Listening and Learning:

Adults with mild learning disabilities' lived experience of individual counselling

Dissertation submitted in part-fulfilment for the award of Doctorate in Psychotherapy

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctorate in Psychotherapy is entirely my own work and that I have exercised reasonable care to ensure that the work is original and does not to the best to my knowledge breach any law of copyright and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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Abstract

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Learning disability services aspire to the social model of disability which acknowledges the expertise of service-users on all aspects of their lives. Counselling is now more widely accepted as a treatment approach for the emotional problems of people with learning disability, where previously pharmacological and behavioural methods prevailed. While the literature attests to the effectiveness of counselling with this population, research has mostly been quantitative. To date, minimal qualitative research exists on how people with learning disability experience counselling and none in an Irish context.

The present study aimed to hear the voices of Irish service-users on this aspect of their service. It explored the lived experience and meaning-making of adults with mild learning disability of individual counselling. The study design was qualitative, specifically interpretative phenomenological analysis (IPA). Participants were ten adults with mild learning disability from Irish learning disability services. Data from semi-structured interviews were analysed using IPA methodology (Smith, Flowers and Larkin, 2009).

The study found that participants valued counselling, experiencing it as relevant to their needs. Four superordinate themes emerged: overwhelming emotions, trepidation to trust, helpful aspects of counselling and the shadow of authority. Participants' experience was linked with existing literature in learning disability and counselling through concepts such as embodiment, emotional intelligence, attachment theory, life events and power relations. Participants' expectation that counselling would reflect prior experienced power relations of subordination/dominance is examined as is the role of staff in facilitating counselling. Participants' experience of counselling as a safe and helpful space primarily due to the therapeutic relationship is discussed.

The implications for counselling practice are considered in terms of the need to attend to emotions, the importance of the counselling relationship, awareness of power dynamics, recognition of social context and flexibility of approach. Finally, issues for learning disability services, counsellor training, policy and social implications are discussed with reference to the findings.

Chapter 1

Introduction

Modern life is complex and difficult at times. Emotional and psychological problems are commonplace and in *A Vision for Change*, the most recent blueprint for mental health services in Ireland, counselling and psychotherapy are recognised as playing a key role in modern mental health services (DoHC, 2006). There has been a major increase in the availability of counselling and psychotherapy services for the general population over the past 30 years in Ireland (Feldstein, 2011) and although much counselling and psychotherapy is carried out in the private sector, there is growing awareness that such a service should be available to all citizens, regardless of financial means.

Due to the move from institutional to community-based services over the past number of decades (Fahey et al., 2010; Emerson and Hatton, 1998), people with learning disability (PWLD) have become more visible in society (Noonan-Walsh and Linehan, 2007). They are citizens who face the same life problems as everyone else and have equal needs for counselling and psychotherapy (Jesper and Stapleton, 2005). They have similar rights to the rest of society and the same principles of citizenship, inclusion, access and community-based services apply to them (DoHC, 2006). The present study is an exploration of the counselling experiences of one section of the learning disability population, namely adults with a mild learning disability.

1.1: Terminology: Counselling vs. Psychotherapy

Much debate has centred on whether psychotherapy and counselling are the same or different phenomena. General consensus is that they can be used interchangeably (Rose, Loewenthal and Greenwood, 2005; Dryden and Feltham, 1992; Patterson, 1986). Indeed, Kwiatkowski (1998, p.5) believes that any differences *'......are slight and depend on context and perception rather than content, skill or process'.* Often the distinction is made in terms of work setting, length of treatment and fees charged and most practitioners regard the distinction as irrelevant (Feltham and Horton, 2006; Palmer and McMahon, 1997). As the term 'counselling' is more familiar and understandable to PWLD, I will mainly use this term through-out the study to avoid confusion. Occasionally the terms may be used interchangeably when reviewing literature using the term psychotherapy.

1.2: Learning Disability and Counselling

Both internationally and in Ireland, great strides have been made in the provision of services for PWLD (NDA, 2010; Atherton, 2007; Hillery, 1993). However, much emphasis has been on meeting practical needs such as for residential and day services (Kelly and Kelly, 2011; Mulvaney, Baron and McConkey, 2007). Current definitions of learning disability emphasise the importance of holistic approaches in understanding individuals' needs and taking into account the context of environment and relationships (WHO, 2010). At a macro level, the Human Rights and Equality perspectives must be considered in designing modern learning disability services (Pattison, 2005). PWLD have traditionally been treated in a paternalistic manner by society and not allowed self-determination and autonomy (Gates, 2007). However, the Self-Advocacy Movement, both internationally and in Ireland, is changing the self-perceptions of PWLD and increasingly they are demanding their rights and their voices to be heard on issues concerning their lives (Buchanan and Walmsley, 2006; Goodley, 2000; Aspis, 2002, 1997). Their mantra has become *'Nothing about us, without us'* (DoH, 2001).

PWLD are -

> *'....more vulnerable to environmental factors that influence mental health as they are less able to adapt and respond to features of their environment and to changes in it and services need to be sensitive to this vulnerability'.*
> (A Vision for Change, 2006, p.124).

Counselling is an important service which can support people to resolve problems and lead more fulfilling lives (Jesper and Stapleton, 2005; Palmer and McMahon, 1997). The popular stereotype of PWLD is of 'smiling, happy-go-lucky eternal children', immune from life adversities (Fletcher, 1993; Stokes and Sinason, 1992). They were traditionally excluded from and not seen as suitable candidates for counselling (O'Driscoll, 2009a; Banks, 2006; Bender, 1993) but in recent years, these exclusionary factors have been questioned and overturned (Cottis, 2009; Simpson and Miller, 2004; Hodges, 2003; Sinason, 1992). In May 2000, the inaugural conference establishing the Institute for Psychotherapy and Disability in London was titled *'Treating with Respect'*. O'Driscoll (2009b) suggests this was an acknowledgment of psychology professionals' historical disrespect towards this group of clients and advocates that more mental health practitioners need to be trained to provide for the psychological needs of PWLD. In 2010 there were 8,841 people in Ireland recorded as having a mild learning disability (Kelly and Kelly, 2011) and this figure is likely but the tip of the iceberg, as only those accessing or requiring learning disability services are included in official figures. It is regarded as about one third of the actual prevalence figure for mild learning disability in society

(DoHC, 2006). The majority with mild learning disability live anonymously in the community, only coming to the attention of specialist learning disability services in times of crisis. Living *'on the outskirts of normality'* (Olin and Janssan, 2009, p.256) between the normal population and specialist services and more vulnerable to mental health problems (Richards et al., 2001), this group has major needs for counselling services which at present are scarce or non-existent.

1.3: Motivations for the Present Study

1.3.1: Research-based Motivation: Camic, Rhodes and Yardley (2003, p.7) state that *'A final pragmatic criterion for good research is that it should be meaningful and useful to at least some people, for some purpose'*. To inform counselling services that meet the needs of adults with mild learning disability and to incorporate an inclusive and rights-based perspective, it is important to seek their opinions. Little is known about PWLD's subjective experiences of counselling (Merriman and Beail, 2009). The current study plans to address this gap. It is anticipated that this study will inform practice through indicating what, if any, benefit counselling has for people with mild learning disability through listening to their experiences and whether any specific issues emerge to improve the delivery of their counselling services. The present study was conceived from the belief that PWLD have important views about the services they receive and the standpoint that their voices can no longer be ignored in the design of services. It set out to explore the experiences of people with mild learning disability who have attended individual counselling.

1.3.2: Personal Motivation: My interest in the field of disability is personal and long-standing. My late brother Billy RIP who died in 2004 had autism and thus from early childhood the world of disability has been a part of my life. Following training as a Clinical Psychologist, I began working within Learning Disability Services in 1976 and continue to work in this area. In my early career, the approaches used by psychologists in learning disability were mainly psychometric testing, behavioural programmes and skills training. While acknowledging the contribution of these approaches in changing the face of services from institutional and care-based to a community and educational model, it seemed to me that the emotional needs of PWLD were sidelined. After further training in counselling and psychotherapy in the mid 1980's, I began tentatively working psychotherapeutically with PWLD and was pleasantly surprised at their capacity to engage at an emotional level and to establish and maintain a therapeutic relationship. Nowadays, I work in a learning disability service where my role is mainly as a Psychotherapist in a Multi-Disciplinary Team providing services for people with mild learning disability who live and work in the community. As a clinician I am interested in knowing how PWLD perceive counselling and the meaning they construct of it.

1.4: Objectives of the Study

Therefore the objectives of the present study are:

1) to explore the lived experience of people with mild learning disability of individual counselling

2) to discover their meaning-making of their counselling experience

Chapter 2

Literature Review

1. INTRODUCTION

1.1: Chapter Outline

Counselling is recognised as an important component of comprehensive services for people with learning disability (PWLD) (Royal College of Psychiatrists Report, 2004) and sizable research now exists in this area. To contextualise the present study, learning disability as a concept with its various explanatory models is delineated. Brief considerations of philosophical positions impacting on learning disability such as Normalization (Wolfensberger, 1972), Social Inclusion (Dept. Of Health, 2009, 2001; Mittler, 2000) and Advocacy (Gray and Jackson, 2002) are provided, followed by literature on service-users' perspective. The Irish learning disability context is discussed in terms of service provision and philosophies.

The main body of the review examines the emotional well-being of PWLD and the history of counselling provision for this group. Research on the effectiveness and process of counselling for PWLD is evaluated, followed by discussion of the current situation as regards access to counselling, clinicians' views, current approaches and training for counsellors. Gaps in the literature are identified and the present study positioned in relation to the current philosophies and existing research findings.

1.2: The Starting Point

Literature searches were conducted on Databases PsycINFO, CINAHL and MEDLINE using search terms ‘Learning Disability’, ‘Intellectual Disability’, ‘Mental Retardation’, ‘Mental Handicap’, ‘Developmental Disabilities’ paired with ‘Counselling’, ‘Psychotherapy’, ‘Counselling and Psychotherapy’, ‘Psychosocial Approaches’, ‘Service-users’ Perspectives’. The resulting 217 references formed the starting point for the Review, along with two policy documents - *‘Psychotherapy and Learning Disability’* from the British Royal College of Psychiatrists (2004) and the Irish Government Mental Health policy *‘A Vision for Change’* (2006).

2. THE MEANINGS AND PREVALENCE OF LEARNING DISABILITY

‘Learning disability’ means many things to different people (Gates, 2007) and no single criterion provides a definitive answer to its essence since it is a complex and multi-faceted concept. Literature on the labelling of PWLD reflects their position in society at different historical periods (Oliver, 1990; Ryan and Thomas, 1980).

> *‘All the terms are struggling with how to name a difference, a difference that has not been chosen and is not wished for by the parents, the child or society’.*
>
> Sinason (2000, p.187)

It is accepted internationally to use the terms ‘mental retardation’, ‘learning disability’, intellectual disability’ or ‘developmental disability’ (Priest and Gibbs, 2004). In the present study ‘learning disability’ will be used, as alongside ‘intellectual disability’ it is the most commonly used term in Ireland and is the term most often used by service-users themselves.

2.1: Definitions

The terms ‘learning disability’, ‘intellectual disability’ and ‘mental retardation’ are currently used to refer to people (American Psychiatric Association, 2000):

i) whose level of intelligence is below a certain point on a standardized intelligence test
ii) whose social and adaptive behaviour is deemed below average relative to the general population
iii) where the condition is manifested prior to the age of 18 years

All three criteria are necessary for a diagnosis of learning disability according to the Diagnostic and Statistical Manual of Mental Disorders (4th Edition-Text Revision): DSM-IV-TR (APA, 2000). This is similar to other classification systems such as the International Classification of Diseases-10 (ICD-10): Mental and Behavioural Disorders (WHO, 2010). In contrast to DSM-IV-TR and ICD-10 which use categories of mild, moderate, severe and profound, the American Association for Mental Retardation (AAMR) classification system emphasises functions and support systems (Luckasson et al., 2002). In Ireland, professionals working in learning disability services tend to use either the DSM or ICD systems in the assessment and classification process (Carr and O’Reilly, 2007).

Table 1 shows the classifications of learning disability in relation to an average Intelligence Quotient (IQ) of 100 as measured on a standardised Intelligence Test.

Table 1: Levels of Learning Disability (DSM-IV-TR)

Level of Disability	**Intelligence Quotient (IQ)**
Mild	IQ level 50-55 to 70 (approx.)
Moderate	IQ level 35-40 to 50-55
Severe	IQ level 20-25 to 35-40
Profound	IQ level below 20-25

Table 2 adapted from the 2010 National Intellectual Disability Database (NIDD) Annual Report (Kelly and Kelly, 2011) shows the distribution and prevalence of the different categories of learning disability in Ireland.

Table 2: Degree and Prevalence of Learning Disability (NIDD (2010)

Classification	**Numbers**	**%**	**Rate per 1,000**
Mild	8,841	33.4	2.09
Moderate	10,564	39.9	2.49
Severe	4,065	15.3	0.96
Profound	998	3.8	0.24
Not Verified	2,016	7.6	0.46
All levels	26,484	100	6.25

*Prevalence rates are based on Census of Population 2006 figures
(Central Statistics Office, 2007)

As can be seen, 33.4% of those on the NIDD database have a mild degree of learning disability, giving a prevalence rate of 2.09 per thousand. This is known as 'administrative prevalence' accounting only for those in receipt of services and does not reflect the true extent of the condition in society. Since those with mild learning disability are the focus of the present study, their profile will be considered in more detail.

