theory from the data (Glaser & Strauss, 1999) was felt to not fit with the mixed methodology planned in the current study to meet the research objectives or the constraints in terms of time and capacity. Content Analysis was considered as it extends beyond simply counting the words by examining the words intensely in order to put them into categories (Weber, 1990). It was felt however that Thematic Analysis would allow a greater depth and analysis of the qualitative data and would be more appropriate for the current study (Braun & Clarke, 2006).

Thematic Analysis is a method to enable the systematic identification and organisation of patterns within the data to offer insight into these patterns of meaning or themes (Braun & Clarke, 2006; 2012). It is an accessible and flexible approach (Braun & Clarke, 2006) that can help the reader to gain a real sense of the prominent and important themes within the data (Alhojailan, 2012). Advocates of the approach view it as separate from the wider qualitative vs. quantitative debates (Braun & Clarke, 2012) as it is compatible with various epistemological positions due to its independence from theory. This means that it can suit mixed methods research designs as long as the researcher's theoretical position is made clear (Braun & Clarke, 2012).

The researcher actively searches the data so that they can identify, code and report what is of interest (Braun & Clarke, 2006). A theme is something that is important about the data in relation to the research question which represents some level of patterned response (Braun & Clarke, 2006).

Braun and Clarke (2006) identify several options, which Thematic Analysis can allow that could provide very different analyses of the same data. These include whether the researcher is interested in a rich description of the whole data set or whether they wish to provide a detailed focus on one aspect of the data, whether the analysis will be conducted using an inductive or a deductive theoretical approach, and lastly whether the themes are coded at the semantic or latent level (Braun & Clarke, 2006). Although Braun and Clarke (2012) do point out that coding often includes both of these approaches, they also state that one tends to dominate and the overall orientation of the research tends to suggest the prioritisation of one approach.

Researchers can use these in a mixture of ways. Usually a realist position would lead to an analysis which would be interested in a rich description of the whole data set, conducted with an analysis using theoretical Thematic Analysis concerned with the semantic level (Braun & Clarke, 2006). This is the approach that was employed within the current study and the procedure used to conduct the Thematic Analysis will be discussed later in this chapter within the Data Analysis section.

### **3.4 Participants**

The participants were sought from within an opportunity or convenience sample of support workers who support adults with learning disabilities within a learning disability charity. The charity supports over 200 adults with learning disabilities across a range of services including residential care homes, supported living and outreach services. There are approximately 512

staff within the charity who are working directly with adults with learning disabilities across the South of England (covering Berkshire, Sussex and London).

It had been calculated that a sample size of 200 participants would be required for a two tailed Pearson's correlation for an effect size of 0.2 and power of 0.81 (Clark-Carter, 2010). Another way to calculate sample size is by using a 95% Confidence level and 5% margin of error which indicated that 220 out of the total 512 potential participants (Clark-Carter, 2010) would be required. Therefore around 200-250 participants were sought for the current study. The number of staff who attempted the questionnaire was 154 with 115 of these fully completing the questionnaire.

The inclusion criteria were:

- Staff had to work in a role that involved direct support work with people with learning disabilities. This included the following roles: Homes Manager, Team Leader, Assistant Manager, Assistant Team Leader, Senior Support Worker or Support Worker. Home Managers and Team Leaders were included as they often provide support with medical appointments and referrals although they may not always be providing direct support.
- Staff must be currently working with people with learning disabilities
- They must have a reasonable understanding of English and be able to use a computer in order to complete the online questionnaire.

Although the staff team who work for the charity have various ethnicities and English is a second language for a number of staff, it was decided that the questionnaire would only be provided in English as a condition for employment is that staff must have a reasonable grasp of English. The organisation expects all communication both written and verbal to be conducted in English so it was felt that all participants should be able to complete the questionnaire. This was also verified through the pretesting of the questionnaire.

#### 3.4.1 Recruitment

Staff were invited to complete the online questionnaire initially through an email (Appendix 1) and through an advert on the organisation's intranet (Appendix 2), both contained a direct link to the online questionnaire. Following a poor response rate, an individualised email (Appendix 3) was sent to each member of staff as recommended by Dillman, Smyth and Christian (2009). Participants were not offered any individual recompense for completing the questionnaire such as any payment but instead were provided with the opportunity to enter into a prize draw for a voucher to the value of £50 as a thank you for completing the questionnaire.

### **3.5 Research Measures**

#### **3.5.1 Questionnaire Development**

As the literature around support workers' opinions of counselling psychology or even psychotherapeutic approaches for people with learning disabilities is sparse, the whole questionnaire had to be developed anew. McColl et al (2001) advise that although there are no universal recommendations for best practice for questionnaire design, that researchers take into account the aims of the study, the population under consideration and the resources available. They state that there is likely to be compromise between the ideal and what is possible.

The factors that might affect the likelihood that someone might consider a referral for counselling for someone with learning disabilities was carefully considered through looking at the professional literature on attitudes to learning disabilities and mental health in general.

Research into attitudes tends to implicate age (Morin et al, 2013b; Scior, 2011; Yazbeck, McVilly & Parmenter, 2004), gender (Morin et al, 2013b; Panek & Jungers, 2008), culture (Coles & Scior, 2012), educational attainment (Morin et al, 2013b; Scior, 2011; Yazbeck et al, 2004), previous experience (Morin et al, 2013b; Scior, 2011; Yazbeck et al, 2004), seniority of staff member's role (Henry, Keys, Balcazar & Jopp, 1996), causality of learning disability (Panek & Jungers, 2008) and level of learning disability (Morin et al, 2013b).

Therefore data on the participant's demographics was collected including gender, age, ethnic origin, educational background, experience of working with learning disabilities and their current role within the organisation. These were collected before the main part of the questionnaire following participants having read the information sheet and consenting to participating in the study (Appendix 5). The questionnaire can be found in Appendix 5.

In addition, information relating to the services staff work in were collected including the type of service (residential care, supported living or outreach), the level of learning disabilities the people they support have (mild, moderate, severe or profound and multiple learning disabilities), the communication methods (verbal, Makaton, augmentative and alternative communication) and identifying any knowledge of counselling being provided for any of the people with learning disabilities that they support. These factors as well as having been identified in the literature are thought to possibly be influential through my own personal experience and discussions with staff.

Finally the participants were asked about their own personal experience of counselling. These questions included the option for staff to opt out of answering them and did not go into any depth. The questions were designed to understand the participant's own personal experience of counselling and whether they had found this beneficial. Edwards et al (2007) found that people in the general public who had themselves sought treatment for an emotional difficulty had a better understanding of a vignette character's difficulties and the consequences of not seeking support. Although this was a pilot study which had methodological issues including sampling concerns, a high refusal rate and reliance on self-reporting, it offers an interesting insight into how previous experience may affect people's views.

It was wondered whether if staff themselves had previously engaged in counselling and they saw that experience as beneficial, they would then see counselling for people with learning disabilities as an available option. The questionnaire can be found in Appendix 5.

### 3.5.2 Measure of Attitudes

A standardised measure of attitudes to learning disabilities was sought to be included as part of the questionnaire. Various measures were considered including measures which focused on general disability such as Disability Attitude Implicit Association Test (Pruett & Chan, 2006), the use of prototypes (McCaughey & Strohmmer, 2005), Multidimensional Attitudes Scale Toward Persons with Disabilities (Findler, Vilchinsky & Werner, 2007) and Attitudes to Disability Scale (Power, Green & the WHOQOL-DIS Group, 2010). Also measures were considered which focussed on learning disabilities such as the Scale of Attitudes toward the Application of Eugenics (Antonak, Fielder & Mulick, 1993), Mental Retardation Attitude Inventory (Antonak & Harth, 1994), Community Living Attitudes Scale (Henry, Keys, Balcazar & Jopp, 1996) and the Attitudes Toward Intellectual Disability- ATTID questionnaire (Morin et al, 2013a).

The decision to use the Attitudes to Disability Scale (Power et al, 2010) involved careful consideration of the relevance of the scale (whether the scale was specific enough for the learning disability population and how long ago it was developed), the length of the scale (many contained more than 50 items which was felt to be too cumbersome for the current study) and whether the psychometric properties including reliability and validity were adequate. The Attitudes to Disability Scale (Power et al, 2010) was developed cross-culturally and drew directly from the experiences and attitudes of people with disabilities including people with learning disabilities. The reliability using item response theory based analyses were found to be good ( $PSI=0.809$ ) and internal validity was also found to be good (Power et al, 2010). It does however have weaknesses as it is designed for both physical and learning disabilities and doesn't differentiate between the two.

As this study would only be interested in learning disabilities, the wording was slightly altered so that instead of it referring to people with a disability, it referred to people with a learning disability (Appendix 5). This is advised by Antonak and Livneh (2000) as it improves the specificity of the scale. It is acknowledged that this very slight alteration could have affected the validity and reliability of the measure, but was felt unlikely to be detrimental enough to affect the overall validity and reliability considering the measure was designed for use within the learning disability population and included people from this group within its development.

### 3.5.3 Vignette

Vignettes are stories which outline a hypothetical character within a hypothetical situation to which a participant is asked to react to (Martin, 2004). They can allow the researcher to gather information that would be difficult to collect due to the nature of the situation or the probable small sample size that have experienced the particular situation.

Although they can never truly be representative of real life, present some issues for generalisation (Hughes & Huby, 2002) and do not allow for the same intensity and affective meaning as experiencing the situation in a laboratory experiment (Collett & Childs, 2011), they do have many advantages.

For instance, questionnaires while having high external validity tend to have low internal validity but by including a vignette, this can help to increase the internal validity due to the available experimental control (Atzmüller & Steiner, 2010). This occurs due to the vignette data validating the other data collected, but it also leads to a more uniformed set of data due to the controlled variables (Hughes & Huby, 2002). In addition they can be selective which can provide a focus for participants and simplify situations which in real life would involve complexities and conflict (Hughes & Huby, 2002).

As I was unsure about the amount of staff that would have had experience of supporting someone with a learning disability who had received counselling, using a vignette provided a different measure. It enabled me to explore people's reactions to a hypothetical person with a learning disability and experimentally control whether variables such as gender or degree of learning disability affect opinion. The vignette, which was included within the questionnaire, describes some of the behavioural features that might be observed if someone had depression. Depression was selected as it is considered one of the most common mental health issues that affect people and has been found by Cooper et al (2007) to be the most prevalent mental health issue affecting adults with learning disabilities after problem behaviour.



The vignette was about either a male/female character and each participant was exposed to one of three conditions where the level of learning disability of the person was either mild, moderate or severe (these were randomly allocated). Questions regarding their first thoughts upon reading the vignette, what their reactions might be, how likely they would be to refer this person with a learning disability for counselling and why they feel that way were included. As each participant was only exposed to one of the three conditions of degree of learning disability, this aspect was a between subjects design (Appendix 5).

#### 3.5.4 Questionnaire Pre-testing

Nassar-McMillan and Borders (2002) assert that although the professional literature is always appropriate for the generation and refinement of questions in the development of questionnaires, using a supplementary method is important. One way is to gain feedback from people in the field. Indeed Kelle (2006) argues that even the most meticulously conducted questionnaire may return misleading or even invalid results if the participants understand the questions in a different way than they were meant, or if the topics are not felt to be relevant to them. Pre-testing a questionnaire is the only way to be able to evaluate in advance whether participants will have any difficulty or issues with the questionnaire (Presser et al, 2004).

There is not much guidance regarding the best method to use in pre-testing (Presser et al, 2004), but Focus Groups presents one method which can be used as a supplementary method as they allow data and insights to be produced that would be less accessible without the interactions that occur in groups (Nassar-McMillan & Borders, 2002).

Focus Groups provide a rich body of qualitative data which can be used for exploration or confirmation (Stewart, Shamdasani & Rook, 2007). Although they do have disadvantages including issues around extension of generalisability, participant's responses being interdependent or biased and difficulties with interpretation of data (Nassar-McMillan & Borders, 2002; Stewart et al, 2007), there are many advantages to using Focus Groups. They do offer many benefits to the researcher including flexibility, versatility, quickness, cost effectiveness and peer validation (Stewart et al, 2007). In addition, for questionnaire development, Focus Groups can ensure that questionnaires contain appropriate language and augment the pre-testing process (Nassar-McMillan & Borders, 2002). Stewart et al (2007) argue that the key to the success of a Focus Group is ensuring that their use is consistent with the objectives and purpose of the research. The advantages mentioned above meant that a Focus Group could provide an effective and valid way to ensure the questionnaire was fit for purpose. It also meant that participants could express their views in their own words and explain the context and interpretation of these views (Stewart et al, 2007).

### **3.6 Procedures**

The questionnaire was initially developed from the available literature regarding counselling and people with learning disabilities. The questionnaire was then refined and pre-tested using a Focus Group and asking questions of additional individuals who had completed the questionnaire. The questionnaire before pre-testing can be found in Appendix 4.

The procedure for the Focus Group followed the guidance that is within Stewart et al (2007). They describe the contemporary Focus Group as containing 8-12 participants who discuss a particular topic under the direction of a moderator who supports the interactions of the group promoting interaction between members and ensuring that the group do not veer too far away from the specific topic.

The Focus Group consisted of 12 support workers who were invited to participate in the group following some organisational training that they were attending. These 12 support workers who decided to be involved in the Focus Group were asked to complete the questionnaire before taking part in group discussions which lasted an hour. I acted as the moderator of the group with an observer recording participant responses and observing non-verbal behaviour and group interactions.

The questions which were provided to the group to encourage discussion about the questionnaire and the experience of completing it were:

- Overall how did you find the questionnaire?
- What did you think about the time it took you to complete the questionnaire?
- Were there any questions where you didn't understand what it was asking?
- Were there any questions that could be worded differently? How would you word it?
- Do you think there are any questions that do not belong in the questionnaire?
- Are there any questions that you would have liked to have been asked?
- If this questionnaire was completed on a computer do you think it would be harder, the same or easier to complete and why?

These same questions were asked individually to 6 additional staff who were randomly selected to take part in this stage of the research. They held varying positions including homes manager, assistant manager, team leader and support worker. This meant that a range of roles that the potential participants hold could be sampled. They answered the questions after completing the questionnaire.

The findings from both the Focus Group and individuals were collated and the questionnaire was changed accordingly. The questionnaire was not changed greatly but wording and clarification of certain things were added (The original and finalised questionnaires can be found in Appendices 4 and 5 respectively). The changes made included the following.

The option for staff to select 'prefer not to say' was removed from the questions and instead participants could leave questions blank if they did not want to answer them. This was detailed in the instructions provided to participants prior to completing the questionnaire. 'Other' was added to the role question as some people felt that they struggled to fit themselves into the available categories.

A description of counselling was added into the questionnaire to clarify what was meant by the term. A question was added which directly asked staff to indicate if they have supported someone with a learning disability to access counselling as well as describing their experience. This question was swapped around with the question asking staff about their awareness of anybody with a learning disability in their service that has received counselling either currently or in the past.

In the questions, which asked participants to rate their likelihood of considering a referral for counselling for someone with a learning disability that they support, it was added in about speaking to the line manager about the referral. This was added as some staff felt that this was more appropriate than them just making a referral without consulting anyone. The wording on the open ended questions was changed from 'Why do you think this?' to 'Please could you explain your reasons for the answer above'.

Where participants were asked about their own personal experience of counselling a statement was added which told participant's that they didn't need to provide any specific details regarding their personal experience of counselling. Lastly a question was added which asked the staff about barriers that they thought prevent people with learning disabilities from accessing counselling.

The questionnaire was tested in the hard copy format for ease and to ensure that the questionnaire was not viewed by people not participating in the pre-testing stage. Therefore the next step was to convert the questionnaire into the online format. SurveyMonkey.com (2015) was used to host the questionnaire due to staff being familiar with completing questionnaires through this programme. This also meant that the format was changed and allowed for questions to be automatically missed if they were not relevant for the participant depending on how they answered certain questions.

The questionnaire was then disseminated via an initial email invitation to all potential participants (Appendix 1). An advert (Appendix 2) was also placed on the staff intranet asking for participants to complete the online questionnaire. The questionnaire was available online for completion for two months during which time several reminder emails were sent out, home managers were asked to remind staff about the questionnaire and an individualised email (Appendix 3) was sent to each potential participant. Staff were asked to confirm their consent to complete the questionnaire after reading an information sheet (Appendix 5) and were provided with a de-brief sheet (Appendix 5) at the end of the questionnaire.

Once the two months ended the quantitative data was transferred into SPSS 22 (IBM, Corp., 2013) and the qualitative data was collated and tabulated within an Excel document so that analysis could begin.

### **3.7 Data Analysis**

#### **3.7.1 Statistical Analysis**

The closed answer questions and those using rating scales produced nominal, ordinal and ratio data. These data were transferred into SPSS 22 (IBM, Corp., 2013) and analysed using different statistical methods. The likelihood of staff considering referring the person in the vignette for counselling were compared for the three different levels of learning disability using an ANOVA. The vignette enabled analysis of what effect the level of learning disability had on the likelihood staff would consider referring someone with a learning disability for counselling. It was hypothesised that being identified as having a mild learning disability would mean that staff see counselling as more of an option than for moderate or severe learning disabilities. The different variables were considered using a variety of appropriate statistical tests with the general likelihood (this question is asked as well as the question related to the vignette) that staff will consider a referral for counselling to investigate different relationships and associations within the data. These included ANOVA, T tests, Mann Whitney U and Spearman's Rho.

It was hypothesised that some of the variables would be associated with an increased likelihood of considering a referral for counselling including staff supporting someone with a mild learning disability, staff's previous experience of supporting someone whilst having counselling if that experience was positive, a positive attitude towards learning disabilities and a positive personal experience of counselling.

### 3.7.2 Thematic Analysis

The data from the open-ended questions were analysed using Thematic Analysis. The data was collated and tabulated within an Excel document as is advised by Alhojailan (2012). This meant that the data was all in one place and could be more easily reviewed and analysed. The procedure for the Thematic Analysis followed was that recommended by Braun and Clarke (2006, 2012). They advocate a 6 phase process. This process began with familiarising myself with the data which involved reading the data several times and starting to write notes of my thoughts, feelings and possible ideas of what the data was saying. Phase 2 involved generating initial codes from the data. The generation of these codes were done at the semantic level and a code was identified every time something was recognised which was relevant to the research question (Braun & Clarke, 2012). Phase 3 was when themes were searched for within the data and codes. Codes were reviewed and areas of overlap between them identified so that clusters of codes could become themes and subthemes (Braun & Clarke, 2012). These potential themes were then reviewed in Phase 4. This was an iterative process where the themes were checked against the codes within the data and the entire data set (Braun & Clarke, 2012). These themes were then defined and named in Phase 5 ensuring that the themes directly addressed the research question, were all related but not overlapping and not trying to cover too much (Braun & Clarke, 2012). Finally the report was produced as part of Phase 6 where a storyline was developed and articulated that summarised the themes identified (Aronson, 1994). It has to be noted that this process was not linear and flowed amongst the phases as the process was undertaken (Braun & Clarke, 2006; 2012). An example of how the Thematic Analysis was completed can be found in Appendix 6.

Braun and Clarke (2006) provide a 15 point checklist which identifies aspects of the analysis that the researcher should be aware of and compare against at different points of the process. This was used to ensure that the Thematic Analysis provided a good quality and robust analysis of the data.

The qualitative analysis was then embedded and merged (Creswell & Plano-Clark, 2011) with the quantitative analysis to support or refute the findings and provide more depth to the answers provided.

### 3.7.3 Mixed Methods

Mixed methods research allows the data to be analysed in a way which offers a more holistic, in-depth insight into the data and in answering the research question (Frost & Shaw, 2015). Careful consideration was made to select appropriate and complimentary methods to ensure

that there is not complete confliction of the analysis. The use of statistical analysis with the use of Thematic Analysis was felt to be a way to investigate the phenomenon from many different angles within the same research study rather than only selecting one aspect. It was hoped that the mixed methods analysis would lead to a colourful picture being created to give insight into the views and attitudes of support workers towards counselling psychology and learning disabilities. As the pluralistic approach aims to take down barriers through allowing dialogue about the complexity within human life (Frost & Shaw, 2015), it was felt that the results should be presented in an integrative way without a clear demarcation between the quantitative and qualitative analysis.

### **3.8 Ethical Considerations**

#### **3.8.1 Consent and Confidentiality**

Before answering any questions all participants were asked to indicate their consent by clicking next after reading an information sheet. The information sheet (Appendix 5) included brief details of the research study, my contact details and that of my supervisor, outlined what the participants would be asked to do, it reinforced that they could withdraw at any time, defined the complaints procedure and provided the phone number of the organisation's counselling service.

All the responses were provided on a confidential basis and were anonymous. This means that no individual participant could be identified from their results. All the responses were kept on the computer anonymously and the computer and files were password protected. Once the research was completed the raw data would be kept securely for three years before being destroyed.

To ensure that participants did not feel forced to answer any particular questions that they did not feel comfortable with, every question could be skipped by clicking next. The information sheet told all participants that they could withdraw their consent for participation from the research study at any time and for any reason which they did not have to provide to the researcher.

It was anticipated that the questionnaire would have a low psychological impact as most of the questions were not of a deeply personal nature. There was only one set of questions within the questionnaire that could be considered personal. These were the questions that asked about the participant's own personal experience of counselling. These questions were included

as it was felt that a participant's own personal experience of counselling could affect their opinions of counselling psychology and people with learning disabilities. These questions did not request any details of their experience but asked about their general opinion of the experience and how beneficial they found it.

Although it was anticipated that these questions were not of a particularly sensitive nature, I did not want to make any assumptions of what could impact on a participant. Therefore participants were provided with the option to not answer these questions. In addition, the complaints procedure provided an opportunity that if any participant was not happy with any part of the research study, then they could make a complaint to the appropriate people and know that it would be dealt with adequately.

Finally, at the end of the questionnaire a de-brief sheet (Appendix 5) was provided which again reinforced that participants could withdraw at any point and provided mine and my supervisor's contact details so that if they had any questions these could be answered. If participants did experience any distress as a result of completing the questionnaire, details were stated of where they could seek support. This included the telephone number of the organisation's counselling service which offers staff up to 10 counselling sessions a year and the number for Samaritans.

### 3.8.2 Ethical Approval

The research was developed in such a way to comply with BPS code of human research ethics (2010). A proposal was submitted in January 2014 and the ethics of the proposal was considered as part of the submission. The proposal passed without any required amendments in February 2014 and the ethics release form was signed in October 2014 by Dr Pavlos Filippopoulos and Dr Jessica Jones Nielsen (Appendix 7).

Approval also had to be sought from the organisation from which the participants would be recruited. This process included meeting with the Director of Operations and providing a summary of the research, which could then be considered by the Board of Directors. Approval was given verbally by the Director of Operations in May 2014 for the research to be undertaken.

### **3.9 Ensuring Rigour within the Study**

#### **3.9.1 Reliability and Validity**

Several efforts were made during the development of the research to ensure the reliability and validity could be as robust as possible of both the quantitative and qualitative elements within the study.

Clark-Carter (1997) suggests several ways of increasing the reliability of quantitative items within a questionnaire. He firstly recommends that an adequate sample size is sought so as to be as representative of the intended population as possible. Through completing calculations which included consideration of power and effect size, an ideal number of participants were aimed for.

The Attitudes to Disability Scale (Power et al, 2010) was partly selected due to its good reliability (PSI = 0.809, using item response theory) and good internal validity. The questions, which used multi-item scales, provided participants with a 5 point scale as advised by Clark-Carter (1997) as it allows participants to express their position of neutrality if held on a topic or issue.

Quantitative research is often criticised regarding issues with validity (McGrath & Johnson, 2003) which was mitigated to a certain degree through using a mixed methods research design, as the qualitative element can help to expose any lack of validity of the quantitative measures and analysis (Kelle, 2006). The internal validity of the experimental vignette was heightened through random allocation of participants to the different conditions (Clark-Carter, 1997).

The qualitative research element presents its own issues when ensuring rigour within the study. Camic et al (2003) argue that for qualitative research to qualify as being that of a good quality then the researcher must display certain skills such as thoroughness, expertise in application and awareness of the context of the research including theoretical, historical, socio-cultural and interpersonal. The onus seems to be placed on the researcher to make clear their relationship with the material and ensure the analysis is grounded within the participant's own accounts (Madill et al, 2000). Most argue that with both qualitative and mixed methods the researcher must make their epistemological position known to the reader, and to ensure that the application of this position is consistently evident throughout the study (Madill et al, 2000; Yardley & Bishop, 2008; Kelle, 2006 and McGrath & Johnson, 2003).



However, Trafimow (2014) has debated whether this is enough. Qualitative analysis relies on subjective judgments of what is salient within the data and research has indicated that subjective judgments including those of professionals are not always very reliable (Einhorn & Hogarth, 1978). This reliability can set an upper limit on validity as it can be questioned how something can be more than slightly valid if it is only slightly reliable (Trafimow, 2014). To overcome this Trafimow (2014) recommends that when appropriate and feasible, researchers should conduct an index of inter-rater reliability on the qualitative analysis. Due to the mixed methodology used within the study it felt appropriate to conduct this measure of reliability to provide an additional way to ensure rigour. Therefore Kappa (Cohen, 1960) a stringent measure of pair-wise agreement was used. This meant that throughout the study both methods were being used to compliment and corroborate the findings of the other method.

### 3.9.2 Reflexivity

Although I have already provided an account of and reflected upon my epistemological position it is also important to reflect on my personal position (Willig, 2001). I have great awareness that this research area was not just selected for a simple reason. Several factors combined as to why this particular topic and methodology were selected.

Having worked in the learning disability field for a number of years and having completed specialist training in the area I was aware that psychological therapies are not regularly offered as an intervention to people with learning disabilities. It was clear though that often the challenging and distressed behaviour that the people I worked with exhibited was communication. Often it was communication that was either misinterpreted or hadn't been listened to early enough to prevent things from reaching a crisis point. The concern from staff was always about keeping people safe and to do so in an environment where there were constant demands on staff time and funding was generally being reduced each year. The unmet needs of people with learning disabilities either not being listened to or not having the opportunity to have a space in which good reciprocal communication could happen meant that I felt that counselling could offer a lot to people.

Through researching the topic and starting to work therapeutically with people with learning disabilities it could be seen how valuable the space could be for people but also how rarely it was offered. The referrals that I received would very rarely specifically request counselling for the person and would instead focus on the impact of the person's behaviour on either themselves or others. This meant that assessments would focus on behaviour or environmental changes in the staff which could lead to reductions in risk rather than the opportunity for the person with a learning disability to gain new skills, develop as a person or

have the opportunity to discuss things that were bothering them. The important role that support workers play in the lives of people with learning disabilities means that they are often the first people to notice changes in the person that they support and may be the only source of help that the person has access to depending on the services that the person accessed.

I therefore wanted to understand more about support workers' opinions of counselling psychology for people with learning disabilities, as I believe they are key to improving access to counselling for people with learning disabilities.

I am aware of the impact that this has had on me so that when I completed the analysis I attempted to be aware of the perspectives, the pre-understandings and pre-suppositions that I brought with me so as to not let these monopolise the analysis. Therefore I kept a reflexive diary throughout the analysis so as to be able to reflect as much as possible on what the analysis brought up for me. I also followed the guidance by Braun and Clarke (2006) to ensure that the analysis was grounded within the data. I completed the diary following the analysis sessions where I completed the qualitative analysis and wrote down any thoughts or feelings that had come up for me when I was reading through the participant's answers or completing the analysis. The process of writing the diary allowed me to explore and reflect on the assumptions, judgements and prejudices that arose in me as I read through the responses participant's had given. I found it interesting to write down what came up for me as this allowed me to think in more depth about the thoughts and feelings than if I had not completed the diary. It also aided the Thematic Analysis (Braun & Clarke, 2006) as some of the themes came together through the thoughts that I had written within the reflective diary.

## **4. Results**

The following chapter will outline the results found from both the quantitative and qualitative analysis of the data collated through the questionnaire. The quantitative and qualitative data was collected concurrently and analysed using a validating quantitative data model (Gelo et al, 2008) which meant that the quantitative data has the dominant status in order to address the research questions. The quantitative analysis was completed first due to this having dominant status with the qualitative data, providing an opportunity to corroborate the findings of the quantitative data analysis and to provide greater depth. A decision has been made to embed the quantitative and qualitative results within each other (Creswell & Plano-Clark, 2011) in order to be able to explore the complex picture which the results weave. This presentation is linked with the epistemological position taken for this research of pragmatism and pluralism.

Individual participant's responses will not be discussed but instead the analyses of the whole group will be explored to ensure the anonymity of the participants. Missing values were treated appropriately and where no answer was provided no analysis could be conducted. Therefore, where different variables are used in the analysis there are different N values due to these missing responses. Due to the large number of respondents, the quotes used in the descriptions of the themes found through the Thematic Analysis will not be referenced back to an individual participant. This is to ensure the anonymity of the participants and that no-one participant is singled out through the analysis or through their responses. The quotes used within the results are the exact words that participants typed and therefore spelling mistakes and grammatical errors remain unaltered.

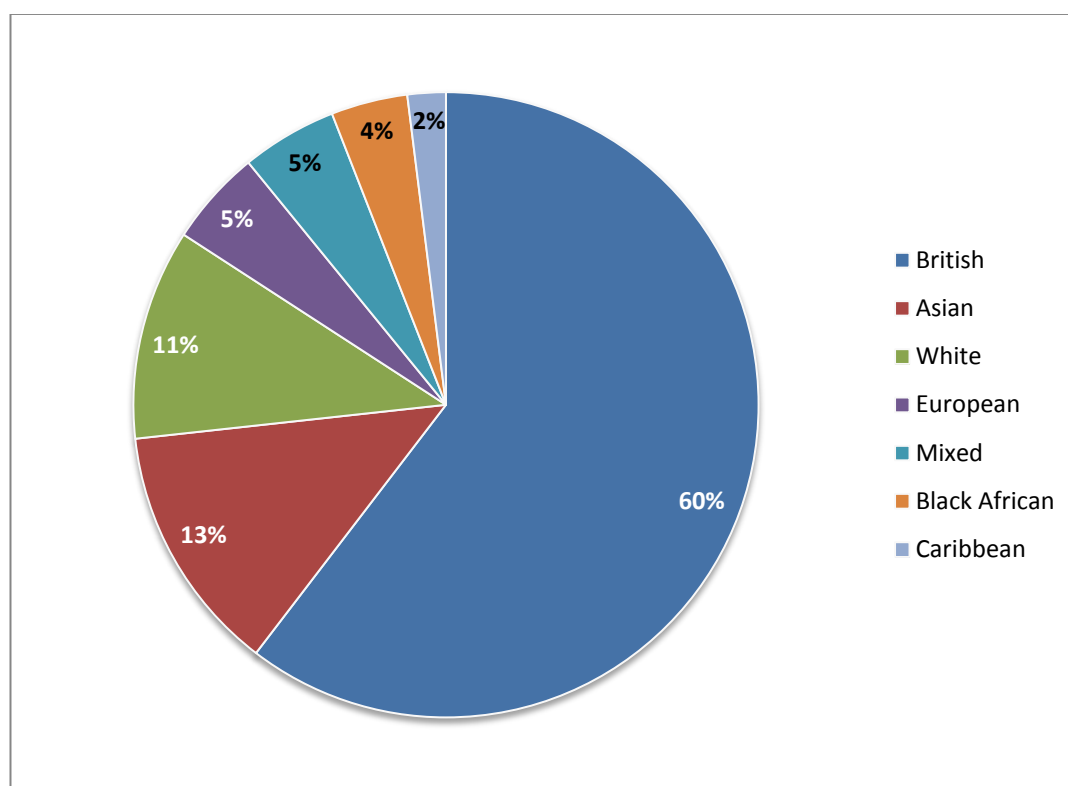
The results will first explore the demographics of the participants as well as looking at other information provided about the types of services and the level of learning disability of people that staff support. The questions which were answered following the vignette will be explored both quantitatively and qualitatively, before an exploration of the factors which affect the likelihood that a referral for counselling (or discussion with their line manager regarding a possible referral) will be considered in the future. Additional themes from open-ended questions will then be looked at to enable a holistic view of the issues and views of the participants.

