"Reflections: An Investigation into Mothers' Experiences of Having an Adult Offspring with Mild Learning Disabilities"

An IPA Study

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Abstract

This is a qualitative study exploring the personal accounts of mothers of adult offspring with a diagnosis of mild learning disabilities (LD). Evidence has shown that the experiences of such mothers is under-represented in counselling and psychotherapy research. This study aims to address the gap. Eight participants were purposively selected for the project and were then interviewed using semi-structured interviews. The interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA).

The results of the analysis represent my interpretation of participants' lived experiences of being mothers of adult offspring with a diagnosis of mild LD. The three superordinate themes which were generated in the participants' personal accounts relating to the mothers' experience are as follows: a) 'Getting on with it': unallowable emotions in living with a disabled offspring, b) Adult disability as invisible: falling off a cliff after the end of childhood, c) Glimmers of adulthood: negotiating transitions without a roadmap. Each theme consisted of two to three subthemes. Firstly, the research findings indicate that mothers of adult offspring with a diagnosis of mild LD often avoid negative emotions, which may prove unbearable in the present. Secondly, as the offspring reach adulthood and formal support significantly decreases, both the offspring and the mothers become 'invisible' to the services. Subsequently the lack of a future plan becomes apparent for both the adults with a diagnosis of LD and the mothers. This is in line with Turner' theory of liminality (1969) which illustrates that despite the fact a person with LD becomes an adult, they often do not conform to a normative pathway and remain in a liminal state. Nevertheless, despite all the difficulties, mothers remain positive and try to focus on any capacity and the glimmers of adulthood displayed by their offspring with LD.

The study highlights the need for improvement of health and social services for mothers of adult offspring with LD. Recommendations for future research are outlined and the role of professionals in future clinical practice is explored.

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Preface

Experiences that shaped my interest in individuals with learning disabilities and their families

My working life has been largely within the company of adults with learning disabilities. I have often experienced this population and their relationships and social networks to be marginalised, misunderstood and poorly supported by governing bodies and professional agencies. When I began employment as a support worker I experienced a wealth of experiences which were rewarding and enjoyable yet also confusing and stressful. Although peer and managerial support was available, often there was a sense of isolation and necessity to learn from my own experiences of being with somebody and the unique transactions that transpired.

My experience of therapy and work in the care environment has led to the view that construction of knowledge is fluid, idiographic and subjectively experienced and developed. As a clinician I integrate therapeutic theories and modalities to meet the unique needs of the client. This bespoke approach facilitates a process of intersubjective construction of experience which can be utilised to inform assessment, formulation and treatment.

My experience as an assistant psychologist and a counselling psychologist in training shaped an understanding that my perspective of reality can be very different to the perspective of other people. Being open to how information, the environment and relationships are experienced enabled me to gain a sense of congruence and understanding with work colleagues, other professionals and clients through leaps of imagination, clarification and learning from interpersonal experience. Drawing on uncertain subjective experiences of affect helped to form relational connections. I have begun to realise how knowledge of myself, relationships and psychological functioning

has changed. I consider in more depth how I think about others and myself in relation to others. I feel more confident in validating and accepting my vulnerabilities and weaknesses. This has proved helpful to bridge how I strive to understand, relate to and connect with clients. Holding in mind the richness, fragility and uncertainty of the human condition. This process of knowledge elucidation and elaboration I view as an ongoing and fluid ontological journey in which what we know of ourselves and others is never truly fixed and static, but nonetheless meaningful.

I have been fortunate enough to work with adults with LD. I have had little experience working with parents of those adults. However, the little experience I gained has influenced my decision to conduct the current project. I have been inspired by parents' daily struggles and success stories, which have had an impact on me as a person and a professional. I hope that this research contributes to the knowledge in the field of Counselling Psychology.

CHAPTER ONE: INTRODUCTION

Disability, difference or discrimination?

"...I didn't like the word, the name 'learning disability', I didn't like people use it, even though it was what it was..."(Karuna, line 119)

Karuna, a participant in the current study and mother of Michael who has a diagnosis of mild LD, was very reluctant to use the terminology 'learning disability' due to its negative connotation. She expressed her anger and disappointment with the society for using such terminology and for perceiving her son as a "problem". Karuna sees her son as 'different' as opposed to 'disabled' and someone who deserves a fulfilling life like everybody else.

What Karuna can be seen to be struggling with is how some individuals understand her son's experiences in the world. She is resistant to the term 'disability' with its stigmatised connotations which position a stable 'problem' located within the person (Shakespeare, 2009). She also acknowledges some difference between her son and other adults, resisting to some extent the full social model of disability (Thomas, 1998). She is left here in limbo, unable to name her son's experiences. This example helps to capture the complexity of 'disability.

Therefore, in my view, we should be talking about people with differences as opposed to people with disabilities. As Shakespeare pointed out, there are other ways of looking at diagnosis, disability and difference rather than the problem being within the person (Shakespeare, 2009). It is here argued that there are other ways of looking at the phenomenon and understanding differences between people. Disability is a complex combination of variety in biological/physical/mental capabilities and the social meanings we attach to these differences to create certain categories (Shakespeare,

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2009). These debates are complex; if we do not acknowledge difference, we may exclude people more as people with a disability may not receive adequate support (Findlay, et al., 2014). On the other hand, diagnosis and labelling can have very negative connotations and reduce disabled people's status (Shakespeare, 2009). Whichever terminology we use to categorise people, it is important to acknowledge that these categories are arbitrary.

As already mentioned, the way disability is viewed is complex and there are many ways we can understand differences between people. The concept of disability seems even more complex when discussing diagnosis of a learning disability where difference seems much less clear. The above vignette hopefully captures the complexity of the term 'disability' and what it means. The phenomenon of disability is based in a way of thinking about people which divides them into the categories of 'able' and 'disabled'.

It is important to acknowledge that the concept of learning disability is not a 'real' category and there are many different definitions of LD (e.g. learning difficulty, intellectual disability) and different ways to look at the whole concept (Baum & Lynggaard, 2006).

. When I am discussing disability I am using categories while being aware that these are categories created by people in order to understand difference. This is a category as opposed to fixed reality. I have used these categories to try and describe this particular group of people; it does not mean that they are inherently different to other people. By using categories the aim is for the concept of disability to be easier understood, rather than categories being a strict reality. I acknowledge that using categories is not the only way to divide things up and this is not the only way to understand disability (Shakespeare, 2009). IQ is essentially arbitrary but at the same

time it does capture and illustrates difference, although the line it draws remains a 'human kind' (Hacking, 1995).

In this thesis I take forward the middle ground proposed by Shakespeare (2001; 2006) which acknowledges the stigmatising impacts of labelling, takes forward the social model's focus on changing environments as well as people, but still maintains the reality of varied capability (biomedical model). Shakespeare (2000) and others (Gabel & Peters, 2004) propose a rights based approach which takes as central the idea that all people deserve a world which facilitates the possibility of living a good life. For those with differing capacities or impairment, this may include differentiated environments or expectations, without taking away from the human rights or dignity of people who may be labelled as disabled. In the LD population, the difference, capacity or impairment in question can be seen as cognitive capacity towards the lower end of most people, with varying impacts on the negotiation of life as an adult person. Some these impacts are to do with the social environment, for instance the set of expectations we have for 'being an adult' in society, and some are emergent from a difference in capability.'

Overview

In the United Kingdom an increasing number of parents continue to provide care for their learning disabled adult offspring for prolonged periods of time (Davys, 2007, Grant, 2010, Cairns, 2012, Hines et al., 2013, Findlay et al., 2013, Pryce et al., 2015). Family care has received significant attention since the 1990s and one focus has been finding ways to better support the needs of informal care providers (Department of Health 1995; Scottish Executive 2006, Sundstrom et al., 2008).

The following study is an exploration of mothers' experiences of their adult offspring with diagnoses of mild learning disabilities (LD). It was carried out in order to gain a greater understanding of such experiences. It draws attention to the emotional, psychological, physical and social impact their circumstances may have on them. It is here argued that a detailed investigation of the experiences and what they mean to those experiencing them will provide a framework of understanding for professionals working with this client group. This study also aims to meet the needs of mothers who care for an offspring with a diagnosis of mild LD by providing them with the knowledge they may require to access and utilise the available services. This project focuses specifically on mothers of adult offspring whose learning disabilities fall in the mild range, due to the fact that this particular condition can be perceived as 'invisible' (Nouwens et al., 2016, Care Quality Commission, 2012) and it can have a significant impact on the individual with LD as well as their parent. Thus, while I acknowledge the importance of support for individuals with LD, the main focus is on their mothers, the mothers' experiences and psychological needs. The study has relevance to Counselling Psychology practice in that it sheds some light on the experiences of such mothers and as a result can inform the way psychological interventions are delivered to parents who have an adult offspring with a diagnosis of mild LD.

The study begins with a review of definitions and considerations of the constructs of learning disabilities. Following this, it delivers a critical appraisal of the existing literature in order to provide the background and context of the research and to outline existing knowledge relevant to the research aims. Due to the fact that there is limited research available on parents of adult offspring with diagnoses of LD, especially in the mild range, literature searches also include other conditions such as autism as well as LD diagnoses. The current study is concerned with exploring mothers' experiences, thus, qualitative studies were prioritised over quantitative studies due to the experiential focus of qualitative research. Following the review of literature, justification for the current project is outlined. The chapter concludes with the research questions, aims and relevance to counselling psychology attention.

The following section reviews definitions and considerations of the constructs of learning disabilities.

1.1 The term 'Learning Disabilities'

As discussed above, the idea of 'learning disabilities', both as a concept and as terminology, is contested. In this thesis, I take Shakespeare's (2001) approach to understanding disability as including both real impairment/difference (biomedical model), and being situated in social and cultural meanings which recursively influence the lives of those labelled disabled (social model). These issues are particularly acute, arguably, with learning disabilities which are not visible in the same way as a missing limb. Learning disability as a concept is indeed inextricably linked to the emergence of psychological testing, creating a 'norm' from which children could vary (Connor & Ferri, 2005).

This was indeed the basis upon which, in the 1960's, Kirk (1962; 1963) first defined learning disabilities as a syndrome found in children with a low intelligence

quotient (IQ), characterised by specific difficulties in learning how to write, read and understand mathematics. Because of the multidisciplinary nature of the field, there is ongoing debate on the issues of definition, with several definitions currently appearing in professional literature. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013) and the British Psychological Society (BPS, 2015) use term 'intellectual disabilities', while the International Classification of Diseases (ICD-10, 2010) still use the term 'mental retardation'. However, in terms of diagnostic criteria, there are a number of characteristics of LD which have gained widespread agreement across professional boundaries within the United Kingdom. Irrespective of the exact terminology or the wording in the various definitions, there are currently three core criteria used to define learning disability: a) significant impairment of intellectual functioning; b) significant impairment of adaptive/social functioning; c) age of onset before adulthood (age 18). For a person to be considered to have learning disabilities, all three criteria must be met (Department of Health, 2001, BPS, 2015).

The levels of learning disabilities, rather than specific learning difficulties, are often categorised into four groups (mild, moderate, severe and profound) based on cognitive impairment, which is based on IQ scores. The average IQ score of a population is 100. According to the DSM-5 (APA, 2013), a person with an IQ score between 50-70 is considered to have mild learning disabilities, between 35-50 it is moderate, 20-35, severe and a person with an IQ score of less than 20 is considered to have profound learning disabilities. However, because IQ scores can fluctuate due to personal development, learning disabilities should not be categorised based on IQ scores alone. As mentioned above, adaptive/social functioning and age of onset before adulthood also play a part. In addition, apart from random errors, there are other factors that can contribute to lower IQ scores. Communication and mental health problems, low self-esteem, motivation and cultural differences all can affect IQ (Ardila, 1995,

Furnham, 2001, Shuttleworth, et.al. 2004). Although the cultural bias of IQ testing is recognised, it is still used in a culture-blind manner (Fernando, 1989). Social impairment is also difficult to categorise due to the wide range of a person's functions (e.g., eating and washing, keeping safe, etc) and social context. Factors such as ethnicity, religion, age and gender should also be taken into consideration when measuring social impairment. It can be seen here, that the definition of learning disability is hence both functional and more purely based on capacity; it is a person's interaction with their environment and ability to complete socially sanctioned tasks which in part attracts a diagnosis. Diagnostic approaches, essentialism, strict criteria and labelling can be problematic and can negatively affect the person with the diagnosis. Stigma, oppression and discrimination are some of many obstacles individuals with LD experience (Khan, 1985).

As mentioned above, the concept of disability seems even more complex when discussing diagnoses of learning disabilities where difference seems much less clear. It is important that as a society we recognise the potential of individuals with an LD diagnosis and empower them to utilise it while promoting social inclusion (Ryan & Runswick-Cole 2008). Individuals with LD diagnosis do need help and support in many areas of daily life, nonetheless, they deserve to experience inclusion instead of exclusion and be able to live a happy and fulfilling life instead of being ostracised (Connor & Ferri, 2005).

The next section will explore the difficulties encountered with definitions and aetiology of learning disabilities while considering the historical context.

1.1.1 Difficulties with definitions

Historically, learning disabilities have been difficult to classify and for the past two decades researchers have started to address issues of classification and definition (Fletcher, 1999, Morris & Lyon, 2006). Traditional classifications viewed LD as a form of unexpected under-achievement. LD was defined as a varied group of disorders with a common discrepancy between IQ and achievement. Although current classification also includes the assessment of adaptive/social functioning, the classification model used today still relies heavily on assessing a person's intellectual functioning using psychometric testing. This is enhanced in the case of assessing someone with mild learning disabilities who might not show significant impairment in adaptive/social functioning.

Switzky, Greenspan and Granfield (1996) argue that in practice, IQ scores are still the main criteria used in classifying those with mild LD and in turn this diagnostic model has created and supported an industry that dominates the identification of learning disabilities. Others (e.g., Fletcher, 1999, Lyon, 2006, Barnes et al., 2002) posit that research on the classification of learning disabilities has provided little evidence that discrepancies in IQ represent a specific learning disability, which is different from other forms of under-achievement. Even today, definitions of learning disabilities are still problematic in that one can argue that people with LD are seen as a group classified subjectively which does not fit into definite scientific categories.

Currently the terms 'learning disabilities' (LD) and 'intellectual disabilities'(ID) have been used synonymously. As such, it has been posited that the term intellectual disabilities is the preferred and used term within the international scientific community (Emerson, 2008). Emerson suggested that this term prevents derogatory labelling, but is still used alongside the terms learning disabilities and mental retardation. The term

learning disabilities generally indicates deficits in learning whereas the term intellectual disabilities more suggests difficulties with the intellect (Emerson, 2008).

The term learning disabilities is the official term currently used in the UK. Participants who took part in the current study used this term as opposed to any other term (e.g., intellectual disabilities). For these two reasons, the term 'learning disabilities' is used throughout the study. Other terms are used in a historical context. The World Health Organisation (WHO) is to publish the 11th Revision of its International Classification of Diseases (ICD-11) this year and propose replacing the term 'mental retardation' with 'intellectual disability'.

1.2 **The historical context**

In order to contextualise the present study on learning disabilities it is important to consider the historical views on the perceived phenomenon and how they have shaped current constructs. Historically, in medieval England, there was a big variety of attitudes to disability. Some people perceived disability as punishment for sin, others thought that disabled people were unique and closer to God. Whichever view people held, many individuals with disabilities experienced exclusion from society in the form of stopping them from having access to educational and other welfare systems. The *Mental Deficiency Act (1913)*, later replaced by the *Mental Health Act (*1959)*, established the start of decades of official policies. *The Mental Deficiency Act* defined grades of impairment and also outlined the individuals who fell within the set parameters. It also had the responsibility of providing medical certificates and orders required to either institutionalise these individuals or to place them under statutory guardianship. It founded the Board of Control as the central authority and defined its membership and functions, ensuring that all councils established a Mental Deficiency Committee. This

committee had the responsibility to assess the amount of need in the area while instituting and maintaining the services for mental impairment in the community. According to Potts and Fido (1991), the drive to institutionalization was based on the fear that mental defectives would 'propagate their stock'. According to Digby (1996) this also exposed the concern that young 'feeble-minded' women were being immoral.

Throughout the 18th and 19th centuries, around the time of Industrial Revolution, the practice was to place identified disabled individuals in asylums, workhouses, and special schools. This led to the isolation of such individuals but also allowed for exhaustive study of treatment of impairments, creating the basis for better scientific understanding and classification. The birth of mental institutions and asylums led to the development of a science of mental disease, rather than mental health, establishing a system of categorisation that has lasted to this day. In his influential thesis on madness and civilization, Michel Foucault wrote that under the cultural context of the early 19th century, the asylum reduced differences, repressed vices and eliminated irregularities (Foucault, 1967). The medical approach that has since followed has tried to provide a "medicalisation of a social problem" and is "indicative of the way our society deals with people it finds useless" (Ryan & Thomas, 1980, p.15), economically inactive and incapable of improving learning (Ryan & Thomas, 1980).

The *Mental Health Act* (1959) made new provisions in relation to the treatment and care of 'mentally disordered' individuals, with respect to their property and various affairs. However, it still followed a clinical model of thinking, seeing people with mental health needs in general, including people with LD, as abnormal. In this medical model of thinking, long-stay hospitals treated people whom society had rejected. Patients were regarded as pathological cases that needed to be admitted and taken into care.

The shift in social and medical perspectives accompanied the sociological approaches that came to prominence in the 1960's together with rights movements. These approaches tried to explain and address concepts of deviance, devaluation, stigmatisation and otherness. The concept of learning disabilities began to be viewed in a context which took into consideration its social dimension, changing the focus from the individual with intellectual deficits to the process of socialisation, which labelled the individual as 'deficient' in the first place (Atkinson, 1997). Despite the influence of these sociological approaches, there was still a great deal of stigma involved in the perception of LD, and segregation and discrimination still occurred (Khan, 1985).

Self-advocacy for people with a diagnosis of LD also emerged in the 1960s when they joined forces to challenge the way they were treated. At the core of its development was the idea that people with LD diagnosis had the same rights as everyone else. As a result of the movement, long-stay hospitals started closing gradually as people who had claimed their full rights were no longer placed in institutions. The growth of the movement has shown how people with an LD diagnosis can participate in research and make a difference to services and the understanding of LD (Shakespeare, 2009). Pugach (2001) has argued that in line with the self-advocacy movement, qualitative research has given a voice to many people with disabilities who otherwise would have never been heard.

The opportunity for people with an LD diagnosis to be more integrated and valued by others came from the concept of '*normalisation*'. The principle of 'normalisation' was first proposed by Nirje (1969) and further developed amongst others by Wolfensberger (1972). Wolfensberger (1975) stated that the label of learning disabilities was powerful and stigmatising. He believed that the only way to stop devaluing people with LD was through re-valuing of people (Atkinson, 1997). Then

Wolfensberger (1983) proposed the concept of 'social role valorisation' in order to prevent people with LD from being stuck in on-going negative social roles. He believed that the only way this would be possible, would be by creating and promoting positive social roles for people with an LD diagnosis, leading them to take part in ordinary community life.

In the UK a number of steps taken by the Government followed in order to bring change into the provision of care for people diagnosed with LD. The 1981 paper *Care in the Community* published by the Department of Health and Social Security (1981) played a large part in bringing about some positive changes, resulting in a shift in control from health services to local authority. For example, during the 1980's, a large number of people with an LD diagnosis were relocated from hospitals to the community (Booth, Simons & Booth, 1989).

Disability studies also emerged in the 1980s and followed the precedents of Marxim, post-colonial studies, feminism, lesbian and gay studies, and all intellectual movements. They had made new enquiries and generated new insights and evidence on the basis of an overt political affiliation with social movements of liberation. Anti-racism, Gay rights, Women's liberation and Disability rights, are similar in many ways. They all challenge the biologisation of difference, involve identity politics and they all have involved an alliance of academia and activism. Shakespeare (2014) argued that "there are similarities between the theorisation of disability and the theorisation of race, gender and sexuality", but differences arise because the oppression faced by disabled people is more complex than sexism, racism and homophobia. The complexity arises from the fact that even with or without the social barriers or oppression it would still be problematic to have an impairment as many impairments are limiting or difficult (Shakespeare, 2014).

In the past 20 years, several qualitative research approaches have been developed and used to study the views and experiences of individuals with an LD diagnosis as well as their carers. Quantitative methods have explored the views of those with LD through surveys and questionnaires, while qualitative methods have focused on meanings through more in-depth engagement with participants. The focus on meanings was applied in studies that investigated the meaning of learning disabilities from an insider point of view (Bogdan & Taylor, 1982, Atkinson,1988, 1997; Jahoda et al., 1988, Shessel & Reiff, 1999, Jones & Miesen, 1992; Miesen & Jones, 1997, Chamberlayne et al., 2000). Researchers have given people with LD and their families the opportunity to have their voices heard (Jahoda, et al., 1998). Many studies focused on different aspects of life such as the family's religion, hierarchical structure, nationality and life experiences, as they all contribute to the manner in which members of the family respond to diagnosis, treatment, and ongoing care of an offspring with a disability (Chambers & Chambers, 2015). Different models of disability have also contributed to how the concept of learning disabilities has been implemented and used by the society over the years and this is discussed in the following sections.

1.3 Models of disability

These models are necessary tools for characterising impairment. They are used as the base from which society and authorities can devise strategies and meet the needs of disabled people. The models help to explain and gain an understanding of disability issues as well as the perspective held by those creating and applying the models. The following section focuses on the biological (medical) model and social models of disability with a particular focus on how they view learning disabilities.