2.1.1: Mild Learning Disability: Many with mild learning disability are outside of learning disability services, with exact numbers hard to ascertain. Within the overall learning disability population, approximately 85% are estimated to have mild learning disability (American Psychiatric Association, 1994). As adults, they can work, maintain good social relationships and contribute to society (ICD-10, 2010). Unless having additional disabilities, most have good communication skills though they may experience difficulties with literacy (Jones, Long and Finlay, 2006) and numeracy (Suto et al., 2006). There is wide variation in their working lives with many working in semi-skilled or unskilled work, while others require supported employment or a sheltered workshop/factory (Scuccimarra and Speece, 1990). Some live independently (Bond and Hurst, 2009) while others need extra support, ranging from supported independent living with staff visiting intermittently, to fully staffed Group Homes (McConkey, 2007). They maintain friendships (Emerson and McVilly, 2004; Knox and Hickson, 2001) and many have sexual relationships and committed intimate relationships (Yacoub and Hall, 2009). With adequate supports, some marry and rear children (Llewellyn et al., 2010; Carr and O'Reilly, 2007). Olin and Jansson (2009, p.257) describe people with mild learning disability as –

> *'....somewhat able to manage on their own, but who also need support to manage parts of their everyday lives. They may largely be said to live on the border and issues of belonging and participating are central to their lives'*

In a Swedish qualitative study of 15 young adults having either a mild learning disability (8) or a mental health diagnosis (7) Olin and Jansson (2009) report that no young adult described him/herself as being intellectually or mentally disabled and had developed strategies to avoid being so identified which demonstrates their awareness of the stigma of disability.

My interest lay in exploring the lived experience of counselling in learning disability. People with a mild degree of disability are more likely recipients of counselling services as most can communicate verbally and relate their experiences, a task more difficult for those with a greater degree of disability, making it less likely that counselling will be offered. Therefore I decided to focus on those with mild learning disability for the present study.

3. MODELS OF DISABILITY

The margins of society were broader and more encompassing of PWLD in earlier centuries (McClimens, 2005). Throughout history PWLD usually lived with family or independently and prior to the mid-nineteenth century had no special supported accommodation provided (Emerson, 2005). Often regarded with tolerance and affection in their communities, in Ireland the term ‘Duine le Dia’ (translation- ‘Person with God’) captures this mixture of regard and caring. However, learning disability was also viewed from a perspective of speculation, fear and scientific enquiry (Clarke, 1986). In the nineteenth century, fear resulted in the segregation of PWLD from mainstream life into institutions where they remained silent and invisible for many years (Ryan and Thomas, 1980).

From the 1970’s onwards, movement began from segregated to community-based settings both internationally and in Ireland (Fahey et al., 2010). Although leading to improved living conditions, increased educational, training and work opportunities, the question remains as to whether PWLD are truly included and equally valued in society (Atherton, 2007). Various lenses have tried to explain and understand their place in society (Ryan and Thomas, 1980) and these models - the medical, the individual and the social – have implications for professional policy and practice (Buntinx and Schalock, 2010). They provide a backdrop to understanding how counselling was regarded for PWLD.

3.1: Outline of the Medical Model

The medical model relates disability to some physiological impairment due to damage or disease needing appropriate treatment (Llewellyn and Hogan, 2000). Up to the 1960's medical investigations and eugenics were dominant in learning disability (Walmsley, 2001) with eugenicists regarding PWLD as a moral danger due to imagined promiscuity leading to the spread of inferior genes (Oliver, 1990; Williams, 1989). In early 20th century Britain, this view contributed to their segregation in large 'Mental Sub-Normality Hospitals' removed from mainstream populations (Simmons, 1978). 'Mental' had associations with mental illness and learning disability was regarded as a medical problem, with Psychiatrists as hospital directors and the 'patients' cared for by nurses. Linking learning disability with mental illness proved particularly problematic (Priest and Gibbs, 2004) and unfortunately in Ireland some PWLD continue to live in psychiatric hospitals (NIDD, 2011). The continuing interchangeable use of the terms in the media suggests that confusion continues in the public mind. The pharmacological model of mental illness treatment *'was bestowed on mentally handicapped people as well – but drugs do not cure mental handicap'* (Hattersley et al., 1987, p.101). The 1980's name change from Mental Handicap to Learning/Intellectual Disability in Britain and Ireland heralded a major advance in acknowledging impaired intellectual and learning capacity as the core of the condition.

3.2: Outline of the Individual Model

Known also as the Psychological Model (Gates, 2007; Priest and Gibb, 2004), this locates pathology within the individual and is linked to the rise of capitalism and wage labour where *'able-bodiedness'* and work capacity were valued (Oliver, 1990, p.47). The individual model emphasises deficiencies rather than abilities (Coles, 2001). Oliver (1996) calls this the personal tragedy theory which perpetuates a culture of dependency and non-acceptance, allowing no self-determination. This model was prominent up to the 1970's where 'special' schools and 'sheltered' workshops predominated and the emphasis was on the presumed failings and deficiencies of PWLD (Dumbleton, 1998) and associated protectionism and paternalism.

3.3: Outline of the Social Model

Discourses of disability are '*fluid, ever-changing and dynamic'* (Goodley, 1997, p.372) and understanding has moved to disability being seen as a dimension of human difference and not a defect (Mertens, 2003). The social model views disability as a construct of social and economic conditions at a particular point in history. Within the social model, society has responsibility to address issues of discrimination and restrictive environments (Goodley, 1997) and promote the personal and political empowerment of disabled people (Swain, Griffiths and Heyman, 2003). Society creates a *'disability identity'* (Reeve 2004, p.95; Reeve, 2002) resulting in feelings of inferiority and disempowerment which disenfranchises PWLD and silences their voices. Chappell, Goodley and Lawthom (2001, p.49) champion the social model as being *'the emancipatory road'* which professionals need to follow.

3.4: Critique of the Models and Implications for Counselling

The medical model has been widely criticised (Simmons, Blackmore and Bayliss, 2008; Williams and Heslop, 2005) and largely displaced although elements persist, particularly when the emotional problems of PWLD are ascribed to their disability (Mason and Scior, 2004; Butz, Bowling and Bliss, 2000). Under the medical model, PWLD were categorised, studied and institutionalised by medical practitioners (Harris, 1995; Rioux and Bach, 1994). The medical model *'tends to prioritise the illness rather than the person behind the label'* and highlight what is *'wrong'* with the individual (Williams and Heslop, 2005, p.232) rather than taking a holistic perspective. Diagnoses are not morally neutral and can have significant negative, social and political implications (Ho, 2004). In terms of counselling, it is more beneficial to regard mental distress as an interaction between intolerable life circumstances (Williams and Heslop, 2005) and inadequate coping skills (van den Hout, Arntz and Merckelbach, 2000) rather than solely as a collection of symptoms requiring diagnosis. Traditionally the emotional lives of PWLD got scant attention (Arthur, 2003; Hollins and Evered, 1990), thus counselling had no role in the medical model where drugs and behaviour management were the modus operandi for people regarded as 'sick', damaged and challenging. This view is changing with Cognitive Behaviour Therapy (CBT) being advocated for mental health problems (Hatton, 2002). However, given its tendency to focus on discrete symptoms (e.g. Willner, 2007; Dagnan and Jahoda, 2006), CBT links to a medical model approach though some CBT practitioners (Jahoda et al., 2006) do consider the social context of symptoms.

The individual model, focusing on deficits rather than abilities ignores that learning disability is a dynamic condition responsive to environmental conditions (Mackenzie, 2005). It is widely acknowledged that a disproportionate number with mild learning disability come from disadvantaged and socially deprived areas of society (Harris, 2006). Being considered incompetent is an extremely stigmatising aspect of a learning disability label and the perception of stigma can lead to negative self-evaluation and psychological distress (Olin and Jansson, 2009; Dagnan and Waring, 2004; Peter, 1999). The individual model can lead to *'oppression within the counselling room'* (Reeve, 2000, p.669). Counsellors are prone to the same negative stereotypes of disability as the general population and may inadvertently focus on individual deficits, lacking awareness of the connection between the social context of disability and personal problems (Reeve, 2000).

In contrast to medical and individual models which emphasise pathology and incompetence, the social model is committed to ability, equality and participation (Swain, Griffiths and Heyman, 2003; Goodley, 1997). It is holistic, humane and empowering, offering choice rather than control and responsive to service-users' needs rather than professionals' judgements (Coles, 2001). The social model values service-users' expertise and the importance of hearing their voices and viewpoints (Williams and Heslop, 2005). Critics of the social model point to the denial of physical/learning disability reality in disability discourse (Corbett, 2011; Shakespeare and Watson, 2001, 1997). However, Watermeyer and Swartz (2008) argue for both a political understanding of disability coupled with appreciation of the personal emotional consequences. It is important to provide individual support while also positioning the problem within society (Williams and Heslop, 2005). Reeves (2000, p.679) argues that a social model of disability sees *'.....counselling as a social and political act* .....(with)......... *emancipation and empowerment as the counselling goals'*. From a social model framework, counsellors, while assisting clients with their individual problems also support change through addressing the impact of societal views on their lives (Reeve, 2004; Swain, Griffiths and Heyman, 2003). Today, the social model holds dominant sway in disability work and while recognising its contribution to progressing the disability agenda, it is important to heed cautions that no model encompasses the total truth and is best regarded as a roadmap to understanding at a particular point in history (Humphrey, 2000; Llewellyn and Hogan, 2000). With this caveat, the present study is grounded in the social model in seeking to empower, through listening and learning, from what PWLD have to say about their experiences of individual counselling.

4. PHILOSOPHIES UNDERPINNING SERVICE PROVISION AND PRACTICE IN LEARNING DISABILITY

A brief discussion of philosophical outlooks underpinning service provision and practice both internationally and in Ireland over the past 40 years provides a context to the relatively recent development of counselling services for PWLD.

4.1: Outline of the Philosophy of Normalization

Originating in Scandinavia, normalization means *'creating an existence for the mentally retarded as close to normal living conditions as possible'* (Bank-Mikkelson, 1980, p.56). It advocated integration into mainstream society thus moving away from a segregation and deficiency model (Nirje, 1970, 1969). Popularised in the United States by Wolfensberger (1972, 1980a, 1980b) who argued that PWLD are seen as deviant by society, leading to stigmatisation and social devaluation. Normalization was an impetus to closing many large institutions and moving to community-based services (Towell, 1982). It worked mainly through staff training to change existing attitudes and thus improve services. Normalization was essentially a movement by professionals for professionals and was developed by academics and professionals without input or participation from PWLD (Walmsley, 2001; Race, 1999). Many of the criticisms levelled at normalization concern the denial and devaluation of difference rather than difference being celebrated as with other devalued groups such as ethnic minorities, gay people and women (Culham and Nind, 2003).

4.2: Outline of the Philosophy of Social Inclusion

Cambridge (1997) contends that the denial of difference is one way in which normalization differs from the Social Inclusion movement which advocates '......*full and fair access to activities, social roles and relationships directly alongside non-disabled citizens'* (Bates and Davis, 2004, p.196). Inclusion is more relevant for a social theory of disability as although normalization and social inclusion both promote the best interests of people with disability, they have different value bases (Culham and Nind, 2003). Inclusion supports participation in society of those who are different through change in social structures to include marginalised groups (Mittler, 2000). Difference is viewed dissimilarly in social inclusion and normalization: *'The former is more celebratory and the latter more apologetic'* (Culham and Nind, 2003, p. 73). Social inclusion theorists advocate the promotion of relationships between PWLD and non-disabled people as contributing greatly to mainstream society (Amado, 1993). The starting point is rights as without equal rights there can be no true inclusion.

4.3: Outline of the Philosophy of Self-Advocacy

The Self-Advocacy movement has become a major vehicle for PWLD to campaign for their rights. While traditional services were characterised by 'vertical relationships' between service-users and staff, the self-advocacy movement sought 'horizontal relationships' (Bates and Davis, 2004). Dating from the mid-1980's when the advocacy organisation for PWLD **'People First'** was set up in Britain (Goodley, 2000), self-advocacy is founded on the competence of PWLD. Through self-advocacy groups PWLD learned the skills of speaking up for themselves, handling meetings and seeking changes in their services. The movement helped the self-definition of PWLD by transforming their personal and social consciousness (Chappell, Goodley and Lawthom, 2001). Hearing their voices (Barron, 1996; Atkinson and Williams, 1990) has provided a window into their lived experience and

> *'Self-advocates who speak out raise important basic issues: freedom, fulfilment, self-determination. Nobody can speak more eloquently on these issues than the people directly concerned'.* (Worrel, 1988, p.13)

4.4: Critique of Philosophies and Implications for Counselling

Although historically important in spearheading deinstitutionalisation and improving the lives of PWLD (Corbett, 2011), normalization is not without its critics (Robinson, 1989). For a long period *'no-one dared question normalization'*, as it linked with all that was positive in services for disabled people (Williams and Nind, 1999, p.659). However, relocation out of institutions is but a first step to full integration (Henley, 2001) since '*....relationships have to change as well'* (Bates and Davis, 2004, p.198). Normalization has been criticized for expecting disabled people to conform and become 'normal' to be accepted rather than their exclusion condemned and society adapting (Ferri and Gregg, 1998). Normalization failed to consider the experience of PWLD within a political framework, offering a theory of service but not of disability and neglecting to examine the power relationships between professionals and PWLD (Chappell, 1992). Counselling is helpful in exploring power relations and developing assertiveness (Lunsky, Straiko and Armstrong, 2003). Power relations also need attention in counselling work itself which requires equality and a horizontal relationship (Bates and Davis, 2004).