## 4.1 Participants

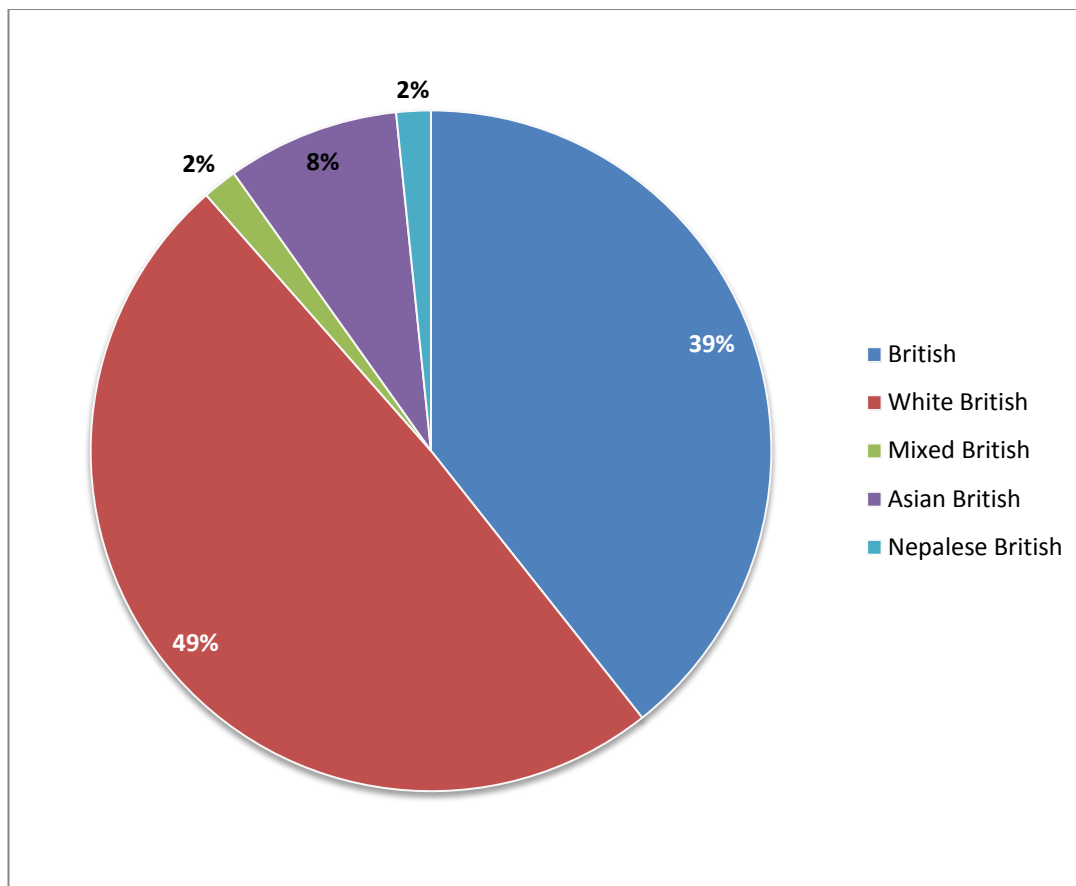
### 4.1.1 Demographics

Of the 115 participants who completed the survey, 72% (83) were female and 28% (32) were male. There were 106 who stated their age which gave a mean age of the participants of 41.25 years with a range of 18-68 years and standard deviation, 11.198.

Participants were asked to describe how they saw their ethnic origin. The broad categories which participants used can be seen in Figure B4-1. There were 60% of the participants that included British within their description of their ethnic origin. The rest comprised of Asian, White, European, Mixed, Black African and Caribbean. When the British category is broken down further (Figure B4-2) it can be seen that the majority of participants stated that they were White British (49%) while another 39% used only the term British. In addition some participants also used Asian British, Nepalese British and Mixed British. The results of this question indicate that although the majority of staff describes themselves as White British, there are also a mixture of cultures and nationalities of the staff who work on a day-to-day basis with people with learning disabilities including a number of people who possibly have English as a second language.



**Figure B4-1: Chart showing the percentage of the different ethnic origins that participants used to describe themselves.**



**Figure B4-2: Chart showing the breakdown of the different explanations of British those participants who used British in their description of their ethnic origin.**

When asked about their highest level of education, all participants answered the question with the majority of participants (52.2%) indicating that they held GCSEs, A levels or their equivalents. There were 23.5% who indicated that they had a degree level qualification which included Bachelors and foundation degrees. There were even 2 (1.7%) participants who indicated that they have a postgraduate level degree. Only one person indicated that they had no qualifications and a further 9.6% selected that their qualifications were 'other' which included overseas qualifications.

The majority of participants (48.7%) had more than 10 years of experience working with people with learning disabilities. Another 29.6% identified that they had been working in the field for between 5 and 10 years and 8.7% between 3 and 4 years. There were 6.1% who stated that they had less than 2 years of experience and 7% who had worked with people with learning disabilities for less than a year.

#### 4.1.2 The Types of Services Participants worked in

The roles that participants held included support worker, senior support worker, assistant manager, home manager and team leader. Support worker was the most selected role with 54.8% of participants indicating they currently hold this role. There were 5.2% of participants who indicated that they held the role of senior support worker and a further 19.1% who were assistant managers. Home manager and team leader accounted for 13.9% and 3.5% respectively. Finally 3.5% indicated that their role fell into 'other' and included volunteer, job coach and travel trainer.

The types of services that people worked in was mostly residential care (79.1%) but participants also worked in supported living (19.1%) and outreach (1.7%). Most participants were based in Berkshire (79.1%) with a fifth (20%) being based in London and only one participant (0.9%) based in Sussex.

Participants could select multiple levels of learning disability when indicating the level of learning disability for the people they support. A moderate learning disability was the most commonly selected (62.3%) followed by severe (35.1%) then profound and multiple learning disabilities (29.8%) and lastly mild (25.4%). There were 4 respondents who were not sure about the level of learning disabilities of those they support and 1 respondent who did not answer the question.

Participants were also asked to indicate the methods of communication used by the people with learning disabilities that they support. Staff could select multiple methods of communication due to the tendency of staff to work with multiple people whether that be within or across services. It was considered that being able to select multiple methods of communication would enable a better reflection of the methods used.

Although verbal communication was the most commonly selected method (88.70%), this was closely followed by behaviour/body language (72.17%), Signing including Makaton a language signing system designed specifically for people with learning disabilities (66.96%) and facial expressions (61.74%). Symbol based communication systems (e.g. Picture Exchange Communication System) (40%), Written (34.78%) and computer aided communication (e.g. Eye Gaze, iPad) (24.35%) were selected less often. This indicates that there is a wide range of communication methods that people with learning disabilities use apart from just verbal language.

#### 4.1.3 Experience of Supporting Counselling and People with Learning Disabilities

Participants were asked if they themselves had ever supported someone with a learning disability to access counselling. The majority said no, 63.5% (73 participants), while 34.8% (40 participants) said yes and 1.7% (2 participants) were unsure. In addition when asked if they were aware of anybody with a learning disability in the service they work in who had either received counselling in the past or was currently, 46 participants said no (40%). This is compared to 39.1% (45 participants) who responded yes, they were aware of somebody and interestingly 20.9% were not sure if anybody had.

Those who had replied yes to the above questions were asked about the number of different people they were aware of who had received/ are receiving counselling. As can be seen from the table below (Table B4-1) the most common response was 1 person with 44.4% of participants reporting this. The frequency decreased as the number of people with a learning disability who had accessed counselling increased.

**Table B4-1: The numbers of different people with learning disabilities who staff were aware of in the service that they work in who had received counselling.**

Answer	Number of participants	Percentage
1	20	44.4%
2	10	22.2%
3	8	17.8%
4+	7	15.6%

## 4.2 The Vignette

### 4.2.1 Statistical Analysis

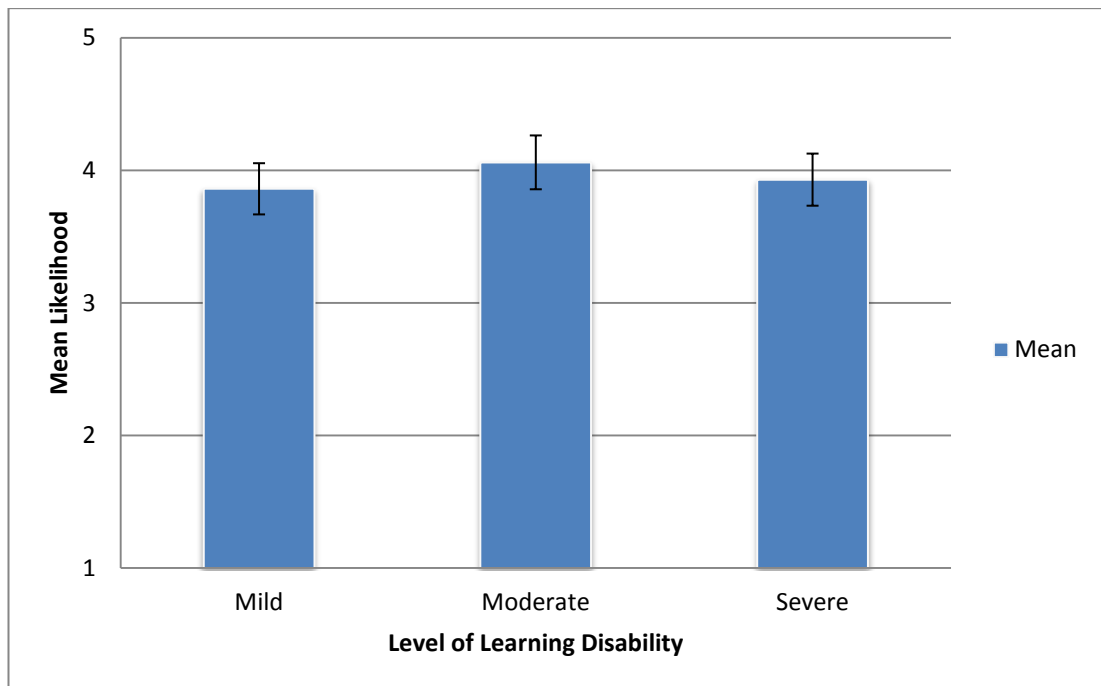
The hypothesis made about the vignette was that the character having a mild learning disability in the vignette would lead to participants being more likely to consider a referral for counselling or speak to their line manager about a referral, than if the character had a moderate or severe learning disability.

The questions which related to the vignette (Appendix 5) were completed by 112 of the respondents. The participants were randomly assigned to one of six conditions which varied the sex of the person and the level of learning disability. The number of participants that completed each condition can be seen in Table B4-2 below.

**Table B4-2: The number of participants who completed each condition of the vignette.**

Condition	Gender	Level of Learning Disability	Number of participants
1	Female	Mild	18
2	Female	Moderate	18
3	Female	Severe	20
4	Male	Mild	18
5	Male	Moderate	15
6	Male	Severe	23

In order to investigate the effect of the different conditions on the likelihood that the participant would be to consider a referral to counselling for the character in the vignette, the data was considered in relation to the parametric assumptions. The Likert scale could be considered an interval level measurement due to it being symmetrical in nature and having equidistant presentation. The data did not fully approximate a normal distribution due to it being negatively skewed. However, due to the homogeneity of variance also being met through a non-significant Levene's test, it was felt that the conditions had been met sufficiently for parametric statistical tests to be used.



**Figure B4-3: A graph showing the means of staff responses regarding the likelihood that they would consider a referral to counselling or speak to their line manager about a referral depending on the level of learning disability of the character in the vignette.**

Using a one way between subjects ANOVA to compare the effect of the six different conditions on the likelihood of a referral for counselling being considered revealed that the differences



between the groups were non-significant [ $F(5, 106) = 0.473, n.s.$ ]. When the groups were collapsed into just the level of learning disability the means for the mild, moderate and severe groups were 3.86, 4.06 and 3.93 respectively (Figure B4-3). The analysis of just the effect of the level of learning disability (mild, moderate and severe) on the likelihood that a counselling referral would be made also resulted in non-significance [ $F(2, 109) = 0.441, n.s.$ ]. This indicates that the level of learning disability of the character within the vignette did not have an effect on participant's decision when considering their likelihood to refer or speak to their line manager about a referral for the person described within the vignette for counselling.

This result was repeated when the data was collapsed into whether the character in the vignette was male or female. A t test was used to compare the effect of the gender of the character on the likelihood of a referral being considered. There was not a significant difference in the scores between the male ( $M = 3.982, SD = 0.798$ ) and female ( $M = 3.911, SD = 0.978$ ) character groups in the vignette,  $t(110) = -0.424, n.s.$ . Therefore neither manipulation of gender or level of learning disability effected the decision making of the participants regarding their considerations of a referral for counselling after reading through the vignette.

#### 4.2.2 Qualitative Results

Prior to being asked about the likelihood of them considering referring or speaking to their line manager about referring the person in the vignette for counselling, participants were asked several open-ended questions about the vignette. Participants were asked what their first thoughts were when reading the vignette, and what they would do if someone they supported presented in the way described in the vignette. The answers to these questions were analysed using Thematic Analysis. There were five out of the 112 participants who didn't answer any of the open-ended questions that they were asked.

##### 4.2.2.1 *First thoughts following reading the vignette*

The first question asked was - What are the first thoughts that enter your mind when reading the above situation? There were three main themes that emerged from the responses provided by the participants. These included: Awareness of "something" happening, Thoughts about the next steps that they might take and Acknowledging the difficulty for the person to communicate or understand what was happening.

##### 4.2.2.1 (i) *Awareness of 'something' happening*

The most common first thought that participants wrote about regarded the possibility of there being a medical problem that could be leading to the situation in the vignette. There were 49 of the participants that described thoughts that the person in the vignette could be "unwell",

have *“a physical illness”* or *“may have developed underlying health issues”* which could lead to the change in behaviour. Some participants would even describe specific possible issues such as a *“UTI”, “pain”, “Hormones? Medication?”* and *“sight”*.

Following the possibility of physical ill health, mental health was also focussed upon. Depression was a very common response with 35 people specifically mentioning depression and a further 5 people mentioning the word *“sad”* or mentioning mental ill health. Another more specific reason mentioned by 13 of the participants was that of the potential of abuse being the underlying cause of the changes in the character.

Many though didn't put a precise reason and instead were more general. There was clear recognition from the staff that not only had there been a change but that there was *“something”* that was underlying this change. There were 41 people who spoke in these more general terms saying *“Something is going wrong.”* or *“I would immediately think that something is wrong and John isn't happy about something in his life”*.

The vast majority of participants responded in a way which exposed tentative thinking and expressed multiple possibilities which could be causing the observed changes. These responses would offer several examples and would use language which showed that there were many different avenues that could be explored. A typical response would be:

*“The change of behaviour could be either because of a medical reason (illness/dementia) or because of a psychological reason (upset/worried about something that has happened or believe could happen. Investigation would be needed to find the reason.”*

There were however 9 responses where the participants had been very certain in their responses saying *“Sally must be unwell”* or only offering one option as a cause such as it is depression, it is abuse or it is illness.

#### 4.2.2.1 (ii) *Thoughts about the next steps*

This theme could be divided into two clear sub-themes: Investigating the possible causes that were described above and Involving professionals. There were 19 staff who spoke about how they *“would question/research”, “explore”* and how *“Investigation would be needed to find the reason.”* There was also though, an acknowledgement, by 16 of the participants that they may need to involve professionals to support them with this. Sometimes it was specified such as a *“GP”, “Doctor”* or *“Psychologist”* or would be more general and refer to *“medical professionals”*. As one person succinctly put it:

*“I need to find out whats wrong, is there something that bothers her, review his care plans, support plans as well as referred to medical professionals as needed”.*

#### 4.2.2.1 (iii) *Acknowledging the difficulty for the person to communicate or understand what was happening*

The last theme that emerged from the data concerned the difficulty that the person in the vignette could be having in expressing what was happening for them. There were 6 participants who wondered about this element within their responses. A couple speculated whether the character was *“unable to communicate”* or *“vocalise”* what they were going through while the others queried whether the character understood their feelings or what was happening in their bodies and that this may be behind the change in behaviour.

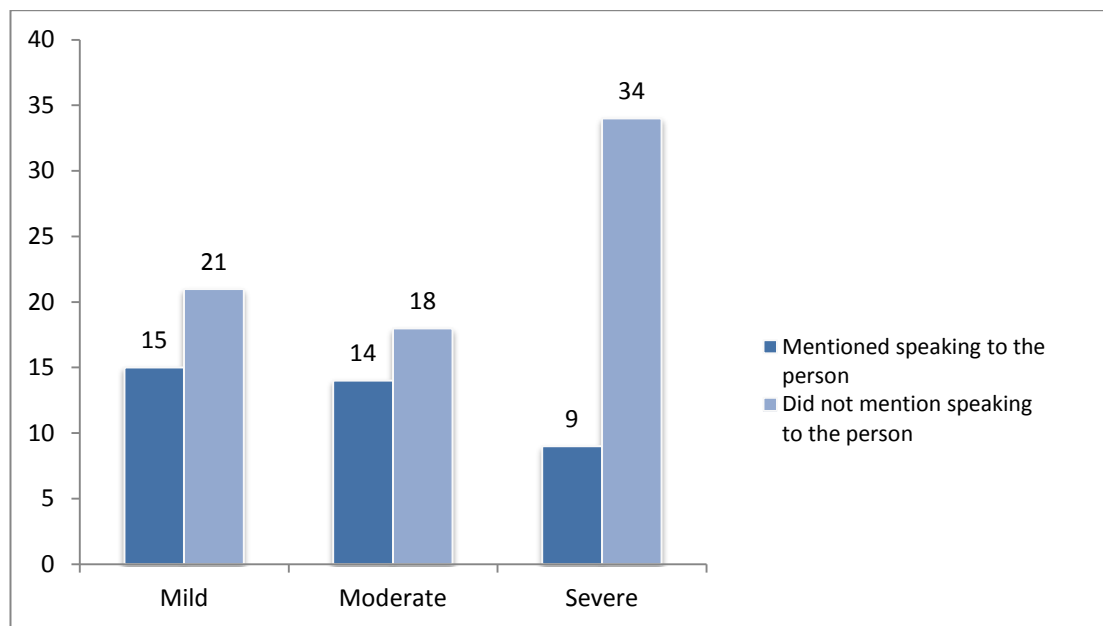
#### 4.2.2.2 *What they would do if someone they support presented like the person in the vignette?*

The second question about the vignette asked participants what they would do if someone that they supported presented in the same way as the character in the vignette. The responses given fell into two main themes, Things that they themselves could do and Others to involve.

##### 4.2.2.2 (i) *Things that they could do*

One of the key things that the staff said that they would do was to speak to the person to see if they might be able to tell staff what was bothering them. There were 38 responses that fell into this sub-theme with staff saying things like they would *“listen to the person”*, *“have a quiet chat”* or *“encourage them to talk”*. As one participant succinctly put it they would *“Sit down with her/spend time with her to see if she wants to talk to try to find out what may be the problem.”* Through further analysis it was found that these responses did seem to vary according to the level of learning disability.

As can be seen in Figure B4-4, there were 15 participants (41.66%) and 14 participants (42.42%) who indicated that they would talk to the person when the vignette character had a mild or moderate learning disability respectively. In comparison only 9 participants (20.93%) whose character in the vignette had a severe learning disability responded that they would talk to the person.



**Figure B4-4: The number of participants who mentioned that they would speak to the person mentioned in the vignette compared to those who did not for the different levels of learning disabilities (Mild, Moderate and Severe).**

These differences were analysed using chi square test for association. There was no statistical difference found between the mild learning disability and moderate learning disability groups,  $\chi^2 (1) = 0.03$ ; n.s. However when the frequency for the severe learning disability group was compared to the mild learning disability group, the difference was statistically significant,  $\chi^2 (1) = 3.984$ ;  $p < .05$  and when compared to the moderate learning disability group the difference was again significant,  $\chi^2 (1) = 4.493$ ;  $p < .05$ . This indicates that those participants whose vignette stated a severe learning disability were less likely than those who had a vignette describing a mild or moderate learning disability to talk to the person about what was happening for them.

In addition within the theme of what they themselves could do, Staff spoke about needing to record all of their concerns. This was explicitly mentioned by 8 of the participants and was said to be done through “Documentation of the situation” or that they might “make a report”. Staff often stated that they needed to find out what the underlying cause was for the change in behaviour. There were 32 participants who spoke about the need to do this. They spoke about it in one of two ways. Some would discuss it as something that they needed to do but would not indicate how they might go about this, while others were very specific in what they would do to find out the underlying cause. Words that were used which portrayed this action included “monitor”, “observe”, “investigate”, “check” and “review”. This sometimes would link into the need to document things as one person spoke of needing to “Make sure everything is

recorded to see if/ where there may be patterns in her behaviour". Most of the answers were very brief and did not go into detail but one person as can be seen below had a step by step idea of what they would do and in what order.

*"1. Check their temperature, i.e., if they are sick. 2. Check previous logs (well-being, appetite, behaviour), handovers, MAR chart (any PRN medication given) 3. Communicate with other members of staff or service users (query about any incidents that might be related to present condition) 4. Check behaviour charts, continence 5. Communicate this incident to management 6. Refer to GP/NHS 111/emergency services/counselling if needed 7. Check any signs of abuse 8. Refer to management if there are signs of abuse 9. Take this further to social worker or CQC if needed"*

The final thing that staff indicated that they themselves could do was to offer support to the person. There were 8 participants who spoke about the need to "Offer support and encouragement". These responses included terms such as "reassure", "help" and "support". There were also responses, which indicated that staff were there for the person such as this response:

*"Remind him that I and all staff are here to help him and if he would like to talk to us he can."*

#### 4.2.2.2 (ii) Others to involve

The most frequently discussed action within the responses for this question was seeking involvement from the GP. There were 42 participants that included this aspect within their responses and often this was the only action that they stated they would do. This response very much fitted with the idea that physical health was a likely cause for the change in behaviour for the character within the vignette. Involvement with the GP was fairly limited to two forms: booking "a GP appointment" and seeing "the doctor for advise".

The GP was not the only professional that staff felt was important to involve in the situation with 32 participants mentioning a professional other than a GP. The professionals mentioned included "MDTS" (Multi-Disciplinary Teams), "psychology", "CTPLD" (Community Team for People with Learning Disabilities), "community team/ talking therapy", "therapist/counsellor", "behavioural support", "psychiatry", "advocacy" and "other professionals".

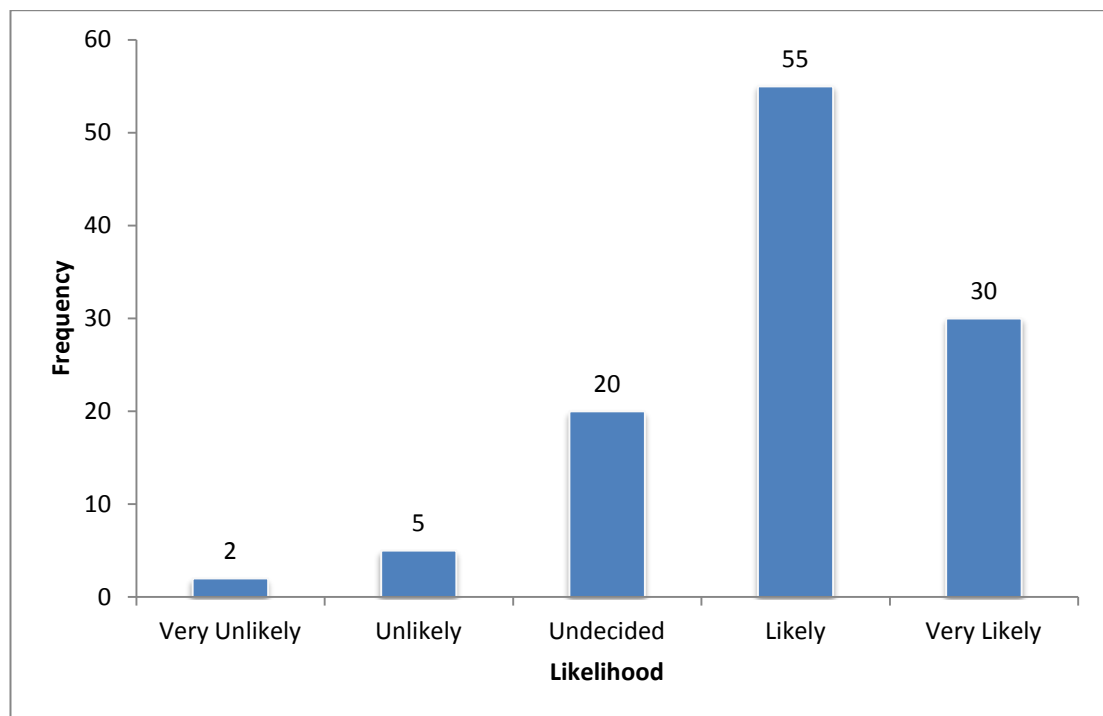
In addition to involving professionals from outside of the home, there were also thoughts of including the member of staff's manager. There were 30 responses which indicated that they would inform or report to their manager in some way, although it was not only the manager that participants felt should be involved in the case. There were 13 participants who indicated

that other staff should be collaborated with and *“others involved in Sallys daily life”*. The involvement of family was not mentioned explicitly within any of the responses, which I found an interesting phenomena and wondered whether it could be related to the way the question was asked. The other possible reason could be in relation to the role that families play within the personal lives of people with learning disabilities and the conflicts which staff may experience in attempting to treat people with learning disabilities as adults. This includes keeping information confidential as well as accessing the support and information which family could provide.

There were responses though that alluded to the need for staff to work within a team to be able to support the person such as one person who said they would *“Communicate with other staff who support her to find out if they have the same observations.”*

#### *4.2.2.3 Likelihood of considering a referral or speaking to their line manager about a referral for counselling for the character in the vignette.*

As has been previously discussed, the likelihood of staff considering a referral or speaking to their line manager about a referral for counselling for the character in the vignette was not associated with the level of learning disability or the gender of the character. Figure B4-5 shows that the most common response from staff regarding their likelihood to consider referring or speaking to their line manager about the character in the vignette for counselling was ‘Likely’ (55 participants).



**Figure B4-5: The number of participants who choose each response to the question regarding how likely they would be to consider referring or speaking to their line manager about a referral for counselling for the character within the vignette.**

This study was also interested in the explanations that staff gave for their answers. Therefore the open-ended question which asked participants to explain their reasons for their decision regarding the likelihood was analysed using Thematic Analysis. The responses were divided according to their response on the question of likelihood to investigate if there were differences between the groups for the reasons they gave for their decisions.

#### 4.2.2.3 (i) *Very Unlikely and Unlikely*

There were two people who selected 'Very Unlikely'. One person did not give any reason for their answer and the other person wrote "*My duty of care for that person*". Unfortunately this was not enough data to find any themes and I was unsure what the person was trying to communicate with the above statement.

There were 5 participants who had responded 'Unlikely'. Of these participants there were 3 who indicated that they would look into the health first but had not completely ruled out a referral for counselling if no medical cause for the change had been found. The other two responses included someone not providing any reason and one person whose answer seemed to contradict their 'Unlikely' response as it indicated that they would refer the character for counselling.

#### 4.2.2.3 (ii) *Undecided*

There were more interesting results amongst those who responded that they were 'Undecided'. The explanations of the responses for those that selected 'Undecided' fell into one core theme, Consideration of all possible options. Similarly to the 'Unlikely' group almost half of the 20 participants who had selected 'Undecided' had wanted to rule out medical causes first before looking into the referral for counselling. Another sub-theme which ran through the explanations for selecting 'Undecided' was that staff wanted to find out the possible cause for the changes in behaviour prior to making a decision about a referral to counselling. This idea is illustrated in the following person's response, *"Because I need to find out first the reasons why there is sudden changes with her. Either she medical problems or an abuse just happened."* There was also one person who indicated that they felt that they did not have enough experience to actually make a decision.

#### 4.2.2.3 (iii) *Likely*

The most common response of 'Likely' (55 participants) also had a theme within it of needing to rule out other causes and particularly possible medical reasons. There were 17 responses that fell into this category. However staff also gave responses which indicated why they might be likely to consider the referral. There were 6 participants who specifically mentioned Depression in their response with some who felt that other options apart from treatment with medication should be explored. One person said that they felt that *"If depression is treated only with medication, it can remain untreated as the root cause might not be explored"*.

In addition, many of the participants who selected 'Likely' felt that counselling could be a good way to actually find out the potential causes behind the behaviour change or believed that it could be something that *"might help to resolve the issue"*. There were 19 participants that included this within their answer which seemed to indicate that they felt counselling is a good option to consider. Finally staff who had indicated that they were 'Likely' to consider a referral recognised what a counsellor/ counselling psychologist could bring to the table. There were 13 responses that explained it meant that someone *"trained"*, a *"professional"*, with *"tools"* and *"knowledge"* could offer something which might be *"beyond the remit"* of a support worker. Furthermore these responses showed that the independence and outside view of a counsellor/counselling psychologist could be helpful. One person summed it up as: *"John may not feel comfortable discussing his issue with staff would work with him daily. He may find it easier to talk to an 'outsider'"*.