1.3.1 The biological model of disability

Research in the field of learning disabilities can be traced to late 1930's when Goldstein (1939) showed that a brain injury rarely caused particular disorders. Werner and Strauss (1940) continued Goldstein's work and helped establish the foundations of the concept of learning disabilities as a syndrome associated with neurological dysfunction. Werner and Strauss' paradigm has been challenged since (see Kavale & Forness, 1985), but it has retained a strong hold on current conceptualisations of learning disabilities.

Previous studies have found that genetic factors are in some cases involved in the development of learning disabilities (e.g., Ingalls & Goldstein, 1999). Asherson & Curran (2001) argued that many people with LD have identifiable chromosomal, metabolic or genetic defects. Naglierei, et al., (2007) proposed that the aetiology of learning disabilities is still unclear. It is likely that there are as many underlying mechanisms involved as there are specific types of LD. Evidence also seems to show that most LD do not stem from a specific area of the brain, but from problems with gathering and processing information from numerous brain areas, and that different learning disabilities have unique neurological footprints (Scott, et al., 2001). In addition, the presence of LD may also occur as the result of environmental factors that interfere with the development of the brain. Even though different causes for LD have been stipulated (Rutter & Taylor, 2008), the unclear aetiology only strengthens the argument that the concept of learning disabilities can and should be constructed in different ways other than it being identified and stabilised by the medical profession alone. One could argue that qualitative research, such as the present study, plays an important role through developing personal stories and meanings, in establishing the emergence of what is perceived as being learning disabilities.

Oliver and Barnes criticised the biological model by saying: "While medical and rehabilitative interventions may be appropriate to treat disease and illness, it is increasingly apparent that they are of little use for the treatment of disability" (Oliver and Barnes, 2012: 19). Shakespeare (2009) argued this further and stated that disabled people are often affected by all of the three following factors: physical, psychological and external (e.g., social) aspects, a position taken in the current study. I argue that multiple approaches to learning disabilities are needed. If the importance of intervening at multiple levels is accepted, this will allow for the improvement of psychological support, help deal with both impairment-related and social exclusion-related complexities, and it will also remind us of the importance of health. According to a Canadian survey for adults (McColl et al., 210), disabled people have higher unmet needs than non-disabled people and those with learning difficulties in particular are at risk of poor healthcare (Redley et al., 2012). Thus, more needs to be done in order to support this particular client group.

Watson and Vehmas (2014) point out some useful aspects of the biological model. They state that categories of impairment and illness can play a positive role in allocating services, including welfare benefits, psychological and social support. It is unfeasible for people to receive public services without some kind of formal proof that they are entitled to them. A process is needed to legitimate and allocate support in a welfare state (Shakespeare, 2009). Diagnosis and welfare assessments are currently the prime means by which individuals get disabled parking badge, freedom pass or any welfare benefits. In academic institutions such as schools, it is the necessary confirmation that there is a real difference, and that the individual is not lazy but that they have a specific medical condition which negatively influences their performance. Subsequently, they may be entitled to extra support or special arrangements during exams, such as extra time. One can argue that this can be liberating and empowering

process which facilitates functioning and inclusion (Farrugia, 2009).

Dan Goodley (2011) criticises the biological model and draws on Foucault's idea of 'biopower'. He suggests that there is only discursive power/knowledge being operated by professionals imposing their principles of 'normality and deviance' and that there is no material reality to these impairments (Goodley, 2011). Any setting such as schools, hospitals, rehabilitation centres can be perceived as places where disability is created. Vehmas & Makela (2008) present a different view and argue that if not for clinics and other settings, LD would either not exist, or at least be less of a problem. For mild learning disability, it may be that the main problem is social treatment. For moderate and profound LD, it is harder to maintain that the intrinsic deficit is not the main source of difficulty (Vehmas, 2010). Recent empirical evidence in the case of autism disproves the claim that diagnosis is a social determinant of health overcomes: there appear to have been neither beneficial nor negative effects for children who received a diagnosis (Russell et al., 2012). I acknowledge that diagnosis may sometimes be oppressive and may have damaging effects on the individual. Therefore we need to strive for a better understanding of impairment, illness, and difference and to be more careful both about how we diagnose and how we respond to people who are diagnosed. Furthermore, the concept of learning disabilities should be constructed in different ways, other than it being identified only by one approach, which is in line with Counselling Psychology humanistic approach.

1.3.2 Social models of disability

Within social approaches to disability, there are varying theoretical and political motivations which influence how people perceive disability. Some of them focus more on discourse (e.g., social constructionism), while others focus more on political or sociological aspects of disability. Regardless of the precise view point, the social model

states that it is neither the form of embodiment nor the attempts to deal with the personal limitations of impairment which proves problematic, rather, the problem lies in the society's ability to address them appropriately. In other words, it is social oppression and social barriers that are the main negative factors for people living with impairment. For many disabled people these factors cause more difficulties than the impairment itself (Shakespeare, 2009). According to the social model, a key element of disability is the extent to which a society eliminates barriers and enables people to participate, regardless of their individual differences. In this way disability is no longer perceived as solely caused by biological deficits but as nothing to do with physical bodies. Thus, the disability movement moved towards demanding that disability be defined entirely by the social aspects such as oppression, relations and barriers, rather than being seen as issues of invalidity, dependency and, reliance.

One of the main aims of the social model is focus on the distinction between impairment and disability. Disability is defined as a social construction whereas impairment is defined on an individual biological basis. Disability is what makes impairment an issue. According to modellists, social oppression and social barriers create disability, and this requires a change in approaches to campaigning and analysis. Although it may seem easy to separate impairment from disability, research has been unable to adequately apply the social model. This is because it is difficult to distinguish impairment from disability in the everyday life (e.g. Watson, 2002, 2003; Grech, 2009; Soder, 2009; Hwang, and Charnley, 2010), for example, people with learning difficulties (Stalker, 2012).

In the social model, there is a shift onto societal inclusion and exclusion rather than on the individuals' physical or mental limitations. There are criticisms that it fails to recognize the role of impairment and fails to embrace the range of experiences in

terms of impairment and disability. For example, Shakespeare (2009), who recognizes the importance played by the social model in stressing the responsibility of society, points out some limitations of the model, and urges the need for a new model that will overcome the "medical vs. social" dichotomy, the position I take in this study. Nonetheless, the value of the social model tradition highlights oppression and exclusion, issues that have been neglected in all previous research on disability (Shakespeare, 2009). Yet impairment almost always plays some role in the lives of disabled people, even if social arrangements or cultural context minimize the exclusion or disadvantage (Shakespeare, 2009). By suggesting that individuals with similar impairments have very different experiences, it is here argued, that the extent of disadvantage is not solely dictated by the nature of impairment, or the extent of the barriers and oppression. It is often the combination of both.

Several authors (e.g., Artiles, 2004; Connor, 2005; Neufeld & Hoskyn, 2005; Rapley, 2004; Rueda, 2005) argue that learning disabilities are not an objective fact or necessarily true, instead, they are social constructs that should be open to interpretation. In a broader context of disability, Albrecht and Levy (1981) argue that there is a degree of objective reality in many types of disability but that essentially what becomes defined as a disability is influenced by the social meanings that individuals attach to psychological and physical impairments. As such, the supposedly objective criteria and reality of disability reflects the assumptions and evaluations of those in a position of power. Lennard Davis said that "disability is not so much the lack of a sense of the presence of physical or mental impairment as it is the reception and construction of that difference" (Davis, 2002:50). Corker and Shakespeare (2002) explain that the concept of disability is a product of social, economic, cultural and political structures of modern society. This has important implications for Counselling Psychology in that practitioners, being what Foucault (1973) called the 'apparatus' by which discourses of

disability are spoken, need to be aware of the role they play when defining people based on a diagnosis. It is not so much a matter of whether impairment exists or not, it is the meaning that society attributes to it. One of the problems with classification (e.g., categorising learning disabilities) is that society assigns more value to some groups than others and this creates unequal power dynamics (Hall, 2000). These standpoints present implications for research. Rather than just focusing on classification and comparing groups of people with and without an LD diagnosis, from a position of the hard sciences (see Thomas & Loxley, 2001), more research is needed to explore the meanings that people assign to perceived differences and impairments and how these are used in the construct of disability. From a social constructionist standpoint, Nunkoosing (2000, p. 50) has argued that:

"The meaning that is shared about learning disability is created through our language, social interaction and culture. These meanings are the product of specific contexts in professions such as medicine, nursing, social work, psychology, education and so on. Thus, what we take to be personal understanding has actually been learned and passed on through our education and employment. In this way some explanations are privileged over others."

Nunkoosing (2000) argued that what is known about learning disabilities is mostly from the point of view of the academics and other professionals and that as long as this continues to happen the principles of participation and empowerment are not going to be fully met. This emphasizes the importance of qualitative research that gives participants with LD the chance to have their voices heard. Craib (1997) for example criticized the social constructionism for focusing on deconstructing terminology rather than engaging with the world as it is. In other words, rather than research the lives of disabled people, research has focused on how 'disability' has been constructed at

different times and in different places (Craib, 1997). Sayer (2011) argues that respect and inclusion are not about words or thoughts but about social justice. This is one of the reasons why Meekosha and others (2009) position themselves as 'Critical Disabilities Studies' and argue that the equality model and the social model do not go far enough, and that the ethical task is to 'mobilize both discursive analysis and substantive intervention' (Shildrick, 2012). Meekosha and Shuttleworth in their work describe how CDS approach moves away from simplistic binaries, and how the struggle for social justice "is not simply social, economic and political but also psychological, cultural, discursive and carnal" (Meekosha & Shuttleworth, 2009: 50). Another valuable aspect of CDS approach is that it makes parallels with other oppressed groups, for example, he concept of 'disablism' paralleling hetero/sexism and racism (Goodley, 2011).

In defining 'disablism', Thomas (2007) refers to an intricate interaction of factors (social, cultural and economic) that contribute to disabled peoples' exclusion. Goodley and Runswick-Cole (2016) posit that analysis of disablism is best done when contrasted to ableism. CDS challenge both disablism and ableism and advocate that activists become empowered to demand their rights in much the same way as feminists or homosexuals have done previously. The benefits from the disability rights movement in Britain are widespread and have had a transformational effect on society with changes such as the Disability Discrimination Acts of 1995 and 2005, The Equality Act 2010 and the development of independent living and direct payments leading to the removal of barriers to access.

The disability rights movement has gone through different forms. For the first decade, it primarily called for the removal of barriers and a change in the status quo. The subsequent formation of the Independent Living Fund (1988), the shift to community care and the passing of the Community Care Act 1996 (Direct Payments),

enabled more independence and autonomy for disabled people. The disability movement became a major service provider in many localities. Meanwhile, the Disability Discrimination Acts of 1995 and 2005 enforced the improved accessibility to public buildings and transport services. Unfortunately the global financial crisis has led to cutbacks in both welfare benefits and services and caused increased difficulties for disabled individuals.

Regardless of their strengths and weaknesses, each of the above models are based on commitment to improving the lives of disabled individuals by the removal of barriers and the promotion of social inclusion. The current study shares these views and this is explained in the following section.

1.3.3 Position taken in the current study

The position taken in the current study is one which tries to avoid the perils of either biological, social or cultural determinism. Instead, it takes a more holistic approach and argues that the critical realist perspective taken in this study permits complexity as rather than resorting to relativism it allows for acceptance of an external reality. Baskar argued that "Things exist and act independently of our descriptions, but we can only know them under particular descriptions" (Baskar, 1975:250). In other words, critical realists make a distinction between ontology and epistemology. There are objects independent of knowledge. Diseases are not constituted by the labels that describe them. Impairment exists and has its own reality of experience irrespective of how it is view by varying cultures. In disability research, strong arguments from the critical realist perspective have been made by Simon Williams (1999), Berthe Danermark (Danermark & Gellerstedt, 2004), and more recently by Nick Watson (2012). Each tries to resolve the differences between the biological model and the social model by an analysis that gives weight to different aspects that contribute to the

complex disability experience. Williams stated that: "disability is an emergent property, located temporarily speaking, in terms of the interplay between the biological reality of physiological impairment, structural conditioning (i.e. enablements/constraints) and socio-cultural interaction/elaboration" (Williams, 1999, 810). Denmark and Gellerstedt (2004) suggest that disability phenomenon can only be approached analytically by understanding that it is not generated solely by biological, socio-economic or cultural mechanisms. The current study agrees with this and the critical realist perspective strengthens this view. By combining the best aspects of social constructionist, traditional approaches and other social model approaches it offers a good base from which to elaborate a workable understanding of disability. I also share the views of Stalker (2012) on disability in that "often the distinction between biological/individual impairment and social/structural disability is conceptually and empirically very difficult to sustain". For example, learning disability may be associated with stigma and discrimination, but the individual deficits and the social responses shade into each other, and it is hard to extricate the contribution of each factor. Impairments, which cause discomfort (such as pain) may be "generated through the interplay of physiological, psychological and socio-cultural factors and thus the individual experience can never be separated from the social context" (Wall, 1999). Therefore, it is here argued that the biological and the social factors are always entwined. For instance, disabling barriers come into play when one has an impairment in the first place. Second, impairments are sometimes caused by social processes (Abberley, 1987). For example, poverty and malnutrition or lack of adequate medical care may contribute to a person's impairment. If social provision was improved, these barriers would be minimized, but if there was no impairment in the first place, there would be no restrictions in the person's life. It is here argued that the problem arises out of the combination of impairment effects and social restrictions. Third, what degree of physical and intellectual limitation counts as

impairment is often a social judgement. For example, mild learning disability, which is defined as two standard deviations below average intelligence as measured by IQ tests, is on a continuum. Here, the numbers of impaired people depend on the definition of what counts as impairment, or rather, what counts as average vision of intelligence. Some argue (e.g the social model) that the term learning disabilities is a social construct, which draws a 'normal/abnormal' measure based on IQ, which in fact is a flawed measure (Shuttleworth-Edwards, et al., 2004). However, prior to the development of intelligence testing, people with below average intelligence were considered to be different (Wright & Digby, 1996). Some people are at the low end of the intelligence spectrum whichever way we decide to measure it. Decades ago it was not such a social problem, because people could flourish in the mainstream while being supported by their family. In the modern society, these individuals often struggle in many areas of daily life. For example, their lower than average cognitive and functional abilities prevent them from entering universities, learn to work in a knowledge economy or even live independently (Shuttleworth-Edwards, et al., 2004). Therefore, a process is needed to identify people who are now in danger of exclusion, and support them to maximise their abilities, and then help them make a productive contribution within their capacities, and to live a full and valued existence. While most high income countries have failed to achieve these objectives, labelling has significantly contributed to devaluing people with disabilities and failed to see the strengths of people with an LD diagnosis. In the case of learning disabilities, especially in the mild range, social constructionists would argue that individuals with a diagnosis of mild LD are broadly competent and can live independently or with minimal support. They would argue that prior to intelligence testing these individuals would probably not have been identified as 'disabled'.

Biomedical sciences are historically and culturally located and ways of thinking about impairment change and develop over time. But this is a different claim to suggesting that there is no underlying reality that these sciences are trying to access. Impairments vary greatly in the nature and extent of their impact on a person. Consequently, disability experience is very varied and disability is an aggregate of different health conditions or impairments is yet more contingent as a category. I acknowledge the fact that social constructionism has often been liberating due to its ideology around disability being socially and culturally constructed and not being fixed, and can thus be potentially changed (Shakespeare & Erickson, 2010). However, I also acknowledge that biomedical sciences play a part in the process too. For example, Goodley (2011) illustrates how Down syndrome has had different names and implications throughout the years, concluding that Down syndrome is a "phenomenon created by signification" (Goodley, 2011: 117). While some agree with the cultural and political meanings and social consequences of what we now know as Down syndrome, all of which affect the lived experience of a person with this condition (Wright, 2011), they argue that this does not mean that Down syndrome, as an organic impairment, is different now from what it was when it was first identified in 1866 (Shakespeare, 2009). It is an intellectual impairment caused by having three copies of chromosome 21. According to Shakespeare (2009), the error that social constructionists make is to confuse objects, and ideas about objects. The idea of Down syndrome is a social construct, but Down syndrome is not a social construct (Hacking, 1999). This is not to say that external social and environmental factors are not relevant but that they often interact with intrinsic biological differences in the individual, a position taken in the current study.

In conclusion, it is here argued that social disability models do not fully account for personal experience of impairment. In addition, they do not fully account for the causality between impairment and disadvantage. However, they do argue how social barriers disable. On the other hand, while biological perspectives provide helpful empirical evidence and explore the impact of impairment on an individual's sense of self as well as their relations, it fails to situate disability in economic and political structures. The bio-psycho-social model that lies at the heart of the International Classification of functioning, Disability and Health (ICF) helps understand the complexity of disability. I strongly support this view and so does the current study. The model recognizes "the role of the environment in causing restriction" (Imrie, 2004) while not using disability in terms of actual limitation, impairment or environmental barriers. It uses it to describe the entire process (Bornman, 2004). Along with Shakespeare (et al., 2009), the current study argues that "disability is a complex interaction of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision". Disabled peoples' lives encompass both the limitations of impairment and the effects of social discrimination imposed on them. A barrier-free world for people with an LD diagnosis is difficult to imagine. However, it would be undesirable to recreate a world in which literacy and numeracy were not important attributes for independence and advancement. Though many people with an LD diagnosis have basic literacy and numeracy skills, there are many examples of people with LD living autonomously and in employment. Creating better opportunities in supported employment for people with disabilities so that they may benefit from the income, self-esteem and social integration should be a priority for any disability policy (Gosling and Cotterill, 2000).

1.4 Current situation

In the United Kingdom, the *Human Rights Act* 1998 and the *Disability Discrimination Act* 2005 act as a legislation which applies to service providers and which protects people with an LD diagnosis. Furthermore, the Crown Prosecution service is developing a new policy on crimes where people with a diagnosis of LD are victims or witnesses. The Department of Health is also working with the Home Office and the Ministry of Justice, amongst other agencies, in order to implement the *Disability Hate Crime* strategy, where issues related to people diagnosed with a learning disability will be tackled.

In 2001, the Department of Health published a white paper entitled, *Valuing People*: A New Strategy for Learning Disability for the 21st Century. This was the first white paper for people with learning disability since *Better Services for the Mentally Handicapped* in June 1971. *Valuing People* stated that we should all be citizens with legal and civil rights. It supported independence, choice and inclusiveness for people with learning disabilities. *Valuing People* stressed the importance of involving people with learning disabilities in decision-making processes that affected their lives. It also emphasised that people with learning disabilities should be seen as active partners in policy development. At the core of the original *Valuing People* were concepts of person centred planning and advocacy and direct payments to give people with learning disabilities more control over their lives.

In 2007, the Department of Health took this further with *Putting People First*, with an emphasis towards greater personalisation of services, including a greater focus on person centred approaches and personal budgets (this was a broad agenda of the NHS). Following *Healthcare for All* (Department of Health, 2008), an independent inquiry into access to healthcare for people with an LD diagnosis, the Department of

Health (2009) published *Valuing People Now*. This paper retains the vision set out in 2001 that people with a diagnosis of LD must be treated with the same respect and dignity and lead their lives with the same opportunities as anybody else. These steps follow the principle of 'normalisation' and equality where people with a diagnosis of LD are helped in achieving positive social roles and taking part in ordinary family and community life.

1.5 Family and social inclusion

Many studies have explored the role families play in how individuals with a diagnosis of learning disabilities cope with life (e.g., Morrison & Cosden, 1997; Switzer, 1985; Vogel & Aldeman, 1990; Vogel et al., 1993). Many of these studies have illustrated that environmental factors, such as family interactions, make the individual with LD more vulnerable to negative outcomes. Research also has shown that parents of children with an LD diagnosis report higher levels of anxiety than parents of children who do not have the condition (Margalit & Heiman, 1986). They report higher levels of conflict among family members (Margalit & Almougy, 1991; Toro, Weissberg, Guare et al., 1990) and seem to perceive their families as more chaotic (Amerikaner & Omizo, 1984). Research conducted by Lardieri, Blacher, & Swanson, 2000 has also revealed that being a parent of an offspring with an LD diagnosis increases the chances of experiencing stress. A study conducted by Antshel & Joseph (2006) showed that mothers of children diagnosed with LD report higher levels of stress than mothers of children without an LD diagnosis. In turn this stress affects the support a child with LD receives from their family. Additionally, Dyson (2003) investigated the global and academic self–concept, and social competence and behavioural problems of children with LD within their family context and found that social competence and behavioural problems were related to their parents' stress.

In a similar study on a maternal perspective of having a child with LD and challenging behaviour, the data identified 'secondary stressors' for the parents. These were social isolation, conflict, limitation of lifestyle and self-blame. The study proposed that the amalgamated impact of these can weaken parents' coping resources and, therefore, may prove to be as significant to the negative association with maternal wellbeing as the problem behaviour (Johnson et al., 2006). Hubert (2011) in her qualitative study on perspectives of mothers of young people with a diagnosis of LD and challenging behaviour, points out the fact that more research is needed on the perspectives of families caring for an offspring with LD and challenging behaviour. The main aim of the research was to gain understanding of the experiences and perspectives of families, especially mothers, of young people with these complex needs, including attitudes to long term residential care. The results of this study highlighted social isolation, family tensions and lack of effective services.

Such findings highlight the need for services to support not only individuals who have an LD diagnosis but also their families. Counselling Psychology can play a role in this by offering interventions that take into account the family context (Ferguson, 2002; Risdale & Singer, 2004; Turnbull & Turnbull, 2001). These can range from family therapy and psychoeducation offered to the family in order to increase their knowledge of LD and identify coping strategies. A recent meta-analysis on the effectiveness of psychoeducation for relapse, symptoms, knowledge, adherence and functioning in psychotic disorders found that interventions that included families were more effective in reducing symptoms by the end of treatment and preventing relapse at 7-12 month follow-up (Lincoln, Wilhelm & Nestoriuc, 2009). Another intervention could be the use of family therapy to deal with family anxiety and stress. Fidell (2000), amongst others, has demonstrated that family therapy can be successfully used with families with individuals with a diagnosis of LD.