Although self-advocacy helped affirm the identity of PWLD, it has been criticized as leading only to small, temporary and cosmetic changes while allowing power to remain within institutions and continuing paternalism, albeit in a more benevolent guise (Aspis, 2002). With regards counselling, normalization has little directly to offer as it mainly concentrates on structural aspects of services (Chappell, 1992). By contrast, social inclusion and self-advocacy provide important buttresses for counselling work in learning disability, being closely linked to the social model. Coles (2001) believes that the social model of disability which promotes equality, inclusion and rights should be taught to all working in learning disability. A key principle of the social model is that services should be service-user led (Williams and Heslop, 2005) and self-advocacy has supported people to speak up and give their opinions. The present study sought to obtain the views of service-users and believes counselling, like all aspects of services, should be responsive to and led by service-users' needs and opinions.

4.5: The Service-Users' Perspective

With the advent of self-advocacy PWLD began to demand that their voices be heard in the provision of services (Hoole and Morgan, 2010). They are rightly considered as having an expertise which needs harnessing both in research and service design (Knox and Hickson, 2001; Knox, Mok and Parmenter, 2000). Following on from the social model, a collaborative approach is now deemed essential in learning disability services. Several studies have canvassed the views of PWLD as a prelude to advising on changing services structures (Chinn et al., 2011; Bond and Hurst, 2009; Healy et al., 2009; Longo and Scior, 2004) while the subjective experience of PWLD on issues such as offending (Isherwood et al., 2007), having autism (Huws and Jones, 2008) and self-harming (Brown and Beali, 2009) have enhanced our understanding of their lives. Their views on group therapy (Macdonald, Sinason and Hollins, 2003 and psychodynamic psychotherapy (Merriman and Beail, 2009) have been elicited and the present study aimed to build on such research and further explore the views of PWLDs' experience of individual counselling, believing that they are the experts on its relevance and importance for them.

4.6: Provision of Services and Philosophies: The Irish Context

Learning Disability Services in Ireland were closely linked to religious orders who in the early part of the 20th century provided accommodation for children and adults with 'mental handicap' (Mulvaney, Barron and McConkey, 2007). These single-sex institutions, mainly in rural settings, provided an alternative to the state-run psychiatric hospitals where large numbers of PWLD were housed alongside the mentally ill. Through-out the 1950's and 1960's the Religious Orders, along with Parents and Friends Groups, became the main providers of services (Hillery, 1993). Their strong commitment allowed for greater flexibility, forward thinking and innovative approaches in service development during the 1970's and 1980's influenced by 'normalization' and 'social inclusion' philosophies. Large scale movement from institutions to community-based services began and continues. *'This move to ordinary living is underpinned by increased advocacy of* service-users *and new rights legislation'* (Mulvaney, Barron and McConkey, 2007, p.75). Irish Learning Disability services aspire, like services internationally, to be person-centred and service-user led (NDA, 2010; Holburn and Vietze, 2002; DoH, 2009, 2001; Coyle and Maloney, 1999) and many have adopted person-centred planning as an alternative to previous paternalistic approaches (Coyle, 2007; O'Brien and Lovett, 1993). Person-centred planning puts the focus on supporting the PWLD in choosing and planning their futures.

5. LEARNING DISABILITY AND COUNSELLING

Counselling can be simply defined as ‘a talking therapy’.

> *‘It is essentially a conversation which involves listening to and talking with those in trouble with the aim of helping them to understand and resolve their predicament.’* (Brown and Pedder, 1991, p.xi)

Counselling serves useful functions apart from resolving problems and expressing distress (Jesper and Stapleton, 2005). It can promote personal development, support decision-making, resolve internal conflict, enhance communicative ability, personal insight and inspire confidence (Cosden, Patz and Smith, 2009; Feltham and Horton, 2006). Hurley (2005, p.446) defined counselling in the context of learning disability as -

> *‘....a treatment that is mental rather than physical and includes the use of relationship, suggestions, persuasions, re-education, reassurance and support as well as specific techniques such as hypnosis, psychoanalysis, role-play, cognitive restructuring and instruction’.*

In the present study, ‘counselling’ covers a range of therapeutic models such as humanistic, psychodynamic and cognitive behavioural approaches (Woolfe et al., 2010). Although having different theoretical bases, all operate on the basis of *‘an alive real relationship’* where there is *‘active emotional understanding’* between the client and therapist (Hernandez-Halton et al., 2000. p.121). Research suggests that it is not specific counselling techniques that bring about change but aspects common across therapeutic approaches such as the quality of the relationship and mutually agreed goals and tasks (Wampold, 2001) and labelled the ‘common factors approach’ (Assay and Lambert, 1999). Surveying over 1,300 clients of Cognitive Behavioural, Person-Centred and Psychodynamic therapies, Stiles et al. (2006, p.555) found, similar to previous findings *‘....that theoretically different approaches* *tend to have equivalent outcomes'.* However, the research was conducted with the general population and may not necessarily apply to clients with learning disability. Counselling is concerned with emotional well-being and there are different facets of well-being for PWLD.

5.1: Well-Being of People with Learning Disability

The emotional lives of PWLD were neglected due to institutionalisation where they were *'out of sight and out of mind'* (Arthur, 2003, p.26). In addition, it was believed they were *'...worry-free and thus mentally healthy...'* (Fletcher, 1988, p.255). There also existed a 'diagnostic overshadowing' bias (Mason and Scior, 2004) where emotional problems were considered intrinsic to the learning disability and overlooked from a treatment perspective.

5.1.1 Attachment Issues: Based on the work of Klein (1960), Bowlby (1969) and Winnicott (1960) early attachment experiences are regarded as crucial for healthy emotional development. Some authors suggest that children with learning disability have greater vulnerability to not receiving 'good enough' early care due to parental grief, possible rejection and separations due to hospitalisations, respite breaks or institutionalisation (Shackleton, 2010; Simpson and Miller, 2004; Clegg and Lansdall-Welfare, 1995). Poor early attachment links with increased susceptibility to emotional problems in adult life in the general population (Wallin, 2007). However, research in learning disability does not fully support views on their attachment difficulties. In a study of 50 (2 with mild LD) adults living in long-stay learning disability institutions, reactive attachment disorder (RAD) was associated with childhood adversity but not with ability level (Minnis, Fleming and Cooper, 2010). Larson, Alim and Tsakanikos (2011) reported on 60 adults with mild/moderate learning disability, finding they showed the same range of attachment styles as the general population. Others consider behavioural problems in institutional settings more related to attachment and relationship difficulties than to learning disability per se (Russell, 1997). However, this is a complex area, needing more research.

5.1.2: Impact of Life Events: Researchers have looked at the relationship between exposure to life events and psychological problems in PWLD. Hastings et al. (2004) found a relationship between stressful life events and increased risk of affective disorder in a study of 1,155 adults, both institution and community-based with a range of levels of learning disability, indicating reactions to painful events similar to the general population. In a review of life events as risk factors, clear evidence emerged between life events and psychological problems for PWLD (Hulbert-Williams and Hastings, 2008). Bereavement is one life event which has been studied extensively (McEvoy, MacHale and Tierney, 2012; Clute, 2010; Boyden, Freeman and Offen, 2009; Blackman, 2008, 2003; Elliot and Dale, 2007; Gilrane-McGarry and Taggart, 2007; Dowling et al., 2006; Dodd, Dowling and Hollins, 2005; Kauffman, 2005; Summers and Witts, 2003; Hollins and Esterhuyzen, 1997; Read, 1996; Oswin, 1991). Indeed, some (Dodd and Guerin, 2009; Dodd et al., 2008; Bonell-Pascual, Huline-Dickens and Hollins, 2001) highlighted the risk for PWLD of prolonged and delayed grief reactions as their grief following bereavement may not be obvious, fully acknowledged or supported.

5.1.3: Mental Health Problems: Evidence has been cited of PWLD having higher levels of mental health problems impacting on their emotional well-being (Zaman, Holt and Bouras, 2007; Priest and Gibbs, 2004; Royal College of Psychiatrists' Report, 2003; Irish College of Psychiatrists' Report, 2004; Dosen and Day, 2001; Prosser, 1999; Borthwick-Duffy, 1994; Menolascino, 1990; James and Snaith, 1979). In a large population-based study of 1,023 Scottish adults with learning disability (38.9% of whom had a mild learning disability) Cooper et al. (2007a) reported over a third had mental ill health, being higher than the UK general population (Singleton et al., 2001). However, they caution against applying prevalence rates, particularly to those with mild learning disability, as many are undiagnosed and never utilize specialist services. Similarly, Whitaker and Read (2006) reviewed prevalence studies of psychiatric disorders among PWLD and found many studies were based on 'administrative samples' i.e. those known to services as having a learning disability. These may have utilized services because of mental disorder thus giving a higher prevalence rate. Richards et al. (2001) compared people with mild learning disability to a non-disabled group, reporting a fourfold increase in risk of affective disorder for those with mild learning disability irrespective of social and material factors. Although there is wide discrepancy in prevalence rates reported, ranging from 7% to 97% (Cooper et al., 2007a) and cautions need to apply, it is accepted that overall, PWLD experience at least equal if not greater prevalence and similar mental health problems as the mainstream population (Smiley et al., 2008; Emerson and Hatton, 2007). It is reasonable to assume that between 20 to 25% with mild to moderate learning disability will experience a mental health problem at some point in their lives (Grey et al., 2010). A combination of biological factors such as behavioural phenotypes, psychological factors e.g. self-esteem and insecure attachments and social-external factors such as life events may interact, accounting for higher rates of mental health problems in PWLD (Martorell and Tsakanikos, 2008). This is a strong signpost for counselling to be part of comprehensive service provision for the mental health problems experienced. Like the rest of the population, PWLD are not immune from problems such as anxiety, depression, psychosis and obsessive compulsive disorders.

Evidence suggests that anxiety disorders are common in PWLD (Reid, Smiley and Cooper, 2011; Hagopian and Jennett, 2008; Emerson, 2003). Reid, Smiley and Cooper (2011) in the Scottish population-based survey quoted previously found that overall 3.8% of PWLD had an anxiety disorder compared with 4.4% in the general population (Singleton et al., 2001). Variables independently associated with anxiety were lack of daytime occupation and adverse life events in the preceding 12 months. Other studies have reported on anxiety and PWLD (Douglass, Palmer and O'Connor, 2007; Dagnan and Jahoda, 2006; Glenn, Bihm and Lammer, 2003; Lindsay, Neilson and Lawrenson, 1997; Turk and Francis, 1990).

Sturmey (2004, p.226) believes PWLD are particularly vulnerable to developing mood disorders due to *'poor social skills, poverty, discrimination and a history of social ostracism from peers'.* Cooper et al. (2007b) in the Scottish population-based study reported a prevalence rate of 3.8% for depression and 1% for bipolar disorder for PWLD, both of which are higher than for the general population (Singleton et al., 2001). Hurley (2008) comments that limitations in verbal ability make diagnosis difficult using DSM-IV, but noted that sad mood, crying and anhedonia were key significant features of depression in PWLD. Several other studies reported on depression in learning disability (Ghafoori, Ratanasiripong and Holladay, 2010; Jahoda et al., 2006; McCabe, McGillivray and Newton, 2006; Nezu et al., 1995; Lindsay, Howells and Pitcaithly, 1993; Dosen and Menolascino, 1990).

PWLD are not immune from psychosis (Barrowcliff, 2008; Oathamshaw and Haddock, 2006; Haddock et al., 2004; Leggett, 1997). Haddock et al. (2004)

reported on 5 cases where individual and family CBT was successfully adapted to work with adults with mild learning disability and schizophrenia. They discovered that the learning disability impacted minimally on treatment

Prevalence figures for OCD in learning disability are reported as ranging from 0.63% to 3.5%, with the belief that OCD is likely under diagnosed in this population (Kostinas, Scandlen and Luiselli, 2001). Willner and Goodey (2006), describe a modification of CBT used to successfully treat a woman with mild learning disability and OCD.

5.1.4: Other Emotional Issues: Other issues impacting on well-being are reported in the literature. PWLD are more prone to being sexually abused (Cederborg and Lamb, 2008; Peckham, 2007; Sequeira, 2006; McCormack et al., 2005; Cooke, 2003; Corbett, 2003; Sequeira and Hollins, 2003; Sinason, 2002; Cooke and Sinason, 1998; Corbett, Cottis and Morris, 1996; Sobsey, 1994; Turk and Brown, 1993) and more likely to develop post-traumatic stress disorder (PTSD) following a traumatic event than the general population (Mitchell, Clegg and Furniss, 2006; Ryan, 1994). Abuse of PWLD often goes unreported, is often disregarded and there is higher risk of repeated victimization (Reiter, Bryen and Shachar, 2007).

Angry/aggressive behaviour seems prevalent in PWLD (Rose, Dodd and Rose, 2008; Taylor and Novaco, 2005; Lindsay et al., 2004; Taylor et al., 2002; King et al., 1999). King et al. (1999) conducted a CBT anger management group with 11 adults with mild learning disability and reported improvements on self-report measures of anger and self esteem at post group and 3 month follow up.

Some PWLD engage in self-harm (Duperouzel and Fish, 2010; Jones, Davies and Jenkins, 2004). Other difficulties reported include bullying (Mencap, 2007; Mishna, 2003), low self-esteem (Whelan, Haywood and Galloway, 2005), nightmares (Stenfert Kroese and Thomas, 2006; Willner, 2004) and offending behaviour (Lindsay and Taylor, 2005; Beail, 2001; Thompson and Brown, 1997).