#### 4.2.2.3 (iv) *Very Likely*

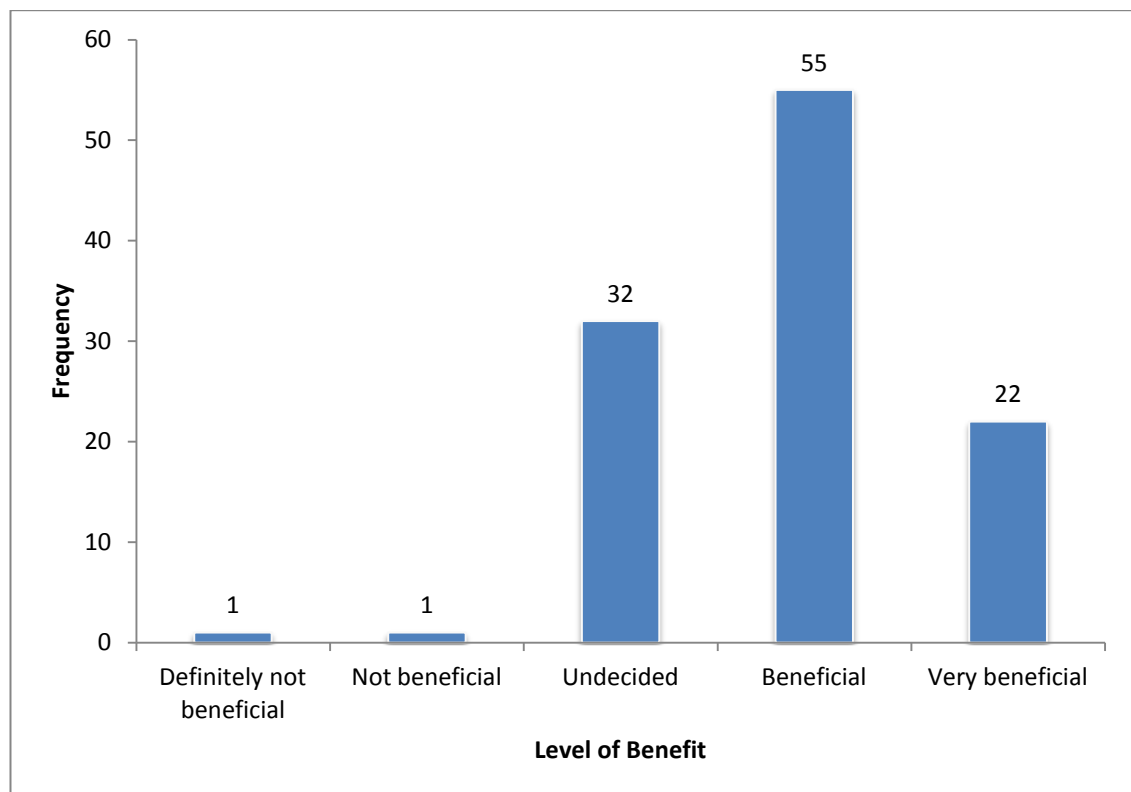
The themes that were found within the responses from those that selected 'Likely' were also found in the explanations for those that selected 'Very Likely'. There were distinct differences though. Only one response spoke about needing to rule out possible medical causes first and there were three responses which included the word "*obviously*" within their explanation.

#### 4.2.2.4 *How beneficial might the counselling be for the character in the vignette?*

Staff were not only asked about the likelihood of considering a referral to counselling for the vignette character but were also asked to consider how beneficial the counselling might be for them. There were 4 participants out of the total 115 participants whose data had to be excluded from this section of the analysis due to them not completing the question relating to the likely benefit that counselling could have for the vignette character. Therefore the analysis for this question was completed for 111 of the respondents.

##### 4.2.2.4 (i) *Quantitative Analysis*

As can be seen in Figure B4-6, the most commonly selected level of benefit of counselling for the vignette character was 'Beneficial' with nearly half of the participants choosing this. There were hardly any participants that selected that it would be either 'Definitely Not Beneficial' or 'Not Beneficial' but there were 28.8% of people who responded to this question who indicated that they were 'Undecided'.



**Figure B4-6: The number of participants who choose each response to the question regarding how beneficial they think counselling would be for the character within the vignette.**

In order to investigate the effect of the different conditions (mild, moderate and severe learning disability) on the likely benefit that the participant considered counselling could have, the data was considered in relation to the parametric assumptions. The Likert scale could be considered an interval level measurement due to it being symmetrical in nature and having equidistant presentation. The data did not fully approximate a normal distribution due to it being negatively skewed. However, due to the homogeneity of variance also being met through a non-significant Levene's test, it was felt that the conditions had been met sufficiently for parametric statistical tests to be used.

The means for the mild, moderate and severe groups were 3.64, 4.03 and 3.93 respectively. Using a one way between subjects ANOVA to compare the effect of the condition (mild, moderate and severe) on the perceived likely benefit of counselling for the vignette character revealed that the differences between the groups were non-significant [ $F(2, 108) = 2.53$ , n.s.]. This indicates that the level of learning disability of the character within the vignette did not have an effect on participant's decision when considering the likely benefit of counselling for vignette character.

#### 4.2.2.4 (ii) *Qualitative Analysis – Explaining their thoughts on how beneficial counselling could be*

All participants were asked to explain the reasons behind their decision regarding the likely benefit of counselling for the vignette character. These responses were analysed using Thematic Analysis. As there was only one person who selected 'Definitely Not Beneficial' and 'Not Beneficial' the analysis of these responses is incredibly limited especially as the person who had selected 'Definitely Not Beneficial' did not provide any explanation for their decision. The participant who selected 'Not Beneficial' explained that *"The above symptoms can exist in someone with an infection, so with the right treatment such as a 7 day course of anti biotics, the person's infection could be treated- they would feel better and may engage again. If not, then this may indicate a need for counselling."*

#### *Undecided*

Those participants who indicated that they were 'Undecided' expressed a range of different reasons why they had felt this way. The theme that ran through almost all the responses was that counselling might not be the most appropriate course of action. There were 17 participants who mentioned this in some form within their answers. Different reasons were given as to why this might be the case. There were 5 participants who indicated that they did not have enough information about the character in the vignette to make a judgement about the likely benefit of counselling. One example of what participants said was that *"without a diagnosis it is difficult to say if that is what John really needs."* Health came up again as 4 participants spoke about the need to rule out health issues and for them it being their *"immediate concern"*.

The capacity and level of learning disability did feature within 5 of the participant's responses. One person actually referred directly to the level of learning disability of the character within the vignette saying: *"I am not sure if someone with a severe learning disability will benefit with counselling."* There was only one person that stated 'Undecided' who had reflected on past experience as a reason behind their answer saying: *"Although I have been involved in supporting people to go to counselling sessions, it has not always been beneficial and can actually make life more difficult for them to cope with."*

#### *Beneficial*

There were two clear themes which emerged from the explanations given by those participants who had indicated that counselling was likely to be 'Beneficial' to the character within the vignette. These were what counselling could offer and what makes counselling different.

Many of the responses fitted into the theme of counselling being likely to be beneficial because of what it could offer. The majority of participants (17) mentioned that having someone to talk to and being listened to was what would make counselling beneficial for the person. The emphasis for finding the cause was also still within the participants responses with 15 people who felt that counselling may aid the discovery or understanding of the possible causes for the changes in behaviour. Not only did participants feel that counselling offered a way to find a cause but also that it might help to develop possible strategies or solutions. This was mentioned by 9 participants who felt that in some way that the counsellor might be able to offer *“advice”* or could *“help support them with their difficulties”*. There was also recognition by a couple of participants that counselling could offer a space to the person. This whole theme is summarised quite succinctly by one participant who said:

*“Again, regardless of the cause, I feel that counselling would give Sally the opportunity to ‘talk’ about her thoughts, fears, feelings etc in a trusted and safe environment. This might help Sally/the counsellor understand why she is feeling the way she does and hopefully we can start to address this.”*

The second theme to emerge from the data identified what might be different from just staff trying to talk to the person. There were 4 participants who indicated that counselling can be ‘Beneficial’ due to the therapist being *“someone from outside the home”* and being *“impartial”*. There also an acknowledgement that the counsellor would have expertise or be trained and so is in a good position to support the person.

#### *Very Beneficial*

The same themes emerged from the responses of those participants who indicated that counselling would be ‘Very Beneficial’ in comparison to those who responded that it would be ‘Beneficial’. The main difference was that an additional theme that counselling could lead to things going back to normal and would lead to improvements in day to day life. There were 4 responses where this seemed to be indicated. As one participant stated, *“counselling will help him to go back to his routine/daily activities”*.

### **4.3 What affects the Likelihood of Support Workers Considering a Referral or Speaking to their Line Manager about a Referral for Counselling for a Person with a Learning Disability that they Support?**

The hypothesis that was made regarding what might affect the likelihood of staff considering a referral or speaking to their line manager about a referral for counselling for a person with a learning disability was that they would be more likely to consider it in future if:

- The respondent was in a position of management (home manager, assistant manager)
- Their previous experience of supporting someone with a learning disability was positive (e.g. they felt that the counselling was of benefit to the person)
- Their general attitudes towards people with learning disabilities are positive
- They themselves have accessed therapy and that experience was positive
- They support people with a mild learning disability

#### **4.3.1 Role**

In order to investigate the effect of different roles on the likelihood that the participant would be to consider a referral for counselling in the future, the data was considered in relation to the parametric assumptions. The Likert scale could be considered an interval level measurement due to it being symmetric in nature and having equidistant presentation. The data did not fully approximate a normal distribution due to it being negatively skewed. However, due to the homogeneity of variance also being met through a non-significant Levene's test, it was felt that the conditions had been met sufficiently for parametric statistical tests to be used.



**Figure B4-7: A graph showing the means of staff responses regarding the likelihood that they would consider a referral to counselling or speak to their line manager about a referral for a person with a learning disability they support in the future depending on the staff member's role.**

Due to the small numbers of participants in some of the categories it was decided to combine some of the groups due to similarity of the roles. The home manager and team leader groups were collapsed into one group (home manager, N = 19) and the senior support worker and assistant managers groups were collapsed into one group (assistant manager, N = 22). The remaining 72 participants identified themselves as support workers. As can be seen above in Figure B4-7 the mean likelihood of considering a referral in the future for the groupings of home manager, assistant manager and support workers was 4.21, 3.55, 3.56 respectively.

Using a one way between subjects ANOVA to compare the effect of the three different roles on the likelihood of a referral for counselling being considered revealed that the differences between the groups were significant [ $F(2, 110) = 3.819, p < 0.05$ ]. Estimated omega squared = 0.0475 which is a small effect size.

A Tukey post-hoc test revealed that the participants who were home managers were significantly more likely to consider a referral than support workers ( $p < 0.05$ ). There was no statistically significant difference between support workers and assistant managers. The

significance level between assistant manager and home manager was marginally insignificant ( $p=0.068$ ). This result is likely to be related with the size of the assistant manager group where the higher N in the support workers group means that the difference is considered significant.

#### 4.3.2 Previous Experience of Supporting Someone with a Learning Disability to Access Counselling

In order to investigate the effect of previous experience of supporting someone with a learning disability to access counselling on the likelihood that staff would consider a future referral for counselling, the data was divided into those who had previously supported someone to access counselling (39 participants) and those who had not (73 participants). This data met the parametric assumptions so an independent T-Test was used to compare the means of those with experience (mean = 4.256; SD = 0.751) with those without experience (mean = 3.370; SD = 0.921). These were significantly different [ $t(110)= 5.163$ ,  $p < 0.01$ ]. Calculating Cohen's  $d = 0.866$ , revealed a large effect size. This shows that those participants who had previously supported someone with a learning disability to access counselling indicated that they would be more likely to consider a referral for counselling in the future than those who had not supported someone previously.

In order to investigate if this difference was dependent on how beneficial the staff felt the counselling was for the person that they had supported another analysis was completed. Those who had previously supported someone with a learning disability to access counselling were asked to rate how beneficial they had felt the counselling was for the person that they were supporting. The different responses can be seen in Table B4-3. There were 7 participants who had previously supported someone who didn't answer this question.

**Table B4-3: The number of participants who selected each level of benefit they felt counselling had for the people with learning disabilities they had supported to access counselling and the mean likelihood of those staff to consider a referral in the future.**

How beneficial?	Number of Participants	Mean likelihood to consider referral
Definitely not beneficial	0	
Not beneficial	1	
Undecided	8	4
Beneficial	15	4.33
Very Beneficial	8	4.5

As there was only one participant who said not beneficial this data was excluded and the 'Undecided' group, 'Beneficial' group and 'Very Beneficial' group were compared against each other using a one-way ANOVA as the data met the parametric assumptions. This test came back as non significant,  $F(2, 28) = 0.962$ , n.s. Therefore the relative benefit for the person with a learning disability that they had supported to access counselling did not affect the likelihood of a future referral.

#### 4.3.3 Attitude Scale Total Score

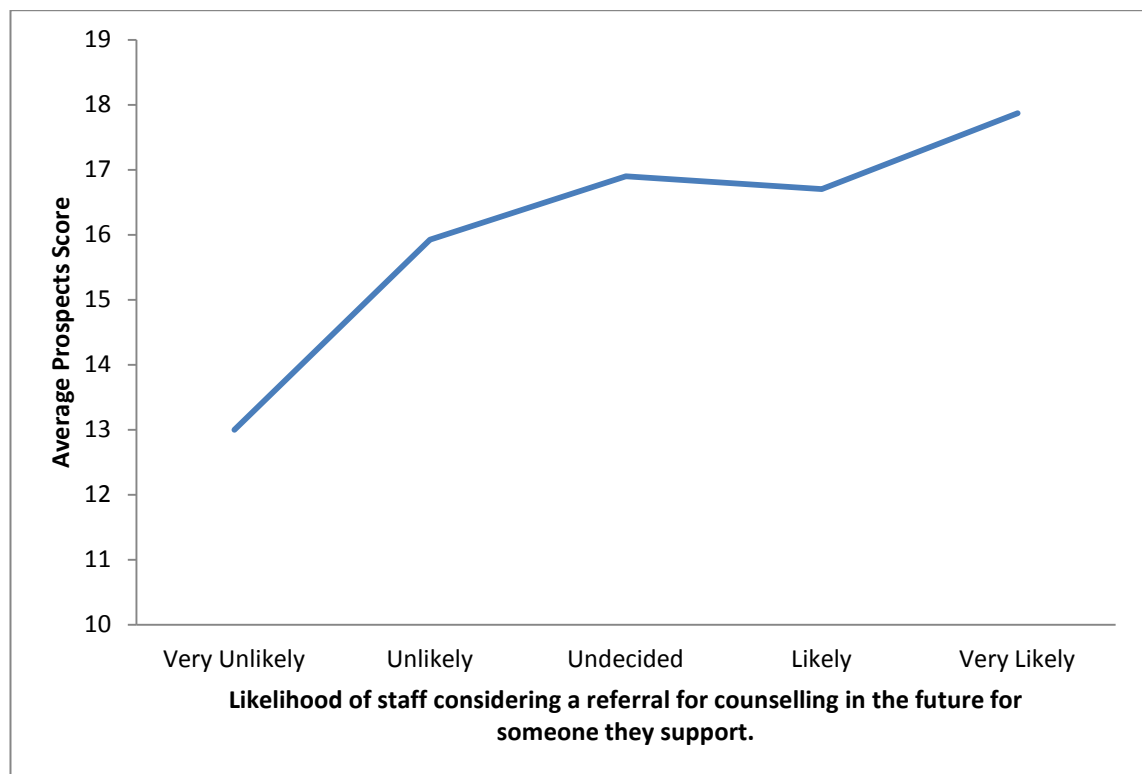
The Attitudes to Disability Scale (Power et al, 2010) measured general attitudes towards people with learning disabilities across four domains of Inclusion, Discrimination, Gains and Prospects. Higher total scores for each domain indicated more positive attitudes towards people with learning disabilities. The relationship between the total score on the Attitudes to Disability Scale and the likelihood of staff considering a future referral was analysed using correlation. Due to the future likelihood variable being ordinal data this meant that a non-parametric statistical test was required to analyse the relationship (Clark-Carter, 2010). Spearman's Rho was calculated revealing that the relationship between the attitude scale and the future likelihood of staff considering a referral for counselling was not significant ( $\rho(105) = 0.037$ , n.s.).

##### 4.3.3.1 *Prospects score from the Attitudes to Disability Scale*

The Prospects domain within the Attitudes to Disability Scale (Power et al, 2010) measures the attitude of people towards the possible prospects that can be expected for people with learning disabilities. It includes items such as people should not expect too much from those with a learning disability and people with a learning disability should not be optimistic (hopeful) about their future (Power et al, 2010).

The relationship between the score from the Prospects domain and the future likelihood of staff to consider a referral for counselling was analysed. The graph below (Figure B4-8) shows the general relationship between the two variables. Due to the future likelihood variable being ordinal data this meant that a non-parametric statistical test was required to analyse the relationship (Clark-Carter, 2010).





**Figure B4-8: A graph showing the average Prospects domain score on the Attitudes to Disability Scale (Power et al, 2010) depending on the participants responses regarding the likelihood that they would consider a referral to counselling or speak to their line manager about a referral for a person with a learning disability they support in the future.**

Spearman's Rho was calculated revealing that there was a small positive correlation relationship between the score on the Prospects domain of the Attitudes to Disability Scale and the future likelihood of staff considering a referral for counselling that was significant ( $\rho(111) = 0.214$ ,  $p < 0.05$ ). The calculation of  $\rho^2 = 0.046$ , indicated that this was a Medium effect size. This indicates that as the participants score on the Prospects domain of the attitude scale increases (more positive views) then the likelihood of the person considering a future referral for counselling for someone they support also increases.

#### 4.3.4 Staff's own Personal Experience of Counselling

In order to investigate the effect of staff's own personal experience of accessing counselling on the likelihood that staff would consider a future referral for counselling, the data was divided into those who had previously personally accessed counselling (38 participants) and those who had not (73 participants). This data met the parametric assumptions so an independent T-Test was used to compare the means of those who had experienced personal therapy ( $M=3.658$ ,  $SD=0.966$ ) with those who had not experienced personal therapy ( $M=3.658$ ,  $SD= 0.989$ ). These were not significantly different [ $t(109) = 0.002$ , n.s.]. This shows that staff's own personal

experience of accessing counselling did not affect the likelihood of staff considering a referral for someone with a learning disability to counselling in the future.

#### 4.3.5 Mild Learning Disability

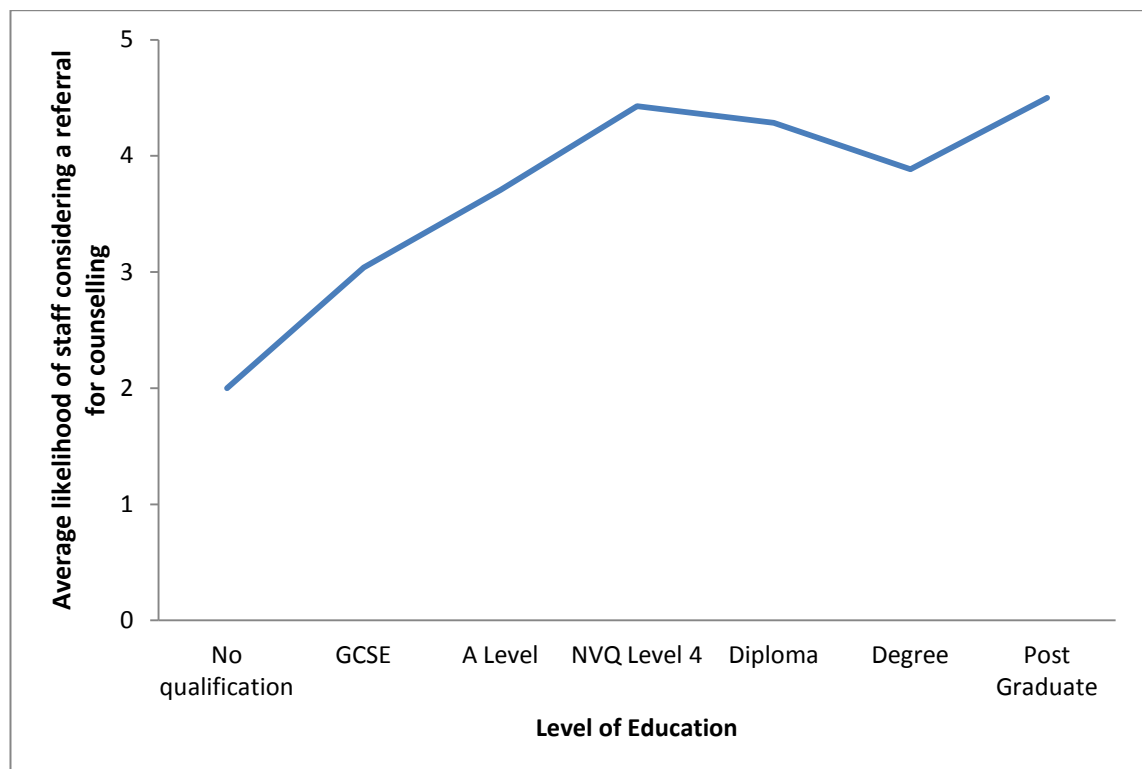
In order to investigate the effect of staff supporting people with mild learning disabilities on the likelihood that staff would consider a future referral for counselling, the data was divided into those who supported people with mild learning disabilities (29 participants) and those who did not (84 participants). The data did not meet the parametric assumptions due to the Levene's test being significant which indicated that there was not homogeneity of variances.

A Mann Whitney U Test was used to compare the means of those who support people with mild learning disabilities (mean = 3.897; SD = 0.817) with those who did not (mean = 3.583; SD = 1.009). The very tiny difference between the two groups was found to be non-significant [ $U = 1020.5$ , n.s.], indicating that supporting people with mild learning disabilities did not affect the likelihood of staff considering a referral for someone with a learning disability to counselling in the future.

### **4.4 Other Possible Factors that could affect the Likelihood of Support Workers Considering a Referral or Speaking to their Line Manager about a Referral for Counselling for a Person with a Learning Disability that they Support?**

#### 4.4.1 Education

The relationship between the highest level of education and the future likelihood of staff to consider a referral for counselling was analysed. The 'Other qualification' option was excluded from the analysis due to concerns regarding the content of the qualifications that staff could have within this group and the effect this had on the increasing order of qualification from lowest to highest. The graph below (Figure B4-9) shows the general relationship between the two variables. Due to the level of education and future likelihood variables being ordinal data this meant that a non-parametric statistical test was required to analyse the relationship (Clark-Carter, 2010).

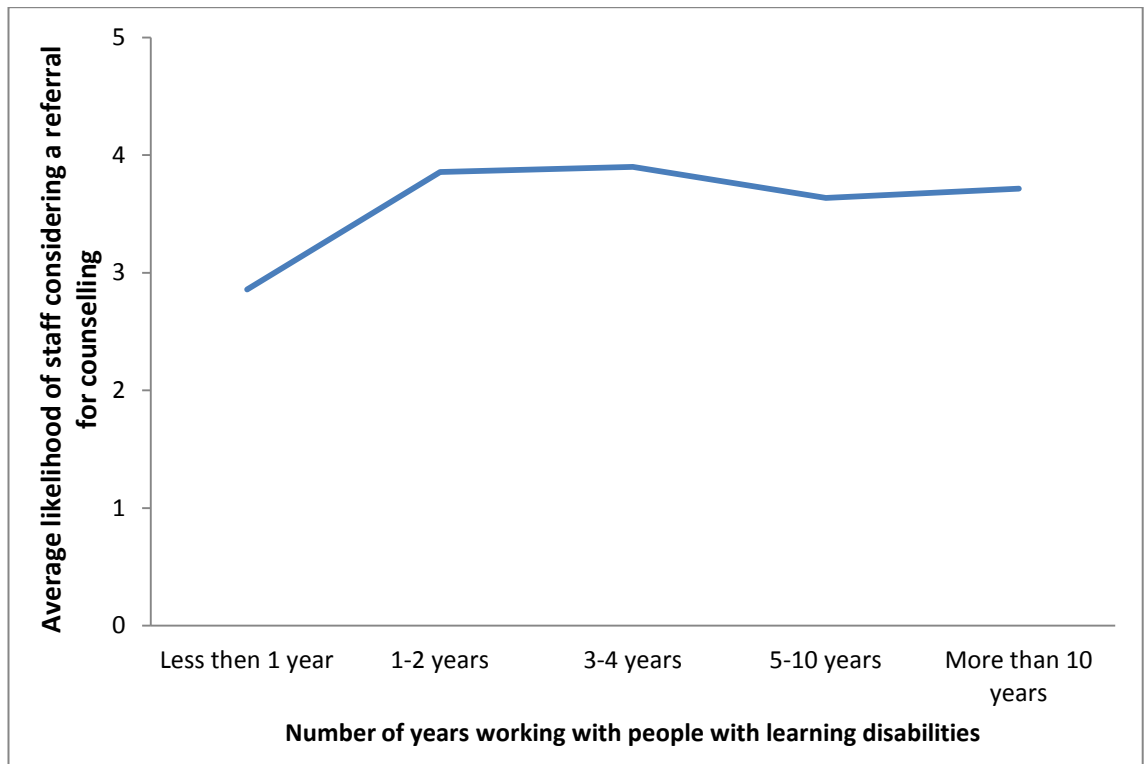


**Figure B4-9: A graph showing the average likelihood of staff considering a referral for counselling in the future depending on the participants responses regarding their highest level of educational attainment.**

Spearman's Rho was calculated revealing that there was a medium positive correlation relationship between the level of education and the future likelihood of staff considering a referral for counselling that was significant ( $\rho(102) = 0.402, p < 0.01$ ). The calculation of  $\rho^2 = 0.162$ , indicated that this was a large effect size. This indicates that as the level of participants education increases then the likelihood of the person considering a future referral for counselling for someone they support also increases.

#### 4.4.2 The Number of Years of Experience Supporting People with Learning Disabilities

The relationship between the number of years experience supporting people with learning disabilities and the future likelihood of staff to consider a referral for counselling was analysed. The graph below (Figure B4-10) shows the general relationship between the two variables. Due to the number of years experience and future likelihood variables being ordinal data this meant that a non-parametric statistical test was required to analyse the relationship (Clark-Carter, 2010).



**Figure B4-10: A graph showing the average likelihood of staff considering a referral for counselling in the future depending on the participants responses regarding the number of years that they have worked with people with learning disabilities.**

Spearman's Rho was calculated revealing that there was no relationship between the numbers of years experience supporting people with learning disabilities and the future likelihood of staff considering a referral for counselling ( $\rho(113) = 0.103$ , n.s).

#### 4.4.3 Type of Service

In order to investigate the effect of different types of service on the likelihood that the participant would be to consider a referral for counselling in the future, the data was considered in relation to the parametric assumptions. The parametric assumptions were met as the Likert scale could be considered an interval level measurement due to it being symmetric in nature and having equidistant presentation. The data did not fully approximate a normal distribution due to it being negatively skewed. However, due to the homogeneity of variance also being met through a non-significant Levene's test, it was felt that the conditions had been met sufficiently for parametric statistical tests to be used.

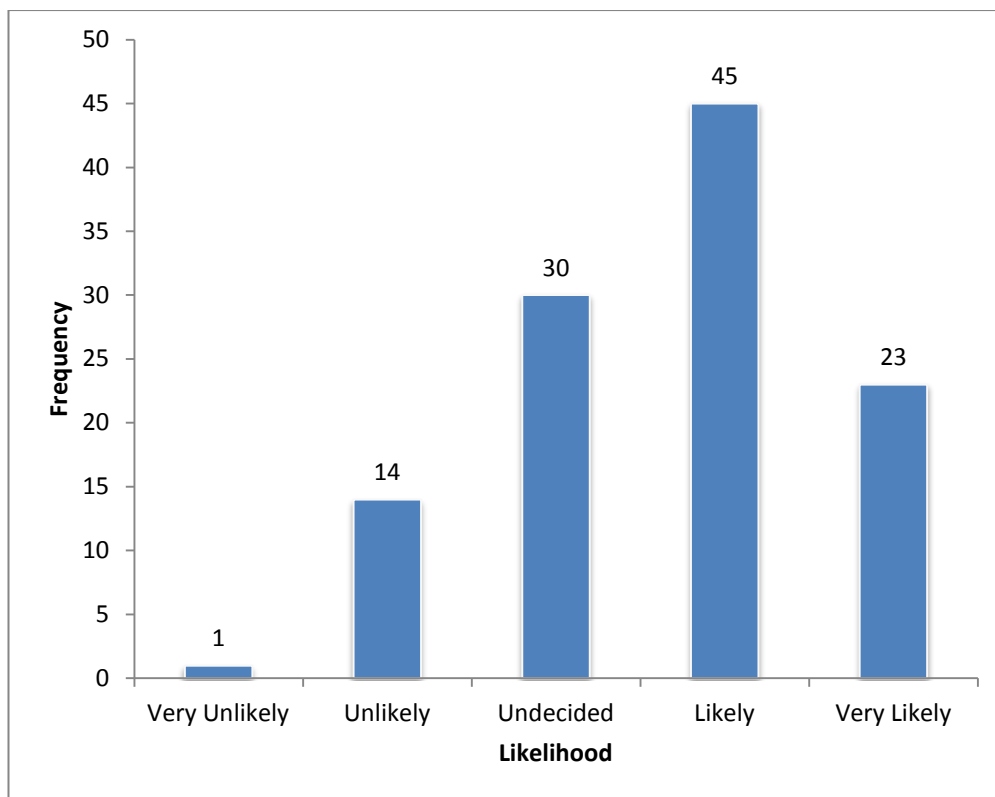
**Table B4-4: The number of participants who selected each type of service as their main place of work and the mean and standard deviations regarding the likelihood of those staff to consider a referral in the future.**

Type of Service	Number of Participants	Mean likelihood to consider referral	Standard Deviation
Residential Care	89	3.517	0.906
Supported Living	22	4.136	1.037
Outreach	2	5	0

The mean likelihood of staff considering a referral for counselling in the future for each type of service can be seen in Table B4-4. Using a one way between subjects ANOVA to compare the effect of the three different services on the likelihood of a referral for counselling being considered revealed that the differences between the groups were significant [ $F(2, 110) = 5.203, p < 0.05$ ]. Estimated omega squared = 0.082 which is a medium effect size.

A Tukey post-hoc test revealed that the participants who worked in supported living were significantly more likely to consider a referral than participants who worked in residential care ( $p < 0.05$ ). There was no statistically significant difference between supported living and outreach. The significance level between residential care and outreach was marginally insignificant ( $p = 0.07$ ). This result is likely to be related with the size of the outreach group where the higher N in the supported living group means that the difference is considered significant.