As illustrated above, a significant area of research within the field of learning disabilities has focused on understanding the impact that a person with an LD diagnosis may have upon their family. The majority of this work has focused on children (e.g. Dumas et al. 1991; Floyd & Gallagher 1997; Deater-Deckard 1998; Stores et al. 1998; Ong et al.1999; Chavira et al. 2000; Dunn et al. 2001; Weiss 2002). The current project acknowledges the invaluable contribution these studies have made in the field of research. However, it takes this further by proposing that more research is needed in the area of families experiences of caring for their adult offspring with a diagnosis of LD.

In one such study Rapanaro (2008) investigated perceived benefits and negative impact of challenges associated with stressful events and caring demands encountered by parents caring for young adults with LD in the transition to adulthood. Repanaro looked at parental personal growth and enhanced personal resources (Rapanaro et al., 2009). The results revealed that parents identified a range of negative as well as positive outcomes, in relation to stressful events and chronic demands encountered in this period. The positive outcomes were personal growth and enhanced personal resources. The study concluded that the language of stress and burden often used to describe parents' experiences during the period of their son or daughter's transition to adulthood, needs to coexist with a language of fulfilment, growth and gain, as expressed by parents themselves. The implications of these findings, in relation to professional interaction with and support of parents in this period, were discussed. However, because the author used a quantitative content analysis, they did not capture the participants' rich experience and its meaning, something the current project aims to do. The current study uses qualitative analysis of data and focuses on mothers' lived experience and its meaning in order to capture their rich experience.

A number of studies have explored the process of transitioning into adulthood (Davis & Vander Stoep, 1997, Settersten & Ray, 2010, Fiorentino, et al., 1998, Osgood, et al., 2010). For many people, the time of transition from adolescence into adulthood is a crucial period that can shape the adult life span (Davis & Vander Stoep, 1997). In the case of individuals with an LD diagnosis, this process tends to be slower (Biwas, et al., 2016) often due formal services being abruptly withdrawn even though the need for them continues (Osgood, et al., 2010). Subsequently, longer transition to adulthood puts strain on the person in transition as well as their family (Settersten & Ray, 2010). The current study aims to address the above issues, however, the main focus is on adulthood in relation to adult offspring with a diagnosis of LD.

Dillenburger and McKerr (2010) in their study on parental experiences of their adult offspring with a disability took a critical realist position. They put forward the idea that reality exists (offspring's impairment) but how they (the parents) experience this reality is different for every one of them. This is in line with the current study. Dillenburger and McKerr (2010) highlighted that research-informed policy and practice is needed for carers of adult offspring with disabilities. The findings show severe lack of support, respite care and future planning, which causes high stress levels for carers. While the study addresses many practical concerns, it seems that psychological concerns are omitted, an issue the current study tries to address. In addition, the authors included conditions such as Down Syndrome, Cerebral Palsy, Autistic Spectrum Disorder, Deafness and Blindness, and Prader-Willy Syndrome. One can argue that this does not constitute a homogeneous group and that the inclusion criteria could be narrowed down to one particular group. This is because the experiences of those who care for deaf people may be very different from the experiences of those who care for autistic individuals with challenging behaviour as each condition will face different

challenges. In a similar way, mothers of an adult offspring with a diagnosis of mild LD may have a very different experience to mothers who care for a child or an adult with a diagnosis of moderate, severe or profound LD. Dillenburger and McKerr's (2010) study demonstrates that many support services still do not meet the needs of parents of adult offspring with LD. This has implications for counselling psychology in that practitioners need to meet the needs of all their clients and should endeavour to advocate for them if they feel that their needs are not being fully met. Counselling psychology can play a role in this by offering psychosocial interventions that take into account the needs of the clients in a broader context (Risdale & Singer, 2004) in order to carry out in-depth assessments that take into account the needs of their clients.

Hill and Rose (2010) in their quantitative study on parenting stress models and their application to parents of adults with LD diagnoses based their study on Mash and Johnstone's model of parenting stress (Mash & Johnstone, 1990). Mash and Johnstone's stress model integrates three domains of characteristics that they hypothesise might interact with parent-child stress. These are: child characteristics, parent characteristics and environmental characteristics. Hill and Rose tested this model on mothers of adult offspring with a diagnosis of LD. Their primary research question was to establish the relative importance of the variables in predicting parenting stress. They concluded that all three characteristics appear to play an important role in parenting stress. The authors stress the importance of addressing how mothers feel about their offspring however, their experience is not captured here. As it is a quantitative study, one may argue that numbers leave us with an incomplete picture, identifying the phenomenon but not exploring it. The authors did not capture the participants' experience and its meaning, a phenomenon the current study aims to address.

Research on parents' experiences of caring for their adult offspring with an LD diagnosis in the UK is still limited. As a result, research looking specifically at mothers' experiences of caring for adult offspring with mild LD in particular is scarce. Thus, I argue, that more research is needed in this area. Previous literature illustrates that it is typically mothers who undertake primary responsibility for the dependent offspring's care (Smith, 1997). They are also likely to outlive their husbands, thereby becoming the sole parent (Greenberg, Seltzer, & Greenly, 1993; Hoyert & Seltzer, 1992). Thus, the current study claims that experiences of mothers are particularly important. The study explores the experiences of mothers who care for an adult offspring with a diagnosis of mild LD specifically. This is because mild learning disability is often what is called an 'invisible' or 'hidden' condition, and one that is not immediately apparent (Nouwens, et al., 2016, Seltzer, et al., 2005, Emerson, et al., 2010). The term 'invisible' or 'hidden' disability is an umbrella term that captures a whole spectrum of hidden disabilities or challenges that are primarily neurological in nature (Fitzgerald, 2000, Matthews et al., 2000, Valeras, 2010). Nearly one in three people in England have a long term condition, and many of these conditions are 'invisible' or not easily noticeable to someone else (Care Quality Commission, 2012). Generally seeing a person in a wheelchair, tells us a person may be disabled. However, what about invisible disabilities such as Crohn's disease, ASD or mild LD, that make daily living a bit more difficult for many people worldwide? Conditions such as depression are similar in this respect. Stone (2005) highlighted that in certain ways invisible conditions are no less problematic than those that are more visible and, in certain ways, may be considered to be more challenging. This is in line with the current study. I argue that supporting a son/daughter with an invisible disability may add a variety of challenges, which otherwise may have not occurred has the disability been visible. For example, potential implications may occur as the expectation of a person with mild learning disability diagnosis can be similar or

the same as the expectations of someone without the diagnosis (Webb & Whitaker, 2012).

The current study acknowledges the potential needs adult offspring with an LD diagnosis present with and the obstacles they may face on a daily basis. However, its main aim is to highlight that more research is needed in order for professionals to recognise the obstacles faced by mothers of adult offspring with a diagnosis of mild LD and improve services offered to them. The study puts forward the argument that a greater understanding of experiences of this client group is needed. It is hoped that it will draw attention to the emotional, physical and social impact their circumstances may have on them. It is also hoped that it will allow professionals to better conceptualise the possible difficulties this client group experiences, highlighting helpful ways of intervening or supporting such people therapeutically. Thus, it is important that mothers' voices are heard. It is here claimed that the current research will increase awareness of the possible difficulties this client group may face with both the professional population (e.g. through journal publications, presentations to relevant services, conferences) and the general population (e.g. through public health campaigns). Interventions and support that better fit this client group will lead to decreases in psychological distress and will improve their general quality of life. Furthermore, enabling parents of adult offspring with an LD diagnosis to disclose their experiences to others could potentially contribute to their increased treatment adherence. It is here argued that the field of Counselling Psychology will benefit from studies such as the one that is being proposed here as they are thought to provide a greater depth into the area of learning disabilities, an area currently considered to be under researched in the field of Counselling Psychology.

With these aims in mind, it here argued that a qualitative study is most appropriate in order to achieve the study aims. Application of qualitative methodology has frequently been used to investigate aspects of the experience of parents of adult offspring with LD diagnoses (Ryan & Runswick-Cole 2008; Findlay et al., 2013; Cairns, 2012; Davys, 2007; Smith, et al, 1995; Griffith et al., 2013). Despite interest in the experiences of parents of adult offspring with LD, there remains limited phenomenological research into the subjective experience of mothers of adult offspring with mild LD in particular. Thus, the chosen research methodology is Interpretative Phenomenological Analysis (IPA) as it is considered to be suitable for exploring individuals making sense of their personal experiences (Smith, 2004). It is hoped that the findings will help to raise professional awareness of mothers' experiences of adult offspring with a diagnosis of mild LD.

In relation to the literature review, a gap in the field has been identified and the current study proposes to investigate the following:

Mothers' experiences of an adult offspring with mild learning disabilities

The general aim of the current study is to gain an understanding of what it is like to be a mother of an adult offspring with mild learning disabilities. The specific research aims are:

- To explore the experience of mothers who have adult offspring with a diagnosis of mild learning disability and to illuminate deeper personal meanings that mothers attribute to this experience.

- To explore mothers' perception of the concept of 'adulthood' in relation to their adult offspring with a diagnosis of mild learning disabilities and how they manage this

⚔ To explore experiences of capacity as well as deficit in relation to their adult

offspring with a diagnosis of learning disabilities.

CHAPTER TWO: METHODOLOGY

Overview

This research aims to understand more about the lived experience of mothers who have adult offspring with diagnoses of mild learning disabilities (LD). It seeks to generate a deeper understanding and the personal meanings these mothers attribute to their experiences, how they make sense of them and what meanings those experiences hold (Husserl, 1931). Interpretative Phenomenological Analysis (IPA) was employed to meet the above aims as it is considered to be suitable for exploring individuals making sense of their personal experiences (IPA; Smith, Flowers & Larkin, 2009). Another reason for selecting IPA as a form of analysis was its purpose of 'giving voice' to participants whilst the researcher is 'making sense' of participants' experiences from a psychological perspective (Larkin, Watts & Clifton, 2006; Smith & Osborne, 2003). This chapter explains the rationale behind the employed methodology, detailing participant recruitment, data collection and the process of analysis. It also summarises the process the researcher has taken to adhere to ethical and quality requirements.

2.1 Epistemological position

When considering different epistemological approaches to research, it is crucial to point out the complexity and diversity of each paradigm and the fact that very often there is no 'clear cut' between them (Madill, et al., 2000, Willig, 2001). While quantitative research tends to adopt positivist paradigms with realist ontology, qualitative research adopts post-positivist paradigms with critical realist/social constructionist ontology (Ponterotto, 2005). Researchers can often move between different positions, however, within each research project it is important to state a position which essentially communicates the underlying assumptions and beliefs guiding the research (Madill, Jordan, & Shirley, 2000, Hays & Wood, 2011).

As the aim of the current study was to capture lived experience, this project is grounded in the critical-ideology paradigm while acknowledging aspects of social constructionist ontology. I take on the standpoint that reality may have an aspect of being socially defined but how we perceive this reality is different for everyone (Bhaskar, 1975, Williams, 1999, Danermark, 2004). Furthermore, I hold the view that there are multiple explanations of reality that are subjective to each individual's experience and in order to understand it we have to evaluate it critically. Thus, my epistemological beliefs are in line with critical realism.

From a critical realist position, this study acknowledges that an external reality exists but it is distinctly perceived by different individuals (Smith, 2004, Larkin et al., 2006; Brocki & Wearden, 2006). Thus, I hold the position that there is some form of reality that can be known, although not universal, whilst I acknowledge that personal experience and interpretations shape the way we understand it. As such, I hope that the study can explore personal experiences as a way of discovering people's realities that could in turn support and add to existing concepts and theories. I believe that this position enables one to recognise the experiences of mothers of adult offspring with a diagnosis of mild LD as being 'real', whilst acknowledging that there is no single 'true' way of understanding such experiences.

My theoretical position has been shaped by my training in counselling psychology, a programme largely informed by a social constructionist philosophy, along with my experiences of working within the NHS. While my understanding of learning disabilities is informed by the [1]biopsychosocial model, it is also informed by my own personal experiences of working with adults who have had LD for the last seven years. The impact I may have had as a researcher on the research process is

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[1] The biopsychosocial model supports the view that biological, psychological and social influences interact and shape people's functioning in the context of illness

discussed in detail in Chapter 4.

2.2 IPA as opposed to other qualitative methodologies

IPA was chosen as opposed to other qualitative approaches due to its interpretative element, along with its use of hermeneutics in understanding and interpreting participants' sense-making. Discourse Analysis for example was felt unsuitable to use in the current study due to its detailed focus on the function language plays in constructing social reality (Willig, 2008). The current study's aim was to understand mothers' experiences of adult offspring with mild LD, which did not appear to fit with Discourse Analysis' aim of analysing the discursive effects of participants talking about a particular experience from a particular context (Willig, 2008).

Grounded theory was also deemed inappropriate to use despite of its similar focus on people's meaning making, as it is more inclined to focus on processes of social phenomena rather than the psychological processes relating to how people make sense of a particular phenomenon (Willig, 2001).

It has been argued that current literature lacks interpersonal accounts of the experience of mothers of adult offspring with mild LD. However, it was felt that since the object of analysis in the current study is lived experience, IPA could provide a useful framework to explore the personal nuanced experiences of this phenomenon. Moreover, as personal experiences occur in relation to others (Schore, 2003), accounts of interpersonal experiences could readily be amenable to interpretation and critique. In summation, IPA was appropriate for exploring mothers' experiences of adult offspring with a diagnosis of mild LD as verbal exploration may help to understand how emotional experience is articulated, perceived and understood. It is the participants' account of their experience, not the narrative that becomes the unit of analysis (Dickson

et al, 2008).

The general aim of the current study is to gain an understanding of what it is like to be a mother of an adult offspring with mild learning disabilities. The specific research questions are:

- ⚔ What are the experiences of mothers who have an adult offspring with a diagnosis of mild learning disabilities?
- ⚔ What is their perception of the concept of 'adulthood' in relation to their adult offspring with a diagnosis of mild learning disabilities and how do they manage this?
- ⚔ What are mothers' experiences of capacity as well as deficit in relation to their adult offspring with a diagnosis of mild learning disabilities?

2.3 Interpretative Phenomenological Analysis

IPA is an approach to qualitative research that explores in detail personal lived experience to examine how people are making sense of their personal and social world. IPA tries to understand what the world is like from the point of view of the participants. At the same time, IPA acknowledges that this understanding is always mediated by the context of cultural and socio-historical meanings. Therefore, the process of making sense of experience in inevitably interpretative and the role of the researcher in trying to make sense of the participant's account is complicated by the researcher's own conceptions.

IPA is a phenomenological form of enquiry based on hermeneutic theories of interpretation. It is considered a flexible approach, enabling insight into participants' subjective experiences (Creswell, et.al., 2007; Smith, 2004). IPA is also influenced by symbolic interactionism (Eatough & Smith, 2008), a theoretical perspective which

proposes that people act on the basis of the meanings that things have for them and that meanings emerge in the process of social interaction between people (Blumer, 1969). Thus, meanings are constructed and modified through an interpretative process that is subject to change and redefinition (Blumer, 1969).

Historically, IPA is a form of qualitative analysis informed by theory from philosophers such as Husserl, Heidegger, Merleau-Ponty and Sarte who explored interpretation (hermeneutics) and symbolic interaction (meaning attached to an event are central to understanding experience) (Smith, Flowers & Larkin, 2009). While Husserl's phenomenological philosophy highlighted the importance of focusing on experience and individuals' own understandings of their experiences, this notion was further developed by Heidegger, Merleau-Ponty and Sartre, who proposed that people are embedded in the world and do not live in isolation (Willig, 2001). According to Heidegger (1962), human beings are thrown into a world in a particular historical, social and cultural context. In Heidegger's conception, every interpretation is already contextualized in previous experience in a particular context, as according to him, human existence is fundamentaly related to the world. (Heidegger, 1962). Influenced by the work of Heidegger, who viewed the 'person in context' and emphasised the concept of 'intersubjectivity', IPA endorses the relational nature of human beings' ability to communicate with and make sense of one another (Smith et al, 2009). Therefore, individuals' experiences of living in the world were understood to influence individuals' perceptions of their own lives and experiences. Consistent with its phenomenological roots, IPA is concerned with obtaining what Conrad (1987) called an 'insider's perspective'. It is interested in trying to understand events and objects from a participant's point of view, typically through the use of interviews, with the intention of getting "close to the participant's personal world" (Smith et al., 1999, p. 218).

Although IPA is grounded in the experiential dimension in its concern with a detailed examination of individual lives experience and how people are making sense of that experience, it 'endorses social constructionism's claim that sociocultural and historical processes are central to how we experience and understand our lives, including the stories we tell about these lives' (Eatough & Smith, 2008, p.184). Phenomenology is seeking after a meaning which is perhaps hidden by the entity's mode of appearing. In that case the proper model for seeking meaning is the interpretation of a text and for this reason Heidegger linked phenomenology with hermeneutics. How things appear or are covered up must be explicitly studied.

Adopting semi structured interviews allows for exploration of participants' experiences of their personal and social world. It facilitates access to conceivable meanings that these experiences have for them (Smith & Osborn, 2003). Subsequent transcription analysis can assist in the explication of what may be unknown or hidden from the participants' awareness. This may add depth to data and sign post future research.

IPA based research is viewed as a dynamic process between the researcher and the participant (Eatough & Smith, 2009). Influenced by Heidegger's philosophy, IPA acknowledges the role of the researcher who is subjectively involved in making sense of participants' experiences, thus it is also connected with the hermeneutic tradition (Palmer, 1969). As researcher is trying to make sense of a participant trying to make sense of their lived experience, through a process of interpretative activity, they engage in what is called a double or two stage hermeneutic (Smith & Osborn, 2003). As all discoveries made are shaped in part by the researcher and participant relationship, IPA stresses the importance of remaining open to one's own biases and preconceptions during the process of engaging with new phenomena (Smith et al., 2009). Consequently,

to preserve transparency, researcher reflexivity is crucial.

IPA puts focus on participant individuality and adopts an idiographic approach. Unlike nomothetic approaches which are concerned with claims at a group level and focus upon the generalisability of findings, idiographic approaches, such as IPA, focus on the interaction between the experience and contexts in which the experience occurs and which is specific to the participant. Such ideographic approaches are concerned with understanding the meaning of individual life based on the experiences and perspectives of a small group of specific people, who find themselves in a particular context (Smith et al., 2009). Based upon these principles, the aim of an IPA approach is to describe in detail the perceptions and understandings of a small group of people as opposed to prematurely making more general claims (Smith and Osborn, 2008).

As human beings, we attempt to make sense of all our experiences. However, less interested in everyday experience, IPA's phenomenological underpinnings allow the researcher to explore experiences which have 'existential significance' for the participant and that have prompted contemplation (Smith et al, 2009). In this sense, human beings can be distinguished from all other beings in that they not only 'are', but they also 'exist' (Heidegger, 1962). All of our investigations and reflections regarding human existence arise out of the indissoluble inter-relationship between 'a being' and 'the world'. This 'being in the world' cannot ever be fully contained, captured, defined or objectified. In this, Heidegger (1962) echoes Husserl's (date) emphasis on the indissoluble inter-relationship between the investigator and the focus of investigation. Even when there is no other around us, or in our presence, even if distance ourselves from or avoid others, we are still 'with-others' in that our stances, attitudes and actions arise out of the existential condition (or 'given') of *being-with*.

There are real objects in the world that exist independently of our conscious knowledge and awareness of them and they will forever remain (Spinelli, 2005). Phenomenology questions this viewpoint and states that how we perceive and experience reality is different for everyone. We make sense of the world by constructing meaning, which subsequently provides us with a variety of invaluable experiences. These can vary immensely for each individual even if they are exploring the same phenomenon. The current study is in line with the above view and puts forward the idea that reality exists but how we perceive this reality is different for everyone. As such, concepts such as learning disabilities and adulthood exist (regardless of what we call these concepts) but how we perceive these concepts is different for every person. Every mother's experience of their adult offspring with LD will differ and the concept of adulthood in relation to their adult offspring will most likely differ too. The process of interpreting mothers' accounts of their experience by talking about this by using this approach enables the researcher to gain an insider's perspective into a relatively under-researched field.

2.4 Method

This section describes the applied methods step by step in order to give a coherent picture of the research process and provide evaluative transparency.

2.4.1 The sample

The study asked parents of adult offspring diagnosed with mild LD to discuss their experiences of being a parent of an adult offspring with this condition. Nine participants were recruited in total, which fits with what is considered an appropriative number for the completion of an IPA within a professional doctorate setting (Smith et al., 2009).

The sampling strategy adopted in this study aimed to enhance the understanding of the experiences of a particular population (i.e., parents of adult offspring with mild LD) so the sampling strategy selected was carried out through purposeful selection of individuals for participation. It is of note, that even though the participant recruitment included both mothers and fathers, only mothers took part in the current research project. Details of the participants are summarised in Table 1.

Inclusion criteria

1. Parents of adult offspring with a mild learning disabilities

2. Age of the adult offspring must be 25 and over (the age mark was set in order to make sure that the participants have had the experience for some time)

3. The level of learning disability of the adult offspring must be in the mild range for the following reasons:

The condition is often 'hidden' and people may have the same expectations of individuals with mild LD as the expectations of general population without the condition. Mothers who took part in the current study reported that their offspring have a diagnosis of learning disability, that this is in the mild range and therefore hidden. They identified their offspring condition as 'invisible' or 'hidden' and one that is not immediately apparent. Supporting a son/daughter with an invisible condition may add a variety of challenges, which otherwise may have not occurred has the disability been visible. For example, expectations of a person with a diagnosis of mild LD can be similar or the same as the expectations of someone without the diagnosis (Webb & Whitaker, 2012). Subsequently, this may bring emotional challenges not only for the person themselves but also for their carer.