5.1.5: Problems specific to Disability: The above 'diagnoses' are underpinned by adverse life circumstances and the probability that PWLD cope less effectively due to poorer cognitive abilities, including memory, problem-solving and planning skills (van den Hout, Arntz and Merckelbach, 2000). Additional to ordinary hardships and less effective coping skills, PWLD face problems directly resulting from their disability and societal perceptions –

> *'In thinking about disability, it is important to recognise that there is not only the organic disability to be considered, but also the child, family and society's response to it and their capacity to cope with disability and the pain of a difference that will not go away'.* Chantrell (2009, p.158)

PWLD must adjust to a disability with the consequent limitations imposed on their lives, the frustration of being dependent on others, difficulties around sexuality and its expression and vulnerability to exploitation (Waitman and Conboy-Hill, 1992).

People with mild learning disability are aware of the stigma attached to this label (Jahoda, Cattermole and Markova, 1988). Experiencing stigma is linked to psychological distress for PWLD (Dagnan and Waring, 2004) with Caine and Hatton (1998) suggesting that stigmatisation may contribute to the acknowledged increased mental health problems of PWLD. Jahoda and Markova (2004) interviewed 28 people with mild learning disability, reporting that all had awareness of stigma associated with learning disability, felt part of a minority group and attempted to distance themselves from stigmatising services and others with learning disability. Sinason (1992) believes that denial is used by many PWLD to cope with the pain of their stigmatised identity. Beart, Hardy and Buchan (2005) discuss how PWLD did not seek to be classified and how their identity, which is socially constructed based on IQ and social functioning, is given by professionals. This identity is usually permanent and life-long. Hughs (1945) saw learning disability as ‘a master status’, affecting all other social identities and in an ethnographic study of 51 adults with mild learning disability in the United States, Edgerton (1967, p.205) concluded that having a learning disability was *‘a shattering stigma.’* Jahoda et al. (2010) discuss a recent British ethnographic study of 17 young adults with mild to moderate learning disability having mental health problems and concluded that all were aware of stigma but actively disputed others’ views of them and tried to shape their own identity. The authors advocate that interventions for mental health problems must deal with social as well as interpersonal factors since the realities of discrimination and social barriers need serious consideration. Support for the conflict about a learning disability identity may well be an area of unmet need in services for PWLD (Craig et al., 2002), where counselling could have an important role to play. Schulman (1984) advises that disability and its stigmatising impact has to be taken into consideration in psychotherapy work with this population.

Individuals with learning disabilities *‘exist in complex systems of relationships in both family homes and residential services’* (Haydon-Laurelut and Nunkoosing, 2010, p.74). Those in day and residential services depend on paid relationships (Widmer et al., 2008) leading to relationship vacuums (Bayley, 1997) where consequent deep feelings of isolation and loneliness contribute to various psychological problems (Lunsky and Benson, 2001). The complexities of their lives and living situations are often discounted, with problems located in the person rather than in environments and societal attitudes (Mason and Scior, 2004). These external dimensions need acknowledging in counselling work with PWLD, and hence the importance of a social model framework for counsellors. (Swain, Griffiths and Heyman, 2003; Reeve, 2000).

5.1.6: General Quality of Life: The concept of 'quality of life' (QoL) is used in -

> *'...setting the goals for services and for assessing their impact on the character of people's day to day lives'* (Felce, 1997, p.126)

Both objective conditions and subjective appraisals need to be taken into account in assessing QoL (Verdugo et al., 2005; Felce, 1997) but most studies focus on objective conditions and staff information (Fahey et al., 2010; McConkey, 2007). However, an Australian study, using a modified, reliable and validated index of well-being from general population studies (Personal Wellbeing Index, 2006), interviewed 114 adults with a mild (72%) and moderate learning disability and found their self-reports of subjective well-being similar to the general Australian population (McGillivray et al., 2009). Little other research on positive aspects of the lives of PWLD emanates from peoples' own self-reports.

5.1.7: Implications for Counselling: Most research on the well-being of PWLD shows them experiencing many problems in their lives linked to increased susceptibility to mental health problems, additional difficulties such as increased vulnerability to sexual abuse and issues specific to their disability. Such a group would benefit from access to counselling services additional to the pharmacological and behavioural approaches widely available. Most of the research discussed above is quantitative, with opinions of PWLD conspicuous by their absence. The present study will contribute to filling this gap.

5.2: Counselling in Learning Disability: Historical Overview

PWLD were traditionally excluded from ‘talking therapies’ and not considered suitable for psychotherapy (Banks, 2006, 2003; Dodd and McGinnity, 2003; Bender, 1993). Low cognitive ability was cited as reducing capacity to benefit from counselling (Benson, 2004) perhaps due to clinical biases related to labelling rather than actual individual cognitive or functional level (Prout and Strohmer, 1995). Facility to form the therapeutic alliance necessary for psychotherapy was doubted due to perceived unresolved attachment issues and separation difficulties from childhood (Clegg and Lansdall-Welfare, 1995; Gaedt, 1995).

5.2.1: Psychoanalytic Influences: Corbett (2011, p.283) quotes Freud that *‘a certain measure of natural intelligence’* was required for psychotherapy. However, Freud did add that *‘I do not regard it as by any means impossible that by suitable changes in the method, we may succeed in overcoming this contraindication’* (Freud, 1904, p.264). Bender (1993) described the ‘therapeutic disdain’ of mental health professionals and the ‘unoffered chair’ while O’Driscoll (2009b, p.7) considers the *‘disability transference’* may have slowed the development of counselling services for PWLD due to therapists’ inability to process negative counter-transference feelings.

5.2.2: American Views: In the 1960’s and 1970’s in the USA treatment for emotional problems in PWLD were pharmacological and behavioural (Matson, 1984a). Carl Rogers (1957) regarded client-centred therapy as unsuitable for PWLD due to their poorer verbal expression and reflection skills. Doubts among clinicians about the efficacy of such work, diagnostic overshadowing, communication difficulties and limited research were additional impediments (Nezu and Nezu, 1994;

Butz, Bowling and Bliss, 2000). Most American mental health professionals had negative attitudes to providing psychotherapy to PWLD (Hurley, 1989) and additionally there was a dichotomisation of mental health and mental retardation services in the United States (Strauser, Lustig and Donnell, 2004).

5.2.3: British Views: O'Driscoll (2009b) discusses the importance of the Tavistock Clinic in London which from 1979 pioneered working psychotherapeutically with PWLD. Clinical psychologist and psychoanalyst, Neville Symington (1992, 1981) was seminal and was later joined by psychoanalyst Valerie Sinason (1992). Other early contributors were Joan Bicknell (1983) and Sheila Hollins (Hollins and Grimer, 1988) also based in London and Pat Frankish (1989) and Nigel Beail (1989) in Northern England. Two important concepts emerged around this time: the notion that PWLD, while having an organic limit to their intelligence, develop a *'secondary handicap'* as a way of coping with the original handicap from attacks on their skills and intelligence (Stokes and Sinason, 1992, p.54) and the distinction between *'emotional'* and *'cognitive'* intelligence (Stokes, 1987). Stokes asserted there was no clear one-to-one relationship between the two, with emotional intelligence being the capacity to be aware of and express feelings. There can be high cognitive intelligence while lacking emotional intelligence and visa versa. Hodges (2003) contended that while PWLD are cognitively challenged, their emotional intelligence may develop age appropriately, giving them the potential to experience and express emotions. Psychodynamic therapy requires emotional rather than cognitive ability, making it suitable for PWLD (Corbett, Cottis and Morris, 1996; Sinason, 1992). Psychotherapy is not primarily an intellectual activity (Schore, 2010; Esterhuyzen and Hollins, 1997) and the essence of therapy is ability to make emotional contact and form a relationship with the therapist (Hollins, 2001) of which many PWLD are fully capable.

5.3: Growing Recognition of the Value of Counselling

Despite the Tavistock beginnings, time elapsed before counselling became accepted as part of the treatment repertoire for PWLD as approaches such as Applied Behavioural Analysis (ABA) and psychotropic medications were well entrenched for emotional problems in learning disability with strong evidence bases (Sturmey, 2004). However, psychodynamic counselling and CBT began to gradually infiltrate as important treatment modalities (Whitehouse et al., 2006).

5.3.1: Psychodynamic Influences: During the 1990's psychodynamic and psychoanalytic approaches were the main contributors to literature on psychotherapy for PWLD in Britain (Beail, 1998; Hollins and Esterhuyzen, 1997; Beail and Warden, 1996; Sinason, 1992; Waitman and Conboy-Hill, 1992). Papers were mainly descriptive with a predominance of single case studies and theoretical reports. Sinason (1992) published an influential book *'Mental Handicap and the Human Condition'* demonstrating the potential of psychoanalytic psychotherapy with PWLD through many descriptive case studies.

5.3.2: Impact of CBT: Although Cognitive-Behavioural Therapy (CBT) was widespread in adult mental health, general opinion up to the 1990's was that it was unsuitable for PWLD (Dagnan, Chadwick and Proudlove, 2000; Dagnan and Chadwick, 1997), due to their *'slowed thinking, poor memory, limited vocabularies and problems with abstract thinking'* (Sturmey, 2004, p.223). Yet, it is debatable that mature, complete cognitive capacity is necessary for good CBT outcomes as children have benefitted from CBT (Taylor, Lindsay and Willner, 2008). In 1997 with the publication of *Cognitive-Behavioural Therapy for People with Learning Disabilities* (Edited by Stenfert Kroese, Dagnan and Loumidis), comprehensive evidence demonstrated that CBT was effective for a wide range of problems such as depression, anger and self-regulation in PWLD. Lindsay (1999) summarized his work with over 50 adults using a CBT framework, showing how the essential elements of Beck's model (Beck et al., 1979; Beck, 1976) could be applied with some modification and simplification of techniques for PWLD.

5.3.3: Other Influences: In America, Hurley et al. (1996) championed psychotherapy as beneficial for PWLD but cautioned that modifications from traditional therapeutic approaches were needed such as language simplification, structuring of therapy and a more directive and active approach. *'Psychotherapy and Learning Disability'* published by the British Royal College of Psychiatrists (2004) outlined how there was neither inclusion nor equity for this client group in accessing psychotherapy despite evidence showing its effectiveness to meet their socio-emotional needs (Prout and Nowak-Drabik, 2003). As the 21st Millennium dawned, growing interest in learning disability and counselling by practitioners and researchers was evident. Over 300 publications were cited in a bibliography on *'Counselling and Psychotherapy with Persons with Mental Retardation'* by Fletcher, Hurley and Bellorde (2000).

5.3.4: Impact on Counselling Provision: With the movement from institutional to community services PWLD were presented with the challenges of living *'an ordinary life'* (Towell, 1982). Despite the upsurge in the literature, provision of counselling services to PWLD remained and continues to remain sporadic and limited in Britain (Corbett, 2011) and also in Ireland. Services in the USA are slow to respond to the emotional needs of PWLD and mental health providers are at an early stage of modifying therapy techniques to suit PWLD (Fletcher, 2011). A survey of American clinicians in community mental health centres discovered that adults with mild learning disability were less likely to obtain counselling/psychotherapy services than adults generally (Dorn and Prout, 1993). PWLD with emotional problems were more likely to be offered behaviourally oriented interventions rather than counselling/psychotherapy (Prout and Nowak-Drabik, 2003).

5.4: Research on Counselling in Learning Disability

Willner, (2005, p.81) states that *'...research in learning disabilities is still in the throes of emerging from a state of widespread scepticism about the feasibility of using talking therapies at all'*. Progress in psychotherapy research in learning disability reflects *'the hourglass model'* (Beail et al., 2005, p.246). First proposed by Salkovskis (1995) as a model of the research process and going from wide angle single case studies describing theory and practice to exploratory single case designs which allow a narrowing of focus on the key effects which is the centre of the hour glass, calling for more rigorous research methods. Then there is a broadening out again to test hypotheses in practice-based research. Compared to general counselling outcome research where moderate effectiveness has been reported across an array of treatment types (Smith and Glass, 1980, 1977), outcome research on counselling in learning disability is in its infancy and in the 'very early' stages of the hourglass model (Beail, 2005). A similar picture is evident for counselling process research in this field. From considering the relevance of counselling/psychotherapy to this group, the question has become 'Is it effective?' (Beail and Warden, 1996). Practice-based evidence had long existed and informed the clinical efforts of many committed therapists and '*The absence of evidence for efficacy is not evidence of ineffectiveness'* (Beail, 2003, p.471). A critical overview of the effectiveness literature will be provided, followed by an account of counselling process research and since the focus of the present study is on service-users' perspectives, attention will be given to studies which sought service-users' opinions.

5.4.1: Overview of Counselling Effectiveness Literature: The evidence base for psychological interventions range from expert opinion, to uncontrolled and controlled single subject designs to randomised controlled studies (RCT's) regarded as the highest level of evidence (Willner, 2005; Ray and Mayan, 2001). RCT's of psychological treatments in learning disability *'are extremely sparse'* (Willner, 2005, p.74). However, there are many obstacles to conducting RCT's to evaluate counselling outcome in learning disability, such as ensuring a large enough number of participants, consent issues and measures problems (Beail, 2010; Oliver et al., 2002). Beail (2010, p.39) believes *'We are running before we can walk, if we aspire to the RCT'.* Due to the difficulties outlined above, most research reviews have concluded that evaluation studies of counselling in learning disability are not methodologically rigorous, have small samples and therefore limited generalizability (Brown et al., 2011; Beail, 2010; Gustafsson et al., 2009; Kellett et al., 2009). A review of published research in Britain concluded that there was inadequate availability of psychological treatments for PWLD, few published outcome studies and mostly consisted of single case studies (Hollins and Sinason, 2000). Kellett et al. (2009) suggest that in the current state of practice, the single case experimental design may provide useful guidelines to clinicians such as appropriateness of particular treatments, length of treatment required, relative impact of a treatment and relevance of particular components. Owing to the paucity and poor quality of evidence, practitioner opinion-based practice in the field has proliferated (Bhaumik et al., 2011).