#### 4.5 Likelihood of Considering a Referral or Speaking to their Line Manager about a Referral for Someone from their Service for Counselling in the Future



**Figure B4-11: The number of participants who choose each response to the question regarding how likely they would be to consider referring or speaking to their line manager about a referral for counselling for someone in their service**

##### 4.5.1 Explanations for the likelihood of referring someone for counselling in the future

The different responses which participants gave to the question regarding the likelihood that they would consider referring or speaking to their line manager about a referral for counselling for someone from their service can be found in Figure B4-11. The most common response was that they would be 'Likely' followed by 'Undecided' and then 'Very Likely'. There were only 15 participants who indicated that they would be 'Unlikely' or 'Very Unlikely'. Participants were asked to explain their reasons for their response to the question.

##### 4.5.1.1 Very Unlikely and Unlikely

There was only one person who selected 'Very Unlikely' and their explanation did not indicate any useful information regarding their response with them saying "*Death of a family Member or someone they may live with.*" There were 14 participants who indicated that they would be 'Unlikely' to consider a referral for counselling in the future. Seven of these participants did

not provide any rationale for their response. There were 3 key themes, which emerged from the remaining participant's responses, the main theme being that they felt that counselling was not appropriate for the people that they support. The reasons why people felt that counselling would not be appropriate included feeling that a stranger would not be appropriate to work with the people they supported, instead they felt that *"...those who work with our people, who they know and built trust would be best people to support this need."* There was even one participant who indicated that they didn't think that the people that they worked with would even need counselling. The second theme related to the communication difficulties of the people they support with one saying, *"The people I work with don't have the communication skills needed"*.

The third theme was about staff not having been listened to in the past. There was only one participant that spoke about this but it felt very pertinent to the question, they explained:

*"i have in the past expressed my opinion the individuals may benefit from input this has not been taken up"*

This past experience of not being listened to meant that they were unlikely in the future to consider a referral.

#### 4.5.1.2 Undecided

There were 30 participants who indicated that they were 'Undecided' regarding their likelihood of considering a referral for counselling for someone from their service. Of these 11 of the participants did not provide any explanation of their answer to the question. There were 6 participants who questioned the appropriateness of counselling for the people that they support. Many felt that a lot of consideration would need to happen before they could consider counselling as an option. One participant summarised their answer with, *"the needs of the service change very quickly, so it is hard to judge if a person is likely to need a counsellor. However should there be a need we would make a referral."*

The knowledge and understanding of the staff emerged as a theme. There were 5 participants who explained that they were either new to the service or did not fully understand what counselling was. One person mentioned that they had *"...not come across this before"*. The ability of the people with learning disabilities that staff support was also raised within four of the participant's explanations. There were questions about the level of understanding that would be needed by the person and whether if they were non-verbal, could they benefit from counselling. One response summed up many of the concerns but also offered a possible solution to support them.

*“It would need a lot of prep before hand to ensure that the S/U was prepared to engage, and understood the reason for them taking counselling. Also, a lot of prep to ensure they knew the benefits of counselling”*

Lastly there were two participants who seemed to be disempowered in their responses. One participant spoke of it being others within the staff team who organise and think about counselling for the people that they supported. Another spoke of the difficulty in accessing services and their response seemed reserved that not much could be done when they said, *“I work with someone who could probably benefit from counselling . My manager is aware but we have a lot of trouble accessing services for her”*.

#### *4.5.1.3 Likely*

This group represented the majority of the responses to the question regarding the likelihood that participants would be to consider a referral for counselling. There were 8 participants who didn't provide any explanation for why they chose 'Likely'. Analysing those answers that were given, it emerged that there were two core themes which very much echoed the explanations given for those participants who felt that counselling could be beneficial for the character within the vignette. These were what counselling might offer and what makes counselling different. There were also other themes that emerged, including that there were current issues which could be supported with counselling now, that it was routine to consider counselling and a previous positive experience.

What therapy might offer represented the largest theme with 24 participants providing responses which could be identified as belonging to this theme. There were two sub-themes within the theme of what therapy might offer, with one being that counselling meant that the person with a learning disability would be able to express themselves and the other being that it could be beneficial for them. It was very clear that participants felt that being able to express what was happening for them might lead to *“relief”* or might *“...help with dealing with their emotions etc”*. There were also clear statements that counselling could be a benefit for the people that they support. This does not mean that there was not an acknowledgement that counselling was not always right for everyone, but the responses gave a clear indication that the participants did see it as a valuable option that was worth considering. One participant said that *“Counselling can be beneficial in most cases, and although it does not suit everyone, is always worth trying”*.



This combination that actually counselling might be able to offer something to the people with learning disabilities, and that they saw the value in it being a possibility indicated that there was a positive view towards counselling. As one participant eloquently stated,

*"I believe counselling can be a strong tool to help people understand their own personal feelings and/or help them deal the issues they are finding difficult within their life"*

The other key theme was that counselling provided something different to what the staff could offer themselves. The two sub-themes within this were again similar to those participants who had felt that counselling could be beneficial for the character within the vignette, with participants mentioning both the independence that a counsellor might be able to bring and the expertise and knowledge that they would have. There were 5 responses which illustrated this theme; a response from one participant was,

*"It helps the client to have an outlet. Sometimes they look forward to it seeing someone who could really empathise with them. Not that the support worker don't but there is a difference talking to someone whom they do not see on a day to day basis and yet can understand them more."*

There were actually 6 participants who could identify specific issues which were occurring in their service which could lead to a need for counselling. These included bereavement, attachment issues, relationship difficulties, staff changes, illness and someone having witnessed an incident. Not all of the responses alluded to the specific issue but instead alluded to there being something that the person needed support with. One participant summarised it adequately with the statement that,

*"We have an individual in our care who has expressed certain issues that maybe best addressed by counselling."*

In addition to those who indicated that their reasons for selecting 'Likely' were in relation to what therapy might offer or why it might be needed, there were 6 participants whose responses indicated that it was routine to consider counselling as an option along with other interventions that might be needed for an individual with a learning disability. Lastly there were two participants who indicated that they were 'Likely' to consider a referral in the future, for someone they support due to previously having a positive experience. Both participants related their positive experience directly to their opinion of counselling for people with learning disabilities. Both responses can be seen below,

*“As according to my experience, the PWS have benefitted from counseling as they learn how to manage their feelings and emotions.”*

*“Having seen a positive outcome from current counselling, I feel others may benefit in the future.”*

#### 4.5.1.4 Very Likely

There were both similarities and differences between the explanations given by those participants who selected ‘Likely’ compared to those who selected ‘Very Likely’. There was still a main theme of what therapy might offer although there was an additional sub-theme which indicated what tools the counselling might be able to give to the person with a learning disability. Such as this person’s response,

*“People receive counselling that is appropriate to their needs and abilities and gain coping skills. They are happier and more confident people.”*

There was also a clear recognition that there was a need for counselling and that it should be something that is considered and again an acknowledgment that the counsellor can offer expertise and knowledge. This was alongside those speaking of having a previous positive experience. There was however a theme which had not emerged from the other groups and this was in relation to the complexity of therapy. These couple of responses showed that consideration was needed to think about therapy from multiple angles, and although the participants felt that considering a referral was ‘Very Likely’, there are multiple factors and complexity of what can affect people and their behaviour. One participant’s response clearly showed the multi-layered issues,

*“This is because of the person's choice not to use the tools given by the counselor as her behaviour remained the same after years of counseling as it was a learnt behaviour of a need for attention from anybody whether this was positive attention or negative attention as the person was lonely and created issues to draw attention to herself as she knew if she created issues she would have a meeting with her social worker and her parents and staff in her flat and so she continued this pattern for many years and still does”.*

#### 4.5.2 Staff's Experience of Supporting Someone During the Time they had Counselling.

Analysing the descriptions of participants' experiences of supporting someone with a learning disability to access counselling led to five main themes emerging from the data. These included it having been: Positive and helpful, Uncertainty, What the therapeutic space could offer, Practical support and the Challenges and complexity of counselling with this client group.

##### 4.5.2.1 *Positive and Helpful*

A key theme, which emerged from the staffs' description of their experience of supporting someone with a learning disability during counselling, was that they experienced it as positive and helpful. There were 18 participants' responses that contained this theme. Staff expressed that they felt that the counselling helped and was beneficial for the person that they were supporting. Some staff spoke of how they could see the counselling was beneficial for the person. One participant said,

*"The experience felt beneficial to the person that I was supporting at the time, it made a noticeable change in their behaviour"*

Other staff spoke about the person themselves expressing the difference that counselling made to them, such as this example,

*"it helped the person I supported he was able to express his feelings and said it made him feel better."*

Staff used many different words to express how helpful the counselling had been including "rewarding", "a good outlet" and "satisfied". There was one particular response that showed just what a difference counselling made to one person's life:

*"Very positive. Following abusive trauma that profoundly affected the persons well being, she had weekly sessions with the Psychotherapist and counsellor and their relationship built trust, we observed warmth and a real connection between both which over time certainly improved the persons life."*

##### 4.5.2.2 *Uncertainty*

There were also a number of staff though who spoke with uncertainty about how beneficial it had been or even that they felt that it hadn't been helpful for the person to be in counselling. There were 10 responses that fell into this theme. A couple of people were very brief in their answers with one saying, "Less than engaging" and another just saying it was a "bit stressful". Some spoke about the negative affects they felt it had on the person's behaviour, such as in the following examples,

*"In some cases could make them more aggressive rather than assertive"*

and

*"... When clients talk about it there it can trigger challenging behaviour which they are having difficulty to resolve or deal with..."*

#### *4.5.2.3 What the Therapeutic Space Offered*

Another theme, which was very evident within the responses regarding their experience, was of what the therapeutic space offered people with learning disabilities. There were two sub-themes within this, one acknowledging that the space offered expression and the other sub-theme was that this space was a different space in comparison to just talking to staff. There were two participants who both used the term *"eye-opener"* which seemed to relate to the difference that they saw in the people they were supporting within the counselling session or what they said to the counsellor in comparison to how they behaved within the home.

One example, which illustrated what the space offered both in terms of expression and quality, was,

*"The environment was quite relaxing which helped the client to stay calm and relaxed. the counsellor was non-judgemental and displayed good listening skills as he encouraged the client to release the bottled up hurts and anger he has kept within his heart for several years..."*

#### *4.5.2.4 Practical Support*

There were a few of the participants who only spoke about the practical support that they offered to the person such as *"reminding them"* about sessions and *"passing on letters"*. One participant spoke of *"advising them they could address and raise issues they were experiencing"* which indicates that they were trying to support the person to use their counselling session effectively.

#### *4.5.2.5 Challenges and Complexity of Working with People with Learning Disabilities*

A final theme that emerged from the responses was that staff noted that there were specific challenges to providing or accessing counselling for this client group. Each of these responses identified a different element of complexity or difficulty which supporting someone with a learning disability to access counselling can bring. One member of staff spoke of their struggle to access appropriate services saying,

*"I have supported an individual to access bereavement counselling following the death of her parents. This was difficult to access and not specifically designed for an individual with learning disabilities. I have also attempted to refer an individual for CBT to address anger outbursts at work - again, this was difficult to access."*

Another spoke of how the expectations from both the person and their family can affect counselling, implying that systemic issues need to be taken into account. There was an acknowledgement that people with learning disabilities might need more support to ensure that they can understand and get the most out of therapy. One member of staff said that, *"lots of learning and understanding work to ensure they understood what the sessions would be and how they would help."* It was also mentioned about the impact that providing this support can have on staff. One response spoke of their personal difficulty with supporting someone who was terminally ill, and the difficulty to balance the empathetic elements with the maintenance of a *"professional front"*.

One response which really illustrates this theme is:

*"Talking focus mostly in reminiscing and past experiences that may be contributing to the present behaviour. Client will mostly talk about the good and happy things and tends to avoid talking about bad experiences. When clients talk about it there it can trigger challenging behaviour which they are having difficulty to resolve or deal with. There is also difficulty in terms of finding the right approach to ensure that the client absorb the information given."*

#### **4.6 Barriers which Might Affect Access to Counselling**

Participants were asked whether they thought that there were any particular barriers which prevent people with learning disabilities from accessing counselling. There were only seven participants who did not write anything to this open-ended question and there were 21 participants who felt that there were not any barriers. Of those who did feel that there were barriers, only four did not elaborate any further on what these barriers might be.

Three key themes emerged from the barriers that were mentioned. The first were barriers that were related to individual factors such as the learning disability, the second were barriers which were felt to be due to staff and the third were service level barriers.

##### **4.6.1 Barriers Related to Individual Factors**

There were several sub-themes which were within this theme of barriers which were related to individual factors. The biggest subtheme was that of communication difficulties, with 36

responses specifically mentioning communication as a barrier. Most of the participants either mention *“communication difficulties”* or speak about the person *“being not able to express self”*. The majority of responses did not have detail regarding whether there might be specific difficulties with communication, but there was both concern over the difficulties that someone with a learning disability might have in expressing how they feel and what is happening and whether someone who has limited verbal language could utilise counselling. One participant acknowledged that verbal communication is not the only way to communicate, saying *“...if someone is unable to speak, or communicate through verbal language, then this could also be difficult, if the counsellor had no knowledge of their preferred method of communication”*.

Another sub-theme that was mentioned by 17 of the participants relates to the difficulty that the person with a learning disability might have of working with a stranger and not having enough time to enable trust and familiarity to be built. As one person concisely puts it, *“a barrier could be talking to a stranger, not having built a working relationship”*.

There was also a real acknowledgement that people with learning disabilities might not be fully aware of what counselling is and what it might offer them. Staff expressed that this could be related to a lack of understanding as to what counselling is, but also that there was likely to be a lack of awareness that services such as counselling could be available to them. One response which summarises the responses which expressed this subtheme was:

*“A lot of people with learning disabilities may not know how to access this service or understand the true benefits it can offer.”*

There was also a subtheme that was mentioned by five people regarding the reliance that people with learning disabilities have on the staff. As one person said very succinctly, *“they need staff to act for them”*. Finally, there were only four participants who made any mention to the level of learning disability and that the level of understanding of the person could impact on the effectiveness of counselling.

#### 4.6.2 Barriers due to Staff

The barriers which were related to staff issues could primarily be divided into two main sub-themes, those regarding staff understanding, and their attitudes and opinions. The understanding sub-theme could further be separated into understanding about counselling and benefits that it may have for people with learning disabilities, and a lack of understanding of the signs that might indicate that there might be a mental health need that counselling might support. Many staff expressed concern about the lack of knowledge that staff have

about mental health, the signs and symptoms and possible treatment options. One response was concerned about a:

*“General lack of knowledge of people providing support to warning signs that someone may be able to make use of such a service.”*

Another person was concerned about staff having an “*over reliance on the medical model*” and so not fully considering options other than medication. Diagnostic overshadowing also came into this with there being the risk of “*Preconceived ideas that the behaviour is related to the LD not an emotional response*”. Knowledge though was not the only concern about staff as there were several responses which very much pointed towards staff opinion and attitudes being a potential barrier, such as the case with this response:

*“I think that some people might not want to go through the trouble of supporting someone to go to counselling.”*

#### 4.6.3 Service Level Barriers

The final theme incorporated barriers which were at a service level. This included those at the level of the individual counsellor as well as wider issues such as the availability of services and the cost of this within a time of austerity.

There were nine participants who specifically mentioned the knowledge and experience of counsellors. There was a real concern that the counsellor needs to have both the experience of working with this client group as well as knowledge and understanding of the learning disability and what it can mean for the person. Responses clearly illustrated that finding a counsellor “*trained*” in how to work with people with learning disabilities and experience of working therapeutically with this client group was difficult.

The identification of access as a barrier both related to physically being able to access a service due to mobility issues and how difficult these can be to access and be referred to. There were eight participants who specifically mentioned access as a barrier. Money was also in some people’s awareness with eight people mentioning funding and the cost of counselling as being a barrier for people with learning disabilities.

Finally, the actual lack of services was mentioned by seven of the participants, who either felt that there was a lack of specialised services which offered counselling for people with learning disabilities or when there were these services, there was a lack of counsellors within them to be able to offer a service. One person also acknowledged the post-code lottery that there can

be with services saying, *“Some areas don't offer services that is appropriate to a particular case.”*

#### 4.6.4 Multiple Barriers

Many of the responses contained more than one theme within them and would talk about barriers at the different levels. There was one response which incorporated so many of the themes within it and gave a real sense of just how many barriers there can be for people with learning disabilities to have access to counselling:

*“Lack of services/funds. Psychologists not having the time to 'get to know the person' and build some trust - in some cases it may be unlikely the person will even agree to talking to a stranger - lots of preparation is required just to get to that stage. Communication difficulties - counsellor not being able to understand the person's preferred method of communication. Staff not appreciating the potential emotional/psychological issues people living in residential care may be contending with - not recognising the need in the first place.”*

### 4.7 Other Opinions about Counselling for People with Learning Disabilities

Participants were asked if they had any other opinions about counselling for people with learning disabilities that they would like to share. There were 50 participants who responded to this question and when the answers were analysed four themes emerged from the data. These themes were that counselling was seen as: Beneficial, a Needed service, that Staff need to be involved in the counselling process and Time is needed to build a therapeutic relationship.

#### 4.7.1 Beneficial

One of the clear themes that emerged from the responses was that many of the staff felt that counselling could be beneficial for people with learning disabilities. The sentiment expressed by 13 of the responses was that it could offer something helpful and that if done with appropriate consideration for the learning disability, then *“Counselling is useful for helping to address these issues in addition to helping people cope better with their disability”*. Staff acknowledged in their responses the psychological needs of the people that they support as the following quotes illustrate:

*“I feel that this could benefit the people who we work with as this may support them emotionally and help their self esteem”*



*"I feel it could be very beneficial to the people I support as they are faced with loss of loved ones."*

#### 4.7.2 Needed Service

Another clear theme that emerged from the responses was that counselling was a needed service. There were 17 responses which included reference to either counselling being a needed service or that more services should be available for people with learning disabilities. One member of staff made reference to the historical disdain towards people with learning disabilities with regards to counselling saying, *"I think it's a much needed service. Historically people with learning disabilities have not been able to access counselling, unless they have been extremely high functioning."*

There were several comments about the availability of counselling for people with learning disabilities and that this needed to be improved. As one participant said, *"I would love to see more counselling made freely available for individuals accessing community services."* However this does raise concerns about the funding of services which was recognised by one person who said,

*"I am optimistic about the future of this; the conjunction of better technology (AT), the breaking down of the stigmas and stereotypes associated with both counselling and disabilities and better appreciation of person centred approaches are all going in the right direction. However, I am concerned about the funding aspect and the current constraints and pressure being put on cost cutting. Will the development, training and access to appropriate counselling for people with learning disabilities be high on the priority list?"*

Staff also felt though that equality was needed in terms of access to services for people with learning disabilities in comparison to the general population, but also acknowledged the specialised nature of the counselling as one person stated, *"The local health services should have specialist professionals that deal with learning disability cases."*

#### 4.7.3 Staff Need to be Involved

There were four staff who expressed that they felt that there was a real need for staff who support the person to be a part of the therapeutic process. One member of staff seemed to express concern about being excluded from the process saying,

*"I understand counselling has to be confidential but how do we support people effectively if we don't know what had been address and issues are sometimes have two side of stories".*

One member of staff spoke about their experience of being involved and supported by the psychologist which led to increased understanding of the process and how best to support the person;

*"Positive experience of staff team being trained in very basic counselling skills by a psychologist. This has certainly informed how this person is supported by his circle of support."*

#### 4.7.4 Time to Build a Therapeutic Relationship

Finally there was a theme about the need for the counsellor to give time for the therapeutic relationship to be built. There was not an explicit mention that this could take longer for people with a learning disability, but there seemed to be an acknowledgement that this needed to be particularly considered for this client group. The responses expressed that both time and familiarity was needed in order to build trust. The two quotes below give examples of what staff were saying in relation to having the opportunity for people with learning disabilities to access counselling. The responses indicated that for the counselling to be worthwhile, more consideration needed to be made to not only spending time with the person with a learning disability in a formal therapeutic setting, but also beyond the therapy room, through consideration of the systemic factors that affect the person.

*"I think it is really good but people who do counselling needs to work directly with the people we support in order to gain trust and confidence and that people we support can express what really their feelings are as they gain trust and confidence to the counsellor"*

*"- sometimes best counselors for people with this particular group of needs may need to fully understand a person's day to day living. that one can only understand if they actually do activities on a day to day basis even if as a background observation. that way, it is possible to get extra information about the person. Otherwise i think that a one to one sit down conversation with an individual with learning disability may not give all the information. In addition to that, due to some disabilities, some individuals have not got the ability to settle down for a long period of time or even settling down at all."*

#### **4.8 Reliability**

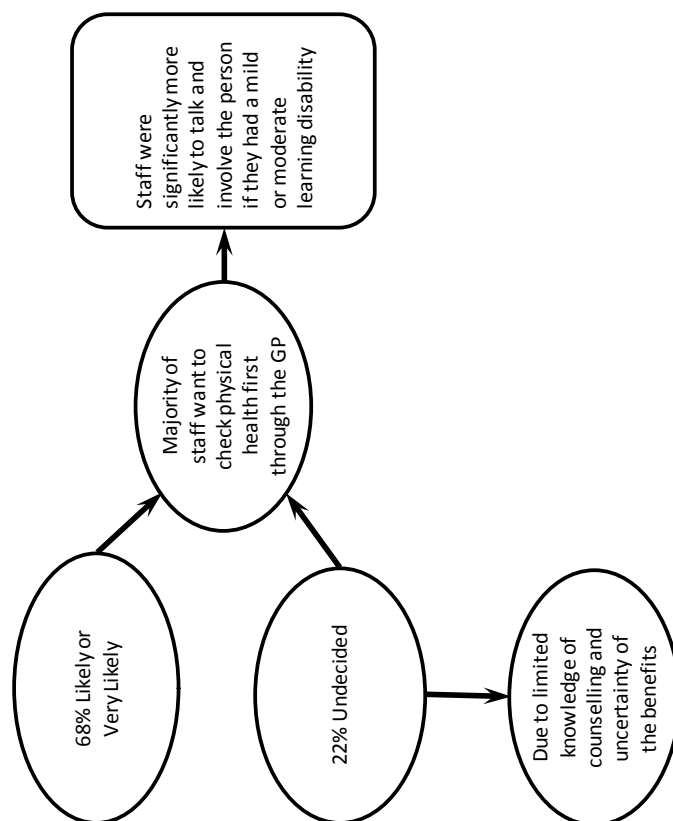
Inter-rater Reliability was calculated for two of the questions (What are the first thoughts that enter your mind when reading the above situation? What would you do if someone you supported presented in the way above?) that were analysed using Thematic Analysis. The responses that were analysed accounted for at least 10% of the total responses that were analysed. A second rater selected responses at random from the two questions and analysed the data using the initial codes which had been identified by me. The codes from the second rater were then compared to my codes and Cohen's  $\kappa$  was computed to determine the level of agreement between the two sets. The first question led to the comparison of 114 codes of which there was substantial agreement (Landis and Koch, 1977),  $\kappa = 0.765$  (95% CI, 0.681 to 0.849),  $p < 0.001$ . The second question led to the comparison of 110 codes of which there was almost perfect agreement (Landis and Koch, 1977),  $\kappa = 0.82$  (95% CI, 0.744 to 0.896),  $p < 0.001$ .

#### **4.9 Summary of Results**

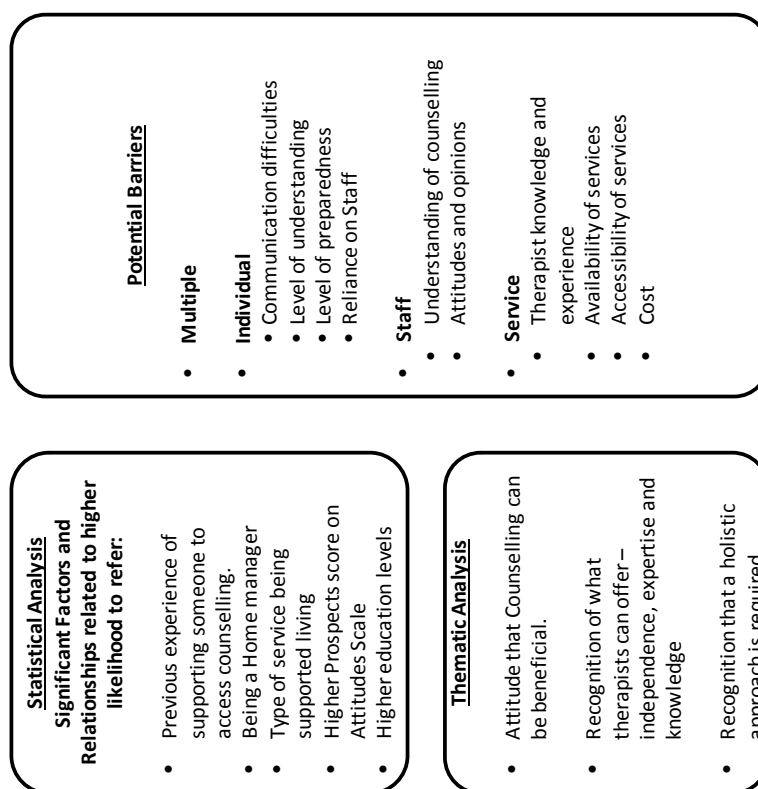
A summary of the results can be seen in Figure B4-12. The majority of support workers were likely to consider a referral or speak to their line manager about a referral for someone they support. Staff responses indicated that they would be likely to consider possible medical causes for behaviour changes before considering a referral to counselling. There were a number of factors that were considered in relation to staff's likelihood to consider a referral. Participants who had previous experience of supporting someone to access counselling were more likely to consider a referral in the future. Home managers were found to be significantly more likely to consider a referral for counselling in the future than support workers. Staff that worked in supported living were significantly more likely to consider a referral for counselling in the future than those who worked in residential care. Higher scores on the Prospects scale from the Attitudes to Disability Scale (Power et al, 2010) were significantly related to being more likely to consider a referral to counselling. Finally higher education levels were significantly related to staff being more likely to consider a referral for counselling.

Staff experiences of supporting people to access counselling showed that although it was mainly positive and they recognised what therapy could offer, there were challenges and people with learning disabilities often needed support to engage. There were also multiple potential barriers identified by participants, which can prevent people with learning disabilities from accessing counselling and these are at various levels.

*How Likely are support workers to consider referring or speak to their line manager about referring someone they support for counselling?*



*What factors affect this likelihood?*



**Figure B4-12: Summary of the main results.**

## **5. Discussion**

### **5.1 Chapter Outline**

The current study sought to investigate the attitudes of support workers in learning disability services towards counselling psychology. The key aim of the study was to find out how access to counselling psychology might be improved for people with learning disabilities through the support staff that many are dependent on to ensure fair access to mental health services (Dagnan, 2007; Crossley & Withers, 2009; Tsiantis et al, 2004). The research sought to address three key questions;

- What are the views of support workers of counselling psychology for people with learning disabilities?
- How likely are support workers to consider referring someone they support for counselling?
- What are the factors that might affect support workers considering a referral for someone that they support for counselling?

To answer these questions a mixed methods design using an online questionnaire was administered to support staff working day to day with people with learning disabilities. Through the use of a vignette, Likert scales, multiple-choice questions and open-ended questions, data was collated that could be analysed in a number of ways to provide a holistic answer to the questions posed.

The data was analysed using both quantitative and qualitative analyses. The vignette was used to investigate if changing the level of learning disability of the vignette character had an effect on the likelihood of staff considering a referral or speaking to their line manager about a referral for counselling for the character. A range of statistical tests were used to analyse the factors that might affect or have a relationship with the likelihood of staff considering a referral or speaking to their line manager about a referral for counselling for someone they support in the future. Finally all the open-ended questions were analysed using Thematic Analysis to discover themes in the participant's responses.

In the current chapter, the results that were found will be summarised and discussed in relation to other research and the available literature. The possible implications of the current research will be outlined before considering the research in relation to counselling psychology. The limitations of the study will then be examined before outlining where future research could explore. Areas of conceivable intervention to improve access to counselling for people with learning disabilities will be proposed and deliberated. Finally thought will be given to my

final reflections on the research and the results and what this will mean for my own practice and identity as a counselling psychologist.

## **5.2 Summary of the Key Research Findings**

### **5.2.1 What are the Views of Support Workers of Counselling Psychology for People with Learning Disabilities?**

It was evident from the responses to the vignette that staff recognised that there was likely to be 'something' that was underlying the changes that were described. There was also a clear indication that support workers would investigate the possible underlying causes to these changes taking place. There were only a small number of participants who seemed very certain about only one possible explanation. Counselling was considered by support workers to be an option but for the vast majority, it was not the first thing that should be explored. Physical health issues were the initial starting point for most staff with a GP's appointment being the most common action for staff to propose. Counselling appeared to be an option along with other possibilities and professionals once an issue with physical health had been ruled out. This could indicate that the dominance of the medical model is still prevalent within the learning disability field (Webb & Whitaker, 2012).

Some participants did express that they wanted to involve the person with a learning disability to find out what may have happened and what they might be able to do to help them, but for the most part the emphasis of responses was on staff to investigate and come up with a plan, rather than the person with a learning disability to do things themselves with support (Bigby et al, 2009).

The majority of support workers expressed (both through the scaled questions and through their responses to the open-ended questions) that counselling can be beneficial for people with learning disabilities. One reason that was provided was that counselling can offer the person a place to express themselves. Some staff also felt that counselling might actually aid the discovery and/or the understanding of the underlying causes to any changes in behaviour. There was also some acknowledgement from staff that counselling might be able to offer some advice and support not only for the person with a learning disability but also their support network including support staff and family. There were hardly any participants who felt that counselling was not beneficial but there were a number who were 'Undecided'. Over a quarter of participant's (28.8%) expressed they were 'Undecided' about whether counselling is beneficial for people with learning disabilities, and explained this was due to reasons such as

previous experience, uncertainty, lack of knowledge, experience and understanding of the person with a learning disability or due to staff attitudes.

Staff that expressed that they would be 'Likely' or 'Very Likely' to consider a referral or speak to their line manager about a referral for counselling explained that the possible benefits were one of the main reasons behind their decisions. Support workers also seemed to recognise that counselling could offer something that was beyond what support staff themselves could offer the person. There was recognition that the therapist was an independent, trained professional with tools and knowledge that might be able to offer something additional to what the medical model or what support staff could provide.