Adulthood within modern industrialised societies is constructed as a central social status, part of which is ascribed and part of which is attained. The achieved status of adulthood depends on crossing various age-specified thresholds and involves both rights and obligations. As adolescents reach adulthood, generally they are expected to be more independent and adhere to a normative pathway laid out by the society (Rapanaro et al., 2008, Robinson & Stalker, 1999). This includes going to university, living independently, engaging in employment, getting married and after all, receiving less support from their parents than in previous years. However, in the case of adults with a diagnosis of LD, this is not always the case as they face more difficulties in achieving independence possibly due to their condition as well societal barriers imposed on them (Osgood, et al., 2010). Their life opportunities are often restricted, which may have negative psychological effect on their wellbeing (Shearn and Todd, 2000).

It is important to acknowledge that the concept of adulthood, just like the concept of disability is not a 'fixed reality' (Wall, 1999). It is yet another category which enables us to understand difference between individuals. It is a product of social, economic, cultural and political structures of modern society (Wall, 1999). Culture, religion, hierarchical structure, nationality and life experiences, all contribute to the manner in which members of the family respond to different categories, diagnosis, treatment, and ongoing care of an individual with a difference (Chambers & Chambers, 2015). Putting people and concepts into categories serves the purpose of a better understanding of difference (Wall, 1999).

In the case of the concept of adulthood, the definition is shifted culturally (Berger, 2013). It has a different meaning in different cultures and this needs to be acknowledged as these categories are not fixed and can be fluid (Robinson & Stalker, 1999). However, as mentioned above, adulthood as a cultural norm tends to suggest independence and even that is not completely culturally set because in many countries

people behave differently. For example, some years ago in the United Kingdom people stayed at home until they got married, which nowadays often is no longer the case (Edgerton, 1984). Therefore these categories change over time what it means to be independent. In terms of disability, disabled people are often infantilised because of the construction of adulthood has involved living independently, working and often having a family (Shakespeare, 2009).

It is clear that the process and time scale of transition to adulthood has changed markedly over the past four decades (Leonard, 1980). Development from childhood through adolescence to adulthood is at one level a process of biological change and as such is not merely a social construction. At the same time, it is evident that within different cultures and at different historical periods the social construction of childhood, adolescence and adulthood changes markedly (Aries, 1973). This implies the existence of a state of interaction between biology and culture so that the physiological and emotional processes of maturation is overlaid by a range of cultural expectations which will be subject to change over time and will be influenced by the wider economic context.

Exclusion criteria:

1. Physical disabilities of the adult offspring (as this may add to parents' difficulties)
2. Adult offspring with visible facial profile

2.4.2 Recruitment of participants

The recruitment began by identifying day centres in London which cater for adults with learning disabilities. The managers of these day centres were initially contacted by phone in order to introduce the project and establish whether they would be willing to support it.

Given permission, the researcher sent an overview of the study with the aim to recruit participants from the day centres with an invitation for parents of adult offspring with mild LD to take part in the study. The overview included a summary and aim of the study as well as the inclusion and exclusion criteria. This allowed the researcher to target and select participants who meet those criteria. The researcher also arranged to meet with management in order to aid the project process and display leaflets at the day centres. One of the day centres invited the researcher to a parents' group in order to introduce the project. Snowballing also became a source of recruitment, which entailed identifying respondents who then referred on to other respondents (Atkinson & Flint, 2001).

Once the participants contacted the researcher, they were sent a participant information sheet. The researcher then contacted the participants one week after the information was sent. The participants were asked if they had any further questions and if they were still willing to take part in the study. Nine participants responded to the advert, one male and 8 females. The male participant withdrew from the study prior to arranging the interview. Participants who consented to take part in the study were allocated a time at their convenience to meet within the center their adult son/daughter attended (provided this has been agreed with the organisation) or at their home address to complete the interview.

It is important to acknowledge the possible impact of recruiting participants whose adult offspring with a diagnosis of LD attend a day centre. Experiences of mothers whose offspring go to a day centre may be different from the experiences of mothers whose offspring receive direct payments and engage in activities of their choice. What might be shaping the current study is that the parents who took part in this study may potentially be looking for additional support and more inclusion for individuals with a diagnosis of LD in future. It is possible that those mothers whose adult offspring attend a day centre seek help and support as they acknowledge they need it and find it beneficial. It is also possible that they hope for a positive change and more support in the future for their offspring and also for themselves. On the other hand, there may be parents who may not wish to be associated with a certain category or belong to a certain group. Therefore they may try to manage on their own within the circle of their family. They may not need additional support or feel the need for it as they themselves do not classify themselves as people with disabilities. These parents did not take part in this study and therefore their views have not been heard or included.

2.4.3 Participants

Table 1: *Participant demographic data*

Participant	Age	Ethnicity	Cares for	Age of adult offspring
Julie	52	White British	Angela	30
Carol	61	British Asian	Christina	27
Angelina	47	White British	Jason	26
Karuna	67	British Asian	Michael	30
Trisha	53	White British	Christopher	26
Debbie	54	White British	Annie	27
Mina	56	British Asian	Kate	31
Margaret	61	White British	Simon	41

It is of note that five out of eight participants who took part in the study were divorced.

Having to support an adult offspring with LD as a single mother may be very different

to the experience of those mothers who share the same responsibilites with their

partners. The potential impact might be lack of opportunities to share responsibilities,

emotional stress as well as positive experiences with their partners in relation to caring for their offspring with LD (Carers UK 2012, Roberto, 1993).

2.5 DATA COLLECTION

2.5.1 Semi-structured interviews

Data was collected by conducting face-to-face semi-structured interviews. This method is recommended for IPA studies as it offers the researcher a unique opportunity to explore the point of view of others and to enter, even if only briefly, their psychological and social world (Miller and Glassner, 1997, Chapman and Smith, 2002, Smith and Osborn, 2008).

The interview schedule was informed through evaluation of literature and guidance on constructing such schedules (Smith & Osborn, 2008) and developed following consultation with the research supervisor. The interview consisted of 10 open-ended questions (see Appendix 5). The questions were varied and constructed with a focus on life experiences as a way of tapping into the participants lived experience of being parents of adult offspring with mild LD. The questions were designed to draw attention to the emotional, physical and social impact their circumstances may have on them. This facilitated the emergence of data, which subsequently informed the analysis of participants' transcripts and their reported unique lived experience of the phenomena under investigation (Smith, 2011).

Once all questions have been explored, each participant was given the opportunity to express anything that they felt was important to them and which was not mentioned during the interview. Each participant was also given the opportunity to reflect on their experiences of the interview with the researcher. When requested,

following completion of the analysis, participants were offered feedback on the completed study verbally.

2.5.2 Interview procedure

Before each interview started, each participant was asked to sign a consent form. Issues relating to confidentiality were explained thoroughly. Participants were reminded that their participation was voluntary and that they had the right to withdraw at any time. A demographic questionnaire was also completed (Table 1, p. 42).

One pilot interview was conducted followed by seven further interviews. IPA guidance indicates that 5 to 6 interviews are a reasonable sample size for qualitative projects (Smith, Flowers and Larkin, 2009). In this study, the inclusion of a larger sample allowed for possible participant withdrawal and it also offered a greater range of data for exploration.

Six participants were interviewed at the day centre that their adult offspring attended. Two participants were interviewed at their homes. Interviews were audio recorded for transcription with a digital audio recorder, each lasting between 45 and 60 minutes.

Although the researcher ensured that the content of what was discussed did not divert too much from the topic, in line with techniques to conduct semi-structured interviews, the researcher did not follow rigidly the sequence on the interview schedule. Some questions were asked before they appeared on the schedule in order to follow up naturally on what the participants were saying. Also, not every question was asked, as some participants covered some questions prior to them being asked. At times, the

interviews covered areas which the participants had not been asked about, but which revealed important to the research information. Smith and Osborn (2008, p.64) argue that:

"Indeed, these novel avenues are often the most valuable, precisely because they have come unprompted from respondents and, therefore, are likely to be of especial importance for them."

All interviews were digitally recorded using a Dictaphone. Smith and Osborn (2008) argue that it is not possible to conduct a semi-structured interview that is usually required for IPA without recording it:

"If one attempts to write down everything the participant is saying during the interview, one will only capture the gist, missing important nuances (Smith & Osborn, 2008, p.64).

Each interview was transcribed verbatim soon after it took place. Transcription included all the words spoken during the interview. It also included pauses, hesitations, laughs, sighs and other conversational features. Generous margins were left on both sides of the transcripts in order to allow for notes and comments during analysis. Langdridge (2008) argues that transcription is a fundamental aspect of phenomenological research, where interviews have been used to collect data.

2.5.3 Ethical issues

The present study received ethical approval from the University of East London's Ethics Committee in September 2015 and followed the British Psychological Society Code of Ethics and Conduct (BPS, 2006). This study was carried out by the researcher as part of their Professional Doctorate in Counselling Psychology.

An information sheet and a consent form were used to ask for consent to take part in the research and to agree to the archiving of transcripts at the end of the research for any future publications. The Social Research Association (2003, p.28) defines informed consent as:

"A procedure for ensuring that research participants understand what is being done to them, the limits to their participation and awareness of any potential risks they incur."

The researcher needed to ensure that they had the participants' ongoing consent to participate in a study and that they were sensitive to participants' wishes to opt out of a study. Participants were advised of their right to withdraw from the research study at any time without disadvantage to them and without being obliged to give any reason. This was made clear in the information sheet given to participants and at prior to each interview. Participants were informed that if they decided to withdraw from the study, the data obtained from them would be destroyed.

At the end of each interview each participant was fully debriefed in order to identify any discomfort that they may have experienced. In line with the British Psychological Society's (2006) guidelines that cover duty of care in research, each participant received a list with details of organisations that offered support (see appendix X). Participants were also reminded that they could contact the researcher if they had any further questions or concerns.

2.5.4 Confidentiality

The researcher followed UEL guidance on research records and procedures for data storage adhering to the Data Protection Act 1998. Once each interview took place, the digital recording was immediately uploaded onto the researcher's computer. The recording on the digital recorder was then deleted.

In order to ensure confidentiality, it was agreed for all names to be made

anonymous, including names of members of family and friends. The same applied to names of organisations mentioned in the interviews. Signed consent forms and details that corresponded to each participant were kept separately from the digital recordings, transcribed materials, and demographic details in accordance with the Data Protection Act (1998). All manual data was kept in locked filing cabinets in the researcher's home. Any identifiable material within the transcripts was anonymised during transcription. Interviews were transcribed by the interviewer. Only the researcher, supervisors and examiners have access to the transcribed material. Data can only be accessed via a password on a computer, and is being kept by the researcher with the view of a possibility of developing the research further in future (e.g., for publication). This information was included in the invitation pack.

Following Craig, Corden and Thornton's (2000) suggestions for a code of practice, the researcher considered the safety issues around meeting strangers in their homes. All the participants were mothers of adult offspring who attend day centres. There were no known identified risks and all interviews took place during the day. Where the interviews took place at the day centres, support staff were on-site at the time of the interviews taking place. The organisation and the support staff on-site were informed of all logistics regarding the interviews.

When the interviews were conducted in participant's home, at the end of each interview, the researcher informed a designated person that the interview had been completed. It was agreed in advance that if the researcher did not approach designated person within an agreed time, they would ring the researcher's mobile phone and if necessary then go to the participant's home and check.

2.6 Analysis procedure

The data was analysed using IPA, guided by the four procedural steps outlined by Willig (2001) and Smith, et al. (2009) and literature by Elliot et al. (1999) and Yardley (2008) on quality in qualitative research.

There is no single right way of conducting IPA and analysing data is a personal process which involves an unavoidable degree of subjectivity (Willig, 2001; Smith & Osborn, 2008). Thus, the analyses in this study are a result of the personal and analytical style of the researcher following IPA guidelines.

Step 1: *Initial encounter with the text*

Having completed the research interviews, the researcher began listening to and transcribing each interview. Transcripts were then printed and the researcher proceeded to lengthy reading and re-reading of individual transcripts, highlighting and annotating anything which seemed interesting or significant and then writing exploratory notes and initial comments in the right margin. This was with the aim to start identifying potential themes and to aid interpretation of relevant material (see appendix 8). The focus was on the semantic context and the use of language, making associations and preliminary interpretation of the meaning of the participants' communication (Willig, 2001). Particular attention was paid to aspects of the data which related to the research question.

Step 2: *Initial exploratory coding*

The transcripts were read several times and emerging tentative themes were noted in the left margin (see Appendix 8). At this stage analysis involved continuous and effortful engagement with transcripts. Descriptive analysis involved focus on

descriptions of what participants said about their experience and identified key ideas and subjects that emerged. Linguistic analysis explored use of participant language including shifting tenses and choice of words, metaphors and phrases used to describe aspects of accounts of experience. This included acknowledgement of non-verbal expression experienced in the interview. Finally, interpretative or conceptual analysis involved interrogating and conceptualising material at a more psychological level (see Appendix 9). This process involved questioning meanings and challenging what's happening within the participants' accounts of their experiences. Initial findings were shared with the researcher's supervisor to ascertain clarity and credibility.

Step 3: *Searching for connections across emergent themes*

The emerging themes were sorted into categories. They were then combined with themes from other transcripts. They were clustered based on the nature of reported emotional experience or possible relational process identified. Clusters were given a descriptive label to indicate the conceptual nature of the themes within them, creating superordinate themes.

Convergences and divergences between individual and group cases were noted and analysed. The process was iterative in that the themes were frequently checked against the original transcript to ensure they accurately represented the data. This process was repeated with each transcript, with themes from previous transcripts used to orientate analysis of subsequent data, taking particular care to bracket ideas that had emerged from the analysis from previous transcripts. Complimentary verbatim text excerpts were noted to ensure themes were fully representative of the source material from participants.

Step 4: *Final list of master themes*

Once all interviews had been analysed, connections between the superordinate themes and subthemes in each participant's summary table were clustered together to create a master table of superordinate and subordinate themes for all participants. Themes were dropped if they did not fit with the emerging structure and/or did not have much supporting evidence. When all transcripts were analysed, a final table of themes was produced and checked back against the original data. The final stage of analysis occurred in the writing up of the research in which subordinate themes and subthemes were presented in the form of a narrative account (Smith & Osborn, 2008). Convergences and divergences were expanded on, leading to the final revision of themes. Each theme was explained and supported by verbatim extracts and interpretation from transcripts. Modifications to text excerpts have been made for ease of reading. Where words were implied but not stated, these were placed in square brackets [ ]. Where material was omitted, the following brackets were used [...].

The research findings indicate that mothers of adult offspring with mild LD often push negative emotions from the present to the past and to the future as a way of avoiding negative emotions, which may be too difficult to bare. Secondly, their son/daughter becomes 'invisible' in formal support once they reach adulthood. The mothers become 'invisible' too. The lack of choice and agency as well as future plan for both adults with LD and their mothers is also apparent. This is in line with Turner' theory of liminality (1969) as despite the fact that a person with LD becomes an adult, they often do not conform to a normative pathway and remain in a liminal state. Nonetheless, despite all the difficulties, mothers remain positive and focus on positive aspects of their adult offspring with LD focusing on capacity and glimmers of adulthood in their offspring with LD.

The three main themes derived from the analysis are: 1) 'Getting on with it': unallowable emotions in living with a disabled offspring, 2) Adult disability as invisible: falling off a cliff after the end of childhood, 3) Glimmers of adulthood: negotiating transitions without a roadmap. This is represented in Appendix 12, with the number of participants who identified each superordinate theme and subtheme in brackets.

CHAPTER THREE: ANALYSIS

Overview

This chapter illustrates the findings that emerged from analysis of the transcripts. Three superordinate themes and eight subthemes have been identified. They highlight how mothers who took part in this study experience their adult offspring with mild LD and what those experiences mean to them. Each presented theme is explained and supported by extracts from the research interviews.

Analysis suggests that mothers of adult offspring with mild LD found it difficult to talk about their emotions, especially negative ones. Firstly, from closer investigation of this phenomenon it emerged, that they do this by displacing these emotions to both the past and the future as if negative emotions were unallowable in the present. Thus, they remain in an emotionally liminal way of being. Secondly, as the offspring reach adulthood and formal support significantly decreases, both the offspring and the mothers become 'invisible' to the state services. Subsequently the lack of a future plan becomes apparent for both the adults with LD and the mothers. This is as a result of lack of adequate support, choice and agency. This is in line with Turner's theory of liminality (1969) which illustrates that despite the fact a person with LD becomes an adult, they often do not conform to a normative pathway and remain in a liminal state. Nonetheless, despite all the difficulties, mothers remain positive and focus on positive aspects of their adult offspring with LD focusing on any capacity and the glimmers of adulthood displayed by their offspring with LD.

3.1 Theoretical background

The theoretical background used in the current study is based on Turner's theory of liminality (Turner, 1969). The theory describes transformative processes which occur when transitioning from one state to another. Turner highlights that the state in which an individual finds themselves during this transition is "ambiguous, neither here nor there, betwixt and between all fixed points of classification" (1974:232). This suggests that they are trapped in between states or political positions with no real prospect for the situation to change. According to Turner (1969), within this liminal state, individuals have the opportunity to ponder about personal as well as societal and hierarchical difficulties.

The phrase "betwixt and between" has been used by many researchers in their studies to describe the in-between period and the experience of transition within different contexts (Deegan & Hill 1991, Cook-Sather, 2006). Some researchers focus on the processes intended to enable transitions into work or educational establishments and normative states within those (Bettis 1996; Irving & Young 2004; Manning 2000; Mannis 1997; Rushton 2003) or to indorse resistance to those normative states (Anfara 1995; Huber et al. 2003). Others concentrate on the transitional state of the person who finds themselves in the ambiguous position within an organization (Garsten 1999). In the current study the theory of liminality aids to understand the processes which individuals with learning disabilities and their mothers might be experiencing. This is illustrated through the themes derived from the analysis and are presented in the next section.

3.2 Themes emerging from the interviews

The three main themes derived from the analysis are: 1) 'Getting on with it': unallowable emotions in living with a disabled offspring, 2) Adult disability as invisible: falling off a cliff after the end of childhood, 3) Glimmers of adulthood: negotiating transitions without a roadmap. Table 2 presents superordinate themes and subthemes which emerged from the analysis of the interview transcripts.

Table 2: Themes emerging from the interviews

Superordinate themes	Subthemes
'Getting on with it': Unallowable emotions in living with a disabled offspring	Negative emotions as unallowable: the "robotic" mode and "getting on with it"
	Pushing negativity away from the present to the past: "Now it's okay but not before"
	Pushing negativity away from the present to the future: "What's gonna happen to him when I'm gone"
Adult disability as invisible: Falling off a cliff after the end of childhood	Parent and offspring stop existing in formal support: "It's like they stop existing"
	Unacknowledged in relationships: "They don't really understand my situation" – support from family and friends
	What about me? Invisible offspring - invisible parent
Glimmers of adulthood: Negotiating transitions without a roadmap	Physical transition into adulthood, but no adherence to a normative pathway – absence of a timeline and future path
	Glimmers of adulthood and finding the positive construct versions of adulthood in behavior of the offspring

3.2.1 Superordinate theme 1: 'Getting on with it': Unallowable emotions in living with a disabled offspring

The notion of 'getting on with it' is present in all accounts. This seems to be a common coping strategy amongst participants. Keeping busy allows people to push negative emotions away, which subsequently enables them to avoid and not deal with these emotions at the time (Hayes, et al, 1996, Krause et al., 2003, Roemer & Salters, 2004). This seems to be the case in the current study. Turner's theory of liminality helps to explain this idea and supports it (Turner, 1969). Both mothers and their offspring with LD are in between states permanently, not allowing negative emotions in the present, thus subsequently pushing them to the past and the future. It seems that they find themselves in an emotionally liminal way of being.

The following sub-themes highlight this further.

3.2.1.1 Subtheme 1: Negative emotions as unallowable: the "robotic" mode and "getting on with it"

Many participants in the current study described their early experiences of being mothers of offspring with mild LD. They seem to have constructed these experiences largely from a very pragmatic position. The following extracts demonstrate this. Carol describes her initial reaction to the fact that her daughter has learning disabilities:

"why me, why, what am I gonna do? Erm… being the first child as well you know, it sort of hits you […] how am I going to cope?" (Carol, line 11-12)

"I was, I was like on automatic drive so not really thinking, it was like I made a barrier to save myself really hard and I just got on with things, my emotions were like put to one side, I didn't feel anything…I just did basic things like put

food on the table, take her for appointments, whatever, it was just robotic at

first" (Carol, line 17-22)

Having discovered that her daughter has learning disabilities, Carol's initial reaction was of an overwhelming anxiety and worry around how she was going to cope with the situation and her daughter's condition. This is in line with studies on parents whose children received diagnosis of a disability (Kandel & Merrick, 2007, Azar & Kurdahi Badr 2010, Poslawsky, et al., 2014, Kim, et al., 2017). For example, Antonak and Livneh (1990) in their study describe parents' initial reactions to their child's diagnosis as a sense of shock, anxiety and denial.

In Carol's case, after the initial reaction, she describes her early years of being a mother of a child with LD as 'robotic'. The above extract suggests that Carol felt the need to protect herself from facing reality and the overpowering feelings of fear that came with it. It seems that by keeping herself busy, going through the motions and by making an emotional barrier, Carol was able to achieve this. She developed a strategy which protected her from feeling pain and which subsequently allowed her to cope with the situation at the time. It seems that she found herself in a liminal state: stuck in the robotic/automatic mode and emotionally unable to move forward, which is in line with Turner's theory of liminality (Turner, 1969).