Despite the difficulties, efforts to systematically review the effectiveness of different psychotherapeutic approaches in learning disability are growing (Brown et al., 2011; Prout and Browning, 2011; Mason, 2007; Whitehouse et al., 2006; Beail et al., 2005; Willner, 2005; Sturmey, 2004). Reviewing the effectiveness of CBT with PWLD, therapy work in anger management and offending behaviour showed most promise, while research in depression was weak due to the lack of experimental studies (Sturmey, 2004). Although concluding that CBT can be used successfully with PWLD leading to behaviour change, Sturmey regards the lack of specificity on the effective components in therapy as problematic in comparison to the rigorous outcome studies done with ABA and psychotropic medication. He critiques the confusion of cognitive therapy with classical behavioural techniques, believing that conclusions cannot be drawn from outcome studies confusing these two elements (Sturmey, 2006b, 2004). Willner (2005), reviewing the effectiveness of psychodynamic, CBT and cognitive therapies agrees with this conclusion, equally having difficulty in specifying the effective elements of therapeutic packages or the optimal way of delivering interventions to PWLD. Reports using CBT with sex offenders with learning disability have shown some success in preventing re-offending but the studies were uncontrolled (Lindsay, 2002; Nezu and Nezu, 1998).

Beail (1998) reported on psychoanalytic therapy with male clients with learning disability, 12 for problem behaviours and 8 for sexual offending over median treatment duration of 6 months. Findings showed behaviour problems were eliminated or almost eliminated in all 12 clients and sexual offending abolished in the 8 offenders and all gains maintained at 6 month follow up. However, the study had a small sample and lacked a control group. Beail et al. (2005) evaluated individual psychoanalytic psychotherapy with 20 adults with learning disability (level of disability not mentioned) and reported significant decreases in psychological distress, reduction in symptoms and improvement in interpersonal functioning and self-esteem. However, limitations were small sample size, no control group, treatment length varied from 5 to 48 sessions and outcome measures used not validated for PWLD. Beail et al. (2007) studied 3 groups having mild learning disability with varied psychological problems who received varying numbers of individual psychodynamic psychotherapy sessions. Results showed that most change appeared to occur in the first 8 sessions with subsequent outcomes trailing off over time. This was a naturalistic study, with no random allocation to groups or control group.

In a single case study of Solution-Focused Brief Therapy (SFBT) of a man with mild learning disability presenting with aggression, no further physical aggression was noted on a 9 month follow-up (Smith, 2005). More research is needed as to the effectiveness of SFBT with PWLD (Roeden et al., 2009). Of general interest is a study which retrospectively reviewed the case notes of 100 sequential referrals to a specialist psychotherapy service for PWLD in south-west London and found the average number of sessions was 10.4, a 33% drop out rate (which they suggested reflected a need for more support in the form of escorts and transport) and no adverse outcomes. Recorded outcomes ranged from reductions in problem behaviours, to getting a job (Parker et al., 2007).

Summarizing reviews published in the past ten years, Prout and Browning (2011) conclude there is evidence that counselling/psychotherapy with PWLD is at least moderately effective, a range of interventions are effective and a variety of problems can be addressed through counselling. This concurs with an earlier comprehensive review by Prout and Nowak-Drabik, (2003) who defined psychotherapy broadly to encompass face-to-face applications of psychological techniques by trained therapists aimed at modifying feelings, values, attitudes and behaviours (Prout and Nowak-Drabik, 2003, p.84). They found 92 studies in learning disability meeting their psychotherapy definition from 1968-1998. An expert consensus model was used in evaluation, with 9 studies considered suitable for meta-analysis and outcome rated on a 5 point scale. Overall results suggested that psychotherapy with adults with learning disability yielded a moderate amount of change and was moderately effective. However, ratings were relatively subjective, there were a wide range of research methodologies with over a third being case studies and few controlled studies. The orientations of investigated interventions were mainly behavioural, over a third could not be classified in terms of theoretical orientation and none were psychodynamic.

Although this study has been quoted extensively to support the effectiveness of psychotherapy (Lynch, 2004), Sturmey (2006b, 2005) is critical, maintaining it is mainly comprised of studies of behavioural interventions and contains no evidence for the effectiveness of more psychotherapeutic interventions such as psychodynamic approaches or CBT. However, his comments were widely critiqued and he was accused of overstating the case for the effectiveness of behavioural interventions (Beail, 2005; Hurley, 2005; King, 2005; Taylor, 2005). Nezu and

Nezu (1994) also included behavioural approaches in their literature review of effectiveness in addition to psychodynamic and group psychotherapy, which clouded matters. However, they did provide direction for future research and a clinical decision-making model for treatment planning in the absence of empirical research. Lindsay and Hastings (2004, p.219) admit that *'The sophistication, sensitivity to individual needs and scientific integrity of …* (behavioural studies)*….present standards to which other therapeutic approaches should aspire'*. As a strong advocate for ABA and the adaptation of effective interventions, Sturmey (2006b) warns of the dangers of '*....treatment fads....which may be ineffective or harmful to clients'* (p.109). Rigour and a stronger evidence base are undoubtedly needed (Emerson, 2006; Lindsay, 2006).

5.4.2: Overview of Counselling Process Research: According to Garfield (1990), psychotherapy outcome and process are inextricably linked. Given the relative growth of outcome and effectiveness research in learning disability counselling, counselling process research with this population has lagged behind and the processes underlying treatment outcomes are uncertain (Willner, 2005; Beail, 1998). Research in general counselling has looked at process from the perspective of the client (Elliott, 2008; Hodgetts and Wright, 2007) and also of the counsellor (Tryon and Winograd, 2002; Hatcher, 1999). Clients are not just passive recipients of counselling but actively shape its process and outcome (Manthei, 2007; Rennie, 2000) and their input is regarded as vital to the process of change (Duncan and Miller, 2000). Clients identify *'...personal qualities and interpersonal skills of the counsellor as fundamental to a good counselling experience'* (De Stefano, Mann-Feder and Gazzola, 2010, p.145). A solid therapeutic relationship (Norcross, 2002) along with the three psychotherapeutic factors of positive expectancies, role preparation and collaborative goal formation influence early psychotherapy process and have proven links to subsequent treatment adherence and outcome (DeFife and Hilsenroth, 2011). However, we have no empirical evidence that similar factors apply in learning disability counselling (Jones and Donati, 2009).

Johnson (2011) highlights the different perspectives of disabled people generally on counselling and how the counsellor's attitudes and values, particularly if unexamined towards disability, can impact the counselling process. A disability model of counselling is proposed to prevent *'...oppression in the counselling room'* from counsellors carrying unaware negative social attitudes (Reeve, 2000, p.669). Swain, Griffiths and Heyman (2003) believe that counsellors should raise clients' awareness of the social model of disability to aid understanding of the impact of social and environmental factors on their emotional well-being. Others propose that an important process in disability counselling involves the client moving from a sense of feeling different and inferior to developing a positive self-identity as a disabled person (Swain and French, 2000). This view is endorsed for learning disability counselling by Hurley et al. (1996, p. 378) who state that - *'Addressing the disability itself is a major treatment objective that builds self-acceptance'.*

Linington (2002, p.413) believes that working with PWLD in psychotherapy '... *is fundamentally the same as working with anyone else and as different'*. Veiga (2012, p.30) writing from a psychoanalytic perspective, discusses how *'The use of psychotherapy recognises that behaviours are a symptom of psychological distress'* and outlines some of the processes which may emerge in therapy sessions but with no supporting empirical evidence. Given the lack of counselling process research, most of the knowledge informing current learning disability counselling has emerged from clinicians' case study reports (e.g. Salvadori and Jackson, 2009; Bliss, 2005;

Razza and Tomasula, 2005; Schulman, 1984) and theoretical writings (e.g. Banks, 2006; Hodges, 2003; Hurley et al, 1996; Sinason, 1992). Salvatori and Jackson (2009) describe short-term psychodynamic treatment of a man with learning disability and discuss issues such as managing the boundaries of the therapeutic relationship, using basic techniques to help the client to tell his story and seeking to understand the unconscious content of his communication, through interpreting the meaning of his anxieties and defence mechanisms. Bliss (2005, p.28) used Solution-Focused Brief Therapy (SFBT) with a woman with learning disability and was surprised at the woman's *'...creativity and intelligence'*. She comments that much can be missed in therapy due to therapists' perceptions of client limitations. Outlining the many difficulties that children with learning disabilities have to navigate, such as slower information-processing due to cognitive impairment, difficulties with social skills, teasing and bullying and repeated experiences of failure, Schulman (1984, p.860) believes that –

> *'Out of this maelstrom of a childhood emerges, usually an adult who is battered and bruised emotionally.'*

It is not surprising that such adults would develop defence mechanisms as a way of coping, such as the 'secondary handicap' proposed by Sinason and Stokes (1992) or 'denial' (Schulman, 1984) which influence the process and outcome of therapy. Newman and Beail (2010) took an empirical approach to exploring the defence mechanisms used by 8 adults with mild learning disability. They evaluated transcripts of psychotherapy sessions using a defence mechanisms rating scale (DMRS) which outlines 28 defences (Perry, 1990) and found 24 of the 28 defences present in the transcripts, with denial and acting out the most frequently used defences. The DMRS has not been validated with PWLD, which is a limitation of the study along with small sample size which limits gereralisability.

The quality of the therapeutic relationship is considered important in all schools of therapies (Clarkson, 2003) and Jones and Donati (2009) surveyed the literature on the therapeutic relationship in psychological therapy for PWLD. They found little empirical work focusing specifically on the significance of the therapeutic relationship in learning disability counselling. They identified 2 studies (Strauser, Lustig and Donnell, 2004; Bihm and Leonard, 1992) which suggested that the therapeutic relationship is equally important in the counselling process in learning disability counselling as in mainstream work. Banks (2006) believes that the therapeutic relationship and other issues such as referral, consent, confidentiality, accessibility and communication assume greater importance in learning disability work and if not addressed can impact on the process of counselling to a degree that the client could be labelled 'unsuitable' for therapy.

A three-stage process in individual therapy in which cognitive and affective exploration precedes insight and change has been proposed by Hill and O'Brien (1999). Noting a dearth of studies examining the change processes occurring in psychotherapy in PWLD, Newman and Beail (2002) utilised the Assimilation of Problematic Experiences Scale - APES (Barkham et al., 1996; Stiles et al., 1990) in a single case study. The model suggests that a problem experience can be tracked through seven predictable stages of assimilation as follows: Warded off, Unwanted thoughts, Vague awareness, Problem statement/clarification, Understanding/insight, Problem solution, Mastery. Findings showed that the APES could usefully be applied to the transcript of a man with learning disability and provided evidence of increasing levels of problem assimilation over the course of eight sessions of psychodynamic psychotherapy. In a later study, Newman and Beail (2005) applied the APES to therapy transcripts of 8 clients with mild learning disability. Using quantitative analysis, the results confirmed that PWLD achieved increased understanding of their problematic experiences during psychotherapy within and across eight sessions. The small sample was a limitation of the study and there was no measure of change outside of therapy.

5.4.3: Research on service-users experiences of counselling: Another approach to evaluating effectiveness is to seek the opinions of service-users which accords with the social model of disability. Yet, the paucity of reported studies on how recipients of counselling/psychotherapy services experience counselling and its value to them is striking. Ideally, there needs to be a rapprochement between objective evidence of effectiveness and subjective views of consumers of counselling/psychotherapy services (Macran et al., 1999) if we are to truly embrace the social model, inclusiveness and advocacy. The present study endeavours to redress this balance.

Macdonald, Sinason and Hollins (2003) conducted an IPA study on satisfaction levels of 9 adults with learning disability (ability level not indicated) who participated in psychodynamic groups. Participants showed ability to participate in and benefit from the group. Superordinate themes were clustered into positive (Non-specific, Communication, Inclusion) and negative (General Avoidance, Negative aspects of group members, Other). Overall findings indicated participants valued the group and the opportunity to talk of painful feelings but were often unaware of any positive changes in themselves. Merriman and Beail (2009) report on another IPA study of 6 adults (level of disability not specified), who had received individual psychodynamic psychotherapy for two or more years. Findings showed that most had a clear understanding of reason for referral, were unsure what therapy would involve, found talking helpful, saw therapy as private, formed a dependent alliance with the therapist and did not like changing therapist. Participants reported positive changes in their behaviour and emotions which they ascribed to therapy and found it difficult to be negative about therapy or the therapist. Participants reporting positive changes in themselves differs from the findings of the Macdonald, Sinason and Hollins (2003) study outlined above. This may be related to differences between group and individual therapy.

5.4.4: Interim Summary re Research: Research in counselling and learning disability is mainly practice-based, small scale and lacking methodological rigour. Outcomes and counselling process research are determined more by therapists' clinical impressions and theoretical views than by independent measures (Brown et al., 2011) and many call for a more robust evidence base (Bhaumik et al., 2011; Brown et al. 2011; Prout and Browning, 2011; Sturmey, 2006). However, a cautiously optimistic picture is emerging, with evidence that psychodynamic and CBT approaches are effective for those with a mild learning disability (Prout and Browning, 2011; Cosden, Patz and Smith, 2009; Willner, 2005). Evidence is lacking for specific process components of therapeutic effectiveness or the optimal manner of delivering interventions (Willner, 2005). Modification of approach in all theoretical orientations is needed to maximize effectiveness (Mirow, 2008; Brown and Marshall, 2006; Whitehouse et al., 2006; Hodges, 2003; Lynch, 2000). There is an obvious dearth of qualitative studies on actual experiences of individual counselling of PWLD. This is a serious gap, given the expressed aim of services to listen to PWLD. In addition, no research on aspects of counselling and learning disability was evident from an Irish perspective, hence the strong rationale for the present study.