Having found previous experience as a significant factor for the likelihood of considering a future referral or speaking to their line manager about a referral for counselling, the descriptions of their experience offered a reason as to why they would be likely to consider it in the future. Participants expressed finding the experience positive and helpful, and although there were a few who expressed uncertainty that psychological therapies are not suitable for everyone, overall the responses were positive (similar to participants in Rikberg Smyly et al, 2008). Again support workers acknowledged what the therapeutic space offered to the person with a learning disability that they supported, and they acknowledged the very practical role that staff can play in supporting the person to be able to access counselling (Kroese et al, 2014). Supporting people to access counselling though is not without its challenges and complexities, and participants very much acknowledged these when writing about their personal experiences. This included difficulty in accessing appropriate services, finding the right therapeutic approach, the influence of systemic factors and staff having to deal with their own emotional reactions to the situations they had to support in (Willner, 2006).

Support workers felt that counselling for people with learning disabilities is needed but that it needs to be thought through with their involvement at some level. Participants expressed that this is not something that can be rushed but that people with learning disabilities need time to develop therapeutic relationships with counsellors (Jones, 2013a). Staff expressed that this might mean spending time with the person outside of the therapy room, gathering information from the circle of support or through allowing the therapeutic work to be longer term.

The barriers that support workers feel are restricting people with learning disabilities from accessing counselling were multiple and at multiple levels. At an individual level, communication difficulties which are so common amongst people with learning disabilities

(Bradshaw, 2001) was talked about by the vast majority of participants. Indeed concern about communication difficulties was repeated through many of the responses for different questions. This issue was also shown through the variety of communication methods that support workers use with the people that they support, including behaviour/body language, signing, facial expressions, symbol based systems and computer aided communication. Also at this individual level, is the level of understanding of what counselling is and the preparedness of the person for entering into this therapeutic relationship. All this has to be considered as well as the reliance on staff to ensure that they can access, attend and make use of counselling.

In addition to this individual challenge, participants also recognised that it is set within a context where the support staff that the person is reliant on may not have the understanding themselves of what counselling is or could offer, or may have attitudes which mean that referrals are unlikely to happen or may lead them to not supporting the process adequately if counselling is accessed (Willner, 2006). Although these were in the minority, I would argue that it needs to be considered as people with learning disabilities are often supported by a team of support workers and if not all of them are working consistently, this can have a major impact on the person's experience and thinking (Mansell & Beadle-Brown, 2004).

Finally support workers were very much aware of the external context of the service level and how barriers at this level will affect the access and effectiveness of counselling for people with learning disabilities. There was a real concern by participants about the number of therapists that have the experience and knowledge to be able to provide counselling for people with learning disabilities (Cumella, 2009). Participants spoke about whether there are enough counsellors that have this and some spoke of their personal experience of struggling to find appropriate services (Jones, 2013b). Indeed the availability of services in general was seen as real barrier, with experience of trying to find and access counselling services for people with learning disabilities being incredibly hard (Prout et al, 1998). Finally support workers recognised that these services cost money, and within the current climate of cuts and reductions in services, it was felt this would be a considerable barrier for people with learning disabilities to access appropriate psychological interventions that are tailored to the person.



### 5.2.2 How Likely are Support Workers to Consider Referring or Speaking to their Line Manager about Referring Someone they Support for Counselling?

Staff were asked in two different situations to consider the likelihood of them considering a referral or speaking to their line manager about a referral for counselling for someone with a learning disability. One situation was regarding the character within the vignette and the other situation asked staff to think about the people that they support regarding counselling at some point in the future. The most common response in each of these situations was 'Likely' with an average of 44.5% of participants choosing this response for these questions. Another common response was 'Very Likely' with an average of 23.4% of participants choosing this response. This indicates that approximately two thirds of staff are generally positive about considering a referral or speaking to their line manager about a referral to counselling for people once you have combined the participants that indicated 'Likely' and 'Very Likely'.

This positivity though does not mean that many people with learning disabilities are accessing counselling. Only 34.8% of support workers have personally supported someone to access counselling and only 39.1% of staff were aware of someone in their current service having accessed counselling. It is difficult to relate this directly to how many people with learning disabilities have accessed counselling due to there being the possibility that different staff may be talking about the same person and no time frame having been specified. It does however, seem to indicate that people with learning disabilities who access counselling might still be in the minority (Division of Clinical Psychology Faculty for people with learning disabilities, 2011).

Although being 'Likely' to consider a referral or speaking to their line manager about a referral for counselling was the most common response, there were a number of participants that selected 'Undecided'. An average of 22.2% of support workers selected 'Undecided' for the two questions where they were asked to consider a referral or speak to their line manager about a referral for counselling. When participants were asked to explain their responses to the likelihood question, the analysis indicated that those who were 'Undecided' did not have much knowledge about counselling for this client group and were unsure about whether it would benefit the people that they worked with (Willner, 2006; Kroese et al, 2014).

The changes described in the vignette did not result in a possible counselling referral being the first consideration for most of the staff, with many regardless of their level of likelihood, saying that they wanted to check all possible physical health aspects before considering a referral for counselling when responding to the vignette. This suggests that physical health is seen as the

priority for support workers to exclude before looking for other alternative causes for changes in behaviour and possible interventions (Melville et al, 2005).

### 5.2.3 What are the Factors that Might Affect Support Workers Considering a Referral for Someone they Support for Counselling?

Looking at the factors which might affect the likelihood of participants considering a referral or speaking to their line manager regarding a possible referral, the results of the current study revealed a number of different factors. The level of learning disability of the character in the vignette did not affect the likelihood of support workers considering a referral but did affect what they would do. Staff were significantly more likely to speak to the person if they had a mild or moderate learning disability than if they had a severe learning disability. Support workers may not see much difference between mild and moderate learning disabilities but may see more deficits for those with a severe learning disability, understanding the possible communication difficulties that people with this level of learning disability may have (WHO, 1992; APA, 2013).

A number of factors were looked at in relation to the likelihood of staff considering a referral or speaking to their line manager about a referral for counselling. There was a significant difference between those who had different roles with home managers being significantly more likely to consider a referral than support workers. It is not surprising that a more senior member of staff is more likely to consider a referral for counselling, as they are often the people with the overall responsibility for the service and those that live within that service (Social Care Association, 2011). Those staff that had previously supported someone to access counselling were significantly more likely than staff who had not and this likelihood did not appear to be affected by the perceived benefit for the person with a learning disability. This could support Bradshaw and McGill's (2015) assertions that support staff learning is more likely to be driven by experience than theoretical concepts. Likelihood to refer was not found to be related to general attitudes towards learning disabilities but those staff that had more positive attitudes towards the prospects of people with learning disabilities were significantly more likely to consider a future referral.

In addition the level of staff's educational attainment was significantly related to higher likelihoods to consider a referral in the future (Morin et al, 2013b; Scior, 2011; Yazbeck et al, 2004). There was also a difference regarding the type of service where staff work and their likelihood of considering a referral for counselling. Those who worked in supported living were significantly more likely than those who worked primarily in residential care. This could be

related to the knowledge and experience of staff which has been found to be different in staff from supported living compared to residential care (Woodward and Halls, 2009).

The themes that emerged from the open-ended questions revealed that a number of participants who were 'Undecided' regarding the consideration of a referral for counselling wanted to rule out all other possibilities first including medical reasons, abuse and something being wrong. This may reflect the issues related to communication and a lack of knowledge which are common for people with learning disabilities (Sowney & Barr, 2004). It may also be that staff have an awareness that there are higher health needs in people with learning disabilities which are often unrecognised and unmet (Cooper et al, 2004).

Even for those who were 'Likely' to consider a referral for counselling, they still wanted to ensure that all possible physical health problems were explored first. Support workers who were 'Likely' or 'Very Likely' to consider a referral felt that counselling may be a good way to understand and investigate what was happening for the person and recognised what a counsellor might be able to offer including independence, expertise, experience and specialist training (Tsiantis et al, 2004). Support worker's responses recognised the complexities of working with people with learning disabilities in that staff need to take into consideration all aspects of a person's health and wellbeing when they support someone with a learning disability (Bradshaw & McGill, 2015).

### **5.3 Possible Explanations for the Findings**

#### **5.3.1 Likelihood of Support Workers Considering a Referral or Speaking to their Line Manager about a Referral to Counselling**

The results of the current study show that the majority of support workers working with people with learning disabilities are willing to consider a referral or speak to their line manager about a referral to counselling if a change in behaviour occurred for someone that they support. However the number of staff with previous experience of supporting someone to access counselling or know of people with a learning disability who have accessed counselling appears to be relatively low. The use of the vignette tried to provide an example of a situation to investigate support workers' reactions to a possible situation that they could face with someone that they support. This again indicated that most support staff were favourable in regards to considering a referral for counselling for the character that was described. This suggests that there are other barriers as to why referrals may not occur.

Support workers responses indicate however that mental health and the possible intervention of counselling would not be the first consideration, and instead that physical health and GPs

are where most staff would turn for support. Indeed other research shows that Primary Health Care Teams are the most frequent health professional to have contact with people with learning disabilities, and yet it has also been identified that there are unmet training needs for these professionals to ensure there is effective identification of needs (Melville et al, 2005).

This may be related to the communication difficulties that were identified by participants, which often people with learning disabilities experience (Bradshaw, 2001) and can be a barrier to accessing not only counselling but health services in general (Lindsey, 2002). The difficulty which some people with learning disabilities may have in having the necessary vocabulary and skill to communicate what might be happening for them means that support workers do have to become a 'detective' to discover the possible underlying cause for any changes (Krahn, Hammond & Turner, 2006). This coupled with the situation where support staff have multiple roles and responsibilities (Windley and Chapman, 2010) and where there may be many different support workers working with the person depending on the service and staff rota staff. This may mean that changes can take time to be noticed. This may be reflected in the participant's comments on the need to record and monitor as well as speaking to their line manager and/or the staff team so that evidence can be collated of the changes in behaviour.

It is not actually very surprising that support workers expressed that they would start their investigations with the GP as the health needs of people with learning disabilities are often higher and yet under-recognised and unmet (Cooper et al, 2004). Ensuring physical health may seem more concrete for staff and less complicated than other possible underlying causes. I also wonder whether the GP offers an opportunity for a quick fix which might take the responsibility away from staff and place it back onto a professional. Indeed if there is a physical medical cause underlying the changes in behaviour and some medication from the Doctor might lead to the person feeling better, then it may be that going to the GP first to rule out possible physical health issues is likely to be beneficial for the person. However, it needs to be kept in mind that just because people with learning disabilities are accessing the services that the GP offers, it does not mean that they are benefitting from them (Sowney & Barr, 2004).

The GP being the first place that support workers seek support from may also be related to culture. It may be that staff values are still rooted in the idea of caring rather than supporting (Bigby et al, 2009). In addition, the dominant medical model (Rioux, 1997) may still be influencing support worker's thinking. Multi-disciplinary case formulation is supposed to be shaping services, thinking and development (Ingham et al, 2008) through the Bio-Psycho-Social model (Engel, 1980) but it may be that the 'Bio' aspect of the model is still taking the emphasis away from the other components. Williams and Heslop (2005) argue that learning disability

and mental health services are still dominated by the medical model mainly due to Psychiatry. This might not only account for why support workers look first to the medical professionals, but may also be a factor in why access to psychological therapies is still so slow and the majority of research is coming from a limited practice-based context (Beail, 2015). It must also be considered whether the support workers feel a power differential between themselves and the health professional (Grabb, 1997). A sense of powerlessness against the professional's 'legitimate opinion' where there can be a lack of recognition and respect of the knowledge and skills of support staff (Rutman, 1996). There were a few of the qualitative answers which did give an indication that, for at least a few of the participants in the current study, they did not feel particularly empowered or that they would be listened to.

Support workers were aware that there was 'something' that was affecting the vignette character's behaviour but most could not elaborate any further. Around a third of participants did query whether the character within the vignette was suffering from depression upon which the vignette had been based. So this may indicate that some support workers do have some awareness of mental health problems. However there were other examples from the results, including participants providing contradicting answers, expressing that they wanted support from other professionals and responses which indicated that staff needed more knowledge about this area. This shows that perhaps support workers do not have enough knowledge overall to identify possible mental health issues (Crossley & Withers, 2009).

Therefore the level of support staff knowledge, understanding and experience to identify mental illness needs to be considered. This could explain why investigating physical health is their first consideration. This idea could have some credence as Tsiantis et al (2004) discuss how key a role support workers play in identifying potential mental health issues for people with learning disabilities and making referrals for appropriate treatment, but their research study indicated that staff usually do not have the necessary level of expertise that is required.

There is a concern that support workers in general, do not have enough knowledge about mental health issues for people with learning disabilities (Crossley & Withers, 2009; Woodward & Halls, 2009). Indeed with Costello et al (2007) finding in their study that a third of people with learning disabilities, who were not felt to have any mental health problems by staff, had significant psychopathology found by the researchers, it adds to this concern. Therefore it is not surprising that most research has focussed on support staff training. Costello et al (2007) also found that support workers knowledge and more positive views of mental health services increased the likelihood of staff seeking a referral. However, the study by Tsiantis et al (2004) provides warning that the picture is more complicated as they found that although there was a

increase in awareness in their study following training, there was no significant changes in practice due to staff feeling that it was difficult to implement the training once back in their services. This suggests that maybe confidence and empowerment might make a difference to support workers likelihood to consider a referral or speak to their line manager about a referral. It may also explain why the factors that were found to be significant in relation to the likelihood of consideration of a referral included role, previous experience, attitudes towards the prospects for people with learning disabilities, level of education and type of service. This is supported by Woodward and Halls (2009) who found that the skills that support staff possess is dependent on experience, training, resources and managerial support - all of which are likely to be more available to staff in a more senior role, who have a higher level of education, or work in a service whose ethos promotes certain values.

Although this current study did not identify the level of learning disability as a factor for support workers considering a referral or speaking to their line manager about a referral to counselling, it did show that the involvement of the person in being consulted and spoken to, was affected by the level of learning disability. This is similar to the findings of Ferguson et al (2010) who found that the severity of the learning disability was a key factor in people with learning disabilities being involved in health care choices. It also leads to questions about what support workers understand about the different levels of learning disability. It could be that support staff do not fully understand and recognise what the level of learning disability might mean in relation to cognitive and communication difficulties for the person.

Previous experience of supporting someone with a learning disability to access counselling was a significant factor for the likelihood of staff considering a referral or speaking to their line manager about a referral. It indicates that by increasing the opportunities for experiencing counselling, it would likely lead to a positive cycle of reinforcement occurring. This supports Bradshaw and McGill's (2015) view that support workers understanding is more likely to be based on experiential learning rather than theoretical concepts..

Woodward and Halls (2009) also found that the setting could make a difference to the skills and knowledge that support workers possess and this is reflected in the current study where the setting affected the likelihood of a referral to counselling being considered. Supported living is presented as an alternative to residential care. The ethos of supported living (Simons, 1998) is a much more individualised service in which as much choice and control is given to the person that is being supported as possible. There is a view and historical experience within the organisation that participants work for, that supported living and outreach tended to be used by people who have more mild and moderate level of learning disabilities, although this is

changing as supported living becomes one of the preferred model of support by government (Department of Health, 2001).

### 5.3.2 General Views of Support Workers about Counselling for People with Learning Disabilities

The current study sought the views from support workers on counselling for people with learning disabilities. The available literature argues that support staff play an extremely key and influential role in referrals for counselling (Stenfert Kroese et al, 2014) and ensuring access to mental health services in general (Evans et al, 2012). Therefore the views of this group needed to be known if increased access to counselling is going to be achieved not only at the referral stage, but in addition, to enable the support which is likely to be needed throughout the therapeutic process. Previous studies though which have included staff views on CBT (Stenfert Kroese et al, 2014) and systemic consultation (Rikberg Smyly et al, 2008) were not restricted to only the views of support workers and instead both studies involved other professionals. This means that the current study allows the voices of support workers to be heard in relation to counselling for people with learning disabilities.

The themes which emerged from the participants responses indicated that they did overall see counselling as being both beneficial for people with a learning disability and a needed service. Generally positive views about systemic consultation for people with learning disabilities were found by Rikberg Smyly et al (2008). This study though was very specifically interested in the experiences of people following involvement in a consultation. Windley and Chapman (2010) who interviewed support staff about their role indicated that they valued the interventions provided by Community Learning Disability Teams, which would include psychologists within them. Indeed it may be that due to a lack of confidence (Woodward & Halls, 2009), support workers feel that having a counselling service available would mean that someone with knowledge and experience would be able to support them and the person with a learning disability with any mental health problems. This support could be seen as extremely valuable considering the supervision offered to support workers may not always be enough to gain appropriate support, knowledge and advice (Windley & Chapman, 2010).

When comparing the views of support workers that were found within the current study there are some similarities to some findings from other studies. Stenfert Kroese et al (2014) found more positive views from staff towards counselling for people with learning disabilities once they had supported people to access CBT. These views also contained concerns though about how long term changes would be maintained for the person with a learning disability and the feeling that continued input from the therapist would be required to make a difference

(Stenfert Kroese et al, 2014). It must be noted that due to the qualitative nature of their study, only a small sample size was used and this does raise many questions about the generality of the answers given by staff. Even so, these views somewhat reflect those of the participants within the current study who felt that time would be needed for a therapeutic relationship to be built, and for counselling to be effective that time would be needed for familiarisation with communication and the context in which the person with a learning disability lives. The view that it can take time to facilitate engagement has been echoed by Bates (1992) who emphasises the need to give time to the process with this client group.

Participants expressed that they do want to be involved in the therapeutic process and when staff were involved in a systemic consultation in Rikberg Smyly et al's (2008) study, 84% of staff indicated that they would choose to attend a consultation again. The systemic model though would inherently want to include support staff within the process while many psychological therapeutic models focus on the 1:1 therapeutic relationship. However this involvement should always be carefully balanced with the need for confidentiality (Chaplin et al, 2009). This balance may be difficult for therapists to achieve as Stenfert Kroese et al (2014) found when looking at CBT, that staff didn't feel like their involvement in the therapeutic process was welcomed. This may be related to support workers viewing their key role as working alongside the professionals to improve quality of life, and therefore may find it difficult if they are excluded from the therapeutic process (Windley & Chapman, 2010). Some therapists though do see the involvement of support staff and other caregivers such as family as vitally important in appropriately adapting counselling for people with learning disabilities (Hurley et al, 1998).

## **5.4 Identified Barriers by Support Workers**

### **5.4.1 Barriers Related to Individual Factors**

The barriers that were identified by participants as being at the individual level included the communication skills of the person with a learning disability, the level of learning disability, the person's awareness of counselling, the reliance on staff and the unfamiliarity with the context of counselling and the time it can take to build a therapeutic relationship.

Communication does present a clear barrier that has previously been mentioned in regards to accessing health services (Lindsey, 2002). As many people with learning disabilities experience communication difficulties, they tend to be reliant on others to support communication (Bradshaw, 2001). As was found through the current study there is a wide variety of communication methods used by people with learning disabilities apart from just verbal communication. Traditional psychological therapies rely on verbal communication but with the



wide variety of communication abilities (McLean et al, 1996) it means that adaption is often needed to ensure that people with learning disabilities can access them (Jones, 2013a).

The level of understanding was mentioned as a barrier and this may be related to the communication difficulties as receptive communication tends to decrease as the level of learning disability becomes more severe (Casella, 2004). The research has focussed primarily on borderline and mild learning disabilities (Mason, 2007) and how applicable this is to those with more severe or profound levels of learning disability is doubted due in part to the limited communication skills and abilities (Bhaumik et al, 2011). Indeed a study by Bradshaw (2001) into severe learning disabilities revealed that 59% communicated primarily symbolically, 19% were non-verbal but had intentional communication and 21% showed no intentional communication. This means that therapists are likely, when developing the therapeutic relationship, to need to check interpretations and pay closer attention to body language including facial expressions, eye gaze, body movements and vocalisations (Bradshaw, 2001). But even when there is verbal communication skills, there can still be barriers as research indicates that overestimation of understanding by people with learning disabilities is not uncommon (Bartlett, 1997; Purcell, Morris and McConkey, 1999).

The importance of the role of support workers in communication (Bradshaw, 2001) is extended into all areas of the person's life (Goble, 1999). Health in particular is an area where people with learning disabilities have a tendency to see 'others' such as support staff as being responsible for making decisions (Crossley & Withers, 2009; Ferguson et al, 2010). The learning disability combined with possible communication difficulties and reliance on others means that the awareness of counselling and how to access it is likely to be reduced. Indeed as a barrier the lack of knowledge of services has been previously suggested (Sowney & Barr, 2004) and Leyin (2011) specifically mentions a lack of knowledge of the available services as being a likely barrier to people with learning disabilities accessing IAPT.

The historical therapeutic disdain (Bender, 1993) towards people with learning disabilities means that they have struggled to access the full range of mental health services that are available including counselling (Prout & Strohmer, 1998). Participants in the current study mentioned in their responses a concern that the person's unfamiliarity with the therapeutic context and therapeutic relationship may present as a barrier. The therapeutic relationship is likely to be different to what people with learning disabilities experience in other areas of their lives (Jones, 2013a). Although there is an emphasis in services on empowerment and autonomy, this conflicts with the idea of increased vulnerability of the person with a learning disability (Windley & Chapman, 2010) which places both support staff and the person in a

difficult situation. People with learning disabilities are typically placed in a position of compliance (Crossley & Withers, 2009) and may fear services being taken away if they express any negativity towards it (Merriman and Beail, 2009). This may mean that they do not truly engage in therapy but instead become passive recipients of it as they do with other relationships in their lives (Goble, 1999). In Merriman and Beail's (2009) study which asked people with learning disability about their experience of psychodynamic therapy, they spoke of the difficulty of building therapeutic relationships with therapists who would then leave meaning they would have to get used to a new person.

It may also take time for people with learning disabilities to understand what the therapeutic relationship is and the boundaries of therapy (Hurley et al, 1998). Indeed when Goble (1999) interviewed people with learning disabilities about their perceptions of staff and services, all but one participant used the term 'friend' to describe members of staff and they had little knowledge or understanding of the roles of staff. If people with learning disabilities experience this for staff who support them on a daily basis, then it is likely to take time for them to understand the therapeutic context and relationship which they may experience once a week. Just with support workers learning being related to the experiential (Bradshaw & McGill, 2015) this is likely to also be the case for people with learning disabilities and the therapeutic process.

#### 5.4.2 Barriers due to Staff

The theme of staff as a barrier contained two sub-themes, staff's understanding and staff attitudes and opinions. The understanding of support workers about the therapeutic process has been found to be limited in some studies (Rikberg Smyly et al, 2008; Stenfert Kroese et al, 2014). The discussion above illustrates that support staff knowledge and understanding of people with learning disabilities and mental health problems has been a key focus of intervention through training (Costello et al, 2007; Tsiantis et al, 2004). The variety of therapeutic models that could be utilised with people with learning disabilities (Beail, 2015) means that even if support workers understand one model, then another could place greater cognitive demands on staff (Willner, 2006). This is in a context where they are already expected to support and know about an increasing number of areas in a person's life and cope with the ever changing social policy and philosophy within learning disability services (Bradshaw & McGill, 2015).

Some participants did express concern about staff views and attitudes about counselling being a barrier to people with learning disabilities accessing counselling. This has previously been implicated in accessing health services (Lindsey, 2002). It has also been expressed by Chaplin et

al (2009) who assert that staff beliefs and attitudes can influence the care provided through a number of ways, both consciously and unconsciously. Arthur (2003) postulates that it can be difficult for support workers to allow themselves to open up about their own feelings due to the reactions possibly including sadness, anger, frustration and rejection. This may make it difficult for staff to support people with learning disabilities to engage with the process of opening up and talking about their feelings. This position is shared by Willner (2006) who felt that the involvement of staff in supporting psychological therapy led to three questions being raised, one of which related to the staff's attitude of therapeutic disdain towards people with learning disabilities.

#### 5.4.3 Service Level Barriers

At a service level participants spoke about a number of potential barriers for people with learning disabilities to accessing counselling. These included concern about the knowledge and experience of therapists, the lack of available services, difficulties accessing these and the cost of counselling for people with learning disabilities.

The knowledge and experience of therapists was raised by support workers as a possible barrier to people with learning disabilities in accessing counselling. This view from staff might have credence as Mason (2007) found that the perceived competence of clinicians was an important factor in the provision of counselling for people with learning disabilities. There has been the argument made that it is unlikely that there are ever going to be enough experienced and trained therapists to provide adequate individual psychological therapy for this client group (Arthur, 2003). Indeed if there is not more training and research opportunities for counselling for people with learning disabilities, then it is likely that provision will remain rare (Hollins & Sinason, 2000).

The lack of counselling psychologists interested and working with this client group is echoed in the calls for more research (Kasket & Gil-Rodriguez, 2011) and for more counselling psychologists to consider this area of work (Massie, 2014). It raises questions about whether the profession has the needed competencies to provide counselling to people with learning disabilities (Jones, 2013b). Indeed training for psychologists in counselling for people with learning disabilities has been recently raised as an area where there has been little progress despite the increased awareness and understanding of mental health issues within this population (Beail, 2015).

Even in clinical psychology where there is teaching on learning disabilities, the six-month placement within a learning disability specific service has been dropped as being compulsory

(Beail, 2015). This feels concerning as the experience that can be gained from placements can be invaluable in ensuring that trainee psychologists have the necessary skills and understanding of this specialist group. My concern is that if clinical psychology are no longer prioritising this client group in their training and counselling psychology as a profession do not yet prioritise this client group (Jones, 2013b), then those with the appropriate level of knowledge and expertise of learning disabilities will not be enough to meet the unmet needs of people with learning disabilities. Even more concerning is that policy and opinion continues to push for people with learning disabilities to access mainstream services (Bouras & Holt, 2004). Where previously clinical psychologists would have had some experience in their training of working with this client group and could make reasonable adjustments, if future clinical psychologists do not have this then it is likely that even more people with learning disabilities will be excluded from psychological therapies.

The government focus seems to be towards the inclusion of people with learning disabilities in mainstream services (Cumella, 2009) but it has been acknowledged that some people with learning disabilities are being excluded from both mainstream and learning disability specific services due to the focus on criteria (Lindsey, 2000). The concern about access is echoed by the Division of Clinical Psychology Faculty for People with Learning Disabilities (2012) who describe a review of studies of people with learning disabilities accessing mainstream mental health services. It showed that referrals for people with learning disabilities were reduced. The reasons behind this are likely to be multi-layered and related to many of the barriers that have already been discussed but it seems that support workers views parallel what the researchers are expressing about this area.

The lack of services for people with learning disabilities and the cost are likely to be related. As the neo-conservative economic agenda (Rioux, 1997) and the emphasis on evidence-based practice continue to grow (British Psychological Society (BPS), 2009), the services provided will increasingly need to be clinically and cost effective. The problem with this is that it raises questions about whether commissioners of services will be willing to commission services for people with learning disabilities when there is still a limited research base from practice (BPS, 2015). This is especially apparent when people with learning disabilities represent a costly group for the government due to their need for a lifetime of support (Cumella, 2009), and there is evidence that there is beginning to be rationing in access to social care due to financial pressure which is incompatible with current policies (Emerson & Hatton, 2008).

## 5.5 Implications

The results of this study provide an insight into views of support workers who work within services on a day to day basis. Although any generalisations about the results need to be made cautiously due to the advertisement of the questionnaire only being within one organisation, it does give information on a number of different factors, which may affect the likelihood of consideration of referrals for counselling for people with learning disabilities. It provides an indication of the views and attitudes of support staff towards counselling for people with learning disabilities and the barriers that they feel can affect this client group from accessing counselling. It also gathers views from support workers from across the South of England including London. The data has come from a large number of participants and gives an overview of the experiences, views and attitudes of support staff in relation to counselling and people with learning disabilities.

It was one organisation but covered multiple locations and covered over 100 members of staff. It must be noted that much of the pressures on this organisation are being felt in multiple organisations as local authorities deal with increasing numbers of people needing support, an aging population with even more complicated health needs and with less specialised services and less money to provide a service with (Emerson & Hatton, 2008). These concerns came through in some of the answers provided by participants. These cuts are likely to mean that the health, well-being and quality of life of people with learning disabilities could be further impacted possibly affecting mental health. This is likely to mean that more and more people with mild and moderate learning disabilities fall through the gap as services make their criteria stricter.

Although often over looked by research or integrated into a professionals group, the views of support workers are very relevant in ensuring that people with learning disabilities access all health services including mental health and psychological therapies. The very key role that support staff play in the lives of people with learning disabilities means that if we can understand what affects their likelihood of considering a referral for counselling, then we as professionals can know what areas and interventions may be helpful to focus on to ensure lasting change in the opportunities for people with learning disabilities to access psychological therapies.

The knowledge gained through this research can give counselling psychologists and other clinicians insight into the possible views and attitudes that might be held by staff that support people with learning disabilities. The need to involve support workers can present a difficulty for counselling psychologists who unless are interested in working systemically tend to work

more with the individual rather than collaboratively with the staff who support the person. One response regarding the input of a psychologist in the current study showed that there is some good practice occurring, but there was not enough information to know what other interventions were occurring at the same time. It could have been that the person was having counselling as well, or that the focus was on building up staff therapeutic skills. Support workers do not have enough knowledge, skills or support to be able to replace trained counsellors (Woodward & Halls, 2009). But until there are more clinicians who have the appropriate experience and training to work with people with learning disabilities, then this is unlikely to occur (Arthur, 2003), and then the pressure is on support workers to advocate and juggle all aspects of the health and well-being of the people that they support.

These multiple roles that support workers hold is likely to place great pressures on staff, when they are not supported enough to deal with the difficult and complex issues which arise when you are in a position where your key role is to support all areas of a person's life (Windley & Chapman, 2010). It really is no wonder that support workers can feel that a service priority is to 'care' (Bigby et al, 2009) or that abuse can occur when it might become easier to see the person not as a person but as a task, otherwise the emotional and psychological toll for staff could be too much (Cambridge, 1999). There is research that suggests that there can be high rates of burnout in support staff roles (Hastings, 2002) especially when staff support people in services where there is challenging behaviour. Support workers turning to the medical model first might be a symptom of this situation. It raises concern about whether a member of staff is well placed to be able to think and reflect on what could be happening for the person that they support when there are so many financial and time pressures, and an emphasis is placed on quality.

This research clearly shows that support workers are interested in counselling for people with learning disabilities and through experiences of supporting someone are more likely to consider a referral or speak to their line manager about a referral for counselling in the future. They are dependent on professionals to be able to support them and provide advice. This is most commonly the GP to ensure that physical health problems are being considered and as a gateway to other services and further referrals. Support workers are very much aware of the multiple barriers that can affect people with learning disabilities from accessing counselling including those at an individual, staff and service level.

Counselling psychologists could be in an ideal position to work within a multi-disciplinary model to think about what might be happening from the person's point of view (Massie, 2014). Support workers want to be involved in the therapeutic process and support the

person to access appropriate services. This challenge needs to be taken by the psychologist to ensure the right balance is achieved between respecting confidentiality and the therapeutic relationship, and recognising the complex systemic network that a person with a learning disability exists in. The results found in this research may help this process to occur by providing some insight and understanding to what support workers think about counselling for people with learning disabilities.