Another participant, Karuna, also describes her initial struggles with accepting her son's diagnosis:

"...at first it was denial, I didn't like the word, the name 'learning disability', I

didn't like people use it, even though, yeah, and erm it was what it was. I

thought: why me? What am I going to do? You think it happens to other people

but not you, you know. I didn't know that much about it and to be honest didn't

really want to know, I was scared I guess and didn't know whether I was going

to be able to cope with it" (Karuna, line 119-125)

It seems that Karuna also found herself in an emotionally liminal state. Accepting her son's diagnosis was difficult and she felt unable to move forward. The notion of her trying to deny reality is very prominent here. There is a strong need to believe that this reality does not exist. This may have played a part in Karuna not allowing herself to get in touch with difficult emotions by stopping them to come up to the surface. Past research supports the notion of denial and suppressing emotions as a way of protecting oneself from psychological pain (Erdelyi, 1993, Garssen, 2007).

While the above participants put focus on their initial reactions to finding out about their offspring's diagnosis, other participants spoke about their current experiences of being mothers of adult offspring with a diagnosis of mild LD:

"So now he is an adult, erm…you, I am trying to enjoy him as he is now, you

know, with his learning disabilities, erm, as I'm aware that things will not

change so we have to make the most of what we do have I suppose, erm, you

know, that's what it means to me now I guess, we have to just carry on, move on

and enjoy him as he is" (Trisha, line 24-29)

"Christopher could have erm developed, erm more sort of normally, erm… but

you know, I tend not to think too much about that now and really sort of try and

to enjoy Christopher as he is…(Trisha, line 47-49)

65

"I don't think I would be able to cope really if I kept on sort of thinking what life

would be like if Christopher did not have a disability" (Trisha, line 463-464)

The above extracts illustrate the current emotional liminal state Trisha has found herself in. Her inability to allow herself to feel the full range of emotions is prominent here. Trisha tends to focus much more on positive aspects of life in relation to being a mother of an adult offspring with LD rather than negatives ones. She is fully aware of the fact that that if she allows herself to ponder about what life would be like if her son did not have a disability, she would not be able to cope. Once again, the notion of unallowable emotions and 'carrying on' is striking. Jacques (2003) and Banks (2003) argue that usually the family grieves the loss of what could have been a 'normal' child whilst having to come to terms with the disability of the child.

It is important to acknowledge that experiencing difficult emotions as well as talking about them is difficult for most of us (Erdelyi, 1993, Garssen, 2007). Thus, we tend to avoid negative emotions in order to protect ourselves from painful and uncomfortable feelings which may be intrusive. It is possible that the participants needed to avoid these in order to protect themselves from psychological pain. This and the lack of acknowledgement of possible negative emotions may have served a very important purpose in that it became a protective factor and a way of survival in a very difficult time.

While most participants struggled to deal with emotionally difficult thoughts and feelings, one participant managed to stop suppressing these and face them instead. Karuna's initial reaction to her son's diagnosis of LD was denial, however, she was

soon able to allow herself to get in touch with some very difficult emotions and accept the situation she found herself in:

"I think unlike my husband or some other people I know, I didn't hope, I, my aspirations died, I killed them the day Michael was diagnosed, you know, you think to yourself: oh, bring your child up, get them to do their GCSEs, A Levels, and they can do whatever they want to do. Even with my daughter…I never pressurised her to do whatever my husband might have liked (I: hmm) and she's done well. But with Michael, my aspirations died for Michael very quickly […] I have accepted Michael the way he is, I love him the way he is, there was a breakdown of a relationship but I didn't stop loving him (sighs) yeah, so that's how it's been. He will never be like any other adult, he will never progress like other people, that's the reality of it all and I have to be okay with that" (Karuna, line 213-228)

Unlike most participants, Karuna managed to face and deal with some negative emotions she experienced as a result of her son's diagnosis. She accepted the reality she and her son have found themselves in. Karuna spoke very openly about not having any hope that things would ever change. It might be that she managed to move on emotionally by dealing with her difficult feelings instead of avoiding and suppressing them. Karuna knows that her son's condition is irreversible and that he will always need support. Thus, according to her, her son will not be able to live a full adult life. It sounds like Karuna is able to accept that.

Those supporting the social model of disability may argue that if social barriers were removed, people like Karuna and her son could experience life no different to that

of most adults. However, imagining how a barrier-free world might be achieved for people with LD is still difficult. Thus, it is here argued that a more suitable position to take a more holistic and all-round approach. The bio-psycho-social model appreciates the role of many factors such as biological, psychological, social and political and cultural. They all interact with each other and this interaction cannot be ignored or removed (Shakespeare et al., 2009).

3.2.1.2 Subtheme 2: Pushing negativity away from the present to the past: "Now it's okay but not before"

Most participants in the current study had a tendency to compare past experiences with current ones in relation to being mothers of offspring with LD. In the following extract, Carol gives a good example of how her attitude has changed over the years:

"So then gradually I started relaxing, accepting and got better and then I moved on (I: right…) loving her and feeling pain, feeling good and feeling bad but at first it was just like I couldn't do it, like there was a bit of stone in there (touches her chest) […] But then after that I think she was about five or six when she started school, things got better and after that it was fine. And then you just learn to live with whatever happens on the day. If it's bad you deal with it, if it's good you deal with it. And that was day to day (I: hmmm) So basically, that was me…and I don't think I did the best job for a few years but now I can say I am a proper mum" (Carol, line 29-40)

Carol describes how gradually she accepted her daughter's condition, which subsequently allowed her to "move on". Carol presents the past in a rather negative light in comparison to the present time. In the early years of her daughter's life Carol felt emotionless: *'there was a bit of stone in there'*, and felt that that she had to block negative emotions in order to protect herself from psychological pain. It seems that in the early years of her daughter's life Carol remained in an emotionally liminal state. If she had been able to allow herself to feel a full range of emotions, this may have allowed her to process these emotions, accept them, move forward and leave the liminal state. Nonetheless, Carol eventually started being more accepting of her daughter's condition and of the situation overall. It is possible that by allowing herself to get in touch with her feelings, positive as well as negative ones, Carol began to accept the situation and deal with it accordingly. Subsequently, instead of her life being 'robotic', Carol was able to experience being what she calls 'a proper mum' and believing that she was doing a good job. Previous research suggests that some mothers of offspring with disabilities question their competence as mothers (Tardy, 2000, Ussher, et al., 2016) and it seems that this happened in Carol's case. The following extract illustrates a similar experience described by Margaret:

> *"I had a terrible time. It was terrifying and that and it put me off from having another child after that (I: hmm). There was a lot of worry and that, no support really. He wasn't perfect and I worried about that (I: hmm), I worried about how I was going to cope with it all, you know (I: hmm), his difficulties, whether I could meet his needs […]Luckily things have changed but the beginning was just awful" (Margaret, line 57-65)*

"...things are going well now, Simon is doing well, he is not totally independent but he is managing well. His got a learning disability but it doesn't frighten me anymore, you know, I guess I panicked at first, erm, anyone would I suppose, it's not every day someone tells you your child has a disability, but things have changed. [...] I now have a piece of mind, we are doing okay really" (Margaret, line 307-315)

Trisha also compares the present to the past in relation to being a mother of an offspring with mild LD:

"Well, it's not been easy but I've tried to...erm...enjoy Christopher, erm... as he is, erm... I mean in the early years erm...when Christopher was first sort of diagnosed, erm... yes, there were lots of sort of feelings of guilt and so forth and after a while I just felt erm that there was a lot of negativity sort of going on and erm... it was important to focus on erm Christopher as he is and looking at his future erm and really to enjoy him, which I felt in the early years I probably wasn't doing that because there were so many sort of guilt feelings and thinking of things could have changed, they could have been different or whatever (Trisha, line 15-24)

Trisha describes how difficult things were for her to begin with and how difficult it was to accept her son's condition. She talks about experiencing feelings of guilt and negativity, which, according to her, prevented her enjoying her son in the early years. Looking at the use of language it seems that while Trisha acknowledges that things have not been easy overall, they were much more difficult in the past. Currently

there seems to be much more acceptance and positivity in her narrative. The notion of pushing negative emotions to the past is very evident here.

This subtheme illustrates how participants experienced the present in comparison to the past in relation to being mothers of offspring with mild learning disabilities. They reported having experienced more negative emotions in the past in comparison to the present. Currently the mothers present a strong sense of positivity, acceptance and drive to look at life as a glass half full rather than half empty and this is very prominent in the mothers' narrative when speaking about the present. It is possible that they felt the need to leave the liminal state they had found themselves in previously, in order to move on in life and enjoy it.

This, to some degree, echoes the previous theme of 'getting on with it', but perhaps this time there is more acceptance of reality and less worry around the condition, parenting capabilities and the situation overall. Not much was said about current fears, instead, fear seems to be pushed to the past: "now it's okay but not before".

3.2.1.3 Subtheme 3: Pushing negativity away from the present to the future: "What's gonna happen to him when I'm gone".

This subtheme reflects the participants' fears for the future. Most mothers in the study expressed their concern about their son/daughter's future and who will look after them when they are no longer able to do so. For example, Karuna acknowledges the fact that with her getting older, there will come a time when she can no longer support her son:

"Yeah, as you get older you have less energy and it's a vicious cycle. Parents are getting older and children are getting older, they are reaching their adulthood and we are reaching our old age kind of stuff so yeah (I: hmm). But Michael will always need some kind of support. I still manage to support him but I worry for how much longer I can do this for" (Karuna, line 107-111)

"... we are getting older, both of us. He's probably scared because he's already seen his father die, so...what happens when I go too? He's probably scared about that. I guess we're, we both worry about it and about each other" (Karuna, line 465-468)

Karuna acknowledges her worry about her son's future. What is interesting is the fact that she goes a step further and expresses her concern not only around her son's future but also around the fact that he is probably worried about the future too. There is a strong sense of responsibility on Karuna's part as a mother. It might be difficult for her to think that her son has to deal with such difficult emotions, emotions she is very familiar with.

Trisha also expresses her concerns around her son's future and she refers to other parents who have adult offspring with LD:

"I do worry about Christopher's future obviously because he is vulnerable, erm, you know, what will happen when we are not around, so yeah, so I think that's a worry for a lot of parents who have a son or daughter with learning disabilities (Trisha, line 242-245)

Mina's goes a bit further and reflects on her fear around her daughter's future as well as the quality of care she may receive:

"*I am terrified to be honest. No one knows Kate like I do, not even my husband. I am always there for her and she is there for me, we get on so well and we understand each other so so well, erm, so I find it hard to think about someone else looking after her, you know, it's really hard to imagine that anyone will support her no matter what like I do*" (Mina, line 97-102)

Mina's narrative also illustrates a strong sense of responsibility as a mother. She questions whether others will be able to support her daughter as well as she does on both physical and emotional level.

Margaret was the only participant who expressed less worry around her son's future in comparison to the other participants:

"*If anything happens to me, my other daughter is going to take over. So I have a piece of mind, I no longer need to worry about that*" (Margaret, line 102-103)

"*Also, stories about people with disabilities whose parents have died and that, I don't have that worry you see, cause my daughter said she'll look after Simon when I'm gone. So this makes me a bit happier. I hope she looks after him as well as I do*" (Margaret, line 537-541)

Margaret's narrative suggests that she is concerned less about her son's future in comparison to the other participants as she has a plan in place. Nonetheless, there seems

to be a hint of worry in her narrative when she says: *"I hope she looks after him as well as I do"*. Similarly to Mina's narrative, it sounds like Margaret is concerned to some degree about the quality of care her son will be provided with and whether it will be as good as the care she has provided for her son so far. There is no mention of current difficulties, instead, fear seems to be pushed to the future: "what's gonna happen to him when I'm gone".

Overall, taking into account the above subthemes and extracts, it is evident that most mothers worry about their offspring's future care. They also tend to avoid talking about current fears as these may bring difficult and uncomfortable emotions. Once again, negative emotions are not easily allowable and are being pushed in different directions: to the past and the future.

Most mothers in the current study are aware that their current situation is unlikely to change, which is in line with theory of liminality (Turner, 1969). It seems that emotionally they are in between states: the past, which was difficult, and the future, which looks challenging too. They remain in the present without allowing themselves to move in either direction as this may prove too much to take on an emotional level. On a practical level, the mothers may fear facing some possible negative aspects of reality and the role they play as mothers of an adult offspring with mild LD. While most mothers of adult offspring do not have the responsibility of looking after their offspring anymore, mothers of adults with LD are not able to do the same. There is a vast amount of literature on parents who care for their adult offspring with disabilities (Pryce, et al., 2015, Cairns, et al, 2013, Ryan & Runswick Cole, 2008, Findlay, et al., 2014, Davys, 2007). Many of these studies are in line with the current study and confirm the fact that parents of an adult offspring with LD are concerned about their future care. The current

study adds to the existing literature by focusing more on lived experience and the meaning of that experience. It reveals some emotional challenges mothers of adult offspring with LD deal with and what function emotional avoidance may serve. This is relevant to counselling psychology in particular as this knowledge may be valuable when working with this particular client group.

3.2.2 Superordinate theme 2: Adult disability as invisible: Falling off a cliff after the end of childhood

This theme has emerged as many participants described challenges they faced once their son/daughter has reached adulthood. Both mothers and their offspring have found themselves in a liminal state without much scope to move on and adhere to a normative pathway. Despite the fact that the offspring have reached adulthood, the mothers' roles have not changed as they continue to be very involved in their offspring's support. This is explored in the following sections.

3.2.2.1 Subtheme 1: Parent and offspring stop existing in formal support: "It's like they stop existing"

Many participants expressed their anger and disappointment with the lack of formal support once their offspring with LD has reached adulthood. Karuna for instance feels very strongly about this issue:

"the sad thing is you know, when they become adults, everything is cut off from them, it's like they stop existing, um, and this is when they need the most support because they … erm, being, going into adulthood is so scary, for even a normal

person (I: yeah), you know, never mind someone with a disability" (Karuna, line 29-33)

"that support when they are in adulthood is not even there. I I just think this is it, the world ignores him, the world thinks: ignore the problem (I: hmm) if you ignore problems than they will go away" (Karuna, line 89-92)

Karuna is fully aware of the vast difference between the amount of formal support her son received prior to reaching adulthood and after he has become an adult. She recognises the challenges adulthood brings for most individuals but especially for someone with learning disabilities. Karuna's raised tone of voice and the use of language is very powerful here, especially when she says "it's like they (people with LD) stop existing". This intensifies her feelings of both anger, sadness and injustice around the fact that once individuals with LD reach adulthood, the formal support is no longer available to them. Karuna takes this further and states that the world 'ignores' her adult son, his needs and his difficulties as if to say that the world 'pretends' that these needs do not exist. Thus, people like her son get forgotten about. Karuna's narrative tends to suggest that Karuna feels that the world sees her learning disabled son as 'a problem'. When the world ignores 'the problem', her son gets ignored and remains forgotten about within the society. If the world pretends that a problem is not there, it is treated as if it does not exist. Other participants expressed their views around the poor quality of formal support their son/daughter has received over the years and especially once they have reached adulthood:

"The negative ones (experiences) are more to do with the system, the lack of support throughout the years, the attitude of some professionals, that sort of

thing and having to fight for everything, having to fight for funding, having to

fight for schools, colleges, the day centre, everything pretty much, you know.

And now we get nothing cause she's an adult'' (Debbie, 361-365)

Angelina also has had similar experiences to Debbie in regards to this issue:

"…the support, it just collapses and collapses and collapses (I: hmm) so when

that support goes, we're back to square one again and we have to start all over

again, going to meetings, answering the same questions, and trying to get

support. And he's now 26 and I started asking for help when he was about 14.

So it's over 10 years of constant requesting some kind of support, erm…yeah,

basically, it's sooo draining" (Angelina, line 28-X)

"it took me to crash to like really suffer severe like depression and anxiety to

actually start to get support he actually should have had years and years and

years ago. So they wait for things to become so bad before they think oh, we

better do something, you know, which is not right (Angelina, line 137-140)

Despite the reported negative experiences in relation to formal support, one

participant spoke about a positive experience she and her son have had:

"the therapist, he comes to see him (Margaret's son) there at the day centre

which is really nice of him and I see him separately, which I've found really

helpful. In fact he's the only consistent person we've had, he's been wonderful

really (Margaret, 480-483)

The importance and benefit of psychological support is evident in Margaret's narrative. She has found this type of support helpful and it sounds like she really appreciates it. Margaret values the consistency of her therapist and states that he has been the only consistent person providing her and her son with support. This tends to suggest that other people or other forms of support have not been reliable. Previous literature confirms this and illustrates that unfortunately many support services still do not meet the physical and psychological needs of parents of adult offspring with LD (Grant, 2010, Piazza, et al., 2014).

It is apparent that most mothers who participated in the current study feel angry, upset and let down by the poor quality of formal support their son/daughter has received over the years. Statements such as: 'having to fight for everything' made by Debbie indicate that she had to get involved very actively in her daughter's care in order to make sure she receives the support to which she is entitled. In Angelina's case, there is a general sense of exhaustion in her account as she describes constant collapse of existing support and her having to start the process "all over again". It seems that many participants have been in a similar situation for some years, which has had a negative effect on them both physically and mentally. Angelina describes how serious her health situation became due to the challenges she had to face when trying to acquire support for her son. This is in line with previous research which suggests, that those who provide care over long periods of time are at a higher risk of physical and mental health problems, than those who do not carry such responsibilities (Carers UK 2012, Roberto, 1993, Hill & Rose, 2010, Gallagher et al., 2013, Cairns et al., 2014). According to participants who took part in the current study, formal support significantly decreases once individuals with LD become adults. The question remains why this might be the case. It seems that while in childhood formal support is more readily available, in

adulthood it is scarce. This might be due to the concept of 'adulthood' and what it represents in today's society. Once an individual becomes an adult, they are expected to cope with every day life the same way most adults do. However, it is here argued that individuals with LD do not always conform to the societal norms of the concept of 'adulthood' and what it tends to represent in today's society. They often need extra support due to the nature of their condition. This may create some dependency on services, however, one can argue, that this dependency is created in people who have disabilities not because of the effects of their physical and psychological limitations on their ability to be independent, but because their lives are restricted by socio-political and economic forces which in fact produce dependency (e.g., lack of adequate adjustments for people with disabilities in a workplace). It seems that the lack of support contributes to creating barriers for individuals with LD and their carers, thus, the liminal state they find themselves in (Turner, 1969). As adult offspring and their carers try to conform to a normative pathway (e.g., jobs, education) this is often not possible and they are unable to leave the liminal state. Thus, their life opportunities are restricted, which may have negative psychological effect on their wellbeing (Shearn and Todd, 2000). It is here argued that services have not been able to provide adequate support for adult offspring with LD as well as their parents (Carers UK, 2006).

3.2.2.2 Subtheme 2: Unacknowledged in relationships: "They don't really understand my situation" – support from family and friends

In terms of the participants feeling supported by their family and friends, there has been a mixture of experiences. Many mothers expressed feeling unsupported by their family and friends and even those who do, they seem to feel only partially supported and understood by them. It seems that they experience a liminal state as they can only find comfort and understanding in certain situations and from certain

individuals without much opportunity and likelihood of this changing. For example, Trisha states that while her family have been very supportive, she feels that her friends who do not have an offspring with LD, are simply not able to fully understand what it is like to be a mother of an adult offspring with LD:

> *"they've been sort of very supportive and erm, you know, but I feel that it's only really talking to another parent who has a son or a daughter with a learning disability that they can fully understand what you are going through (Trisha, 539-542)*

Mina describes a similar experience:

> *"They don't really understand my situation, but how can they? Don't get me wrong, they've always been there for me but they can't really put themselves in my shoes, you know, yes, they can try but the reality is that they cannot possibly know what it's really been like for us" (Mina, line 285-290).*

Trisha describes a different experience. She is a member of a support group and she elaborates on what it has been like for her to be a part of the group:

> *"Oh, it's absolutely fantastic, erm..I think a lot of parents have benefitted from joining the group, erm, obviously myself included, so, erm…because obviously their worries and concerns are the same as yours and I think sort of sharing that and chatting about it is quite therapeutic" (Trisha, line 342-X)*

It seems that being a member of a support group has helped Trisha overcome some of her worries in relation to being a mother of an adult offspring with LD. There is

a strong sense of belonging, 'sameness' and feeling fully understood and supported by other parents who are in a similar position, parents who also have an adult offspring with LD. Trisha's narrative suggests that the support provided by friends and family is not always satisfactory due to their inability to fully understand her experience and challenges as a mother of an adult offspring with LD. Mina shares this view and states that as much as she appreciates her friend's trying to provide her with moral support, they are unable to meet these needs fully.

Karuna has had a very different experience from most participants who took part in the study. The extract below demonstrates this:

"when you have a disabled child, then your relatives, friends, etcetera… disappear. They don't want to know in case you impose problems on them which makes you feel even more isolated and lonely because the world doesn't want to know you when you have a problem" (Karuna, line 141-145)

Karuna's experience of her friends and family support in relation to her caring for an adult son with LD is one of loneliness, isolation and perhaps even rejection. Karuna assigns her family and friends' 'disappearance' to the fact that her son has a disability. She wonders whether they may be afraid of being asked for help, which may be seen as Karuna imposing her problems on them and becoming a burden. Karuna's narrative is very powerful here and it implies that people do not want to be involved in relationships, which can be demanding in some way and which require commitment and significant amounts of support.

Overall, it seems that although most participants have experienced some support from family and friends, many felt that they could not be fully understood by them unless they too had an offspring with LD. Subsequently this contributed to feelings of isolation and living in a liminal state as many mothers may have had limited opportunities to feel heard and understood by others. Previous research supports this and illustrates that individuals with LD and those who support them lack social networks (Pockney, 2006). This is not surprising as making and maintaining friendships require the opportunities that many people with LD and their carers cannot easily access (Bignall & Butt, 2000; Emerson & Robertson, 2002; Sim & Bowes, 2005).