5.5: Current Situation re Counselling

To contextualise the present study I will consider the current situation with regard to counselling for PWLD. Despite mounting evidence on the benefits of counselling for this group (Brown et al., 2011; Prout and Browning, 2011; Cooke and Hargovan, 2005) there is still '*a monotherapy'* approach to treating mental health problems in PWLD, usually psychotropic medication or behaviour therapy (Dosen 2007, p.67). Arguing that the emotional problems of PWLD -

> *'....are very complex and deserve an approach that can cover various existential aspects and life problems of these individuals'* (Dosen, 2007, p.71)

Dosen advocates integrative treatment models using medical, behavioural and psychotherapeutic methods directed to underlying processes rather than just symptoms.

5.5.1: Access to Counselling: Despite recognition of its benefits, access to counselling remains *'...patchy and in some cases non-existent'* in Britain (Brown et al., 2011, p.41), and also in Ireland. Mainstream counselling services tend to exclude PWLD (Jackson, 2009; Palmer, 2007). A project begun in Britain in 2006 to increase access to counselling (Improving Access to Psychological Therapies – IAPT) for the general population included a guide for adapting the project to PWLD. However, little attention has been paid to their needs so far (Dodd et al., 2011) and specialist services continue to provide whatever meagre counselling services are available (Corbett, 2011). The situation is similar in Ireland.

5.5.2: Clinicians' views re Counselling: A survey of interventions used by UK clinical psychologists working in learning disability discovered many using psychotherapeutic interventions frequently or very frequently – 35% used CBT, 31%

used humanistic/person-centred and 17% used psychodynamic approaches (Nagel and Leiper, 1999). Additionally, 41% believed themselves competent to work psychoanalytically with PWLD. The delivery of psychotherapy services to PWLD has been ad hoc and modelled on generic counselling services without adaptation of approach and acknowledgement of disability issues (Palmer, 2007; Hurley et al., 1996). A survey of 223 clinicians (clinical psychologists and psychiatrists) in the UK reported that key factors in working psychotherapeutically with PWLD were their own perceived competence, level of the clients' disability and the diagnostic overshadowing bias (Mason, 2007). Respondents felt that psychological therapy became less effective with increase in disability level and that signs of psychological distress were often misread and misattributed to being 'learning disabled'.

5.5.3: Current Approaches to Counselling: Psychodynamic and CBT approaches dominate the literature. Dependence on descriptive single cases continues in recent psychodynamic writings (Alim, 2010; Beail and Jackson, 2009; Chantrell, 2009; Salvatori and Jackson, 2009). Kellett et al. (2009) recommend single case experimental evaluation of psychodynamic psychotherapy as providing a more robust evidence base than pure description. Recent research examining the processes of CBT with PWLD found that ability to discriminate among thoughts, feelings and behaviours was significantly associated with higher IQs and good receptive language, indicating that CBT should be effective with the mild learning disability population (Sams, Collins and Reynolds, 2006). Although having more difficulties in talking about events, beliefs and emotions than those without learning disability (Hebblethwaite, Jahoda and Dagnan, 2011), positive findings were reported from an experimental study of PWLDs' learning to link thoughts and feelings (cognitive mediation) when trained (Bruce et al., 2010). Prior assessment, some preliminary training and modified approaches enable PWLD to benefit more from CBT (Dagnam, Mellor and Jefferson, 2009; Joyce, Globe and Moody, 2006; Whitehouse et al., 2006; Willner, 2005). Other approaches being used are Solution-focused brief therapy (Roeden et al., 2009; Smith, 2005), narrative therapy (Foster and Barnes, 2009; Atkinson, 2005) and systemic models (Haydon-Laurelut and Nunkoosing, 2010; Kaur and Scior, 2009; Baum, 2006).

5.5.4: Training Needs for Counsellors in Learning Disability: The inadequacy of counselling/psychotherapy training and supervision in learning disability has been highlighted (Corbett, 2011; Fletcher, 2011; Hollins and Sinason, 2000) and clinicians have concerns about their own perceived competence in this area (Mason, 2007). Beasley (2004) drew attention to the need for specialist skills and training. Those working psychotherapeutically with PWLD require a thorough grounding in the social model of disability (Swain, Griffiths and Heyman, 2003; Reeve, 2000) to understand the social and emotional impact of disability (Sequeira, 2006; Reeve, 2004). These views are supported by training recommendations in the Royal College of Psychiatrists Report (2004). Many mainstream counsellors doubt their ability to provide an effective service to PWLD due to lack of training and supervision and ignorance of research in the area (Fletcher, 2011; Raffensperger, 2009) and need additional ‘top up’ training (Mason, 2007; RCP Report, 2004). The present study on the experiences of PWLD of individual counselling may shed light on whether they felt it met their needs and what if any modifications are required.

Following the establishment of the Institute of Psychotherapy and Disability (IPD) in London in 2000, there have been efforts to create a specialism of Disability Psychotherapist (Frankish, 2009). The IPD developed criteria for training and some training courses in disability psychotherapy have been established in Britain. The

Royal College of Psychiatrists Report (2004) recommends psychotherapists working in the NHS should accept clients with learning disability while also supporting disability psychotherapists to work with clients having more severe learning disability. The Irish Government report ‘A Vision for Change’ (DoHC, 2006) also recommends that people with mild learning disability have their mental health needs met through generic services.

5.6: Conclusions

The literature review shows a preponderance of quantitative studies on various aspects of counselling and learning disability but minimal qualitative accounts of how PWLD experience individual counselling. The ethos of modern services is to support rights, independent living, control and inclusion (DoH, 2009) so as to enable service-users to experience ‘a good life’ (Johnson and Walmsley, 2010). Moving away from a paternalistic outlook, services must involve service-users in creating supports that are responsive to their needs. Counselling is one such support. Therefore it is surprising that so little effort has been expended in ascertaining the opinions of service-users on their counselling provision.

6. RATIONALE FOR THE PRESENT STUDY

Internationally and in Ireland, great strides have been made in service provision for PWLD (Atherton, 2007; Mulvany, Barron and McConkey, 2007), with the emphasis largely on practical needs such as residential and day services developments (Kelly and Kelly, 2011). With increasing integration, PWLD are exposed to everyday living and its inevitable stresses and strains. Like the mainstream population, they may need counselling to resolve problems and lead more fulfilling lives (Zaman, Holt and Bouras, 2007; Jesper and Stapleton, 2005; Priest and Gibbs, 2004). With emotional needs similar to the general population, but less effective coping skills (van den Hout, Arntz and Merckelbach, 2000), more susceptibility to mental health problems (Bouras, 2008; Cooper et al., 2007a) and additional problems specific to disability (Lunsky and Benson, 2001), they may have increased requirements for counselling. Acknowledging that PWLD are capable of benefitting from counselling and encouraging outcome evidence (Brown et al., 2011) indicates the value of a range of counselling approaches for various psychological problems (Willner, 2005).

The Self-Advocacy Movement internationally and in Ireland is changing the self-perception of PWLD who are increasingly demanding to be heard on issues impacting their lives (Buchanan and Walmsley, 2006; Goodley, 2000; Aspis, 2002, 1997). The present study believes that PWLD have important viewpoints about their experiences in the services they receive and we cannot make assumptions about what is useful and beneficial for them without their input. There is a dearth of research into the views of PWLD of their counselling experiences and none in an Irish context. The present study aimed to contribute in enabling the voices of PWLD to be heard and lessons learned from their experiences. Through listening to their views and learning about their experiences the study findings will contribute to ensuring that counselling becomes more relevant and responsive to their needs.

Chapter 3

Methodology

1. INTRODUCTION

1.1: Chapter Outline

This chapter discusses the chosen qualitative research design, outlining how the methodology namely Interpretative Phenomenological Analysis (IPA) was selected and implemented. It outlines participant recruitment and data collection, examines ethical considerations, provides an overview of data analysis and concludes with how rigour was ensured in the study.

1.2: Objectives of the Study

Given the scarcity of research into how PWLD experience counselling, the study aim was to illuminate the individual counselling experiences of people with mild learning disability. A challenge for counselling and psychotherapy research is to discover how the different elements can be configured and integrated to meet the needs of different groups (McLeod, 2001). Hence, the objectives of the present study were:

1) To explore the lived experience of people with mild learning disability of individual counselling.
2) To discover their meaning-making of their individual counselling experiences.

2. DESIGN

The study focused on the lived experience of individual counselling of people with mild learning disability. The first decision was around whether a quantitative or qualitative approach best suited the objective of the research. Quantitative research is interested in hypothesis testing, large samples, the use of statistical methods to measure and analyse causal and correlational relationships between variables and issues of reliability and validity (Denzin & Lincoln, 2000). In exploring peoples' lived experience, there can be no pre-set hypotheses, meaning needs to emerge from rather than be superimposed on the data. How people make meaning of subjective experiences and understand their place in the world is the concern of qualitative approaches (Elliot, Fischer and Rennie, 1999). Since I was concerned with eliciting lived experience and meaning-making, a qualitative stance was eminently suitable in *'attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them'* (Denzin and Lincoln, 2005, p.3). Through-out the past two decades, various qualitative methodologies have gained respectability in the social sciences (Hammersley, 2008) with relevance for researching counselling since -

> *'.....in the search for objectivity, many researchers appear to have forgotten that counselling is very much a subjective interpersonal experience'.* (Macran et al., 1999, p.327)

I considered various qualitative approaches such as Thematic Analysis, Grounded Theory and Phenomenological approaches (Howitt, 2010). However, I was drawn towards phenomenology, initially from my background in Gestalt Therapy, a phenomenological approach to psychotherapy. More importantly, a phenomenological approach seemed most fitting for my research into individual counselling experiences as phenomenology tries *'to capture as closely as possible* *the way in which a phenomenon is experienced within the context in which the experience takes place'* (Giorgi and Giorgi, 2008a, p.26). Having considered various phenomenological research methods (Giorgi and Giorgi, 2008b; Giorgi, 1997; Moustakas, 1994; Van Manen, 1990), I deemed Interpretative Phenomenological Analysis (IPA), developed by Jonathan Smith (Smith, Flowers and Larkin, 2009; Smith and Osborn, 2008) as the most suitable. IPA, which emerged in the mid-1990's (Smith, 1996) has its roots in psychology and phenomenology and psychology '*...have a long and often interdependent history'* (Larkin, Eatough and Osborn, 2011, p.320). Psychology being my own discipline, I felt IPA offered *'...an adaptable and accessible approach to phenomenological research that adheres to guidelines regarding rigour and validity'* (Pringle et al., 2011, p.24). As an increasingly commonly used methodology in psychology, IPA seemed most appropriate to capture the essence of what I was seeking in my research as it fitted with my study objectives. IPA is concerned with -

> *'.......the detailed examination of personal lived experience, the meaning of experience to participants and how participants make sense of that experience'* (Smith, 2011, p.9)

Being idiographic, IPA matched my interest in individual experience, as the unit of study is an experiential account (Shaw, 2010). My study focused on the meaning-making of individuals with mild learning disability of their 'lived experience' of counselling. I wanted to get *'the insights of the experts'* i.e. the research participants (Reid, Flowers and Larkin, 2005, p.20) and IPA has shown itself particularly helpful in understanding people's meaning-making (Smith, 2004). While Smith (2011a) regards focus on individual experience as the essential feature of IPA, he accepts Todorova's (2011) call for sensitivity to socio-cultural context as *'...experience takes* *place in a context and is influenced by the social, historical and linguistic milieu into which... (people).. are 'thrown'.* I felt this viewpoint was particularly important and necessary in the field of learning disability.

2.1: Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) has *'a long and a short history'* (Eatough and Smith, 2008, p.179). First conceptualised in the mid-1990's by psychologist Jonathan Smith (Smith, Flowers and Larkin, 2009; Smith and Osborn, 2008), it is a development of the phenomenological tradition. It aimed to *'capture the experiential and qualitative ....and still dialogue with mainstream psychology ......while drawing on concepts and ideas which have much longer histories'* (Smith, Flowers and Larkin, 2009, p.4).

> *'To 'use' any approach requires an understanding of the origin of the thought implicit within the approach, what view of reality it promotes and conversely what view it suppresses'.* (Cheek, 2000, p.4)

IPA is influenced by the core ideas of phenomenology and hermeneutics and strives to *'illuminate the embodied, cognitive-affective and existential domains of psychology'* (Smith, Flowers and Larkin, 2009, p.34). According to Moran (2002, p.2) *'Phenomenology focuses on the structure and qualities of objects and situations as they are experienced by the subject'.* Phenomenology is concerned with lived experience rather than conceptualising, theorizing or categorizing (van Manen and Adams, 2010; Dowling, 2007). Seeking to enrich our understanding of everyday experience and *'articulate the obvious'* (Davidson, 2004, p.151), phenomenology was initially developed by Edmund Husserl (1858 -1938) in the early twentieth century and expanded and developed by his pupil Martin Heidegger (1889-1976).

For Heidegger, our access to reality is never direct. We live in an interpreted world and are interpreters and constructors of our experience. As embodied beings always living in a particular culture and context, *'nothing can be encountered without reference to our background understanding'* (Leonard, 1989, p.47).