## **5.6 Counselling Psychology and this Research**

This research looks at an interesting dilemma about providing counselling to a group of people who have largely remained outside of mainstream services (Dorn & Prout, 1993) and instead have been viewed as a specialism from those in the mental health field (Bouras & Holt, 2004; Rose et al, 2007). If there are not the services available for people to be referred to then requests for counselling are not likely to happen. This research clearly shows that counselling is felt by support workers to be wanted and needed for people with learning disabilities. One barrier that is seen by support staff is that therapists might not have the appropriate skills and experience of working with this client group.

Therefore awareness of learning disabilities for counselling psychologists is critical to ensure that counselling is made more available for this group. This is not only so that people with learning disabilities who are already known to services can access counselling but also the 'hidden learning disability' group (Whitaker, 2004) in mainstream services need to be considered. To ensure they do not fall through the criteria gaps of services (Lindsey, 2000). Understanding of what a learning disability is and the impact that it can have on the person, may mean that somebody is understood and therapy is adapted rather than somebody ending up being excluded from service after service who don't quite understand how to work with them.

Counselling psychologists do have much to offer this client group (Massie, 2014) and through adaptation of therapeutic techniques can offer a unique therapeutic relationship that could make a big difference to the life of that individual (Jones, 2013a). A challenge for counselling psychologists though, is that both this research and other studies emphasise the need to work with others including support workers when working with this client group (Jones, 2013a; Whitehouse et al, 2006; Munro, 2011; Willner, 2006) and to be open to thinking systemically (Rikberg Smyly et al, 2008). This challenges the traditional 1:1 therapeutic session, but the involvement of support workers could be seen as similar to when interpreters are used in therapy and it may be that some of the challenges and benefits of using interpreters (Quinn, 2011) are similar to when staff enter the therapeutic space. Having an awareness of how

support workers might view counselling for people with learning disabilities is only likely to give more benefit to what can be offered to someone with a learning disability.

### **5.7 Limitations of the Study**

The generalisations of the findings of this study are somewhat limited due to the questionnaire having only been advertised to staff from one learning disability organisation. This means that their views and experiences may not be representative of support workers in general across the country as there may be different availabilities of services in different places. The participants did work though in various different locations across the South of England and would be covered by different local authorities and health trusts. The culture within the organisation also needs to be considered in the interpretation of the results as this may not be reflective of other learning disability organisations. The research attempts to give an initial insight into the views and opinions of support workers which could be investigated further and shines a light on something which has previously not been researched in this depth.

One factor that needs to be considered is that participants may have been responding with what they felt the expected/favourable answer was and responding with a social desirability bias (Nederhof, 1985). This may mean that when asked a direct question regarding consideration of counselling they respond favourably to it, when actually in a real life situation they would not consider it. This could be reflected in the relatively low numbers of staff who had actually supported someone with a learning disability to access counselling.

Although the research is specifically interested in counselling psychology and people with learning disabilities, this exact wording was not used within the questionnaire given to participants. It could be argued that not using this wording within the questionnaire limits its specific relevance to counselling psychology. This decision was made due to a number of different reasons. The difficulty with identity within the field of counselling psychology (Woolfe & Strawbridge, 2010) means that outside of the field there is much confusion about what counselling psychology is as a profession and the differences between the different types of psychologist. It has also been identified through research and commentary that not much is known about counselling psychologists working within the learning disability field (Jones, 2013b) and that their number in comparison to clinical psychology is relatively small (Bor & Archilleoudes, 1999). This made it difficult to restrict the research to only counselling psychology. Looking at counselling in general allowed participants greater flexibility in what they could discuss in their answers, but does mean that it not only covers counselling psychology but clinical psychology and counsellors. This should not affect the impact of the



results as counselling for people with learning disabilities is seen as a specialised area and any insights will be helpful for the profession and other clinicians working in the field.

Using an online questionnaire meant that the depth and richness of the qualitative responses were limited. There was no additional information that could be drawn from to interpret and analyse responses such as body language and the way people communicate. This meant that the analysis had to rely on people's words that they had typed and this restricts the depth and interpretations that could be made. However through the focus group it was found that staff liked the prospect of being able to complete the questionnaire online and felt that typing would make it easier to complete compared to completing it by hand. Using an online version meant that I could gather responses from staff who work at multiple sites within the organisation and meant that it could be completed at a time and place that was convenient for the member of staff.

If I had instead completed interviews then although I may have increased the depth of the responses and the analysis, this would have led to more of an exploration rather than an investigation. The ontological basis of the research of critical realism meant that the research needed to include objective measures and due to the dominance of the quantitative elements, it meant that the qualitative element needed to be limited. It also could not have been achieved for the number of support workers reached through the questionnaire and this could have affected people's responses if they knew they could have been questioned further on their answers. However, this did mean that no clarification or additional information could be sought from the participants about what they meant from a particular response. This may be something that could occur in future research either through the use of additional interviews following the online questionnaire or through the use of in-depth semi-structured interviews.

The questions that were asked within the questionnaire were done so to explore the research questions but this does mean that there may have been other variables which could have affected opinions and views that were not covered within the study. There will always be more which could be done with research and a decision has to be made about what the limits of the study will be. Although there are limits within the current study, the results provide a good starting place for considering the views of support workers and what might affect their behaviour in relation to considering referrals to counselling for people with learning disabilities.

## **5.8 Possible Future Research**

This research gave some understanding into support workers thinking and decision making processes when considering a referral for counselling for someone with a learning disability. It may be helpful to replicate the current study with support workers from other services, settings and organisations in order to be able to check the reliability and ecological validity of the results that were found.

There are other questions that emerge through the results of the current research that could be studied further. Could it be that support workers although happy to consider counselling, are not sure where to go or how to refer? Are there actually the services out there for them to refer to? This query may have some credence from the experiences that some participants discussed of the difficulty in actually finding appropriate services once a need had been identified.

It would also be interesting to find out more about the support worker's processes when supporting someone to access counselling once the referral has been accepted, and also how the person with a learning disability experiences being supported by staff to access therapy.

More research is needed into how best counselling psychologists can work alongside support staff so that collaboration can occur, while still ensuring that the person having the counselling remains central and that their views and boundaries are respected. Advice around this would likely benefit many psychologists that have to cope with this challenge.

Research is needed into Community Learning Disability Teams regarding what therapeutic interventions are being offered and how these teams can support more access into mainstream services. Research indicates that there are many small areas of good practice and research happening but research into the efficacy and effectiveness is limited due to the small numbers which are being offered therapy (Beail, 2015). If more unified working could occur across the Community Teams then there may be opportunity for research that includes larger sample sizes to build the research base further.

## **5.9 Possible Ways to Improve Access to Counselling for People with Learning Disabilities**

It is likely that to make a difference, any interventions that are implemented to improve access to psychological therapies for people with learning disabilities will need to be part of a multi-layered approach. It may not be enough if only one of the barriers which have been described is targeted due to them being multiple inter-related.

This study found that experience is one of the factors to possibly affect support workers future consideration of a referral or speaking to their line manager about a referral for counselling for someone with a learning disability. Therefore if more opportunities are provided through proactive interventions which reach out to both people with learning disabilities and support workers, it could not only improve access but could lead to the prevention of deterioration of mental health. This could include access to preventative interventions such as therapy groups and building up of resilience skills. Research often suggests that placing money in preventative strategies is far more cost effective than having to pay for reactive strategies (Allen et al, 2013). This is especially when research has indicated that a small number can take up a huge amount of resources (Spiller et al, 2007) as they go from one unsuitable service to another or the conditions can become well-established and more resistant (Allen et al, 2013).

One solution might be to provide a number of support workers with experience of the psychological model and therapeutic process through the use of psychological consultation with staff as suggested by Arthur (1999). Arthur (2003) feels that this provides an alternative or complimentary therapeutic tool to counselling. The process can provide the opportunity for support workers to gain insight and understanding of the emotional lives of people with learning disabilities while getting support. Arthur (1999) found that by using this with a staff team it helped to facilitate the emotional development of the people that they supported, improved relationships and decreased symptomatic behaviour. A positive experience through this model could result in support staff being more psychologically minded and therefore might be more likely to consider counselling as an option in the future.

The dependence of staff on GP's may explain some of the reasons for the lack of referrals to counselling as research indicates that there is often a failure to recognise mental health as a result of a number of factors including diagnostic overshadowing (Woodward & Halls, 2009), failure of primary care professionals to understand the manifestation of mental health in those with a learning disability and how the level of learning disability can affect this presentation (Lennox, Diggins & Ugoni, 1997). Psychological services that are available through the NHS are diverse and offer support that may benefit people experiencing a spectrum of mental health difficulties. The use of common point of entry systems or general services could offer the opportunity for appropriate referrals for people who have learning disabilities to be given to a counselling psychologist who could then either offer support or direct the patient to another service.

As the GP and medical concerns seem to be the first port of call for support workers, possibly this is where future intervention needs to take place so that GPs and Clinical Commissioning Groups keep counselling for people with learning disabilities as an option. This may mean that psychologists speak to GP's or provide GP's with some information about what can be offered for people with learning disabilities and counselling and where they might refer.

Support workers need to have a greater awareness of mental health and learning disabilities and be aware of possible risks, symptoms and treatments. The most obvious way to accomplish this is through staff training which could be addressed through opportunities for continuous professional development. This could include a range of different opportunities such as workshops on general or specific mental health issues or could be specifically designed to fulfil knowledge that might aid a particular service or individual who has a dual diagnosis. However we need to be aware that we are not overloading support staff who are often low paid and do not have the educational level for the amount of complex and intricate knowledge that is often expected. This is in addition to being competent practitioners dealing with difficult situations and dilemmas on a daily basis without much support, and as costs are cut, this is only going to get worst. Through more frequent but less intensive training opportunities, it is likely that support workers will be able to take in the much needed knowledge on mental health and learning disabilities.

Support workers also need more support. The expectations on support staff to be able to identify and support people with every aspect of their lives means that support workers have to deal with extremely intimate and emotional issues. The amount of supervision and own personal therapy that counselling psychologists have in order to be able to provide psychological therapies is there for a reason and yet support staff are lucky if they have 1:1 supervision once a month. Every day they deal with the emotional toll of supporting the most complex and vulnerable people in society in so many intimate areas. These include decision making, sexuality, personal care, physical health, emotional health, well-being, safeguarding, supporting relationships, integration and inclusion. All this whilst being one of the lowest paid professions with high levels of burn-out and turn-over (Hastings, 2002) mean that facilitated support groups for staff could provide support staff with the opportunity to talk about the demands and challenges within their role. It would also allow them to find support in each other in how to deal with the difficulties that might arise.

### **5.10 Final Reflections**

The current research has challenged me to really think about counselling psychology and working with people with learning disabilities. Although I was aware before starting the research that the numbers of counselling psychologists working with people with learning disabilities was small, I didn't fully realise just how small this number and interest was. The amount of research published by those that identify themselves as counselling psychologists in relation to working with people with learning disabilities is extremely limited. Clinical psychology is dominant within the field in advocacy, research, training, information and guidelines. The networking and continuous professional developments offered through the Division of Clinical Psychology in comparison mean that the opportunity to learn from and network with other counselling psychologists remains limited.

Although people with learning disabilities can present challenges to work with, the majority of research highlights the value and benefits that psychological therapies can provide (Beail, 2015). The emphasis in counselling psychology of the therapeutic relationship and working with difference and diversity means that as a profession, we could be leading the field in research and practice but I wonder if the dominance of clinical psychology means that the voices are few and far between. The fact that there was no teaching within the Counselling Psychology Doctorate, which specifically addressed working therapeutically with this client group reflects the specialism that they present. Additional experience or training is likely to be needed in order to become a competent practitioner to work with people with learning disabilities.

What has struck me in completing this research is that progress is very slow even though the communications from government and continued outrage from learning disability advocates is that this needs to be a priority. This is apparent whether we are talking about the research into the efficacy of psychological therapies for people with learning disabilities, support for people to access mainstream services or having appropriately trained and experienced clinicians. The fact that we continue after more than a decade to have calls for more research, more training opportunities and more access to services shows that this is not a group that are seen as a high priority and yet the work of individuals shows such great promise (Beail, 2015). There are individuals for which learning disabilities has become a passion and for which such hard work and determination is put in to ensure a better quality of life and equality for the individuals that fall into this group. There have been comments that due to the economic situation, money is disappearing from those considered most vulnerable and those who cost more

money than others, and for society learning disabilities falls into this category (Learning Disability Coalition, 2011) .

This is a group of people who are acknowledged to be one of the most vulnerable in our society, and yet they are a group where change is very slow to come as well as being a group that clinicians seem to find difficult to work with (Jones, 2013a). Clinical psychology are the clear voice for this group while counselling psychologists who could have so much expertise and value to offer have stayed relatively quiet. I hope that the infancy of the profession means that as we develop, that this will change. Our training does make us ideal to adapt the therapeutic approaches to enable people with learning disabilities to access psychological therapies (Massie, 2014). Our emphasis on the therapeutic relationship means that we can offer something which is often very much lacking for people with learning disabilities, a connection with another person on a level which means the pain and difficulties can be bared and not ignored.

### **5.11 Conclusion**

The present study explored the views of support staff working with people with learning disabilities towards counselling psychology in a learning disability organisation. Through using an online questionnaire and a mixed methods approach the study found a number of interesting results about support workers views of counselling for people with learning disabilities and what affects the likelihood of staff considering referring or speaking to their line manager about referring someone for counselling. Support workers hold overall positive views about counselling for people with learning disabilities and feel it is needed, but would usually look towards the GP and possible medical causes when presented with changes in someone that they support. Experience of supporting someone to access counselling, being in a senior role, having positive attitudes towards the prospects of people with learning disabilities, level of education and working in supported living were factors that appeared to affect the likelihood that a support worker would consider referring or speaking to their line manager about referring someone with a learning disability in the future. The results indicate that there are multiple barriers that are likely to affect people with learning disabilities from accessing counselling and that multiple interventions are likely to be the most effective way to improve access.

## 6. References

- Alexander, D. (1998). Prevention of Mental Retardation: Four decades of research. *Mental Retardation and Developmental Disabilities Research Reviews*, 4, 50-58
- Alhojailan, M.I. (2012). Thematic analysis: A critical review of its process and evaluation. *West East Journal of Social Sciences*, 1(1), 39-47
- Allen, D., Langthorne, P., Tonge, B., Emerson, E., McGill, P., Fletcher, R., Dosen, A. and Kennedy, C. (2013). Towards the prevention of behavioural and psychiatric disorders in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 26, 501-514
- American Association on Intellectual and Developmental Disabilities (2004). *Supports Intensity Scale User's Manual*. Washington DC: Author
- American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*. Arlington, VA; American Psychiatric Association
- Antonak, R.F., Fielder, C.R. and Mulick, J.A. (1993). A scale of attitudes toward the application of eugenics to the treatment of people with mental retardation. *Journal of Intellectual Disability Research*, 37, 75-83
- Antonak, R.F. and Harth, R. (1994). Psychometric analysis and revision of the Mental Retardation Attitude Inventory. *Mental Retardation*, 32(4), 272-280
- Antonak, R.F. and Livneh, H. (2000). Measurement of attitudes towards persons with disabilities. *Disability and Rehabilitation*, 22(5), 211-224
- Aronson, J (1994). A pragmatic view of thematic analysis. *The Qualitative Report*, 2(1), 1-3
- Arthur, A.R. (1999). Using staff consultation to facilitate the emotional development of adults with learning disabilities. *British Journal of Learning Disabilities*, 27, 93-98
- Arthur, A.R. (2003). The emotional lives of people with learning disabilities. *British Journal of Learning Disabilities*, 31, 25-30
- Atzmüller, C. and Steiner, P.M. (2010). Experimental vignette studies in survey research. *Methodology*, 6(3), 128-138
- Bailey, N.M. (2007). Prevalence of psychiatric disorders in adults with moderate to profound learning disabilities. *Advances in Mental Health and Learning Disabilities*, 1(2), 36-44
- Bailey, N.M. and Andrews, T.M. (2003). Diagnostic criteria for Psychiatric Disorders for use with adults with learning disabilities/Mental Retardation (DC-LD). and the diagnosis of anxiety disorders: A review. *Journal of Intellectual Disability Research*, 47(1), 50-61
- Bartlett, C. (1997). The Importance of communication partnerships: A study to investigate the communicative exchanges between staff and adults with learning disabilities. *British Journal of Learning Disabilities*, 25, 148-153
- Bates, R. (1992). 'Psychotherapy with people with learning disabilities'. In: Waitman, A and Conboy-Hill, S. (Eds.) *Psychotherapy and Mental Handicap*. London, Sage.

Bates, P., Priest, H. and Gibbs, M. (2004). The education and training needs of learning disability staff in relation to mental health issues. *Nurse Education in Practice*, 4, 30-38

Beail, N. (2010). The challenge of the randomised control trial to psychotherapy research with people who have learning disabilities. *Advances in Mental Health and Learning Disabilities*, 4(1), 37-41

Beail, N. (Ed.). (In consultation) *Psychological Therapies and People who have Intellectual Disabilities*. Leicester: British Psychological Society. Retrieved from <http://www.bps.org.uk/what-we-do/our-influence/consultations/internal-consultations/internal-consultations> (11/8/15)

Bell, R. (2012). Does he have sugar in his tea? Communication between people with learning disabilities, their carers and hospital staff. *Tizard Learning Disability Review*, 17(2), 57-63

Bender, M. (1993). The unoffered chair: The history of therapeutic disdain towards people with a learning disability. *Clinical Psychology Forum*, 54 April, 7-12

Bernal, J. and Hollins, S. (1995). Psychiatric illness and learning disability: A dual diagnosis. *Advances in Psychiatric Treatment*, 1, 138-145

Bhaumik, S., Gangadharan, S., Hiremath, A. and Russell, P.S.S. (2011). Psychological treatments in intellectual disability: The challenges of building a good evidence base. *The British Journal of Psychiatry*, 198, 428-430

Bigby, C., Clement, T., Mansell, J. and Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research*, 53(4), 363-379

Bihm, E.M. and Leonard, P.J. (1992). Counseling persons with mental retardation and psychiatric disorders: A preliminary study of mental health counsellors perceptions. *Journal of Mental Health Counseling*, 14, 225-233

Bor, R. and Achilleouides, H. (1999). Survey of BPS Division of counselling psychology members: 1999. *Counselling Psychology Review*, 14(4), 35-45

Borrell-Carriò, F., Suchman, A.L. and Epstein, R.M. (2004). The Biopsychosocial Model 25 years later: Principles, practice and scientific inquiry. *Annals of Family Medicine*, 2(6), 576-582

Bouras, N. and Holt, G. (2004). Mental health services for adults with learning disabilities. *British Journal of Psychiatry*, 184, 291-292

Bouras, N. and Jacobson, J. (2002). Mental Health care for people with mental retardation: A global perspective. *World Psychiatry*, 1(3), 162-165

Bradshaw, J. (2001). Communication partnerships with people with profound and multiple learning disabilities. *Tizard Learning Disability Review*, 6(2), 6-15

Bradshaw, J. and McGill, P. (2015). Commentary on 'Why study the history of learning disability?' *Tizard Learning Disability Review*, 20(1), 11-14



Braun, V. and Clarke, V (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101

Braun, V. and Clarke, V. (2012). Thematic Analysis (pages 57-71). In Cooper, H., Camic, P.M., Long, D.L., Panter, A.T., Rindskopf, D. and Sher, K.J. (Eds), (2012). *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological*. Washington, DC, US: American Psychological Association

British Medical Association (2014). *Recognising the Importance of Physical Health in Mental Health and Intellectual Disability: Achieving Parity of Outcomes*. London: BMA Publications

British Psychological Society (2000). *Learning Disability: Definitions and Contexts*. Leicester: The British Psychological Society

British Psychological Society (2009). *British Psychological Society statement on psychological well-being and the economic crisis*. Leicester: The British Psychological Society

British Psychological Society (2010). *Code of Human Research Ethics*. Leicester: The British Psychological Society

British Psychological Society (2015). *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood*. Leicester: The British Psychological Society

Bronfenbrenner, U. (1989). Ecological systems theory, *Annals of Child Development*, 6, 187-249.

Brown, H. (2013). Commentary on "The effectiveness of psychodynamic interventions for people with learning disabilities: A systematic review". *Tizard Learning Disability Review*, 19(1), 25-28

Bryman, A. (2007). Barriers to integrating quantitative and qualitative research. *Journal of Mixed Methods Research*, 1(1), 8-22

Cambridge, P. (1999). The first hit: A case study of the physical abuse of people with learning disabilities and challenging behaviours in a residential service. *Disability and Society*, 14(3), 285-308

Camic, P.M., Rhodes, J.E. and Yardley, L. (2003). Naming the stars: Integrating qualitative methods into psychological research. In Camic, P.M., Rhodes, J.E. and Yardley, L. (Eds). *Qualitative research in psychology: Expanding perspectives in methodology and design*. Washington, DC, US: American Psychological Association

Carlson, T., Hames, A., English, S. and Wills, C. (2004). Referrals to a learning disability service and consent to treatment. *Tizard Learning Disability Review*, 9(2), 11-17

Cascella, P.W. (2004). Receptive communication abilities among adults with significant intellectual disability. *Journal of Intellectual and Developmental Disability*, 29(1), 70-78

Chamberlain, K., Cain, T., Sheridan, J. and Dupuis, A. (2011). Pluralisms in qualitative research: From multiple methods to integrated methods. *Qualitative Research in Psychology*, 8(2), 151-169

- Chaplin, E., Halls, S., Carlile, G., Hardy, S. and Joyce, T. (2009). Barriers to user involvement in mental health services for people with learning disability. *Advances in Mental Health and Learning Disabilities*, 3(3), 28-33
- Clarke, D.J. (1997). Towards rational psychotropic prescribing for people with learning disability. *British Journal of Learning Disabilities*, 25, 46-52
- Clark-Carter, D. (1997). *Doing Quantitative Psychological Research: From Design to Report*. Hove: Psychology Press
- Clark-Carter, D. (2010). *Quantitative Psychological Research: The Complete Student's Companion (3rd ed.)*. Hove: Psychology Press
- Cohen, J. (1960). A co-efficient of agreement for nominal scales. *Educational and Psychological Measurement*, 20, 37-46
- Coles, J. (2001). The social model of disability: What does it mean for practice in services for people with learning difficulties? *Disability and Society*, 16(4), 501-510
- Coles, S. and Scior, K. (2012). Public attitudes towards people with intellectual disabilities: A qualitative comparison of white British and South Asian people. *Journal of Applied Research in Intellectual Disabilities*, 25, 177-188
- Collishaw, S., Maughan, B. and Pickles, a. (2004). Affective problems in adults with mild learning disabilities: The roles of social disadvantage and ill health. *The British Journal of Psychiatry*, 185, 350-351
- Collett, J.L. and Childs, E. (2011). Minding the gap: Meaning, affect and the potential shortcomings of vignettes. *Social Science Research*, 40, 513-522
- Cooper, M. and McLeod, J. (2011). *Pluralistic Counselling and Psychotherapy*. London: SAGE Publications
- Cooper, S.A., Melville, C. and Morrison, J. (2004). People with Intellectual Disabilities: Their health needs differ and need to be recognised and met. *British Medical Journal*, 329(7463), 414-415
- Cooper, S.A., Smiley, E., Jackson, A., Finlayson, J., Allan, L., Mantry, D. and Morrison, J. (2009). Adults with intellectual disabilities: Prevalence, incidence and remission of aggressive behaviour and related factors. *Journal of Intellectual Disability Research*, 53(3), 217-232
- Cooper, S.A., Smiley, E., Morrison, J., Williamson, A. and Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. *The British Journal of Psychiatry*, 190, 27-35
- Costello, H. and Bouras, N. (2006). Assessment of mental health problems in people with intellectual disabilities. *Israel Journal of Psychiatry and Related Sciences*, 43, 241-251
- Costello, H., Bouras, N. and Davis, H. (2007). The role of training in improving community care staff awareness of mental health problems in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 20, 228-235

- Creswell, C. (2001). A case of 'soap therapy': Using soap operas to adapt cognitive therapy for an adolescent with learning disabilities. *Clinical Child Psychology and Psychiatry*, 6(2), 307-315
- Creswell, J.W. and Plano Clark, V.L. (2011). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage Publications, Inc.
- Crossley, R. and Withers, P. (2009). Anti-psychotic medication and people with intellectual disabilities: Their knowledge and experiences. *Journal of Applied Research in Intellectual Disabilities*, 22, 77-86
- Cumella, S. (2009). Mental Health Services for People with a Learning Disability. *Advances in Mental Health and Learning Disabilities*, 3(2), 8-14
- Cunningham, C.C., Morgan, P.A. and McGucken, R.B. (1984). Down's Syndrome: Is dissatisfaction with disclosure of diagnosis inevitable. *Developmental Medicine and Child Neurology*, 26(1), 33-39
- Dagnan, D. (2007). Psychosocial intervention for people with learning disabilities. *Advances in Mental Health and Learning Disabilities*, 1(2), 3-7
- Dagnan, D., Chadwick, P. and Proudlove, J. (2000). Toward an assessment of suitability of people with mental retardation for cognitive therapy. *Cognitive Therapy and Research*, 24(6), 627-636
- Dagnan, D. and Jahoda, A. (2006). Cognitive-behavioural intervention for people with intellectual disability and anxiety disorders. *Journal of Applied Research in Intellectual Disabilities*, 19, 91-97
- Dagnan, D. and Waring, M. (2004). Linking stigma to psychological distress: Testing a social-cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology and Psychotherapy*, 11, 247-254
- Davidson, T. and Baker, P. (2010). Commentary: Learning Disability classification: Time for re-appraisal? *Tizard Learning Disability Review*, 15(2), 42-44
- Deal, M. (2007). Aversive Disablism: Subtle prejudice toward disabled people. *Disability and Society*, 22(1), 93-107
- Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*. London: Department of Health
- Department of Health (2003). *Better or worse: A longitudinal study of the mental health of adults living in private households in Great Britain*. London: HMSO
- Department of Health (2009). *Valuing People Now: A new three-year strategy for people with learning disabilities. 'Making it happen for everyone.'* London: HMSO
- Department of Health (2012). *Winterbourne View Review: Concordat: A programme of action*. London: HMSO
- Dillman, D.A., Smyth, J.D. and Christian, L.M. (2009). *Internet, Phone, Mail and Mixed-Mode Surveys: The Tailored Design Method*. New Jersey: John Wiley & Sons

Division of Clinical Psychology Faculty for People with Learning Disabilities (2011). *Commissioning Clinical Psychology Services for adults with Learning Disabilities*. Leicester: British Psychological Society

Division of Clinical Psychology Faculty for People with Learning Disabilities (2012). *Good Practice Guidelines for UK Clinical Psychology Training Providers for the training and Consolidation of Clinical Practice in relation to adults with Learning Disabilities*. Leicester: British Psychological Society

Dorn, T. and Prout, H.T. (1993). Service delivery patterns for adults with mental retardation at community mental health centers. *Mental Retardation*, 31(5), 292-296

Eaton, L.F. and Menolascino, F.J. (1982). Psychiatric disorders in the mentally retarded: Types, problems and challenges. *American Journal of Psychiatry*, 139, 1297-1303

Edwards, S., Tinning, L., Brown, J.S.L., Boardman, J. and Weinman, J. (2007). Reluctance to seek help and the perception of anxiety and depression in the United Kingdom: A pilot vignette study. *The Journal of Nervous and Mental Disease*, 195(3), 258-261

Einhorn, H.J. & Hogarth, R.M. (1978). Confidence in judgment: persistence of the illusion of validity. *Psychological Review*, 85(5), 395-416.

Equality Act (2010). London: HMSO

Emerson, E. and Baines, S. (2011). Health Inequalities and people with learning disabilities in the UK. *Tizard Learning Disability Review*, 16(1), 42-48

Emerson, E. and Hatton, C. (2004). *Estimating the current need/demand for supports for people with Learning Disabilities in England*. Lancaster University: Institute of Health Research

Emerson, E and Hatton, C (2008). *Estimating the Future Need for Adult Social Services for People with Learning Disabilities in England*. Lancaster: Lancaster University Centre for Disability Research

Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S. and Glover, G. (2011). *People with Learning Disabilities in England 2010*. London: Improving Health and Lives: Learning Disability Observatory.

Emerson, E., Robertson, J.M. and Wood, J. (2004). Levels of psychological distress experienced by family carers of children and adolescents with intellectual disabilities in a multi-cultural urban conurbation. *Journal of Applied Research in Intellectual Disabilities*, 17(2), 77-84

Engel, G.L. (1980). The clinical application of the Biopsychosocial Model. *The American Journal of Psychiatry*, 137(5), 535-544

Ericsson, K., & Mansell, J. (1996). Introduction: Towards Deinstitutionalization. In J. Mansell & K. Ericsson (Eds.), *Deinstitutionalization and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA* (pp. 1-16). London: Chapman and Hall.