3.2.2.3 Subtheme 3: What about me? Invisible offspring - invisible parent

All mothers who took part in the current study were able to reflect on their roles as mothers of adult offspring with mild LD, what these roles entail and how they affect their lives. The concept of liminality is prominent here as the mothers engage in caring roles for prolonged periods of time, with not much prospect for this to change. The following extracts illustrate how this prolonged care affects these mothers.

Angelina's interview uncovers the intensity of her involvement in supporting her son throughout the years, which she has found challenging both physically and psychologically:

> *"It makes me really cross cause instead of them doing their job, I am trying to help my son, I'm doing their job really but at what expense? At the expense of my own health, it's not fair and it certainly is not right, and I'm not sure how much longer I can do this for, as I said to you before, I am simply worn out (Angelina, line 754-758)*

"…people used to say to me: oh, you need to make time for yourself, and I'm going: "No, I'm fine, I'm fine", where am I going to make time anyway? you know like, and I just carried on, that's the way it was, you know, and it still is but I'm trying to… I'm thinking now that I have to have time for my own health, otherwise, you know, I can't carry on (Angelina, line 146-150).

There is a clear sense of unfairness and lack of choice and agency in Angelina's narrative. She feels angry with the formal support system and the fact that she and her son have been denied help, which should have been provided for them long time ago. Angelina realises that this situation has taken its toll on her physical and mental health. Nonetheless, it seems that she has finally started to recognise her own needs, whereas in the past she put her son's needs first without considering her own. However, it seems that her motivation to stay healthy is so that she can continue to look after her son. It is interesting that on the one hand Angelina feels a strong need to exercise her choice and agency by trying to meet her health needs, however, on the other hand, it seems that she does this in order to be able to continue providing support for her son. Angelina remains in a liminal state which does not allow her to move forward and met her needs.

In the following extract Trisha expresses her frustration around the lack of freedom, choice and agency in her life. Her liminal state of being is also apparent here:

"my husband and I couldn't just go off and have a holiday, just the two of us, cause obviously we've got Christopher too to consider (I: hmm), so it's all those aspects really to consider […] it can be frustrating, yes, erm…knowing that I haven't got that same freedom, yes, hmm…yeah…but it is what it is I guess, erm, and we have to find a way round it, that's what we do (Trisha, 554-593)

Margaret presents a similar story:

"I didn't get that much space, d'you know what I mean? My friends would go out for lunch or something and I couldn't, I still don't always get the opportunity to do that even though Simon is an adult now, and after all his disability is only mild, I still have to work round his schedule, obviously, which, I'm not gonna lie, can be tiring and <u>frustrating</u> at times"(Margaret, 202-207)

Margaret puts emphasis on the word 'frustrated', which indicates her powerful emotions triggered by lack of freedom and agency. It sounds like there is an expectation of her son to manage his life more independently since his disability is in the mild range. Despite this, Simon requires significant amounts of support, which may not always be apparent. Trisha's narrative also represents feelings of unfairness as other people have got more autonomy than her when it comes to making life choices, engaging in pleasurable activities and putting their own needs first. It seems that as much as these mothers try to meet their own needs, they can only do this once their offspring's needs are met. It is apparent that while the offspring with LD becomes invisible in society, the mothers become invisible too.

Karuna also reflects on the fact that it is time she attended to her own needs but it seems that she struggles with implementing this in practice, which is evident in her narrative:

"I feel a little resentful now, I'm reaching 63, I, I feel that for once I need to think about me, which is so awful for him, I am thinking, what about me!? I've never done that before and I'm just thinking it's awful for Michael that I'm feeling like that because he probably senses the resentment and I'm just being honest as to how I feel. I don't care" (Karuna, line 173-177)

"I wonder why doesn't anyone ever ask how you are, how you're coping with life? Is that too much to ask? The bottom line is I need to take care of myself, I still need to let go of him really"(Karuna, line 509-511)

Karuna expresses her feelings of resentment towards her son, which subsequently evokes feelings of guilt in her. She is very mindful of her son's emotions, which tends to suggest that she is once again considering his needs over her own. Karuna finds herself in a liminal state. On the one hand she wants to achieve more freedom, but on the other hand she feels guilty at the thought of 'letting go of her son' and leaving him without support. Thus, she seems trapped in this ambiguous situation. Karuna does not adhere to a normative pathway as a mother, in fact, none of the interviewed mothers do. The theory of liminality is useful here to explain this concept. It seems that as offspring with LD need significant amounts of support, their mothers are unable to stop providing this support for them. Their offspring do not adhere to a normative pathway either. Despite being adults, their needs are greater than those of most adults, which subsequently has an effect on their mothers' time.

It is of note that Karuna feels resentful towards not just her son but the world in general, since no one seems show any interest in her wellbeing. Thus, the current study aims to address the issue of lack of support for mothers of adult offspring with mild LD. Previous studies have also identified a breadth of support needs for carers of offspring with a diagnosis of LD and it has pointed out that over time the services available have not fully met those needs (Davys, 2007, Hines et al., 2013, Findlay, et al., 2014).

To sum up, the lack of freedom, choice and agency is evident in all participants' accounts. All mothers were able to reflect on how little time they had to themselves as a result of caring for their adult offspring with mild LD. The mothers' accounts highlighted a profound sense of responsibility for the care of their offspring with LD.

Many recognized that while they were trying to meet their son/daughter's needs, they were not attending to their own. Nonetheless, they all recognized that their own needs were important too but these cannot be met without obstacles. This is because before they can attend to their own needs, they feel the need to attend to their adult offspring needs first. Thus, their choice and agency can be exercised only to a point. It seems that the mothers remain in a liminal situation: even though their offspring is an adult, they need significant support and this is unlikely to change. It seems that in this case mothers become invisible as their needs never come first even if they are recognized.

3.2.3 Superordinate theme 3: Glimmers of adulthood: Negotiating transitions without a roadmap

This superordinate theme emerged as many participants revealed that the definition of 'adulthood' does not fully match their son/daughter's presentation. This is because despite being adults, they do not conform to societal norms mainly due to having more support needs than adults without LD. The following subthemes explore this in more detail.

3.2.3.1 Subtheme 1: Physical transition into adulthood, but no adherence to a normative pathway – absence of a timeline and future path

Mothers who took part in the study explored the concept of adulthood in relation to their adult offspring with mild LD by describing different scenarios. In the following extract, Mina focuses on her daughter's current situation:

"it's so upsetting cause for most people life is about to start when they become adults, it's an exciting time for them, you know, but for adults with LD everything is at a standstill. She is able to work and she would love to have a job, and after all that's what others expect of her, you know, but then no one wants to give her a chance" (Mina 63-68)

Mina discloses her difficult feelings around the fact that there is no clear life progression and opportunities for her adult daughter in site. She recognizes that her daughter does not have the same life prospects that most adults do. While for many people entering adulthood often brings excitement and new beginnings, this has not been the case for her daughter Kate. It seems that Kate is in a liminal state in the society; she is an adult who is possibly expected to engage in work, like most adults do, yet, because of her diagnosis, career opportunities are not available to her. The lack of normative pathway, natural progression and future path is visible here, which is in line with Turner's theory of liminality (Turner, 1969). Both Mina and her daughter are stuck in a situation, which is unlikely to change. The social model may argue that if social barriers were removed and people like Kate received more support when entering work environment, there would be more equality and less division between people with and without disabilities. Studies illustrate that few people with LD have jobs, and because there is a misconception that they cannot work, very few opportunities to do it are offered to them (Gregg, et al., 1992; Harzell & Compton, 1984). The issue of unemployment is a pertinent one for counselling psychology as there are several studies showing a link between poor mental health and unemployment and associated economic hardship (Petticrew et al.,1995).

Angelina's narrative is in line with the social model ideology and removing social barriers in order to promote independence and equality amongst all individuals in the society:

"Not seeing Jason as an adult makes me feel concerned, so, you know, most, the most worry I have is for his future, really, that is it really, erm, if society accepted him how he was and allow him to progress in his own time, erm…to develop, then that would be ideal" (Angelina, line 616-619)

Another participant Debbie describes her frustration around her daughter facing a different type of 'barrier' in her life:

"… even some professionals, but with the doctors especially, it's a totally different story altogether, and if they look on their system and read what condition she has and she comes in and she sits down (I: yes) and the doctor says 'oh what's wrong', they straight away look at me, <u>but she is an adult</u> and she is able to explain what's wrong and why she came to see them so I don't understand why in hospitals, surgeries, they don't have any training to address this, I find it appalling to be honest, they don't have any empathy for the person, <u>all they see is the label</u>, they don't see that there is still a person underneath it"(Debbie, 242-251)

The above extract illustrates Debbie's feelings of anger and disappointment around others not treating her daughter as an adult. In Debbie's view, some professionals do not consider the person as a whole but instead, they respond to them on the basis of their diagnosis. The statement: *"all they see is the label, they don't see that there is still a person underneath it"* represents the fact that the person is almost

invisible. It seems that during that particular GP visit Annie's point of view was not even considered. Despite the fact that she is an adult, Annie was not given an opportunity to express herself and her needs, the same way other adults do.

Trisha describes everyday experiences of her son whom does not adhere to a 'normative' pathway:

"I've had to accept that he'll never really be like any other adult [...] because of his learning disability he will never have the kind of life most of us have, you know, with a job, family, and so on" (Trisha, line 374-534)

Trisha finds it difficult to see her son Christopher as an adult. She clearly recognizes the notion of her and her son's liminal state. Nonetheless, it seems that Trisha has been trying to accept the situation, possibly as a way of steering away from getting in touch with negative and painful emotions.

Margaret describes a similar scenario:

"Simon has friends and that but I know that he will probably never marry and that, erm, and he will never have children, which is sad when you think about it. His life will never be like ours" (Margaret, line 234-236)

Margaret recognizes the fact that despite her son's physical transition into adulthood, there is no adherence to a normative pathway and natural progression into adulthood. Since the natural progression in life tends to occur in stages such as attending school, college, university and then engaging in employment and possibly marriage, most people would expect this process to take place within the majority of the

adult population. However, it seems that many adults with mild LD do not get these opportunities in life and experience the full process. Thus, this leaves them, as well as their parents, in a liminal state, with significant amounts of uncertainty, no sense of direction in terms of their future path, and with no roadmap. For many people, the time of transition from adolescence into adulthood is a crucial period that can shape the adult life span (Davis & Vander Stoep, 1997). In the case of individuals with LD, this process tends to be slower (Biwas, et al., 2016) often due formal services being abruptly withdrawn even though the need for them continues (Osgood, et al., 2010). Subsequently, longer transition to adulthood puts strain on the person in transition as well as their family (Settersten & Ray, 2010).

3.2.3.2 Subtheme 2: Glimmers of adulthood and finding the positive construct versions of adulthood in behaviour of the offspring

It is apparent that many participants perceive their adult offspring with mild LD differently to how they perceive other adults. This is mainly because adults with LD require more social and family support than most adults without LD diagnosis. Nonetheless, all participants recognise many aspects of adulthood in their offspring and they see these aspects in a positive light. This positivity might be seen as a strategy for dealing with the situation. The following extracts illustrate this in more detail.

Mina describes an emotive situation in which she recognizes adult behavior in her daughter Kate:

"I was really down that day and she could sense that. She asked me: mum, what's wrong? She said, you know, whatever it is it won't last forever, nothing does; I thought to myself, what a thing to say, how mature is that? She made me a cup of tea

and she stayed with me, which made me feel better, I felt really looked after, it was wonderful. I thought my little girl has grown up" (Mina, line 385-390)

The above statement confirms that Mina experiences her daughter as an adult. Although in many situations it is Mina who provides her daughter with support, it seems like this time the roles have changed and Mina recognizes this when her daughter responds to her in a very mature and supportive way. Subsequently, Mina feels proud by her daughter's response to the situation and recognizes Kate's maturity.

Margaret describes similar observations:

"I am proud that he goes to work, erm, while he's there, he's like everybody else, he does his job well and they love him there. When he's happy - I'm happy, it gives me a piece of mind. But while at home, he needs a lot of support, with cooking, washing his clothes and so on. I told you I have to take him to appointments and that cause he may not be able to express himself properly and that or comprehend fully what's being said

…" it's not all negative, here are positives too, you know, if you constantly focus on the negative stuff, it will just get you down and that" (Margaret, line 237-239)

Margaret has also found positive construct versions of adulthood in the behavior of her son Simon. For example, this is apparent through Simon's ability to engage in work. Simon has been able to feel a sense of belonging, sameness, inclusion and acceptance, which is important to both him and his mother. This gives Margaret a sense of relief and pride. When looking at the concept of adulthood in relation to her son, Margaret is also aware of some deficits in this area, nonetheless, she tries to focus on the positive aspects of Simon being an adult and what he can do as opposed to what he

struggles with. It seems that Margaret feels the need to push negative thoughts away and stay positive in order not to feel emotional discomfort.

Angelina describes aspects of adulthood her son presents with and how she feels about it:

"The fact that he works and that he is committed makes me feel very happy and I am very proud of him […] he needed to grow up, he needed to be out of the house, he needed to be wanted and needed to do something with his life, you know, and he is realising now that he can actually do things […]but it's taken time but he is improving with things. But in the long run it gives me such a piece of mind, I can step back a little and breathe, which I couldn't ever allow myself to do before" (Angelina, line 242-251)

Angelina's gratification and pride are very apparent in the above extract. She values her son's independence and adult behavior. She is pleased with the fact that her son is gaining confidence through working and that he is recognizing his potential. This positive view on her son's adult life tends to suggest Angelina's hope for a future in which her son can be more independent. This may also suggest that in terms of her own involvement as a mother, Angelina recognizes the fact that she is now able to 'step back a little and breathe', in line with mothers whose adult offspring can adhere to a 'normative' pathway. Perhaps she and her son can leave the liminal state they have lived in for many years.

It seems that for Julie it is clear that since her daughter has reached adulthood, this is how her daughter should be perceived and treated:

I can't really tell her (what to do) because she is 30 years old, she is an adult now, you know, (I: hmm…) It's not like years ago I could tell her and make her do it and make her be there and everything else but I can't do that if she's thirty, do you know what I mean" (Julie, line 406-410)

Julie recognises that her daughter is an adult, thus she is determined to treat her like an adult. Perhaps Angela uses this strategy as a way of dealing with the current situation. The fact that Angela has mild LD tends to suggest that she does need support in some areas of daily life. It is possible that by recognizing aspects of adulthood in her daughter, Julie is trying to negotiate a way out of the liminal and ambiguous state they have found themselves in.

It is apparent that all participants recognise aspects of adulthood in their adult offspring with a diagnosis of mild LD. It is also clear that they are aware of the deficits their son/daughter presents with in relation to being an adult. The notion of liminality is present in most accounts. The offspring experiences this and so does the parent. They face personal, social and political barriers while trying to adhere to a normative pathway. Despite all the difficulties, the mothers recognise their son/daughter's capacity in both positive as well as less positive light in relation to adulthood. It might be that the mothers focus more on the positive aspects of their offspring in relation to being an adult as these 'glimmers' of adulthood can be seen as a way of negotiating out of a liminal situation. This perhaps can never be satisfactory, as they will always be comparing to a pathway which is not likely or possible.

CHAPTER FOUR: DISCUSSION

Overview

The current chapter aims to summarise the research project and provide answers to the research questions. It offers a critique of the research method and illustrates limitations and implications of the study for Counselling Psychology practice and research. Recommendations for future research and improvement to the services for mothers of adult offspring with LD are outlined and the role of professionals in future clinical practice is explored.

4.1 Key findings

The study was conducted in order to explore the experience of mothers of adult offspring with a diagnosis of mild LD and to illuminate deeper personal meanings these mothers attribute to this experience. A gap was identified within the literature around the subject. IPA methodology (Smith & Osborn 2008) was utilised to meet the research aims.

Three superordinate themes and eight subthemes emerged from analysis of the research interviews. The superordinate themes identified were as follows: a) 'Getting on with it': unallowable emotions in living with a disabled offspring, b) Adult disability as invisible: falling off a cliff after the end of childhood and c) Glimmers of adulthood: negotiating transitions without a roadmap.

The general aim of the study was to gain an understanding of what it is like to be a mother of an adult offspring with a diagnosis of mild learning disability. The specific research questions were:

⚔ What are the experiences of mothers who have an adult offspring with a
diagnosis of mild learning disability?

⚔ What is their perception of the concept of 'adulthood' in relation to their adult
offspring with a diagnosis of mild learning disability and how do they manage
this?

⚔ What are mothers' experiences of capacity as well as deficit in relation to their
adult offspring with a diagnosis of mild learning disabilitiy?

**4.1.1 Research question one: What are the experiences of mothers who have an
adult offspring with mild learning disabilities?**

The research findings indicate that despite facing many challenges while caring
for an adult offspring with a diagnosis of mild LD, mothers tend to remain positive
about life and the current situation. They do this by displacing negative emotions to
both the past and the future. The findings suggest that staying positive enables them to
avoid negative emotions, which may prove unbearable in the present (Erdelyi, 1993,
Garssen, 2007). This emotional avoidance may have a valuable function as it may be a
useful strategy for dealing with painful emotions (Erdelyi, 1993, Garssen, 2007). It may
also play a role of a protective factor. The theory of liminality helps to explain this idea
and supports it (Turner, 1969). Mothers and their offspring with an LD diagnosis are in
between states permanently, not allowing negative emotions in the present by pushing
them to the past and the future, subsequently remaining in an emotionally liminal way
of being.

The research findings also highlight the mothers' profound sense of
responsibility for the care of their offspring. The lack of freedom, choice and agency is
evident in their accounts as they report not having time to themselves as a result of

caring for their offspring. Thus, their choice and agency cannot be exercised fully (Antshel & Joseph, 2006). Once again, the mothers remain in a liminal situation: even though their offspring is an adult, they need significant amounts of support and this is unlikely to change. Thus, the mothers become invisible as their needs never come first even if these needs are recognized.

Some mothers reported having health issues related to the extensive care of their adult offspring with an LD diagnosis. This is in line with previous research which suggests, that those who provide care over long periods of time are at a higher risk of physical and mental health problems, than those who do not carry such responsibilities (Carers UK 2012, Roberto, 1993, Hill & Rose, 2010, Gallagher et al., 2013, Cairns et al., 2014).

Many participants experienced some support from family and friends, however, some felt that they could not be fully understood by them unless they too had an offspring with a diagnosis of LD. Subsequently this contributed to feelings of isolation and living in a liminal state as these mothers may have had limited opportunities to feel heard and understood by others. Previous research illustrates that individuals with LD and those who support them lack formal and informal support and social networks (Pockney, 2006). This is not surprising as making and maintaining friendships require the opportunities that many people with LD and their carers cannot easily access (Bignall & Butt, 2000; Emerson & Robertson, 2002; Sim & Bowes, 2005). The study also confirms previous research, which illustrates how lack of formal services contributes to mothers' worry about their offspring's future care (Pryce, et al., 2015, Cairns, et al, 2013, Findlay, et al., 2014, Davys, 2007).

4.1.2 Research question two: What is mothers' perception of the concept of 'adulthood' in relation to their adult offspring with mild learning disabilities and how do they manage this?

Most mothers who participated in the study revealed that the definition of 'adulthood' does not fully reflect their son/daughter's presentation and that despite them being an adult, this is not always reflected in their daily life. This might be due to the concept of 'adulthood' and what it represents in today's society. Once an individual becomes an adult, they might be expected to cope with every day life the same way most adults do. However, individuals with LD tend to have bigger support needs (Biwas, et al., 2016) than adults without the condition. When this support is not available, transition to adulthood (Settersten & Ray, 2010) and what comes after, puts strain on the person in transition as well as their family. The common issue reported by the interviewed mothers was lack of formal support, which is often withdrawn from their offspring once they have reached adulthood, even though the need for it continues (Osgood, et al., 2010). Subsequently this has a negative effect on their offspring as well as themselves. The mothers commented on the lack of clear pathway, provision and future plan for their adult offspring.

Support needs may create some dependency on services, however, one can argue, that this dependency is created in people who have disabilities not because of the effects of their physical and psychological limitations on their ability to be independent, but because their lives are restricted by socio-political and economic forces which in fact produce dependency (e.g., lack of adequate adjustments for people with disabilities in a workplace). It seems that the lack of support contributes to creating barriers for individuals with LD and their carers, thus, the liminal state they find themselves in (Turner, 1969). As they try to conform to a normative pathway, this is often not possible and they are unable to leave the liminal state. Thus, their life opportunities are

restricted, which may have negative psychological effect on their wellbeing (Shearn and Todd, 2000). It also leaves them with significant amounts of uncertainty, no sense of direction in terms of their future path, and with no roadmap. The findings suggest that mothers of adult offspring with mild LD tend to manage this by focusing on the capacity of their offspring and positive aspects of their abilities as opposed to negative ones.

4.1.3 Research question three: What are mothers' experiences of capacity as well as deficit in relation to their adult offspring with mild learning disabilities?

As mentioned above, all mothers were able to reflect on the notion of capacity and deficit in relation to their adult offspring in relation to adulthood. The findings suggest that mothers tend to focus more on positive rather that negative aspects of this. Despite all the challenges they face on a daily basis, they find 'glimmers' of adulthood displayed by their offspring with LD. These 'glimmers' can be seen as a way of negotiating out of a liminal situation. This perhaps can never be satisfactory, as they will always be comparing to a pathway which is not likely or possible. This positivity might be seen as a strategy for dealing with this challenging and difficult at times situations and feelings.