> *'Following Heidegger, IPA is concerned with examining how a phenomenon appears and the analyst is implicated in facilitating and making sense of this appearance.'* (Smith, Flowers and Larkin, 2009, p.28)

We are always constructing our world and although *'what is **real** is not dependent on us ....the exact meaning and nature of **reality** is'* (Larkin, Watts and Clifden, 2006, p.107). Their implication can be captured by the adage – 'Does a tree falling in a forest make noise if there is no one there to hear it'? In terms of research, *'...any discoveries we make must necessarily be a function of the relationship that pertains between researcher and the subject matter'* (Larkin, Watts and Clifden, 2006, p.107). Smith (2011, p.10) states that-

> *'...experience cannot be plucked straightforwardly from the heads of participants, it requires a process of engagement and interpretation on the part of the researcher and this ties IPA to a hermeneutic perspective'.*

Originally a method for interpreting Biblical texts, hermeneutics is now a widely known theory of interpretation (Shaw, 2010). IPA assumes that individuals seek to interpret their experience in a way that is meaningful to them. My study endeavoured to allow participants' interpretations of their experience to be primary while conscious that my own preconceptions and background would inevitably impact on my interpretation of their stories (the double hermeneutic). I needed awareness of my own positive views of counselling for PWLD and the capacity to put them aside to allow their views to predominate. Since the other's experience is never available directly to the researcher, the double hermeneutic makes IPA a dynamic process (Shaw, 2010) and IPA involves an active role for the researcher (Smith and Eatough, 2007). There is recognition that -

> '*...the researcher's own conceptions are required in order to make sense of the personal world being studied through the process of interpretative activity.'* (Chapman and Smith, 2002, p.126)

Being phenomenological and idiographic, IPA focuses on the uniqueness of individual experience (Smith, Flowers and Larkin, 2009; Smith and Eatough, 2007). Smith (1996) sees a chain of connection between embodied experience, talking about that experience and a participant's sense-making of that experience.

> *'The aim of IPA is to explore how participants make sense of their experiences; IPA engages with the meaning that experiences, events and actions hold for participants'.* (Chapman and Smith, 2002, p.126)

IPA combines both an empathic and a critical hermeneutic (Smith and Eatough, 2007). Initially the researcher is trying to get 'an insider' perspective on the participants experience and later in the analysis of data, asks critical and curious questions of their accounts -

> *'There is a phenomenon ready to shine forth, but detective work is required by the researcher to facilitate the coming forth and then to make sense of it once it has happened.'* (Smith, Flowers and Larkin, 2009, p.35)

2.1.1: IPA and Learning Disability: I was interested in how people with mild learning disability experienced and made sense of individual counselling, regarding them as experts on their experience and having valuable insights which needed hearing -

> *‘When we talk about experience in IPA research, we are talking about something that matters to the participants and something of which they have some understanding, we seek to understand their perspective on it.’* (Shaw, 2009: DCU Summer School Presentation)

I wondered about the applicability of IPA in learning disability, particularly as it depends heavily on language to provide access to the person’s inner world. I was reassured that others successfully used IPA in learning disability research (e.g. Elford, Beail and Clarke, 2010; Clarkson et al., 2009; Brown and Beail, 2009; Merriman and Beail, 2009; Huws and Jones, 2008; Isherwood et al., 2007; McNally, Beail and Kellett, 2007; Mitchell, Clegg and Furniss, 2006). Reading these studies convinced me of IPA’s appropriateness as a methodology to address my research objectives, particularly since my participants were adults with mild learning disability who had verbal skills. I was also interested that Shaw (2011, p.31) regarded IPA studies as *‘...able to offer insight to those generating guidelines for good practice to health care professionals on the ground’* since I come from a clinical background.

2.1.2: Critiques of IPA: Being relatively new, critiques of IPA as a qualitative research methodology are few as yet. IPA studies are conducted with relatively small samples, providing detailed and rich accounts of particular people and are concerned with detailed description rather than explanation or theory building. Questions arise about general applicability of results, in marked contrast to quantitative research where large samples provide some confidence in generalisability. Smith and Eatough (2007) suggest IPA studies be regarded from theoretical rather than empirical generalisability i.e. findings can be linked to the researcher’s personal and professional experience and existing literature in the area. In quantitative studies, there is rarely allusion to the personal and professional experience of the researcher. Given my long experience in learning disability I felt excited at the prospect of facets emerging which might confirm/disconfirm my own understandings or uncover and illuminate entirely new aspects.

IPA studies are generally conducted through face-to-face interviews. In all phenomenological research, the interview is -

> *'....a purposeful data-gathering activity characterised by the particular philosophical position adopted by the researcher.'*
>
> (Lowes and Prowse, 2001, p.471)

In contrast to quantitative approaches where structure, consistency and predictability is essential, IPA interviews are more flexible, usually semi-structured and interview schedules can be changed or departed from as seems appropriate to the researcher. Some have criticised the over-reliance on the interview in qualitative inquiry (Hammersley, 2008) and others (e.g. Silverman, 2007; Seale, 1999) maintain interview data may be shaped by the researcher and neglects contextual variations. Wooffitt and Widdicombe (2006, p.48) view interviews as social interactions and caution that the interviewer's contribution needs attention as it ultimately shapes the data for qualitative analysis. They critique the fact that in IPA work, the utterances of the interviewer are not subject to the analytic process. They maintain that-

> *'Interviews are interactional occasions conducted through language and that certain features of the talk-in-interaction have consequences both for the interview itself and the nature of the data thereby collected.'*

I outlined my personal motivations for choosing this research topic In Chapter 1 in the interests of openness and transparency.

Since IPA is primarily ideographic which could be regarded as a further limitation of the approach, it needs to consider social and cultural factors which may be impacting on subjective experience (Smith, 2011a; Todorova, 2011). Hence, the present study's provision of a historical and social context to learning disability which impacts on how PWLD experience all aspects of their lives, including counselling. Brocki and Weardon (2006) reviewed fifty two articles using IPA, concluding that it was applicable and useful in a wide variety of research topics. Their only criticism was that authors sometimes lacked transparency about the researcher's interpretative role and they advised researchers to acknowledge their particular perspectives and theoretical groundings and be open as to motives in selecting a particular research topic. All of the above are legitimate critiques of qualitative methods and researcher reflexivity may not always be sufficient to prevent unaware influence creeping into the process. However similar criticism, and to a stronger degree, can be levelled against quantitative research as researchers usually disregard reflexivity and are not transparent about their vested interests and prejudices (Richards, 2011; Cheek, Onslow and Cream, 2004).

In an extensive critique of IPA Giorgi (2010, p.4) maintains that the theory and practice of IPA are not based on *'...continental philosophical phenomenology'* and are not good science e.g. its methodological flexibility, issues of replicability due to the lack of rules with regard to the researcher's conscious processes, the lack of a critical perspective towards analysis and the capacity to be selective with raw data. Smith (2010, p.187), countered these criticisms by accusing Giorgi of being selective in sources he used for his critique and argues that IPA *'...clearly has theoretical underpinnings in phenomenology and hermeneutics'*, outlined in detail in Smith, Flowers and Larkin (2009). While Smith agrees that IPA is not a prescriptive methodology in the quantitative sense, he argues that constraints are built-in through the professional and personal skills of the researcher and also through the quality control criteria advocated (Yardley, 2000). Neither does he regard replicability *'...as an appropriate referent for judging most qualitative approaches to psychology'* *(p.189).* The dispute between the two authors continued in a further rebuttal of Smith's position by Giorgi (2011) which mainly reiterated his earlier points and expanded further on phenomenological theory. The arguments presented by Giorgi are complex and demand in-depth knowledge of Husserl's work. At the close of his article he does admit that Smith may be more aligned to Heideggerian phenomenology (interpretative) whereas his own allegiance is to Husserlian transcendental phenomenology (descriptive). The debate will no doubt continue because as Chamberlain (2011, p.49) points out *'...applying phenomenological philosophy and theory to research practice is both varied and contested'.* Howitt (2010, p.292) maintains that IPA is a relatively new approach and *'...is nowhere nearly so highly developed as other qualitative analysis methods'.* IPA still has the status of *'a new kid on the block'* (Shaw, 2011, p.30) and it is healthy to see lively debate and critiques of the approach among various researchers. However, Reid, Flowers and Larkin (2005, p.23) believe that *'the future of IPA looks bright' and according to Willig (2008, p.73)* -

> *'....interpretative phenomenological analysis is a new and developing approach which leaves more room for creativity and freedom to explore on the part of the researcher who uses it'.*

3. PARTICIPANTS

The study focus was on in-depth interviews with a small sample. There is no 'right' sample size in qualitative research (Smith and Osborn, 2008). Reviewing IPA studies, sample sizes ranged from one to thirty (Brocki and Weardon, 2006). As previously discussed, most adults with mild learning disability are outside of specialist services and these would be difficult if not impossible to recruit. Therefore

I decided to seek participants from within learning disability services, where I could be assured that they had been formally psychologically assessed as having a mild learning disability. During preliminary preparations I consulted colleagues in learning disability services in Galway, Clare, Limerick, Cork and Dublin as to their counselling provision for service-users. Counselling was broadly interpreted to include the three major theoretical models of humanistic, psychodynamic and cognitive-behavioural approaches. Most reported having no specialised counselling service for people with mild learning disability in contrast to the dedicated counselling service in my own learning disability agency (The Brothers of Charity, Galway). Since this limitation in counselling provision posed difficulty for recruiting adults with mild learning disability who had undergone individual counselling, I aimed at an upper sample limit of ten which was achieved.

Following IPA, a purposive sampling strategy was used i.e. a '......*closely defined group for whom the research questions will be significant'* (Chapman and Smith, 2002, p.127). The participants were 10 adults (age 18+ years) assessed in Irish learning disability services as having a mild learning disability and who had undergone individual counselling. Inclusion criteria for selection were:

(i) Participants could communicate verbally

(ii) Participants had a minimum of 5 individual counselling sessions (to give a sense of process)

(iii) Participants were in ongoing counselling or had finished counselling within the past 24 months to aid recall

Participants were sourced within my own learning disability agency, the Brothers of Charity Services, Galway and from the National Learning Network (NLN), Galway. Three other learning disability services in Ireland were additionally contacted to recruit a sufficient sample. The final sample of nine men and one woman came from four different Agencies and ranged in age from 22 years to 62 years. All participants had been formally psychologically assessed by psychologists in learning disability services as having a mild learning disability.

Six different counsellors provided counselling to the participants: two were qualified Counselling Psychologists, one an accredited Psychotherapist and three were Clinical Psychologists, two of whom had additional counselling/psychotherapy training. They described their theoretical orientations as Person-Centred, Humanistic, Integrative, Positive Psychology and Cognitive Behaviour Therapy (CBT). The number of counselling sessions attended by participants varied from five to sixty eight with a mean of twenty sessions. Five had finished counselling while the remainder were in ongoing counselling. The ten participants are introduced through brief pen pictures given below (Appendix H provides further information). Pseudonyms have been used to preserve participants' privacy. Any information which might identify them has been changed, while preserving the essence of the interviews. All place names and other third party names have also been altered.

Robert

Robert is a 42 year old man whose parents are dead. He has regular contact with his siblings. He lives in a staffed Community Group Home with four other men and attends a Day Centre every day. Robert is a sports fanatic, having a particular love of soccer and rugby. Robert had 11 counselling sessions and is continuing.

Linda

Linda is 22 years old. She was reared by grandparents who both died in recent years. Linda lives in a staffed Community Group Home with three other young women. She is involved in a daily Community Education Project. Her interests are popular music and fashion. Linda had 15 counselling sessions and has finished counselling.

Mark

Mark is 27 years old and lives alone in a house with staff visiting daily. He visits his family, being particularly close to one sister. Mark has a girlfriend whom he sees regularly. He attends a VEC programme during the day. He had counselling with a Psychologist from age 18, for several years and now sees Sheila, a counsellor. Mark had 28 counselling sessions with Sheila and is continuing.

Paul

Paul is 60 and lives on his own in an apartment with live-in staff. His parents are dead and he has one brother whom he visits regularly. He previously worked in open employment in a factory but now attends a Day Centre. He has had several psychologist/counsellors over many years and his most recent counsellor was Carol. Paul had 15 counselling sessions with Carol and planned to resume again.

Alan

Alan is 23 and lives at home with his parents. He is participating in a Work Experience programme extending over three years. Alan lives a very sociable life in his local community and loves going to Night Clubs. He broke up with a girlfriend in recent times. Alan had 6 counselling sessions and has finished counselling.

Jim

Jim is aged 33 and lives in a staffed Community Group Home with four other men from Monday to Friday, going home to his family every week-end. He attends a Day Centre part-time and works for 3 days a week in a sheltered factory. He travels independently by bus to work and to his home at the week-ends. He likes to socialise in the local pub when at home. Jim had 68 counselling sessions and is continuing.

Keith

Keith is a 50 year old man who lives independently in his own house. His parents live in the same locality. He worked for many years in open employment but moved to the sheltered factory where he now works. He lives a very independent life and is involved in church activities in his local community. Keith had 12 counselling sessions and has finished counselling.

Denis

Denis is 46 years old and lives with his widowed father. All of his siblings are married. He works in a sheltered factory to which he travels by local bus every morning. Denis had 15 counselling sessions and is continuing.

Tom

Tom is 47 and lives with his sister. Both his parents are dead. He is from a large family who are very close. He attends a Day Centre. Tom is very sociable and loves going to soccer and rugby matches. He also sings in his local church choir. Tom had 25 counselling sessions and is continuing.