Esterhuyzen, A. and Hollins, (1997). Psychotherapy. In Read, S. *Psychiatry in Learning Disability* (ed.), pp 332-349, London: W.B.Saunders

- Evans, E., Howlett, S., Kremser, T., Simpson, J., Kayess, R. and Troller, J. (2012). Service development for intellectual disability mental health: A human rights approach. *Journal of Intellectual Disability Research*, 56(11), 1098-1109
- Felce, D. (1999). The Gerry Simon Lecture 1998: Enhancing the quality of life of people receiving residential support. *British Journal of Learning Disabilities*, 27, 4-9
- Ferguson, M., Jarrett, D. and Terras, M. (2010). Inclusion and health care choices: The experiences of adults with learning disabilities. *British Journal of Learning Disabilities*, 39, 73-83
- Fidell (2000). Exploring the use of family therapy with adults with a learning disability. *Journal of Family Therapy*, 22, 308-323
- Findler, L., Vilchinsky, N. and Werner, S. (2007). The Multidimensional Attitudes Scale toward persons with disabilities (MAS): Construction and validation. *Rehabilitation Counseling Bulletin*, 50(3), 166-176
- Flynn, J.R. (2007). *What is intelligence? Beyond the Flynn Effect*. Cambridge: Cambridge University Press.
- Frankish, P. (2009). History and formation of the institute of psychotherapy and disability. *Advances in Mental Health and Learning Disabilities*, 3(4), 10-12
- Freud, S. (1953). *On Psychotherapy (1904) In the Standard Edition of the Complete Psychological Works of Sigmund Freud. Vol VII*. London: Hogarth Press
- Frost, N.A. and Shaw, R.L. (2015). The Emergence of Mixed Methods Research in Psychology, In Johnson B. and Hesse-Biber, S. (eds) *The Sage Handbook of Mixed and Multi-method Research*, Oxford University Press.
- Frost, N. and Nolas, S-M. (2011). Editorial: Exploring and expanding on pluralism in qualitative research in psychology. *Qualitative Research in Psychology*, 8(2), 115-119
- Gelo, O., Braakmann, D. and Benetka, G. (2008). Quantitative and Qualitative Research: Beyond the debate. *Integrative Psychological and Behavioral Science*, 42, 266-290
- Glaser, B.G. and Strauss, A.L. (1999). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. London: Aldine Transaction
- Gillberg, G. and Soderstrom, H. (2003). Learning Disability. *The Lancet*, 362, 811-821
- Gil-Rodriguez, E. and Hanley, T. (2011). Research methods in counselling psychology: What would Wilhelm Wundt think? *Counselling Psychology Review*, 26(4), 3-8
- Goble, C. (1999). "Like the secret service isn't it". People with learning difficulties, perceptions of staff and services: Mystification and disempowerment. *Disability and Society*, 14(4), 449-461
- Goertzen, J.R. (2010). Dialectical pluralism: A theoretical conceptualization of pluralism in psychology. *New Ideas in Psychology*, 28, 201-209
- Goodey, C.F. (2015). Why study the history of learning disability? *Tizard Learning Disability Review*, 20(1), 3-10

- Goodley, D. (2001). 'Learning Difficulties', the social model of disability and impairment: Challenging epistemologies. *Disability and Society*, 16(2), 207-231
- Gore-Felton, C. (2005). Understanding quantitative research in counseling psychology: An elusive endeavor in an increasingly diverse discipline. *The Counseling Psychologist*, 33(3), 367-374
- Grabb, E.G. (1997). *Theories of Social Inequality: Classical and Contemporary Perspectives*. 3<sup>rd</sup> edn. Toronto: Harcourt Brace
- Greene, J.C. and Caracelli, V.J. (2003). Making paradigmatic sense of mixed methods practice. In Tashakkori, A. and Teddlie, C. (Eds). *Handbook of mixed methods in social and behavioural research*. Thousand Oaks, CA: Sage
- Hames, A. and Carlson, T. (2006). Are primary health care staff aware of the role of Community Learning Disability Teams in relation to health promotion and health facilitation? *British Journal of Learning Disabilities*, 34, 6-10
- Hampton, S.J. (2005). Family Eugenics. *Disability and Society*, 20(5), 553-561
- Handley, E., Southwell, O. and Steel, J. (2012). Recovery and intellectual disabilities: A review. *Advances in Mental Health and Intellectual Disabilities*, 6(4), 192-198
- Harris, J.C. (2013). New terminology for Mental Retardation in DSM-5 and ICD-11. *Current Opinion in Psychiatry*, 26(3), 260-262
- Hastings, R.P. (2002). Do challenging behaviors affect staff psychological well-being? Issues of causality and mechanism. *American Journal on Mental Retardation*, 107(6), 455-467
- Hayes, S. C., Barlow, D. H., and Nelson-Grey, R. O. (1999). *The scientist-practitioner: Research and accountability in the age of managed care* (2nd ed.). New York: Allyn & Bacon.
- Hegarty, J.R. and Last, A. (1997). Relaxation training for people who have severe/profound and multiple learning disabilities. *The British Journal of Developmental Disabilities*, 43(2), 122-139
- Henry, D., Keys, C., Balcazar, F. and Jopp, D. (1996). Attitudes of community-living staff members toward persons with mental retardation, mental illness and dual diagnosis. *Mental Retardation*, 34(6), 367-379
- Henry, D., Keys, C., Jopp, D. and Balcazar, F. (1996). The community living attitudes scale, mental retardation form: Development and psychometric properties. *Mental Retardation*, 34(3), 149-158
- Heslop, P., Marriott, A., Fleming, P., Houghton, M. and Russ, L. (2012). Commentary on "Does he have sugar in his tea?" *Tizard Learning Disability Review*, 17(2), 64-68
- Hollander, R. (1989). Euthanasia and Mental Retardation: Suggesting the Unthinkable. *Mental Retardation*, 27(2), 53-61
- Hollins, S. (2000). Developmental Psychiatry – Insights from learning disability. *British Journal of Psychiatry*, 177, 201-206

- Hollins, S. and Sinason, V. (2000). Psychotherapy, learning disabilities and trauma: New perspectives. *British Journal of Psychiatry*, 176, 32-36
- Howe, K.R. (1988). Against the quantitative-qualitative incompatibility thesis or dogmas die hard. *Educational Researcher*, 17(8), 10-16
- Hughes, R. and Huby, M. (2002). The application of vignettes in social and nursing research. *Methodological Issues in Nursing Research*, 37(4), 382-386
- Hurley, A., Tomasulo, D.J. and Pfadt, A.G. (1998). Individual and group psychotherapy approaches for persons with intellectual disabilities and developmental disabilities. *Journal of Developmental and Physical Disabilities*, 10, 365-386
- IBM Corp. Released 2013. *IBM SPSS Statistics for Windows*, Version 22.0. Armonk, NY: IBM Corp.
- Ingham, B., Clarke, L. and James, I.A. (2008). Biopsychosocial case formulation for people with Intellectual Disability and Mental Health problems: A pilot study of a training workshop for direct care staff. *The British Journal of Developmental Disabilities*, 54(1), 41-54
- Jackson, T. (2009). Accessibility, efficiency and effectiveness in psychological services for adults with learning disabilities. *Advances in Mental Health and Learning Disabilities*, 3(4), 13-18
- Jahoda, A., Dagnan, D., Jarvie, P. and Kerr, W. (2006). Depression, social context and cognitive behavioural therapy for people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19, 81-89
- Jahoda, A., Selkirk, M., Trower, P., Pert, C., Stenfort-Kroese, B., Dagnan, D. and Burford, B. (2009). The balance of power in the therapeutic interactions with individuals who have intellectual disabilities. *British Journal of Clinical Psychology*, 48, 63-77
- James, C.W. and Stacey, J.M. (2013). The effectiveness of psychodynamic interventions for people with learning disabilities: A systematic review. *Tizard Learning Disability Review*, 19(1), 17-24
- Johnston, M. (1996). Models of disability. *The Psychologist*, 9(5), 205-210
- Johnson, R.B. and Onwuegbuzie, A.J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33 (7), 14-26
- Jones, R.A. (2013a). Therapeutic relationships with individuals with learning disabilities: A qualitative study of the Counselling Psychologist's experience. *British Journal of Learning Disabilities*, 42, 193-203
- Jones, R.A. (2013b). Counselling psychology and people with learning disabilities: Some reflections. *Counselling Psychology Review*, 28(1), 47-52
- Jones, R.A. and Donati, M. (2009). The therapeutic relationship in psychological therapy for individuals with learning disabilities: A review of the existing literature. *Advances in Mental Health and Learning Disabilities*, 3(1), 47-51

- Joyce, T., Globe, A. and Moody, C. (2006). Assessment of the component skills for cognitive therapy in adults with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 19, 17-23
- Kanellakis, P. (2010). Counselling Psychology and Disability. *Europe's Journal of Psychology*, 2, 123-149
- Kasket, E. (2012). The Counselling Psychologist researcher. *Counselling Psychology Review*, 27(2), 64-73
- Kasket, E. and Gil-Rodriguez, E. (2011). The identity crisis in trainee counselling psychology research. *Counselling Psychology Review*, 26(4), 20-30
- Kelle, U. (2006). Combining qualitative and quantitative methods in research practice: Purposes and advantages. *Qualitative Research in Psychology*, 3(4), 293-311
- Kenyon, P. (Presenter), (2011, May 31). *Undercover Care: The Abuse Exposed*. [Television series episode]. In Chapman, M. (Producer), Panorama. London: BBC.
- Kolappa, K., Henderson, D.C. and Kishore, S.P. (2013). No physical health without mental health: Lessons unlearned? *Bulletin of the World Health Organisation*, 91, 3-3A
- Krahn, G.L., Hammond, L. and Turner, A. (2006). A cascade of disparities: Health and health care access for people with Intellectual Disabilities. *Mental Retardation and Developmental Disabilities*, 12, 70-82
- Landesman-Dwyer, S. (1981). Living in the community. *American Journal of Mental Deficiency*, 86, 223-234
- Landis, J.R. and Koch, G.G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 33(1), 159-174
- Learning Disability Coalition (2011) Social Care – The Continuing Crisis: from the perspective of local authorities in England. England: Learning Disability Coalition
- Leech, N. L., & Onwuegbuzie, A. J. (2009). A typology of mixed methods research designs. *Quality & Quantity: International Journal of Methodology*, 43, 265-275.
- Lennox, N.G., Diggins, J.N. and Ugoni, A.M. (1997). The general practice care of people with intellectual disability: Barriers and solutions. *Journal of Intellectual Disability Research*, 41(5), 380-390
- Leyin, A. (2010). Learning Disability classification: Time for re-appraisal? *Tizard Learning Disability Review*, 15(2), 33-41
- Leyin, A. (2011). Improving access to psychological therapies for people with learning disabilities. *Tizard Learning Disability Review*, 16(5), 29-37
- Lindsay, W.R. (1999). Cognitive therapy. *The Psychologist*, 12, 238-241
- Lindsay, W.R., Michie, A.M., Baty, F.J., Smith, A.H.W. and Miller, S. (1994). The consistency of reports about feelings and emotions from people with intellectual disability. *Journal of Intellectual Disability Research*, 38, 61-66



- Lindsey, M. (2000). Services for people with learning disabilities and mental health problems. *The Mental Health Review*, 5(2), 5-13
- Lindsey, M. (2002). Comprehensive health care services for people with learning disabilities. *Advances in Psychiatric Treatment*, 8, 138-148
- Llewellyn, A. and Hogan, K. (2000). The use and abuse of models of disability. *Disability and Society*, 15(1), 157-165
- Lovell, A. (2007). Learning disability against itself: The self-injury/self-harm conundrum. *British Journal of Learning Disabilities*, 36, 109-121
- MacKenzie, D. (1976). Eugenics in Britain. *Social Studies of Science*, 6(3/4), 499-532
- Madill, A., Jordan, A. and Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91, 1-20
- Mansell, J. (2005). Deinstitutionalisation and community living: an international perspective. *Tizard Learning Disability Review*, 10(1), 22-29.
- Mansell, J. and Beadle-Brown, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities*, 17, 1-9.
- Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B. and MacDonalds, S. (2002). Engagement in meaningful activity and 'active support' of people with intellectual disabilities in residential care. *Research in Developmental Disabilities*, 23(5), 342-352
- Mansell, J. and Emerson, E. (Eds). (1996). *Deinstitutionalization and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA*. London: Chapman and Hall
- Martin, E. (2004). Vignettes and Respondent Debriefing for Questionnaire Design and Evaluation (pages 149–171). In Presser, S, Couper, M.P., Lessler, J.T., Martin, E., Martin, J., Rothgeb, J.M. and Singer, E. (Eds). *Methods for testing and evaluating survey questions*. Hoboken, NJ: Wiley
- Mason, J. (2007). The provision of psychological therapy to people with intellectual disabilities: An investigation into some of the relevant factors. *Journal of Intellectual Disability Research*, 51(3), 244-249
- Mason, and Scior, (2004). 'Diagnostic Overshadowing' amongst clinicians working with people with intellectual disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*, 17, 85-90
- Massie, N (2014, July). *Working with people with a learning disability. Who are these individuals? Why are Counselling Psychologists so well place to work with this population?* Workshop presented at the Division of Counselling Psychology Annual Conference 2014, London.

Matson, J.L. and Sevin, J.A. (1994). Theories of Dual Diagnosis in Mental Retardation. *Journal of Consulting and Clinical Psychology*, 62(1), 6-16

Maughan, B., Collishaw, S. and Pickles, A. (1999). Mild mental retardation: Psychosocial functioning in adulthood. *Psychological Medicine*, 29, 351-366

McAteer, D. (2010). Philosophical pluralism: Navigating the sea of diversity in psychotherapeutic and counselling psychology practice. In Milton, M. (Ed.). *Therapy and Beyond: Counselling Psychology Contributions to Therapeutic and Social Issues*. (p 5-20). London: Wiley-Blackwell.

McCaughey, T.J. and Strohmer, D.C. (2005). Prototypes as an indirect measure of attitudes toward disability groups. *Rehabilitation Counseling Bulletin*, 48(2), 89-99

McColl, E., Jacoby, A., Thomas, L., Soutter, J., Bamford, C., Steen, N., Thomas, R., Harvey, E., Garratt, A. and Bond, J. (2001). Design and use of questionnaires: A review of best practice applicable to surveys of health service staff and patients. *Health Technology Assessment*, 5(31),

McGrath, J.E. and Johnson, B.A. (2003). How both qualitative and quantitative paradigms shape evidence and its interpretation. In Camic, P.M., Rhodes, J.E. and Yardley, L. (Eds). *Qualitative research in psychology: Expanding perspectives in methodology and design*. Washington, DC, US: American Psychological Association

McLean, L.K., Brady, N.C. and McLean, J.E. (1996). Reported communication abilities of individuals with severe mental retardation. *American Journal on Mental Retardation*, 100(6), 580-591

Melville, C.A., Finlayson, J., Cooper, S.A., Allan, L., Robinson, N., Burns, E., Martin, G. and Morrison, J. (2005). Enhancing primary health care services for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 49(3), 190-198

Mencap (2012). *Out of Sight Report*. London: Mencap

Merriman, C. and Beail, N. (2009). Service user views of long-term individual psychodynamic psychotherapy. *Advances in Mental Health and Learning Disabilities*, 3(2), 42-47

Morin, D., Crocker, A.G., Beaulieu-Bergeron, R. and Caron, J. (2013a). Validation of the attitudes towards intellectual disability – ATTID questionnaire. *Journal of Intellectual Disability Research*, 57(3), 268-278

Morin, D., Rivard, M., Crocker, A.G., Boursier, C.P. and Caron, J. (2013b). Public attitudes towards intellectual disability: a multidimensional perspective. *Journal of Intellectual Disability Research*, 57(3), 279-292

Morse, J.M., Niehaus, L., Woolfe, R.R. and Wilkins, S. (2006). The role of theoretical drive in maintaining validity in mixed-method research. *Qualitative Research in Psychology*, 3(4), 279-291

Moss, S., Prosser, H., Costello, H., Simpson, N. and Patel, P. (1996). *PAS-ADD Checklist*. Hester Adrian Research Centre, Manchester.

Munro, J.D. (2011). A positive couple therapy model: Improving relationships for people with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, 5(5), 34-39

- Murphy, G. (1987). Are intelligence tests outmoded? *Archives of Diseases in Childhood*, 62, 773-775
- Nagel, B. and Leiper, R. (1999). A national survey of psychotherapy with people with learning disabilities. *Clinical Psychology Forum*, 129, 14-18
- Nassar-McMillan, S. C., and Borders, L. D. (2002). Use of focus groups in survey item development. *The Qualitative Report*, 7(1) retrieved from: <http://www.nova.edu/ssss/QR/QR7-1/nassar.html>
- Nederhof, A. J. (1985). Methods of coping with social desirability bias: a review. *European Journal of Social Psychology*, 15, 263-280
- Neville, H.A., Carter, R.T., Spengler, P.M. and Hoffman, M.A. (2006). Quantitative research designs and counseling psychology: Historical development, current application, and best practices. *The Counseling Psychologist*, 34(5), 597-600
- Newman, I., & Benz, C. R. (1998). *Qualitative-quantitative research methodology: Exploring the interactive continuum*. Carbondale, Illinois: Southern Illinois University Press.
- Nirje, B. (1985). The Basis and Logic of the Normalization Principle. *Australia and New Zealand Journal of Developmental Disabilities* 11: 65-68.
- Oathamshaw, S.C. and Haddock, G. (2006). Do people with intellectual disabilities and psychosis have the cognitive skills required to undertake cognitive behavioural therapy? *Journal of Applied Research in Intellectual Disabilities*, 19, 35-46
- O'Driscoll, D. (2009). A short history of psychodynamic psychotherapy for people with learning disabilities. *Advances in Mental Health and Learning Disabilities*, 3(4), 4-9
- Panek, P.E. and Jungers, M.K. (2008). Effects of age, gender, and causality on perceptions of persons with mental retardation. *Research in Developmental Disabilities*, 29, 125-132
- Power, M.J., Green, A.M. and THE WHOQOL-DIS Group (2010). The Attitudes to Disability Scale (ADS): Development and psychometric properties. *Journal of Intellectual Disability Research*, 54(9), 860-874
- Presser, S, Couper, M.P., Lessler, J.T., Martin, E., Martin, J., Rothgeb, J.M. and Singer, E. (2004). Methods for Testing and Evaluating Survey Questions (pages 1–22). In Presser, S, Couper, M.P., Lessler, J.T., Martin, E., Martin, J., Rothgeb, J.M. and Singer, E. (Eds). *Methods for testing and evaluating survey questions*. Hoboken, NJ: Wiley
- Prout, H.T. and Strohmer, D.C. (1998). Issues in mental health counselling with persons with mental retardation. *Journal of Mental Health Counselling*, 20(2), 112
- Pruett, S.R. and Chan, F. (2006). The development and psychometric validation of the Disability Attitude Implicit Association Test. *Rehabilitation Psychology*, 51(3), 202-213
- Psaila, C. and Crowley, V. (2005). Cognitive analytic therapy in people with learning disability: An investigation into the common reciprocal roles found within this client group. *Mental Health and Learning Disabilities Research and Practice*, 2(2), 96-108

- Purcell, M., Morris, I. and McConkey, R. (1999). Staff perceptions of the communicative competence of adult persons with intellectual disabilities. *The British Journal of Developmental Disabilities*, 45(1), 16-25
- Quinn, L (2011). Working with interpreters in therapy. *Contemporary Psychotherapy*, 3 (1), retrieved from <http://www.contemporarypsychotherapy.org/vol-3-no1-spring-2011/working-with-interpreters-in-therapy/> on 3<sup>rd</sup> September 2015
- Reid, K.A., Smiley, E. and Cooper, S.A. (2011). Prevalence and associations of anxiety disorders in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 55(2), 172-181
- Rescher, N. (1993). *Pluralism: Against the Demand for Consensus*. Oxford: Oxford University Press.
- Rhodes, P., Watson, L., Mora, L., Hansson, A., Brearley, K. and Dikian, J. (2011). Systemic hypothesising for challenging behaviour in intellectual disabilities: A reflecting team approach. *The Australian and New Zealand Journal of Family Therapy*, 32(1), 70-82
- Richards, S.B., Brady, M.P. and Taylor, R.L. (2015). Historical Concepts and Perspectives. In Richards, S.B., Brady, M.P. and Taylor, R.L. (2015). *Cognitive and Intellectual Disabilities: Historical Perspectives, Current Practices and Future Directions*. 2<sup>nd</sup> ed. Abingdon: Routledge
- Richards, M., Maughan, B., Hardy, R., Hall, I., Strydom, A. and Wandsworth, M. (2001). Long-term affective disorder in people with Mild learning disabilities. *British Journal of Psychiatry*, 179, 523-527
- Rikberg Smyly, S., Elsworth, J., Mann, J. and Coates, E. (2008). Working systemically in a learning disability service: What do colleagues and carers think? *Learning Disability Review*, 13(2), 15-24
- Rioux, M.H. (1997). Disability: The place of judgement in a world of fact. *Journal of Intellectual Disability Research*, 41(2), 102-111
- Roeden, J.M., Bannink, F.P., Maaskant, M.A. and Curfs, L.M.G. (2009). Solution-focused brief therapy with persons with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6(4), 253-259
- Rogers, C.R. (1957). The necessary and sufficient conditions of psychotherapeutic personality change. *Journal of Consulting Psychology*, 21, 95-103
- Rose, J., Loftus, M., Flint, B. and Carey, L. (2005). Factors associated with the efficacy of a group intervention for anger in people with intellectual disabilities. *British Journal of Clinical Psychology*, 44, 305-317
- Rose, N., O'Brien, A. and Rose, J. (2007). Investigating staff knowledge and attitudes towards working with adults with learning disabilities and mental health difficulties. *Advances in Mental Health and Learning Disabilities*, 1(3), 52-59
- Roth, W. (1983). Handicap as a social construct. *Society*, 20, 56-61
- Royal College of Psychiatrists (2001). *DC-LD (Diagnostic Criteria for Use with Adults with Learning Disabilities/ Mental Retardation)* Occasional Paper op 48. Gaskell, London

- Rutman, D. (1996). Caregiving as women's work: Women's experiences of powerfulness and powerlessness as caregivers. *Qualitative Health Research*, 6, 90-111
- Rutter, M. (2005). How the environment affects mental health. *British Journal of Psychiatry*, 186, 4-6
- Sale, J.E.M., Lohfeld, L.H. and Brazil, K. (2002). Revisiting the quantitative-qualitative debate: Implications for mixed-methods research. *Quality and Quantity*, 36, 43-53
- Sameroff, A.J. (1991). The social context of development. In Woodhead, M., Carr, R. and Light, P. (Eds) *Becoming a Person*. London: Routledge
- Sams, K., Collins, S. and Reynolds, S. (2006). Cognitive therapy abilities in people with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19, 25-33
- Schalock, R.L., Luckasson, R.A. and Shogren, K.A., With Borthwick-Duffy, S., Bradley, V., Buntinx, W.H.H., Coulter, D.L., Craig, E.M., Gomez, S.C., Lachapelle, Y., Reeve, A., Snell, M.E., Spreat, S., Tassé, M.J., Thompson, J.R., Verdugo, M.A., Wehmeyer, M.L. and Yeager, M.H. (2007). The renaming of Mental Retardation: Understanding the change to the term Intellectual Disability. *Intellectual and Developmental Disabilities*, 45(2), 116-124
- Scheerenberger, R.C. (1982). *A History of Mental Retardation*. Baltimore: Paul H. Brookes Publishing
- Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. *Research in Developmental Disabilities*, 32, 2164-2182
- Simpson, N. (1997). Developing mental health services for people with learning disabilities in England. *Tizard Learning Disability Review*, 2(2), 35-42
- Simons, K. (1998). Getting a foot in the door: The strategic significance of supported living. *Tizard Learning Disability Review*, 3(2), 7-15
- Sinason, V. (1992). *Mental handicap and the human condition: New approaches from the Tavistock*. London: Free Association Books
- Smiley, E. (2005). Epidemiology of mental health problems in adults with learning disability: An update. *Advances in Psychiatric Treatment*, 11, 214-222
- Social Care Association (2011). Champion, Leader, Protector – The Role of the Registered Manager in Residential Care for Adults in England (Pre-publication draft for consultation). England: Social Care Association
- Sowney, M. and Barr, O. (2004). Equity of access to health care for people with learning disabilities: A concept analysis. *Journal of Learning Disabilities*, 8(3), 247-265
- Sovner, R. and Hurley, A.D. (1983). Do the mentally retarded suffer from affective illness? *Archives of General Psychiatry*, 40, 61-67
- Spiller, M.J., Costello, H., Bramley, A., Bouras, N., Martin, G., Tsakanikos, E. and Holt, G. (2007). Consumption of mental health services by people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 20, 430-438

- Stenfert Kroese, B., Jahoda, A., Pert, C., Trower, P., Dagnan, D. and Selkirk, M. (2014). Staff expectations and views of Cognitive Behaviour Therapy (CBT) for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27, 145-153
- Stewart, D.W., Shamdasani, P.N., & Rook, D.W. (2007). *Focus groups: Theory and practice*, 2nd edition. Thousand Oaks, CA: Sage.
- Strauser, D.R., Lustig, D.C. and Donnell, C. (2004). The relationship between working alliance and therapeutic outcomes for individuals with mild mental retardation. *Rehabilitation Counseling Bulletin*, 47(4), 215-223
- Sturmey, P. (2004). Cognitive therapy with people with intellectual disabilities: A selective review and critique. *Clinical Psychology and Psychotherapy*, 11, 222-232
- Sturmey, P. (2006). On some recent claims for the efficacy of cognitive therapy for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19, 109-117
- Sturmey, P., Lindsay, W.R. and Didden, R. (2007). Editorial – Special Issue: Dual Diagnosis. *Journal of Applied Research in Intellectual Disabilities*, 20, 379-383
- Supple, S. (2005). Getting our house in order. *The Psychologist*, 18(7), 418-420
- SurveyMonkey.com, (2015). *SurveyMonkey: Free online survey software & questionnaire tool*. [online] Available at: <http://www.surveymonkey.com> [Accessed 8 Jan. 2015].
- Taylor, J.L., Lindsay, W.R. and Willner, P. (2008). Cognitive behaviour therapy for people with intellectual disabilities: Emerging evidence, cognitive ability and IQ effects. *Behavioural and Cognitive Psychotherapy*, 36, 723-733
- Taylor, J.L., Novaco, R.W. and Johnson, L. (2009). Effects of intellectual functioning on cognitive behavioural anger treatment for adults with learning disabilities in secure settings. *Advances in Mental Health and Learning Disabilities*, 3(4), 51-56
- Todd, S. and Jones, S. (2003). ‘Mum’s the Word!’: Maternal accounts of dealings with the professional world. *Journal of Applied Research in Intellectual Disabilities*, 16(3), 229-244
- Toomela, A. (2010). Quantitative methods in psychology: inevitable and useless. *Frontiers in Psychology*, 1(29), 1-14
- Trafimow, D. (2014). Considering quantitative and qualitative issues together. *Qualitative Research in Psychology*, 11(1), 15-24
- Transforming Care and Commissioning Steering Group (2014). *Winterbourne View – Time For Change: Transforming the commissioning of services for people with learning disabilities and/or autism*. London: Transforming Care and Commissioning Steering Group
- Trower, T., Treadwell, L. and Bhaumik, S. (1998). Acute in-patient treatment for adults with learning disabilities and mental health problems in a specialised admission unit. *The British Journal of Developmental Disabilities*, 44(1), 20-29
- Tsiantis, J., Diareme, S., Dimitrakaki, C., Kolaitis, G., Flios, A., Christogiorgos, S., Weber, G., Salvador-Carulla, L., Hillery, J. and Costello, H. (2004). Care staff awareness training on mental

health needs of adults with learning disabilities: Results from a Greek sample. *Journal of Learning Disabilities*, 8(3), 221-234

Üstün B. and Jakob R. (2005). Calling a spade a spade: Meaningful definitions of health conditions. *Bulletin of the World Health Organisation*, 83, 802.

Watermeyer, B. and Swartz, L. (2008). Conceptualising the psycho-emotional aspects of disability and impairment: The distortion of personal and psychic boundaries. *Disability and Society*, 23(6), 599-610

Webb, J. and Whitaker, S. (2012). Defining Learning Disability. *The Psychologist*, 25(6), 440-443

Weber, R.P. (1990). *Basic Content Analysis*. Beverly Hills, CA: Sage

Wechsler, D. (2010). *Wechsler Adult Intelligence Scale – Fourth UK Edition: Administrative and Scoring Manual*. London: The Psychological Corporation.

Wertz, F.J. (1999). Multiple methods in psychology: Epistemological grounding and the possibility of unity. *Journal of Theoretical and Philosophical Psychology*, 19, 131-166

Whelan, A., Haywood, P. and Galloway, S. (2007). Low self-esteem: Group cognitive behaviour therapy. *British Journal of Learning Disabilities*, 35, 125-130

Whitaker, S. (2004). Hidden Learning Disability. *British Journal of Learning Disabilities*, 32, 139-143

Whitaker, S. (2008). Intellectual Disability: A concept in need of revision? *The British Journal of Developmental Disabilities*, 54 (Part1), No 106, 3-9

Whitaker, S. (2010). Are people with Intellectual Disabilities getting more or less intelligent? *British Journal of Developmental Disabilities*, 56 (Part 1), No 110, 49-55

Whitaker, S. and Read, S. (2006). The prevalence of psychiatric disorders among people with intellectual disabilities: An analysis of the literature. *Journal of Applied Research in Intellectual Disabilities*, 19, 330-345

Whitehouse, R.M., Tudway, J.A., Look, R. and Stenfort Kroese, B. (2006). Adapting individual psychotherapy for adults with intellectual disabilities: A comparative review of the cognitive-behavioural and psychodynamic literature. *Journal of Applied Research in Intellectual Disabilities*, 19, 55-65

Williams, V. and Heslop, P. (2005). Mental Health support needs of people with a learning difficulty: A medical or a social model? *Disability and Society*, 20(3), 231-245

Willig, C. (2001). From recipes to adventures. In Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory or method*. Philadelphia: Open University Press

Willner, P. (2004). Brief cognitive therapy of nightmares and post-traumatic ruminations in a man with learning disability. *British Journal of Clinical Psychology*, 43, 459-464

Willner, P. (2006). Readiness for cognitive therapy in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19, 5-16

- Willner, P (2007). Cognitive behavioural therapy for people with learning disabilities: Focus on anger. *Advances in Mental Health and Learning Disabilities*, 1(2), 14-21
- Willner, P. and Goodey, R. (2006). Interaction of cognitive distortions and cognitive deficits in the formulation and treatment of obsessive-compulsive behaviours in a woman with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 19, 67-73
- Windley, D. and Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities*, 38, 310-318
- Woodward, P. and Halls, S. (2009). Staff training in mental health needs of people with learning disabilities in the UK. *Advances in Mental Health and Learning Disabilities*, 3(2), 15-19
- Wolfensberger, W. (1983). Social Role Valorization: A proposed new term for the principle of Normalization. *Mental Retardation*, 21(6), 234-239
- Woolfe, R. and Strawbridge, S. (2010). Counselling Psychology: Origins, developments and challenges. In Woolfe, R., Strawbridge, S., Douglas, B. and Dryden, W. (Eds.), *Handbook of Counselling Psychology* (3<sup>rd</sup> ed., p 3-22). London: Sage
- World Health Organisation. (WHO). (1948). Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June 1946, and entered into force on 7 April 1948.
- World Health Organisation. (WHO). (1992). *ICD-10 Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines*. Geneva: World Health Organisation
- World Health Organisation (WHO). (2002). *Towards a common language for functioning, disability and health: ICF*. Geneva: WHO
- Yardley, L. and Bishop, F. (2008). Mixing qualitative and quantitative methods: A pragmatic approach. In Willig, C. and Stainton-Rogers, W. (Eds). *The SAGE Handbook of Qualitative Research in Psychology* (pages 352-372). London: Sage
- Yazbeck, M., McVilly, K. and Parmenter, T.R. (2004). Attitudes toward people with intellectual disabilities: An Australian perspective. *Journal of Disability Policy Studies*, 15(2), 97-111



## **Appendices**

## **Appendix 1 – Email to all Staff**



Hi

My name is Abigail Goss and I am currently completing a Doctorate in Counselling Psychology at City University London. As part of my course I am completing a research study looking at Counselling Psychology and people with learning disabilities. I am looking for support workers and managers who support adults with learning disabilities with their day-to-day lives who would be willing to complete an online questionnaire about their views on Counselling and people with learning disabilities. It takes about 20 minutes to complete and you can be entered into a prize draw to win a £50 voucher.