4.2 Quality of research

I used Yardley's (2000) criteria for quality as a guide as these comprise a comprehensive list of indicators of quality and rigour in qualitative studies. Yardley (2000) listed the following criteria which will be discussed in turn below: sensitivity to context; commitment and rigour; transparency and coherence; transferability, reliability, and validity, and impact and importance. I consulted key commentators in the field of interviewing and analysis (Kvale & Brinkmann, 2009; Smith et al., 2009; Willig, 2012)

throughout the study to ensure a rigorous approach. Therefore, issues such as my role as researcher, ethical considerations, power relations between myself and participants, and reflexivity were considered throughout the study.

4.2.1 Sensitivity to context

Sensitivity to context was reflected in the choice of research topic; I was familiar with the topic and context in which the study took place. Furthermore, I was familiar with the types of issues experienced by participants and so was able to appreciate the topic in some depth. I adopted a sensitive approach in the selection of participants and took care that they would not experience distress. In addition, I selected participants on the basis that they were experts on the topic, that they were unknown to me, the researcher, and that they were comfortable being involved in the study.

4.2.2 Commitment and rigour

Commitment and rigour were demonstrated in the manner in which the study was carried out. I gave a full commitment to undertake the study to its completion and to address issues relating to quality. I took a rigorous approach to the design of the study, including selection of the most suitable method to address the research questions (Please refer to chapter two).

4.2.3 Transparency and coherence

I made every effort to be explicit about my own role in the study and about my role in interpretation. I provided evidence for each research claim made. A sample of an interview transcript has been made available for scrutiny in the appendices as have the coding and development of themes. I made the nature and focus of the study explicit to participants and this has been outlined in detail.

I made every effort to explain the findings in a coherent manner and to refer to the literature on the topic. I have explained and detailed abstract features of the analysis, such as the hermeneutic process, to show the reader how the process was undertaken and how interpretation was carried out. I have provided comprehensive information on topics, including the context and the findings, in the appendices to supplement the information given in the main text.

4.2.4 Transferability, reliability and validity

IPA is a method which is idiographic and inductive (Brocki & Wearden, 2006; Smith & Eatough, 2006); the principal aim is to perform an in-depth analysis and interpret individual experiences, not to make general claims. It is more accurate to say that findings can be transferred across cases in an IPA study rather than generalised (Smith & Eatough, 2006; Smith & Osborn, 2003).

In the present study, I analysed experiences and phenomena in detail, examined areas of convergence and divergence and conducted a cross-case analysis. Examining how the findings in this study fit into the overall literature is an attempt to find out how the experiences of participants in this study transfer across areas of common human experience; by examining individual experiences of phenomena, I built up a case-by-case picture of particular phenomena (Smith & Eatough, 2006). I made links to similar research studies and discussed areas of similarity and difference to build up a picture of parents' experiences of their adult offspring with mild LD.

Qualitative studies do not aim to fulfil objective commitments to validity and reliability; validity can be measured by the expertise of the researcher and the extent to which the study investigated what it set out to investigate. Reliability can be measured by efforts towards achieving consistency and trustworthiness (Kvale & Brinkmann,

2009). I made efforts in this study to apply the most appropriate research method to the research questions in a rigorous fashion.

4.2.5 Impact and importance

This study adds to the literature on the topic. Some new, and hopefully useful, findings have been identified and described in detail.

I intend to write up the study as a journal article and submit it for publication in a peer-reviewed journal. I will share the findings with colleagues in the LD service at a journal club meeting. The information will be used to inform practice around supporting parents of adult offspring with LD. I will share findings with other professionals who attend training workshops on LD service. I will share the findings with the participants in this study.

4.2.6 Role of researcher

I took care to consider my role as researcher at each stage of the study from the design to reporting of the findings. I gave due note to the opinions of commentators such as Kvale and Brinkmann (2009) who maintained that the interviewee's statements were not collected, they were co-authored; that the fixed written form took over as the original face-to-face interaction of the interview faded away.

4.2.7 Ethical considerations

I consulted ethical guidelines from the BPS and UEL and applied these throughout each stage of the study, from the design, the selection of participants, through the interviewing phase, the treatment of data, to the writing up stage. Participants were guaranteed anonymity and confidentiality. I considered potential distress and guaranteed participants the right to withdraw at any time during the study

or afterwards. I informed them verbally, and in writing, of the aims of the study and the extent of their participation. I offered follow up support if participants experienced distress or had questions about the study.

4.2.8 Respondent Validation

In terms of evaluating research, Yardley (2000) suggests that carrying out participant validation can improve the sensitivity and credibility of a qualitative study. In line with this recommendation, respondent validation was sought from the participants as a way of giving the participants the opportunity to give feedback on the findings and enhance the sensitivity and credibility of the study. Lewis and Porter (2004) argue that the minimum participants should expect for their participation is to have accessible feedback. Unfortunately in this study, only 2 participants requested a feedback session. Their feedback was taken into account and implemented in the write up of the findings of the study. Future research should ensure that feedback is provided to all participants in order to ensure validity of the research.

4.2.9 Unique and distinctive contribution

In conducting a study of this type, it is useful to have knowledge of LD and social and health systems. Furthermore, it is necessary to have sensitivity to the issues that impact on individuals with LD and their carers. I have experience in the area as a result of working for a learning disabilities service. Having contacts with professionals in different agencies and day centres was helpful because it made the recruitment relatively easy.

The findings in this study yielded an in-depth insight into the experiences of mothers of adult offspring with mild LD. The study offers an interpretative, hermeneutic analysis of participants' experiences. Gaining an insight into the salience of

individual parental experiences and concerns addresses a gap in the literature. The findings from this study corroborate some of the findings from previous studies, such as parental feelings of stress, future worry and the need for collaboration with professionals.

4.3 Strengths and limitations

In this section strengths of the study are explored followed by its limitations.

IPA was used to analyse the data generated in this study as it has a specific emphasis on the inner experiences, thoughts and feelings of participants. Given the nature of the study, analysis based a phenomenological epistemological framework also suited this research. A qualitative approach also seemed to fit with the study's intentions of understanding a relatively small sample of participants' own experiences in depth, instead of testing a predetermined hypothesis using a large number of participants (Smith, 2008). Personal experiences and attached to them meanings are important in counselling psychology as without them it is difficult to provide appropriate help and support (Rennie, 2007). Studying narrative accounts of participants allowed the full range of participants' support needs to be captured, which was a strength of the study.

In regards to conducting research, qualitative approaches are well suited when exploring novel areas of research (Barker et al., 2002). In this study, the research questions were addressed and a number of findings identified, which have added to previous findings on the subject.

The researcher was familiar with the topic and the types of issues experienced by mothers of adult offspring with LD and so was able to appreciate the topic in some depth. They adopted a sensitive approach in the selection of participants and took care that they would not experience distress. In addition, they selected participants on the

basis that they were experts on the topic, that they were unknown to the researcher, and that they were comfortable being involved in the study.

Commitment and rigour were demonstrated in the manner in which the study was carried out. The researcher gave a full commitment to undertake the study to its completion and to address issues relating to quality. They took a rigorous approach to the design of the study, including selection of the most suitable method to address the research questions.

Nonetheless, in a study of this kind, there can be questions about power relations between researcher and researched. Questions can arise about who owns the meanings of what is found and therefore, any resulting power asymmetry should be examined (Kvale & Brinkmann, 2009). In this study, the researcher explained to participants that they were a researcher and that the current study may be used in future journals and other research. Thus, they have been explicit about their role in interpretation and their role in co-construction of the findings. The principal authority of the participants was also acknowledged.

Power relations between researcher and researched may have influenced the study in a negative way. It might be that some participants found it difficult to disclose their true feelings. Mothers who tend to avoid negative emotions on a daily basis may do this in an interview too. When deciding to talk about their experiences as mothers of adult offspring with LD, they may therefore find themselves having to balance the need to obtain the benefits associated with disclosure, whilst attempting to avoid the negative consequences derived from sharing such information. They may also not be completely transparent due to the fear of being judged by the researcher. Nonetheless, the end result is an account of what participants think and present to the researcher. Analysis in an IPA study is subjective and therefore, truth claims are tentative (Smith et al., 2009).

Furthermore, IPA examines people's perceptions of events which may not reflect accurate occurrences. This study includes the assumption that the experiences captured are typical of mothers of adult offspring with mild LD to a certain extent. It is possible that some mothers who did not take part in the current study have very different experience of their adult offspring and that this has not been captured.

4.4 Implications

The following recommendations have been made on the bases of the findings in the current study.

Support provided for mothers of adult offspring with LD should be person-centred. Individuals with LD present with different levels of support needs even if the level of their disability is in the same range. Thus, their mothers' needs will vary too.

Professionals should be aware of the variety of different feelings mothers of adult offspring with mild LD may present with in relation to caring for their offspring. They may experience worry, uncertainty and fear. They may also be experiencing pride, relief and hope.

Professionals should be aware of the difficulty and uncertainty mothers face in supporting their adult offspring with mild LD on a daily basis. The offspring's diagnosis of LD may entail an unfamiliar world of bureaucracy and challenges when requesting formal support. Parents need information on the support available. The current study revealed lack of formal support especially once adult offspring with LD reached adulthood. Subsequently, this had a negative impact on their mothers.

The impact of having LD diagnosis can cause worry, which may have a negative psychological impact on individuals with LD and their mothers. Mothers may worry that diagnosis may cause exclusion and segregation. They are aware that their offspring

may be vulnerable to bullying, discrimination and inequality. They may worry about their son/daughter's social skills and their ability to fit in with other individuals and in a variety of environments. Findings indicate that their biggest worry is how their adult offspring will manage in the future. Professionals should be sensitive to the parents' concerns and provide adequate support.

Professionals should understand the complexity of the lives of mothers of adult offspring with mild LD diagnoses and the impact on their families overall. It would be useful for professionals to be aware of the unseen difficulties that many mothers experience and to bear this in mind in their dealings with this particular client group. The current study addressed the concept of adulthood in relation to adult offspring with mild LD and challenges this may bring.

It is important to acknowledge that psychological interventions alone will be limited considering that people with LD, and their families, are a socially disadvantaged group. As such, practitioners need to consider not only their therapeutic responsibility but also their social responsibility (Vera & Speight, 2003) and address their clients disadvantage within the remit of their posts. This means that practitioners may need to refer clients to and liaise with different services providing advice, advocacy, support with employment, benefits, housing, access to community services, education and leisure.

Professionals should be aware of power differences between themselves and mothers who may find dealing with professionals intimidating, unnerving, and a battle. The mothers who took part in the study reported great difficulties when dealing with professionals in the past, especially when seeking formal support for their offspring. Thus, they may be reluctant to seek help due to their negative past experience.

It is important that parents of adult offspring with LD are provided with the opportunity to participate in research and have a say in how support services can be shaped. The current study aimed to do this.

Counselling Psychology can play a role in this by offering psychological interventions These can range from individual to systemic family therapy as well as psychoeducation in order to increase their knowledge of LD and identify coping strategies (Ferguson, 2002; Risdale & Singer, 2004; Turnbull & Turnbull, 2001).

4.5 Reflexivity

The process of conducting this research project has been complex but at the same time very insightful. I tried to engage with the material to my best ability by following qualitative research guidelines and reading relevant materials. Research supervision has enabled me to follow these guidelines correctly throughout the whole process.

Supervision has been most beneficial during the revision of my interpretation of the data as it helped me understand and clarify the content of the material from a researcher point of view. I was able to discuss drafts of each chapter with my supervisor, which I have found extremely helpful. This process was very reassuring as it provided me with an expert eye on the subject. The literature review has provided me with a great insight into the word of disability today as well as in the past.

In an attempt to obtain meaningful and relevant data, careful thought was applied to the criteria for sample inclusion, the emergent themes and their meanings. This included ensuring maximum coverage of work features that increase the likelihood of emotional contact with clients and contexts which might elicit a need for emotional

expression. I initially intended to interview both mothers and fathers. I had no difficulties recruiting mothers of adult offspring with LD, however, it proved much more difficult to recruit fathers. Only one father showed interest in the study and he withdrew from it after having expressed his initial interest.

I tried to adhere to a rigorous and focused approach to analysis at all times. I always went back to the research questions and tried to work within the parameters set by the IPA method. I compared identified themes to existing literature. I also used previous literature on the topic in order to explain the findings and support them in a coherent manner. This was in order to ensure relevance to the studied phenomena in acquisition of knowledge that enhances current understanding of findings. It was also to provide an extension of existing theory.

I provided evidence for the process of interpretation and for each research claim made. A sample of an interview transcript has been included in the appendices as well as the coding and development of themes. I was explicit about the nature and focus of the study in explaining to participants the nature of the research project.

Taking ownership of my role in co-creating the findings allowed me to go beyond the descriptive, manifest interpretation and make step towards more in-depth interpretation. A reflexive log was used to aid in adopting a reflexive approach.

I tried to be reflexive at every stage of the study (Kolb, 1984), which helped me understand the phenomenon studied. Supervision has helped me immensely to stay focused and not divert from the topic in question. It has also helped to gain clarity and reassurance while interpreting participants' experiences. The findings were a product of my interpretation of the participants' words, which I acknowledge may not reflect their intensions. I appreciate the fact that this is only one reading of the data set and that other

researchers working with the same data set may have interpreted it differently. Furthermore, due to the lack of participants' feedback on the analysis process may have influenced the study in a negative way (only 2 participants responded). Given the opportunity, my future research would hopefully attract and involve much fuller participants' involvement in the process of analysis in order to gain a much more reliable picture of the studied phenomenon. It is likely that participatory analysis would have enhanced the purpose of 'giving voice' to participants instead of the researcher 'making sense' of participants' experiences while providing more reliable findings.

I acknowledge that my previous experience as a clinician working in a learning disability service has had an impact on the analysis of the current study. My direct contact with clients and their parents has most likely influenced my decision to conduct the study. I am passionate about working with this particular client group and I am mindful of the impact LD may have on families. I am also fully aware that my knowledge and experience in the area of LD has influenced my decisions in how to conduct this particular study and what to focus on. Having had contact with mothers as well as their adult offspring with LD throughout my working career has motivated me to try and contribute to the field of research in this particular area. Despite the fact that I have tried to bracket off my personal experiences, I am aware that this was not possible and that my personal experience has had an impact on the study.

I acknowledge the fact that my clinical experience, the concept of stigma and negativity associated with the concept of disability has influenced the lack of focus in the analysis on the presence of positive emotions. In my line of work I come across families with more negative experiences as opposed to positive ones, thus, it is likely that I focused more on the participants' negative experiences. On reflection, I do acknowledge the fact that many mothers of adult offspring with LD have very positive

experiences but that I do not often see this in my line of working. Therefore, my personal experience has most likely influenced the particular reading of the data. Furthermore, it is possible that in the current study the participants have accepted their situation. They may be happy and content as opposed to trying to avoid difficult emotions.

As already mentioned, I acknowledge that my experience as a clinician and my previous knowledge of the concept of LD has impacted the research. I have learnt that in order to get a full picture of the situation I need to be more open-minded and notice both positive and negative experiences participants experience. I do not think that the process of conducting this research has changed my understanding of the concept of learning disabilities. I have, however, learnt more about the impact of the bio-psycho-social model on disability and how it recognizes "the role of the environment in causing restriction" (Imrie, 2004) while not using disability in terms of actual limitation, impairment or environmental barriers. Disability is a complex interaction of biological, psychological, cultural and socio-political factors. Disabled peoples' lives encompass both the limitations of impairment and the effects of social discrimination imposed on them. A barrier-free world for people with LD is difficult to imagine. Creating better opportunities in supported employment for people with disabilities so that they may benefit from the income, self-esteem and social integration should be a priority for any disability policy (Gosling and Cotterill, 2000).

4.6 Further research questions

An interesting finding from this study was the gap revealed in the literature around what is known about the experiences of mothers of adult offspring with mild LD. Finding out about the experiences of fathers of these adults would be a suitable topic for further research. Previous literature illustrates that it is typically mothers who

assume primary responsibility for the dependent offspring's care (Smith, 1997). They are also likely to outlive their husbands, thereby becoming the sole parent (Greenberg, Seltzer, & Greenly, 1993; Hoyert & Seltzer, 1992). Currently, little is known about fathers' experiences in this area. Previous research indicates that men in particular struggle to validate and express their feelings (Kingerlee 2011) and can influence empathic practice (Neff, 2007).

Another topic of future research could potentially be the exploration of the experiences of siblings of individuals with mild LD as it would also be of interest to counselling psychologists and other professionals.

4.7 Relevance to Counselling Psychology

An exploration of mothers' perceptions and feelings around caring for their adult offspring with mild LD is an area that merits investigation as it is important for professionals, policy makers and service providers to be aware of the views and experiences of this population. Given that a literature on mothers' unique perspectives on the topic has been limited, it is envisaged that this study will give greater insight into the concerns and experiences of this particular client group.

This research complements existing practices that support adults with LD and their families. The findings in this study illustrate the difficulties that mothers face as their offspring reach adulthood. By giving professionals insight into topics such as parental physical and psychological stress, isolation and future worry, greater understanding could be fostered, thereby facilitating effective communication and minimising parental struggles. The findings of this study could be disseminated to other relevant professionals who would take on the role of advocate for parents of adult offspring with LD, communicating their issues and needs to others, making sure they

are included, supported and heard in the process. Counselling psychologists could be involved in providing training to other professionals in relation to this advocacy role.

The findings of the current study are in line with previous research in that people with learning disabilities and their families are socially excluded. They highlight the need to address issues of isolation, stigma, lack of support and other issues in therapy. Kingdon, Ramon, Perkins et al. (2005) have suggested a number of practical steps that services can take to promote social inclusion. Additionally, the practitioner can help the client explore how isolation affects their mental health and check how it affects their social self-perception. This is important as previous research indicates correlation between social exclusion and mental health problems (Congdon, 1996; Whitley, Gunnell, Dorling et al., 1999; Department of Health, 2001). Furthermore, several studies have found that having social support can protect individuals from mental health problems (Baker & Taylor, 1997; Schoevers, Beekman, Deeg, et al., 2000).

Counselling psychologists can play an important role in addressing issues of liminality in different areas of their clients' lives. For example, awareness of the liminal range of emotions and the function emotional avoidance may have for mothers of adult offspring with LD, may have a valuable role in psychologists providing this client group with the adequate psychological support.

4.8 Conclusion

The findings in this study have produced an in-depth insight into the experiences of mothers of adult offspring with mild LD. They reveal some emotional challenges these mothers face on a daily basis. They also reveal the extent of emotional avoidance used by these mothers and what role it plays for them. This is relevant to counselling psychology in particular as this knowledge may be valuable when working with this

particular client group. The findings from this study corroborate some of the findings from previous studies, such as parental feelings of stress, lack of freedom and agency, support, future worry and the need for collaboration with professionals.

This project has identified that research on mothers who have adult offspring with LD has been limited and that research on mothers of adult offspring in the mild range in particular has been scarce. In line with previous research, the current study has identified a breadth of support needs for this particular population, it has also pointed out that over time the services available have not fully met those needs. Still, such studies have yielded knowledge about the experiences of mothers of adult offspring with LD and have given them an opportunity to have their voices heard. However, it is believed that much more research is needed in this area.

The current project has highlighted the need for services to support mothers of adult offspring with mild LD. It has also looked at the role counselling psychology can play in this by offering psychosocial interventions. It has highlighted the need for practitioners to consider not only their therapeutic responsibility but also their social responsibility and refer clients to and liaise with different services providing support. Overall, the study has argued that research in this area will help improve the services offered to mothers whose adult offspring have mild learning disabilities. It is hoped that this project will also contribute to the wealth of knowledge in the area of learning disabilities, specifically when considering LD and the concept of adulthood.

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APPENDICES

Appendix 1: Invitation Sheet for Participants

Appendix 2: Covering Letter

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Appendix 14: Set of recommendations for practitioners working with adults with LD and their families

Participants required

Are you a parent who has an adult offspring with mild learning disabilities?

Are they 25 or above?

Would you be interested in sharing your parental experiences and expertise confidentially?

Would you like to take part in a research project exploring your experiences of having an adult offspring with mild learning disabilities?

If your answer to these

questions is **'yes'** then

I would like to talk to you

Please contact:

Monika Copija on:

Email: u1319113@uel.ac.uk

████████████████

Thank you for your time

Appendix 2: Covering Letter

Dear (name of participant),

RE: Experience of having an adult offspring with mild learning disabilities

Research Project

Thank you for showing interest in this research project.

I have attached some information for you to read about the research project. Inside this letter you will find:

Information leaflet: This will tell you more about the research, what you will be asked to do if you take part, information about confidentiality and a list of sources of support and advice.

Consent form: If you choose to take part you will be asked to sign the consent form before the interview begins.

If you would like to take part in this research or if you have any questions about the information inside this letter, please contact me by e-mail: u1319113@uel.ac.uk or by ████████████

Many thanks in advance

Best Wishes,

Monika Copija

Trainee Counselling Psychologist

University of East London

Appendix 3: Information Sheet for Participants

Information Leaflet

What is it like to be a parent of an adult offspring with mild learning disabilities?

You are invited to take part in a research study. Before you decide to take part, it is important that you understand why the research is being carried out and what it will involve. Please read the following information carefully and then decide if you would like to take part.

Background to the study

The main aim of the study is to understand more about what it is like to have an adult offspring with mild learning disabilities (LD). The focus is on parents' experiences and meaning making, their perception of the concept of 'adulthood' in relation to their adult offspring with mild LD and how they manage this. Experiences of capacity as well as deficit in relation to their adult offspring with mild LD will also be explored. In addition, the concept of mild learning disabilities as a hidden condition will be explored as the condition is not always visible to others.

The advantages of taking part are that you will be providing information that could help to increase the awareness and understanding of what it is like to be parent of an adult offspring with mild LD. This could affect the way professionals work with parents of adult offspring with mild LD in future. It may also provide appropriate services for such parents.