If you're interested please click on the link below.

[https://www.surveymonkey.com/s/abigail\\_goss\\_research](https://www.surveymonkey.com/s/abigail_goss_research)

Please pass this onto anyone who may be interested but may not have received this email.

Thank you in advance

Abigail Goss

## **Appendix 2 – Advert on Organisation Intranet**

- Do you work as a support worker or manager supporting adults with learning disabilities with their day-to-day lives?
- Would you like the chance to win a £50 voucher?
- Would you be willing to spend 10-15 minutes answering an online questionnaire on your opinions on counselling psychology and people with learning disabilities?

If interested, please click on the link below.

[https://www.surveymonkey.com/s/abigail\\_goss\\_research](https://www.surveymonkey.com/s/abigail_goss_research)

## **Appendix 3 – Individualised Email**

Hi \_\_\_\_\_,

I have a favour to ask. As you may already be aware I work as \_\_\_\_\_ at \_\_\_\_\_ and I am currently completing a Doctorate in Counselling Psychology at City University London. As part of my course I am completing a research study looking at Counselling Psychology and people with learning disabilities.

If you have already completed the survey then thank you so much.  
If you have not yet had the chance please can I ask you to consider completing the online questionnaire. It only takes about 10 minutes to complete and you can be entered into a prize draw to win a £50 voucher.

It doesn't matter if you don't know much about counselling and people with learning disabilities as I just want to find out people's views. This research could help to develop more services to support the emotional well-being of the people we support so I need to get as many responses as possible.

If you're interested please click on the link below.

[https://www.surveymonkey.com/s/abigail\\_goss\\_research](https://www.surveymonkey.com/s/abigail_goss_research)

Thank you

Abby Goss

## **Appendix 4 – Questionnaire before Pre-testing**



# Questionnaire

## Demographic information

1) Gender:

- ☐ Male
- ☐ Female
- ☐ Prefer not to say

2) What is your age?

- ☐ Prefer not to say

3) How would you describe your ethnic origin?

- ☐ Prefer not to say

4) What is the highest level of qualification you have completed?

- ☐ No qualifications
- ☐ Other qualifications (including foreign qualifications)
- ☐ Vocational qualifications at level 1 (e.g. NVQ)
- ☐ GCSE/O Level, Vocational level 2 and equivalents
- ☐ A levels, Vocational level 3 and equivalents
- ☐ Diploma in higher education
- ☐ First Degree level qualification (including Bachelors and foundation degrees)
- ☐ University Higher Degree (e.g. Masters, PhD)
- ☐ Prefer not to say

5) How many years experience do you have working with people with learning disabilities?

- ☐ Less than 1 year
- ☐ 1-2 years
- ☐ 3-4 years
- ☐ 5-10 years
- ☐ More than 10 years

6) Which of the following best describes your current role working with people with learning disabilities?

- ☐ Support Worker
- ☐ Senior Support Worker
- ☐ Assistant Manager
- ☐ Home Manager
- ☐ Assistant Team leader
- ☐ Team leader

## Service Information

- 7) Which of the following best describes the service you currently work in for the majority of your working week?
- ☐ Residential care
  - ☐ Supported living
  - ☐ Outreach
- 8) In what location is your service based?
- ☐ Berkshire
  - ☐ London
  - ☐ Sussex
- 9) What level of learning disability do the people you currently support have? Please select all that apply.
- ☐ Mild
  - ☐ Moderate
  - ☐ Severe
  - ☐ Profound and Multiple Learning Disabilities (PMLD)
  - ☐ Not sure
- 10) What communication methods do the people you support mainly use? Please select all that apply.
- ☐ Verbal Communication
  - ☐ Signing including Makaton
  - ☐ Symbol based communication system (e.g. PECS)
  - ☐ Computer aided communication (e.g. eye gaze)
  - ☐ Written
  - ☐ Facial expressions
  - ☐ Behaviour/Body language
  - ☐ Not sure
- 11) Has anybody with a learning disability in the service you work in received counselling?
- ☐ Yes
  - ☐ No
  - ☐ Not sure
- 12) If no/not sure to question 11, how likely would you be to consider referring anyone from your service for counselling support?

Very Unlikely	UnLikely	Undecided	Likely	Very Likely
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- 13) If yes to question 11, how many have received counselling?
- ☐ 1
  - ☐ 2
  - ☐ 3
  - ☐ 4 or more



## Attitudes

17) INSTRUCTIONS: The following questions are for the purpose of collecting data about your general attitude towards people with learning disabilities. Please indicate how much you agree or disagree with each statement below.

### Scale 1: Inclusion

	<b><i>Strongly disagree</i></b>	<b><i>Disagree</i></b>	<b><i>Neutral</i></b>	<b><i>Agree</i></b>	<b><i>Strongly agree</i></b>
People with a learning disability find it harder than others to make new friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability have problems getting involved in society	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability are a burden on society	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability are a burden on their family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Scale 2: Discrimination

	<b><i>Strongly disagree</i></b>	<b><i>Disagree</i></b>	<b><i>Neutral</i></b>	<b><i>Agree</i></b>	<b><i>Strongly agree</i></b>
People often make fun of learning disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability are easier to take advantage of (exploit or treat badly) compared with other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People tend to become impatient with those with a learning disability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People tend to treat those with a learning disability as if they have no feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Scale 3: Gains

	<b><i>Strongly disagree</i></b>	<b><i>Disagree</i></b>	<b><i>Neutral</i></b>	<b><i>Agree</i></b>	<b><i>Strongly agree</i></b>
Having a learning disability can make someone a stronger person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a learning disability can make someone a wiser person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some people achieve more because of their learning disability (e.g. they are more successful)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability are more determined than others to reach their goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Scale 4: Prospects

	<b><i>Strongly disagree</i></b>	<b><i>Disagree</i></b>	<b><i>Neutral</i></b>	<b><i>Agree</i></b>	<b><i>Strongly agree</i></b>
Sex should not be discussed with people with learning disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People should not expect too much from those with a learning disability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability should not be optimistic (hopeful) about their future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability have less to look forward to than others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Vignette

Please read through the following situation.

Sally/John is 35 years old and has a mild/moderate/severe learning disability. In the past two weeks you have noticed that they have been behaving out of character and appeared down. When supporting them in the morning they have had difficulty getting up and are slower getting ready. They have been refusing to go out even to activities which they have always enjoyed. Even the smallest of tasks seems difficult and they lose concentration really quickly. They aren't communicating as much as normal and not requesting items that you know they like, indeed their appetite has reduced and are not eating all their meals. They have less energy and seem exhausted by the evening but are having difficulty sleeping at night.

18) What are the first thoughts that enter your mind when reading about the above person?

19) What would you do if someone you supported presented in the way above?

20) How likely would you be to consider referring the above person for counselling?

Very Unlikely	UnLikely	Undecided	Likely	Very Likely
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21) Why do you think you would do this?

22) How beneficial do you think counselling could be for the above person?

Definitely not beneficial	Not Beneficial	Undecided	Beneficial	Very beneficial
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23) Why do you think this?

--

### **Personal Experience of Counselling**

24) Have you ever attended counselling yourself?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

25) If yes, how beneficial did you find the counselling?

Definitely not beneficial	Not Beneficial	Undecided	Beneficial	Very beneficial
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26) If yes to question 24, what was your experience of counselling? Please provide an overall view of your experience of counselling.

--

- ☐ Prefer not to say

### **And finally**

27) Do you have any other opinions about counselling for people with learning disabilities that you would like to share

--

## **Appendix 5 – Questionnaire on Surveymonkey.com**



## Welcome to My Research

Thank you for being interested in participating in this research study. This study is being conducted by Abigail Goss, a student from City University London. You were asked to participate in this study because you support people with learning disabilities to live their day-to-day lives.

The purpose of this research is to gain an understanding of the opinion of support staff in learning disability services regarding counselling for people with learning disabilities. If you agree to take part in this study, you will be asked to complete an online questionnaire. This questionnaire will ask about counselling for people with learning disabilities, your views about learning disabilities and your own experience of any counselling. It will take you approximately 20 minutes to complete.

Your participation in this study is completely voluntary and you can withdraw at any time. You may skip any questions you do not wish to answer by indicating 'prefer not to say' or leaving the answer blank. If you do not wish to complete this questionnaire or decide you do not want to whilst completing it, just close your browser.

All responses will be completely anonymous and no person will be able to be identified from their responses. Once all the questionnaires have been completed all the answers will be downloaded and kept securely (via password protection) on a computer. Once the results have been analysed the data will be kept safely for a few years before being destroyed.

At the end of the questionnaire you will be asked to enter your email address if you would like to be entered into the prize draw for the chance to win a £50 voucher.

If you have questions about this project or if you have a research-related problem, you may contact the researcher, Abigail Goss at 07540671639 or via email, [Abigail.Goss.1@city.ac.uk](mailto:Abigail.Goss.1@city.ac.uk). Please contact my supervisor if there is anything that you do not wish to discuss with myself. My supervisor is Dr Pavlos Filippopoulos at City University London and can be contacted on 02070404557 or via email at [pavlos@city.ac.uk](mailto:pavlos@city.ac.uk)

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone 02070403040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is Attitudes of support workers in learning disability services towards counselling psychology.

You could also write to the Secretary at:

Anna Ramberg  
Secretary to Senate Research Ethics Committee  
Research Office, E214  
City University London  
Northampton Square  
London  
EC1V 0HB  
Email: [Anna.Ramberg.1@city.ac.uk](mailto:Anna.Ramberg.1@city.ac.uk)

This study has been granted ethical approval by Dr Pavlos Filippopoulos and Dr Jessica Jones Nielsen from City University London Psychology Department.

By clicking "Next" below you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study. Please print a copy of this page for your records.

After you click "Next" some demographic questions will be asked before the main questionnaire is

started. These are asked so that a picture can be gained about the type of people completing the questionnaire.

## Demographic Information

If you would prefer not to answer any questions then please click on the next button at the bottom of the page.

### 1. What is your gender?

- ☐ Female
- ☐ Male

### 2. What is your age?

### 3. How would you describe your ethnic origin?

### 4. What is the highest level of qualification you have completed?

- ☐ No qualifications
- ☐ Other qualifications (including overseas qualifications)
- ☐ Vocational qualifications at level 1 (e.g. NVQ Level 1)
- ☐ GCSE/O Level, Vocational level 2 and equivalents (e.g. NVQ Level 2)
- ☐ A Level, Vocational level 3 and equivalents (e.g. NVQ Level 3)
- ☐ Vocational level 4 (e.g. NVQ Level 4) and Assessors Awards
- ☐ Diploma in Higher education
- ☐ Degree level qualification (including Bachelors and Foundation degrees)
- ☐ Post-graduate degree level (including Masters and PhD)

## Service Information

### 5. How many years experience do you have working with people with learning disabilities?

- ☐ Less than 1 year
- ☐ 1-2 years
- ☐ 3-4 years
- ☐ 5-10 years
- ☐ More than 10 years

**6. Which of the following best describes your current role supporting people with learning disabilities?**

- ☐ Support Worker
- ☐ Senior Support Worker
- ☐ Assistant Manager
- ☐ Home Manager
- ☐ Assistant Team Leader
- ☐ Team Leader
- ☐ Other (please specify)

**7. Which of the following best describes the service you work in for the majority of your working week?**

- ☐ Residential Care
- ☐ Supported Living
- ☐ Outreach

**8. In what location is your service based?**

- ☐ Berkshire
- ☐ London
- ☐ Sussex

Service Information

**9. What level of learning disability do the people you currently support have?  
Please select all that apply.**

- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Profound and Multiple Learning Disabilities
- ☐ Not sure

## 10. What communication methods do the people you support mainly use?

Please select all that apply.

- ☐ Verbal Communication
- ☐ Signing including Makaton
- ☐ Symbol based communication system (e.g. PECS)
- ☐ Computer aided communication (e.g. eye gaze, Ipad)
- ☐ Written
- ☐ Facial Expressions
- ☐ Behaviour/ Body Language
- ☐ Not sure

## Counselling and People with Learning Disabilities

This questionnaire is interested in the types of therapies offered by a Counselling Psychologist which are typically known as counselling or talking therapies. Many different terms may be used to describe the type of counselling or the model of therapy including person-centred counselling, cognitive behaviour therapy (CBT), psychotherapy, psychological therapies, among others. These can all provide a person with a safe, confidential space to communicate their problems and feelings with a trained professional. This may happen in a 1:1, couple, family or group context and may be in the person's home or other setting. Sessions usually happen on a regular basis either weekly, bi-weekly or monthly and depending on the therapist, staff may be asked to attend a session(s) with the person receiving the therapy.

This study is **only** interested in **counselling or talking therapies** and not other therapies that someone with a learning disability may access such as music therapy, art therapy, aromatherapy or drama therapy.

## 11. Have you supported someone with a learning disability to access counselling? (e.g. supported them to attend a counselling session or reminded them about the time of a counselling session)

- ☐ Yes
- ☐ No
- ☐ Not sure

## Counselling and People with Learning Disabilities

## 12. How would you describe your experience of supporting someone with a learning disability during the time they had counselling?

## Counselling and People with Learning Disabilities

**13. Are you aware of anybody with a learning disability in the service you work in receiving counselling either currently or in the past?**

- ☐ Yes
- ☐ No
- ☐ Not sure

### Counselling and People with Learning Disabilities

**14. How many of the people in your service have received/ are receiving counselling?**

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4 or more

**15. Thinking about one person who has received counselling most recently, how beneficial do you feel the counselling was for them?**

Definitely not beneficial	Not Beneficial	Undecided	Beneficial	Very beneficial
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Counselling and People with Learning Disabilities

**16. How likely in the future would you be to consider referring or speaking to your line manager about referring someone from your service for counselling?**

Very Unlikely	Unlikely	Undecided	Likely	Very Likely
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**17. Please could you explain your reasons for the answer above.**

### Attitudes to Learning Disabilities

**18. The following questions are for the purpose of collecting data about your general attitude towards people with learning disabilities. Please indicate how much you agree or disagree with each statement below.**

	Strongly Disagree	Disagree	Neither Disagree Nor Agree	Agree	Strongly Agree
People with a learning disability find it harder than others to make new friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability have problems getting involved in society.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability are a burden on society.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability are a burden on their family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People often make fun of learning disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability are easier to take advantage of (exploit or treat badly) compared with other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People tend to become impatient with those with a learning disability.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People tend to treat those with a learning disability as if they have no feelings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Attitudes to Learning Disabilities

**19. Please indicate how much you agree or disagree with each statement below.**

	Strongly Disagree	Disagree	Neither Disagree Nor Agree	Agree	Strongly Agree
Having a learning disability can make someone a stronger person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a learning disability can make someone a wiser person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some people achieve more because of their learning disability (e.g. they are more successful).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability are more determined than others to reach their goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex should not be discussed with people with intellectual disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People should not expect too much from those with a learning disability.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability should not be optimistic (hopeful) about their future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with a learning disability have less to look forward to than others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Vignette**

Please read through the following situation and answer the questions below.

Sally is 35 years old and has a **severe** learning disability. In the past two weeks you have noticed that she has been out of sorts and appeared down. When supporting her in the morning she has had difficulty getting up and is slower getting ready. She has been refusing to go out even to activities which she has always enjoyed. Even the smallest of tasks seem difficult for her and she loses concentration really quickly. She isn't communicating as much as normal and not requesting items that you know she likes, indeed her appetite has reduced and she's not eating all her meals. She has less energy and seems exhausted by the evening but is having difficulty sleeping at night.

Respondents: 16.67%

John is 35 years old and has a **mild** learning disability. In the past two weeks you have noticed that he has been out of sorts and appeared down. When supporting him in the morning he has had difficulty getting up and is slower getting ready. He has been refusing to go out even to activities which he has always enjoyed. Even the smallest of tasks seem difficult for him and he loses concentration really quickly. He isn't communicating as much as normal and not requesting items that you know he likes, indeed his appetite has reduced and he's not eating all his meals. He has less energy and seems exhausted by the evening but is having difficulty sleeping at night.

Respondents: 16.67%

John is 35 years old and has a **moderate** learning disability. In the past two weeks you have noticed that he has been out of sorts and appeared down. When supporting him in the morning he has had difficulty getting up and is slower getting ready. He has been refusing to go out even to activities which he has always enjoyed. Even the smallest of tasks seem difficult for him and he loses concentration really quickly. He isn't communicating as much as normal and not requesting items that you know he likes, indeed his appetite has reduced and he's not eating all his meals. He has less energy and seems exhausted by the evening but is having difficulty sleeping at night.

Respondents: 16.67%

John is 35 years old and has a **severe** learning disability. In the past two weeks you have noticed that he has been out of sorts and appeared down. When supporting him in the morning he has had difficulty getting up and is slower getting ready. He has been refusing to go out even to activities which he has always enjoyed. Even the smallest of tasks seem difficult for him and he loses concentration really quickly. He isn't communicating as much as normal and not requesting items that you know he likes, indeed his appetite has reduced and he's not eating all his meals. He has less energy and seems exhausted by the evening but is having difficulty sleeping at night.

Respondents: 16.67%

Sally is 35 years old and has a **mild** learning disability. In the past two weeks you have noticed that she has been out of sorts and appeared down. When supporting her in the morning she has had difficulty getting up and is slower getting ready. She has been refusing to go out even to activities which she has always enjoyed. Even the smallest of tasks seem difficult for her and she loses concentration really quickly. She isn't communicating as much as normal and not requesting items that you know she likes, indeed her appetite has reduced and she's not eating all her meals. She has less energy and seems exhausted by the evening but is having difficulty sleeping at night.

Respondents: 16.65%

Sally is 35 years old and has a **moderate** learning disability. In the past two weeks you have noticed that she has been out of sorts and appeared down. When supporting her in the morning she has had difficulty getting up and is slower getting ready. She has been refusing to go out even to activities which she has always enjoyed. Even the smallest of tasks seem difficult for her and she loses concentration really quickly. She isn't communicating as much as normal and not requesting items that you know she likes, indeed her appetite has reduced and she's not eating all her meals. She has less energy and seems exhausted by the evening but is having difficulty sleeping at night.

Respondents: 16.67%

## 20. What are the first thoughts that enter your mind when reading the above situation?



**21. What would you do if someone you supported presented in the way above?**

**22. How likely would you be to consider referring or speaking to your line manager about a referral for the above person for counselling support?**

Very Unlikely

Unlikely

Undecided

Likely

Very Likely

☐☐☐☐☐

**23. Please could you explain your reasons for the answer above.**

**24. How beneficial do you think the counselling could be for the above person?**

Definitely not beneficial

Not Beneficial

Undecided

Beneficial

Very beneficial

☐☐☐☐☐

**25. Please could you explain your reasons for the answer above.**

## Personal Experience of Counselling

**26. Have you ever attended counselling yourself?**

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

## Personal Experience of Counselling

**27. How beneficial did you find the counselling?**

Definitely not beneficial

Not beneficial

Undecided

Beneficial

Very beneficial

☐☐☐☐☐

**28. What was your experience of counselling? Please do not feel that you need to provide any specific details about the counselling but just an overall view of your experience.**

## Barriers to Counselling

**29. Do you think that there are any particular barriers which prevent people with learning disabilities from accessing counselling?**

Other Comments

**30. Do you have any other opinions about counselling for people with learning disabilities that you would like to share?**

Prize Draw

**31. If you would like to be entered into the prize draw for the chance to win a £50 voucher, please enter your email address here. This will only be used to contact the winner following the prize draw. The winner can select what type of voucher they would like to receive.**

End of Questionnaire

Thank you again for taking part in this research study. I really appreciate your help.

It is hoped that this study will provide a greater understanding of the views of support staff of counselling psychology and people with learning disabilities. The results will hopefully indicate what affects counselling being seen as beneficial for people with learning disabilities and what factors affect the likelihood that people with learning disabilities are referred for counselling.

Following the completion of the research I will write a brief summary of what I found out which will be emailed to all those invited to participate in the research and will be posted on the intranet.

If you have questions about this study or if you would like to withdraw your consent or participation at any time, you may contact the researcher, Abigail Goss at 07540671639 or via email, [Abigail.goss.1@city.ac.uk](mailto:Abigail.goss.1@city.ac.uk)

Please contact my supervisor if there is anything that you do not wish to discuss with me. My supervisor is Dr Pavlos Filippopoulos at City University London and can be contacted on 02070404557 or via email at [pavlos@city.ac.uk](mailto:pavlos@city.ac.uk)

If as a result of participating in this research you have experienced any difficult feelings or have found that some questions or aspects of the questionnaire have triggered any distress then talking to someone may help. Below are some details of your employer's counselling service and the Samaritans where you could seek some support.

**Your employer offers a free at the point of access counselling service for all employees.**

**Counselling Helpline** (24 hours answer machine)

020 7391 9161

A therapist will return your call within 2 days

**Samaritans** provides 24 hour confidential emotional support for those experiencing feelings of distress.

0845 790 9090

Website: [www.samaritans.org.uk](http://www.samaritans.org.uk)

Please make sure you click **Done** to end the survey and register your response.

**Appendix 6 – Example of How Thematic Analysis was Completed for the Question: How would you describe your experience of supporting someone with a learning disability during the time they had counselling?**

Question: How would you describe your experience of supporting someone with a Learning disability during the time they had counselling?

<b>Initial Notes from Phase 1</b>	<b>Sample of Participant Responses</b>	<b>Initial Codes from Phase 2</b>
Negative, persistence, giving it a go, engagement	The S/U didn't want to be there, but did listen and give it a go. It was a lot of hard work trying to get them engaged	Uncertainty, Worth a try
Space, qualities of counsellor	The environment was quite relaxing which helped the client to stay calm and relaxed. the counsellor was non-judgemental and displayed good listening skills as he encouraged the client to release the bottled up hurts and anger he has kept within his heart for several years. the counsellor has arranged with client to have art therapy and role play to help deal with his past.	Different space, Expression, Positive/Helpful
Practicalities	At the time, it was supporting an adolescent - so reminding them about their session, advising them they could address and raise issues they were experiencing (feelings/questions etc.) when they had their counselling session with the therapist.	Practicalities, Expression
Family, shame, difficulties, quick fix	Difficult due to the expectations of the person and thier family as they expect a quick fix and the family have a difficult time as i have found they do noy accept in the first place that thier child has the learning difficulty or mental health issues in the first place and i feel that the families need help and sessions to overcome the gulit they feel and shame that they have a child with learning difficulties. This is not always the case but in most i feel this as the families tell the child what to do what not to do and often treat them like the age of a younger person than they really are and try to controll them	Uncertainty, Challenges
Beneficial, positive	Observed this has helped the person.	Positive/Helpful
Beneficial, positive	Positive for the resident as expressing new verbal communication	Positive/Helpful, Expression
Uncertainty, helped staff more	It was helpful to a point for the PWS but the information staff received on how to deal with certain situations were good.	Uncertainty
Variety of issues addressed	varied experiences with people coming to terms with traumatic incidents re abuse, having behavioral issues, sleeping patterns being disrupted etc	Complexity of therapy
How the session was used by the client	They share things discussed during the session and how satisfied they can be seen. It seems that the level of counselling received does work.	Positive/Helpful

### Potential themes that emerged from the codes – Phase 3

Practicalities

Positive/Helped

Complexity within the therapy

Counsellor as expert

Uncertainty/Negative  
Different Space

Expression

Challenges

### Themes- Phase 4

- Positive and Helpful

- Uncertainty

- What the therapeutic Space could offer:

  - Space offered expression

  - Space was different

- Practical Support

- Challenges and complexity of counselling with this client group

### Themes defined and named- Phase 5

- Positive and Helpful – Responses that mentioned counselling helped or was beneficial for the person. It made a difference in terms of behaviour, expression of emotions and communication outside of therapy or had a positive impact on the person's life.

- Uncertainty – Staff expressed uncertainty regarding the benefits and helpfulness of counselling. Includes any negative comments about behaviour outside of the therapy room during the period of counselling or shortly afterwards.

- What the therapeutic space could offer:

  - Space offered expression – Related to what the person with a learning disability expressed in therapy and comments regarding the opportunity that it provided for expression of communication, feelings or difficult aspects of their life.

  - Space was different – Responses which indicated that the therapeutic space is different from what staff could offer to the person with a learning disability. Includes comments about the qualities of the therapist.

- Practical Support – Comments regarding the practical support provided by staff to the person with a learning disability to access or use therapy. Includes staff reminding the person about sessions, taking the person to sessions, discussing what could be taken to sessions and staff being in the session to aid with communication.

- Challenges and complexity of counselling with this client group – Responses indicated a complexity or difficulty that supporting someone with a learning disability to access or use counselling. Includes issues in finding or accessing appropriate services, managing expectations, requirements for more support to be able to use the therapy and the impact that it can have on staff.

Phase 6 - A storyline was developed and written to summarise the themes identified

## **Appendix 7 – Ethics Form**

## Appendix 1

# Ethics Release Form for Student Research Projects

All students planning to undertake any research activity in the School of Arts and Social Sciences are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal clearly stating aims and methodology**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department or the Schools does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2009) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by Research Supervisor and the Department's Ethics Representative.**

### Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

BSc                  M.Phil                  M.Sc                  **D.Psych**                  n/a

Please answer all of the following questions, circling yes or no where appropriate:

#### 1. Title of project

Attitudes of support workers in learning disability services towards counselling psychology

#### 2. Name of student researcher (please include contact address and telephone number)

Abigail Goss,  
47 Victoria Road, Tilehurst, Reading ,RG31 5AB. 07540671639

#### 3. Name of research supervisor

Dr Pavlos Filippopoulos



4. Is a research proposal appended to this ethics release form? Yes No

5. Does the research involve the use of human subjects/participants? Yes No

If yes,

a. Approximately how many are planned to be involved?

250

b. How will you recruit them?

They will be recruited through a learning disability charity. An invitation to participate will be posted on the organisations intranet and potential participants will be invited to participate through an email.

c. What are your recruitment criteria?

*(Please append your recruitment material/advertisement/flyer)*

Participants must be currently working as support workers or managers supporting adults with learning disabilities to live their day-to-day lives. (Appendix 2)

d. Will the research involve the participation of minors (under 18 years of age) or vulnerable adults or those unable to give informed consent? Yes No

d1. If yes, will signed parental/carers consent be obtained? Yes No

d2. If yes, has a CRB check been obtained? Yes No  
*(Please append a copy of your CRB check)*

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? *(If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).*

Participants will be asked to fill out an online questionnaire that will take approximately 20 minutes to complete. Questions will be asked about their attitudes and experience of people with learning disabilities and counselling. They will be asked to read a vignette and then asked to answer questions related to the vignette. One set of questions asks about participants personal experience of counselling. (Appendix 4)

7. Is there any risk of physical or psychological harm to the subjects/participants? Yes No

If yes,

a. Please detail the possible harm?

One set of questions asks about participant's own personal experience of counselling so this may bring up some difficult feelings for some participants.

b. How can this be justified?

It is felt that personal experience of counselling is likely to affect opinions of how beneficial counselling for people with learning disabilities can be.

c. What precautions are you taking to address the risks posed?

The questions do not ask for any detail and just asks for general feeling about how beneficial the counselling was and their experience of it. There is the option of 'prefer not to say' so that people do not feel that they have to disclose this information. Telephone numbers for a free counselling service and the Samaritans will be provided in the de-brief information.

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

Yes

No

*(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)*

9. Will any person's treatment/care be in any way be compromised if they choose not to participate in the research?

Yes

No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

Yes

No

If no, please justify

As the questionnaire will be administered online consent will be provided through participants clicking to confirm their consent. (Appendix 3)

If yes please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

Computer records of participant's responses will be kept, all data will be provided anonymously so participants should not be able to be identified from their responses.

12. What provision will there be for the safe-keeping of these records?

All data will be kept on a computer that is password protected and if possible to the files will have a different password as protection.

13. What will happen to the records at the end of the project?

Once the research has been completed the will be kept securely for a couple of years before the raw data is destroyed.

14. How will you protect the anonymity of the subjects/participants?

All data will be provided anonymously so participants should not be able to be identified from their responses

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15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

In the de-brief information (Appendix 5), participants will be provided with the researchers and their supervisors details so they may contact with any queries or problems with the research. In terms of psychological and emotional support participants will be provided with a number for a free to use counselling service and the Samaritans.

*(Please append any de-brief information sheets or resource lists detailing possible support options)*

If you have circled an item in **underlined bold** print or wish to provide additional details of the research please provide further explanation here:

Signature of student researcher ----- AGoss ----- Date 2/5/14

**CHECKLIST:** the following forms should be appended unless justified otherwise

Research Proposal  
Recruitment Material  
Information Sheet  
Consent Form  
De-brief Information

### **Section B: Risks to the Researcher**

1. Is there any risk of physical or psychological harm to yourself?      Yes      **No**  
If yes,

a. Please detail possible harm?

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b. How can this be justified?

c. What precautions are to be taken to address the risks posed?

**Section C: To be completed by the research supervisor**

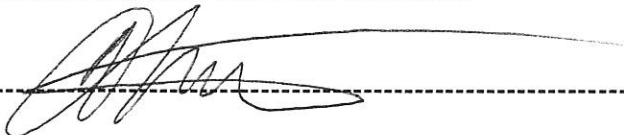
*(Please pay particular attention to any suggested research activity involving minors or vulnerable adults. Approval requires a currently valid CRB check to be appended to this form. If in any doubt, please refer to the Research Committee.)*

Please mark the appropriate box below:

Ethical approval granted

Refer to the Department's Research and Ethics Committee

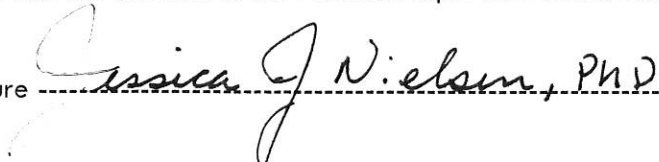
Refer to the School's Research and Ethics Committee

Signature  Date 01/10/14

**Section D: To be completed by the 2<sup>nd</sup> Departmental staff member**

*(Please read this ethics release form fully and pay particular attention to any answers on the form where **underlined bold** items have been circled and any relevant appendices.)*

I agree with the decision of the research supervisor as indicated above

Signature  Date 02/10/2014