Who are we looking for to take part?

We are looking for people who:

- Are Parents (mothers and fathers) of adult offspring with mild learning disabilities

- The age of the adult offspring must be 25 and over

✠ The level of learning disabilities of the adult offspring must be in the mild range

Do I have to take part?

No. It is your decision as to whether you take part in the study. If you decide that you would like to take part, please get in touch with the researcher by phone or e-mail.

You are free to pull out of the study at any time and you will not be asked to give a reason.

What will happen if I take part?

You will be asked to read and sign a consent form. You will then take part in an interview with a female researcher. The interview will last around one hour. This interview will take place on a date and time that is convenient for you.

The interview will be digitally recorded and transcribed (typed into text). The transcribing will be done by the researcher, the names of the people who take part will be changed when the research is written up to for confidentiality purposes.

What does Confidentiality mean?

Confidentiality is a set of rules that limits access or places restrictions on certain types of information being shared. Confidentiality means not telling other people about what you've said. It means that you can feel safe talking about something.

Will my confidentiality be respected?

Your participation will be kept confidential. All material will be stored in a locked cabinet. Any information identifying you (like the consent form) will be stored separately from the typed copy of your interview.

Comments made in the interview will be used in the write up of the research, however all information that might identify you (for example: names and places) will be removed. The recording of your interview and the transcript will be kept in a locked cupboard.

Only the researcher, supervisors and examiners will have access to the transcribed material. Data will only be accessed via a password on a computer, and will be kept after the study had finished with the view of a possibility to develop the research further in future (e.g., for publication). Your participation in the research will remain anonymous. Only the researcher will know the identity of the people who take part.

What are the possible risks and benefits of taking part?

We do not expect that taking part in this research will cause harm. The advantages of taking part are that you will be providing information that could help to increase the awareness and understanding of what it is like to be parent of an adult offspring with mild LD.

This could affect the way professionals work with parents of adult offspring with mild LD in future. It may also provide appropriate services for these parents.

What will happen to the results of the research study?

The results of the study will be written up and submitted as a research project as part of a Doctorate in Counselling Psychology.

Has the research obtained ethical approval... and what does this mean?

The people who take part in research have moral and legal rights and it is important that researchers do not violate these rights. Ethical approval means that research meets agreed standards of acceptable behaviour for researchers, which protects the rights of the people taking part.

This research has been given ethical approval by The University of East London's Ethics Committee.

How do I Find Out More or Take Part?

If you would like to take part or have any questions or please contact Monika Copija on:

E-mail: u1319113@uel.ac.uk

Thank you very much for taking the time to read this leaflet.

Monika Copija

Trainee Counselling Psychologist

University of East London

Appendix 4: Consent form

Research consent form

Research title: "Reflections: An Investigation into Mothers' Experiences of Having an Adult Offspring with Mild Learning Disabilities"

Researcher details: Monika Copija Counselling Psychologist in training. Student No. u1319113

Institution: University of East London.

Participant:

I have read this form and I am aware that I am being asked to participate in a research study. I have read the Participant Invitation Letter (attached to this form) and understand the information that is included. I have had the opportunity to ask questions and have had them answered to my satisfaction. I am aware I can continue to ask questions throughout my involvement in the study and that I can withdraw at any stage of the research process. I understand that consent will be checked with me before, during and after the interview.

I understand that I will be offered time after the interview to discuss my experience and raise any concerns. I am aware that the researcher is bound by duty of care to disclose any information which alludes to risk to my-self or other people. I voluntarily agree to participate in this study. I am not giving up any legal rights by signing this form. I will be given a copy of this form**.**

Print name   **Signature**

Date and time

Appendix 5: Interview Schedule

Prior to the interview taking place the researcher will thank the participant for coming, introduce herself and clarify the aims of the interview. Inclusion criteria will be confirmed and minimal background information will be collected (name and age of participant and their offspring). The use of the tape recorder will be explained and issues of confidentiality outlined in the participant's information sheet will be addressed. The participant will then be asked to read and sign the appropriate consent form. Once this has been completed, some background information will be collected. Following this, the researcher will ask if the participant has any further questions. The interview will then start.

Interview questions:

- What has your experience of being a parent of an adult offspring with mild learning disabilities been like and what does it mean to you?

- What positive experiences have you encountered as a parent of an adult offspring with mild LD such as love, pride, laughter?

- What negative experiences have you encountered as a parent of an adult offspring with mild LD such as anger, disappointment or feeling upset?

- Can you explore the concept of mild learning disabilities as a 'hidden' condition?

- Can you say more about the condition in terms of any hidden issues related to it such as reactions of others and their expectations of your adult offspring with mild LD.

- What are your expectations of your adult offspring with mild LD in terms of daily living and other skills?

- Can you explore the experiences of capacity as well as deficit in relation to your adult offspring with learning disabilities.

- What is your perception of the concept of 'adulthood' in relation to your adult offspring with mild learning disabilities and how do you manage this?

✴ Can you tell me about a time when you saw your adult offspring with mild LD as an adult?

✴ Have you experienced situations in which you experienced your adult offspring differently? If so, please explain the situation and how it made you feel.

Debrief

Ask participants about their experience of the interview process and give contact details and inform participants that the researcher or supervisor can be contacted if any queries or concerns about the research need clarification at any stage in the research process.

Remind participants of the opportunity to be involved in the research during data analysis and enquire how contact should be made when the preliminary analysis is ready.

Give contact details of local support agencies and other self-help information that may be relevant.

Appendix 6: Additional information for Participants

Thank you taking part! After the interview, I will listen to the recordings, type these up and analyse them. The results will be written up as a thesis and could also be written up in other forms such as a journal article. If you would like a summary of the results these can be sent to all who take part once the project is finished.

Further support

If you become upset or distressed as a result of the research interview and require support, the organisation **Mencap** may be able to help. Mencap is the leading voice of learning disability. This organisation promotes valuing and supporting people with learning disabilities, their families and carers.

Information, advice and Mencap services in England

If you live in England and would like impartial advice on all learning disabilities issues, please contact:
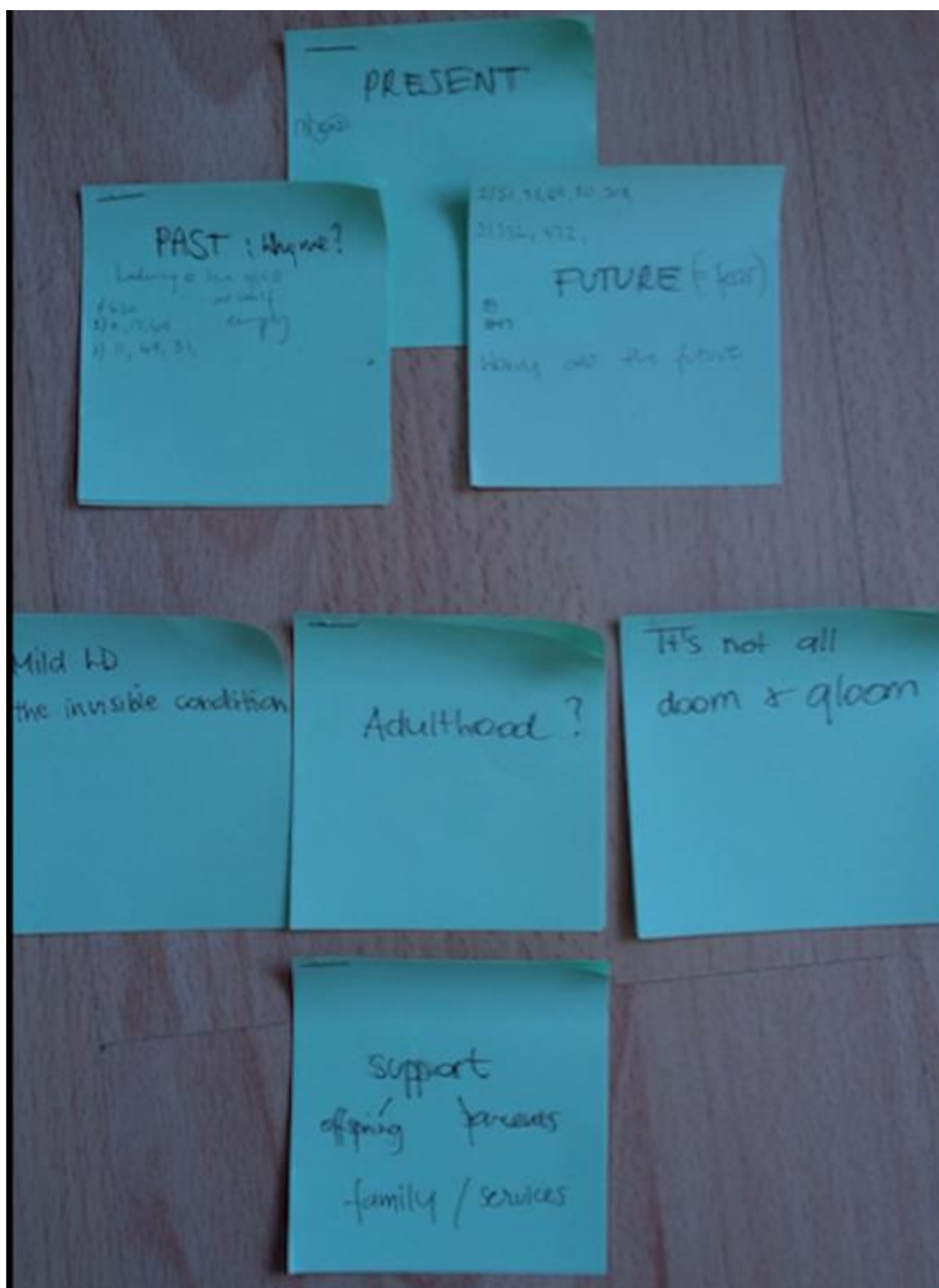
Mencap Direct
Telephone: 0808 808 1111
Email: help@mencap.org.uk

Mencap Direct telephone line is open 9am - 5pm Monday to Friday.

Appendix 7: Emerging themes

Appendix 8- Sample of transcript analysis (Interview 5)

1 I: Thank you very much for taking part in this interview. We have started
2 talking about being a parent of somebody who has mild learning disability
3 (P: Hmm). Perhaps we could go straight to the questions I would like to
4 ask you?
5
6 P: Yeah
7
8 I: What has your experience of being a parent of an adult offspring
9 with mild learning disability been like?
10
11 P: Very challenging because trying to get the support that he needs in
12 place (I: hmm) and also trying to get support that I need, because as a
13 child, I, when he was a child, I didn't think about what I needed, I just
14 got on with it because Jason is my first child (I: hmm) and I've got 4
15 children altogether (I: alright) so he is the eldest and we just got on with
16 what we had to do. But when he became a teenager, I started to ask for
17 help because I knew he would need help with his development and his
18 own self independence... and (pause) trying to get it was very very long
19 winded... lots of meetings, lots of people, talk and no action. So it was just,
20 it started to become like I was banging my head against a brick wall, all
21 the time because every time I came up there was something that may be
22 possible, but then there was a barrier in the way. So... I found (pause), I
23 find it very challenging... still but erm... I have like now, erm...you
24 know, how can I put it, I have this vision that you know, that Jason should
25 be supported in order to erm... progress with his future (I: hmm) but he
26 struggles, like he'll get to a point and then he'll slip and he needs that little
27 bit of a push to keep on going (I: hmm) and the support, it just collapses
28 and collapses and collapses (I: hmm) so when that support goes, we're
29 back to square one again and we have to start all over again: going to
30 meetings, answering the same questions, and trying to get support. And
31 he's now 26 and I started asking for help when he was about 14. So it's
32 over 10 years of constant requesting some kind of support, erm... yeah,
33 basically.
34
35 I: It sounds difficult, it sounds like it has been difficult for you and for Jason
36
37 P: It has been, yeah, it has been difficult for the whole family, not just me
38 and Jason, erm... and I've nearly lost my job three four times over,
39 because of the challenges and support that Jason has required, and it's
40 always, you know, with him, it's, you can't, I don't think you can say that,
41 you know, every individual is different, and every day is different, so the
42 requirements of his support change but it's like: well, we can do this, we
43 can do that, the options come up but it's, it doesn't always, it's not flexible
44 enough, erm, in order to just help him to assist him moving on in life,
45 really, you know, if they could say: well, we've got these people or we've
46 got that organisation, erm or we've got these kind of groups, or
47 somewhere where he can go and make friends, and develop from there.
48 He doesn't fit within the society, in that, in that, erm, how can I explain
49 it... (pause) His disability; he's like always sitting on a fence, like, he went

Appendix 9: Example of interview transcript

Emergent Themes	Original Transcript	Exploratory Comments
Adult disability as invisible	P: Yes! And I stood up and I said: 'you know, **they don't stop existing once they reach that age'** so (I: yeah) basically they started another club for over 16s or 18s, whatever the age was, but I think at the end of the day, the sad thing is you know, **when they become adults, everything is cut off from them, it's like they stop existing**, um, and this is when they need the most support because they … erm, being, going into adulthood is so scary, for even a normal person (I: yeah), you know, never mind someone with a disability	*'it's like they stop existing'- expresses frustration by using a metaphor* describes lack of support once adult with LD becomes an adult adult becomes invisible in society
Adult disability as invisible	**I:** How do you feel, or how did <u>you</u> feel at that point in time when he reached adulthood P: Well, I, you know, you try not to think about it really but when all these little incidents happen, and he can't do this and he can't do that and (sighs) and that's when I started thinking (pause) I was quite scared really because I'm thinking to myself that, erm, you know, **he's reached adulthood, but all the support is being taken away from him (**I: hmm)	Lack of formal support in adulthood adult becomes invisible in society *support being taken away-expresses frustration*

Unallowable emotions	so and don't forget that as they are getting older, so are we (pause) (I: hmm) so it's even more important, because when you start getting old<u>er </u>(I: hmm) you start thinking more in terms of erm…you know, **what happens when you're not there? It's terrifying**. So it means that one day the carer, main carer, parent, may, like my husband is no longer here for instance, and, they will be on their own, with so much support taken away from them, they're left with virtually nothing, basically, I think	Describes future worry <u>Pushing negativity to the future</u> *It's terrifying – expresses fear by using strong words*
Getting on with it	I: And you know, we've talked about adulthood a little bit…What is your perception of the concept of adulthood in relation to your son and how do you manage this?	
Unallowable emotions	P: Well, I think, you know, this…bringing up any children is like you just do it, **there's no experience rehearsals, you've just got to get on with it** once you have your children, you know, and erm I think even in the earlier days if I had more support things would be different and (sighs) if I had to give advice to anybody who has children younger than my son, it would be to prepare them more for life experiences like living, day to day living activities, i.e. cooking, looking after themselves, bla bla bla. This didn't happen to us …	*'you just get on with it -uses metaphor to express keeping busy, not thinking* Describes not having a choice <u>No time to stop and think, thus keeping busy as a way to avoid emotions</u>

| Adult disability as invisible | I: Could you say a bit more about this?

P: So for instance although Michael now is an adult, he is lacking certain skills because you know, he's not like the average adult. I, in the past I wasn't aware that he needs those skills more than anybody else to be honest, to survive even. So he needs to be taught those you know, he is not able to just pick up these skills (I: hmm) you know, if you don't know how to use a washing machine, you just need to read the instructions and maybe fail once but Michael is like, he needs to be taught again and again, you know, a lot more, so so much and **that support when they are in**

P:I I just think this is it, **the world ignores him, the world thinks: ignore the problem (I: hmm) if you ignore problems than they will go away** (I: hmm) | The world pretends her son's disability does not exist

Uses metaphor 'the problem' to describe how the world perceives her son and his disability

Person with disability as invisible |

Appendix 10: Themes which emerged from the interviews with the number of participants who identified each superordinate theme and subtheme in brackets.

Superordinate themes (number of respondents)	Subthemes (number of respondents)
'Getting on with it': Unallowable emotions in living with a disabled offspring (8)	Negative emotions as unallowable: the "robotic" mode and "getting on with it" (6)
	Pushing negativity away from the present to the past: "Now it's okay but not before" (5)
	Pushing negativity away from the present to the future: "What's gonna happen to him when I'm gone" (5)
Adult disability as invisible: Falling off a cliff after the end of childhood (8)	Parent and offspring stop existing in formal support: "It's like they stop existing" (6)
	Unacknowledged in relationships: "They don't really understand my situation" – support from family and friends (6)
	What about me? Invisible offspring - invisible parent (5)
Glimmers of adulthood: Negotiating transitions without a roadmap (8)	Physical transition into adulthood, but no adherence to a normative pathway – absence of a timeline and future path (7)
	Glimmers of adulthood and finding the positive construct versions of adulthood in behavior of the offspring (5)

Appendix 11: UEL Ethics Committee Approval Form

<div style="border:1px solid black">

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational
Psychology

</div>

SUPERVISOR: Laura McGrath   **REVIEWER: Zetta Kougiali**

STUDENT: Monika Copija

Title of proposed study: Reflections: An Investigation into Parents' Experiences of
Having an Adult Offspring with Mild Learning Disabilities

Course: Professional Doctorate in Counselling Psychology

DECISION *(Delete as necessary)***:**

***<mark>APPROVED</mark>**

***APPROVED, BUT MINOR CONDITIONS ARE REQUIRED <u>BEFORE</u> THE
RESEARCH COMMENCES**

***NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED**

APPROVED: Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is <u>not</u> required but the student must confirm with their supervisor that all minor amendments have been made <u>before</u> the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*

Student number:

Date:

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

If the proposed research could expose the <u>researcher</u> to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

☐ MEDIUM

☒ LOW

Reviewer comments in relation to researcher risk (if any):

Reviewer *(Typed name to act as signature)*:   *Zetta Kougiali*

Date: 17/07/2015

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee (moderator of School ethics approvals)

PLEASE NOTE:

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and

confirmation from students where minor amendments were required, must be obtained before any research takes place.

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here:
http://www.uel.ac.uk/gradschool/ethics/fieldwork/

Appendix 12: Change of Project Title

ResearchUEL

Dear Monika

Change project title - Miss Monika Copija

The Psychology Research Degrees Sub-Committee on behalf of the University Quality and Standards Committee has considered your request. The decision is: Approved

Your new thesis title is confirmed as follows:

Old thesis title: Reflections: An Investigation into Parents' Experiences of Having an Adult Offspring with Mild Learning Disabilities.

New thesis title: 'Reflections: An Investigation into Mothers' Experiences of Having an Adult Offspring with Mild Learning Disabilities'

Your registration period remains unchanged.

Best wishes

Claire

Change project title - Miss Monika Copija

Appendix 13: Electronic data file – participants' transcriptions

See CD data file

Appendix 14: Set of recommendations for practitioners working with adults with LD and their families

The following recommendations have been made on the bases of the findings in the current study.

Support provided for mothers of adult offspring with LD should be person-centred. Practitioners working with individuals with LD need to be aware of the fact that these individuals present with different levels of support needs even if the level of their disability is in the same range. Subsequently, their mothers' needs will vary too.

Professionals should approach every individual with LD with care and professionalism their patients deserve. It is important that they focus on the patient's needs without making judgements about what they can and cannot do based solely on their diagnosis. In addition, they must focus not only on the physical needs of the patient but also on the emotional and social issues that may be affecting their patient.

Professionals should be aware of the variety of different feelings mothers of adult offspring with mild LD may present with in relation to caring for their offspring. They may experience worry, uncertainty and fear. They may also be experiencing pride, relief and hope.

Professionals should be aware of the difficulty and uncertainty mothers face in supporting their adult offspring with mild LD on a daily basis. The offspring's diagnosis of LD may entail an unfamiliar world of bureaucracy and challenges when requesting formal support. Parents need information on the support available. The current study revealed lack of formal support especially once adult offspring with LD reached adulthood. Subsequently, this had a negative impact on their mothers.

The impact of having LD diagnosis can cause worry, which may have a negative psychological impact on individuals with LD and their mothers. Mothers may worry that diagnosis may cause exclusion and segregation. They are aware that their offspring

may be vulnerable to bullying, discrimination and inequality. They may worry about their son/daughter's social skills and their ability to fit in with other individuals and in a variety of environments. Findings indicate that their biggest worry is how their adult offspring will manage in the future. Professionals should be sensitive to the parents' concerns and provide adequate support.

Professionals should understand the complexity of the lives of mothers of adult offspring with mild LD and the impact on their families overall. It would be useful for professionals to be aware of the unseen difficulties that many mothers experience and to bear this in mind in their dealings with this particular client group. The current study addressed the concept of adulthood in relation to adult offspring with mild LD and challenges this may bring.

It is important to acknowledge that psychological interventions alone will be limited considering that people with LD, and their families, are a socially disadvantaged group. As such, practitioners need to consider not only their therapeutic responsibility but also their social responsibility (Vera & Speight, 2003) and address their clients disadvantage within the remit of their posts. This means that practitioners may need to refer clients to and liaise with different services providing advice, advocacy, support with employment, benefits, housing, access to community services, education and leisure.

Professionals should be aware of power differences between themselves and mothers who may find dealing with professionals intimidating, unnerving, and a battle. The mothers who took part in the study reported great difficulties when dealing with professionals in the past, especially when seeking formal support for their offspring. Thus, they may be reluctant to seek help due to their negative past experience.

It is important that parents of adult offspring with LD are provided with the opportunity to participate in research and have a say in how support services can be shaped. The current study aimed to do this.

Counselling Psychology can play a role in this by offering psychological interventions. These can range from individual to systemic family therapy as well as psychoeducation in order to increase their knowledge of LD and identify coping strategies (Ferguson, 2002; Risdale & Singer, 2004; Turnbull & Turnbull, 2001).