Shane

Shane is aged 62 and lives on the campus of a large learning disability centre. Up to 3 years ago he lived in a staffed Community Group Home in another town for 10 years where he formed strong attachments with the staff. His parents are dead and he is close to his sister whom he sees regularly. Shane worked for many years in open employment and is now in a Day Centre. He initially had counselling with a psychologist (Ann K) and more recently saw Teresa for counselling. Shane had 5 counselling sessions with Teresa and failed to attend a further 2 sessions.

4. INTERVIEW SCHEDULE

Consistent with IPA, data was gathered through face-to face interviews using a semi-structured schedule (See Appendix A). The interview schedule was devised from reviewing the literature (Hugh-Jones, 2010; Kvale and Brinkman, 2009; Breakwell, 2006) and from my personal experience of working psychotherapeutically with PWLD. Areas covered were: awareness of problems, referral process, initial experiences, views on counselling and ending of counselling. The National Disability Authority Guidelines on Research for People with Disabilities (NDA, 2009) were helpful in constructing the schedule. These Guidelines advocate that principles of dignity, autonomy, equality and diversity be incorporated in research design. I was careful not to be intrusive as to counselling content unless participants volunteered such information to ensure participant dignity and communicated throughout the research that participants had complete choice as to participation. I endeavoured in my interview style to promote equality and collaboration through a friendly, non-threatening demeanour, spending time on initial rapport building and through attentive listening.

The Interview Schedule allowed initial questions to be modified in the light of participants' responses through using probes. From my experience, I was aware that participants would very likely have difficulty in providing extensive verbal responses and paid particular attention to developing probing questions. Questions in the schedule were open-ended and a non-directive style was used through-out the interview. In the spirit of IPA I endeavoured from the outset to set a relaxed tone and through encouragement and probes provide an environment where participants felt comfortable to 'tell their stories' in a free-flowing way. It is more effective if the researcher can come at the research question *'sideways'* and facilitate the relating of relevant topics so that the research question can be answered subsequently in the analysis (Smith, Flowers and Larkin, 2009, p.58). As is usual in IPA studies, interviews were audio recorded but in hindsight, it may have provided a greater richness of data if video-recording had been used.

5. PILOT STUDY

Given the cognitive difficulties inherent in learning disability, it was vital that questions be understandable to participants to elicit the sought-after material. To establish its 'fit for purpose' and whether modifications were needed, the Interview Schedule was piloted with one participant. The pilot interview was used in the study and included in the analyses. Subsequent to the pilot interview the first question in the Schedule was revised as it proved too abstract at the beginning of the interview, being off-putting and anxiety-provoking for participants. 'What does the word counselling mean to you?' was changed to 'Could you tell me what it was like when you went for counselling?' The remainder of the Schedule worked well and was retained for subsequent interviews. The participant in the pilot study had a significant speech defect and needed considerable time in rapport-building prior to the formal interview to become familiar with his communication style. The actual formal interview lasted for eighteen minutes. I allocated an hour and a half per subsequent interview, recognising that rapport-building time was crucial to the success of interviews and also in the event of some participants being more vocal. The Pilot Interview also alerted that turning on the voice recorder during rapport building was less intrusive and anxiety provoking than waiting until the start of the formal interview.

6. PROCEDURES

As a first step in participant recruitment, an Initial Flyer (See Appendix B), detailed Information Sheet (See Appendix C) and Consent Form 1 (See Appendix D) were developed. Phone contact was made with colleagues such as Psychologists and Social Workers from various learning disability agencies in Ireland with which I was familiar to explain the purpose of the study. Those indicating awareness of people who met the criteria for inclusion were invited to consider discussing the matter with the potential participant. All initial contacts with participants were made by a 3rd party who was sent written instructions (See Appendix E) in how to approach potential participants so as not to exert undue influence (NDA Guidelines, 2009, p.32). They were requested to circulate the Initial Flyer to potential participants which briefly described the research and invited participation (See Appendix B).

Individuals expressing interest in participating could either inform the 3rd party or contact me directly (a contact number was provided on the flyer). In at least two services, I was aware the flyer was displayed on Notice Boards visible to service-users. However, nobody contacted me directly, all came through third parties. This may reflect literacy problems or difficulty for service-users in initiative-taking to make contact.

I had a face-to-face meeting with all interested potential participants, providing to them and fully explaining the detailed Information Sheet on the study (See Appendix C). This provided them with an opportunity to meet with me prior to agreeing to participate in the research so in effect, each participant was met with twice. Particular attention was paid to consent and potential participants assured that it was totally their choice whether or not to participate. Consent Form 1 (See Appendix D) was discussed and the concept of ongoing consent explained (NDA Guidelines, 2009, p.36). Two people decided not to participate following their initial meeting with me. As certain factual information required was unlikely to be known accurately by participants, they were informed that it would be necessary to obtain their written consent (Consent Form 2) to collect some information directly from their counsellors i.e. the theoretical orientation of their counsellors, the dates counselling commenced and finished, the number of sessions attended, who had referred them for counselling and their travel arrangements to attend counselling (See Appendix F). Participants were assured that apart from this written contact (See Appendix G), there would be no further communication with their counsellors.

Given the high level of literacy problems in this population (Kennedy and Deshler, 2010; Young, 2004; Fawcett, 2003), the Information Sheet, Consent Form 1, Letter to Psychotherapists/Counsellors and Consent Form 2 were read aloud to each potential participant by me and explained in detail. Participants were provided with copies of the forms to take away, encouraged to discuss participation with significant others if they wished and asked to consider whether they wanted to participate in the research. They were informed that I would make telephone contact within 3-5 days to learn of their decision.

Those indicating willingness to participate in the study were met in a previously agreed location. A brief explanation of the research was again given and following the signing of Consent Form 1, the interview took place. All participants were interviewed using the semi-structured Interview Schedule and all interviews were completed in one meeting. Length of interviews ranged from 11 minutes to 41 minutes with a mean of 25 minutes (see Appendix H). Accepting that *'the phenomenon of counselling and psychotherapy are complex, elusive and sensitive'* (McLeod, 2001, p. 138), the interview was guided rather than dictated by the schedule, in line with IPA methodology. I remained open to what emerged from the interviews, while recognising that PWLD *'....may need the researcher to take a stronger role in guiding them than is usual in IPA interviews'* (Smith, 2004, p.49). Some participants willingly detailed the content of their counselling with little prompting, providing a privileged insight into their lives and a valuable window on their experience. Others were more reticent and revealed little.

All interviews were digitally recorded and brief notes taken during the interview. Following the interview, participants were asked for the name of their Counsellor and their written consent (See Appendix F) obtained for the letter seeking factual information (See Appendix G) from their counsellor which had been explained at the preliminary meeting. This was additional to Consent Form 1 (See Appendix D) which participants signed as agreeing to participate in the research. The signed

Consent Form 2 was forwarded to the Counsellors along with the letter seeking the information required. A pre-stamped envelope was enclosed and all counsellors returned the information.

At the end of the interview participants were asked if they would like a short summary of the study findings in easy to read format following completion of the research project. All indicated their interest and their addresses were recorded.

6.1: Interview Process

Being aware that in IPA work *'interviewing is a critical part of the process'* (Smith, 2011, p.23) I endeavoured to conduct the interviews in a respectful, collaborative manner (Reid, Flowers and Larkin, 2005). Particular care was taken to ensure that the interview would not be too burdensome and that participants would have support for any stress arising. Therefore, following agreement to participate, each participant identified a support person who could be contacted if necessary following the interview in the event of any distress. Most identified their key worker or Social Worker. In the event, none required that support. I invited participants to indicate if they needed a break during the interview and watched for non-verbal signs of fatigue. The confidential nature of the interview was emphasised and I ensured a private space was available. Interviews took place in setting chosen by and most convenient for the participants and included their homes (three participants), workplaces (five participants) and my office (two participants). Building a trusting, egalitarian relationship and managing the interpersonal dynamics of the interview are vital (Tee and Lathlean, 2004; Roberts, Geppert and Brody, 2001). My extensive experience of working with this population was an asset in conducting the interviews. In addition to putting participants at their ease through a non-threatening demeanour and initial chit chat, I was aware of the importance of simple language and rephrasing questions to aid understanding.

7. ETHICAL CONSIDERATIONS

Ethical Guidelines issued by the National Disability Authority (NDA, 2009) were followed in designing the study and adhered to through-out the research. The guidelines specify that '*The wellbeing of research participants must be at the centre of the research process'* (NDA, 2009, p.19) and the values of dignity, autonomy, representativeness and inclusiveness must be upheld at all stages. PWLD are regarded as a vulnerable population for research purposes. Vulnerable populations are those with *'diminished autonomy due to physiological/psychological factors or status inequalities'* (Silva, 1995, p. 15) requiring special safeguards to ensure that their rights are protected. In the care context, vulnerability implies open to exposure to harm (Parley, 2010).

Several authors (Iacono, 2006; Ruof, 2004; Tee and Lathlean, 2004; Anderson and Hatton, 2000; Moore and Miller, 1999) draw attention to the complex issues which arise with vulnerable populations such as sensitivity to their vulnerability, assessing risk to benefit ratio, preventing adverse repercussions, achieving a balance between autonomy and paternalism, unintended manipulation, care for the researcher and obtaining informed consent. Confidentiality also required careful consideration.

7.1: Consent

Issues of consent need particular care when dealing with a learning disability population (Cameron and Murphy, 2006; Fisher et al., 2006; Dye et al., 2004; Rodgers, 1999; Arscott, Dagnan and Stenfert Kroese, 1998). Vulnerability and power dynamics are connected and PWLD are often very acquiescent to those in positions of authority (Parley, 2010). Therefore, it was important that potential participants were fully informed about the nature of the research and aware that they had choice whether or not to participate and could withdraw at any stage. During preliminary information meetings I emphasised the choice element and was careful not to exert pressure to participate. Two people declined participation following the initial meeting. Consent-giving is best regarded as a process open to negotiation through-out the research (Ramos, 1989). One participant (Denis) presented a dilemma around consent. Although he agreed to participate, his behaviour during the interview was ambivalent and unforthcoming. I reminded him of his withdrawal rights from the study but he indicated a wish to continue. King (2010)) recommends that the researcher should never decide for a participant that he/she should withdraw. However, as the interview seemed deadlocked I felt I had no option but to conclude after eleven minutes. I was unsure that Denis fully understood the purpose of the research or that he was able to give informed consent. I did however use his data in the study as he had not signalled a desire to withdraw.

7.2: Confidentiality

Since participants were providing personal experiences of counselling, confidentiality was crucial. All potential participants were reassured that information disclosed would be treated with utmost confidentiality and no identifying information would appear in the study. Confidentiality arose during the interview with Jim and I again reiterated that interview material would not be discussed with staff. However, confidentiality could not be total and absolute and methods for dealing with possible disclosures impacting on participants' safety were discussed during the Information session. In conjunction with participants, supports were identified in the event of distress arising during the interview. Finally, plans to dispose of data on completion of the study were communicated to participants. They were informed that recordings and all notes would be destroyed.

Although I have worked psychotherapeutically with PWLD over many years, none of my clients or former clients was approached to participate in the research. I felt they would be compromised and might find it difficult to speak openly of their psychotherapeutic experience with me, particularly if they wished to make negative comments (Iacono, 2006).

7.3: Ethical Approval

In June 2009 the Research Proposal was sent to DCU School of Nursing Ethics Advisory Committee for advice and their feedback incorporated into the research. In November 2009 the Proposal was submitted to the Brothers of Charity, Galway Research Ethics Committee and also to NLN Ethics Committee, Dublin. Both agencies granted approval for the research to proceed. Approval was also needed and obtained from the DCU Research Ethics Committee in December 2010, due to participants being recruited from additional agencies in other counties.

8. DATA ANALYSIS

Larkin, Watts and Clifden (2006, p.104) suggest that it is more appropriate to regard IPA as a '*stance'* or perspective towards data analysis, as -

> *'.... it is not a prescriptive approach; rather it provides a set of flexible guidelines which can be adapted by individual researchers in light of their research aims'.*
>
> (Smith and Eatough, 2007, p.45)

According to Smith (2011, p.10) *'IPA is idiographic in its commitment to analyse each case in a corpus in detail'* and only when each case has been analysed exhaustively does one attempt to search for patterns across cases. Guidelines recommended by Smith, Flowers and Larkin (2009) were followed to analyse the data. The approach used was as follows:

(i) I transcribed all interviews verbatim to get as close as possible to the words and experience of the participants.

(ii) An idiographic approach was firstly taken. I read each transcript while listening to the audio recording to become immersed in the data and get a sense of each individual and their concerns. This process was followed for all ten transcripts.

(iii) Each transcript was then analysed separately and exploratory coding firstly completed and then Emergent Themes identified.

(iv) The emergent themes from each transcript were then coded and Superordinate Themes identified for each participant, with each superordinate theme having a number of themes.

(v) When all ten cases had been separately analysed, I compared across cases to look for patterns. Similar themes were grouped under headings which seemed to have resonance for the group as a whole and formed new superordinate themes.

(vi) Although some commonalities were identified, it was important to keep in mind the divergences between participants, ensuring the idiographic and phenomenological dimensions of the study were not lost.

(vii) Finally, I used interpretation to bring all the various strands of the data together but always ensuring that participants' accounts and the interpretation were identified separately and that interpretation was soundly grounded in the data.

In order to provide transparency and to illustrate the analytic process, a worked example of the analysis of one participant's data (Alan) is provided in Appendix J.

Although supervision was helpful through-out the study as an external check on the analytic process, ultimately in IPA work it is the researcher's own interpretation of the data which stands. At the same time, an important issue for all research is assessment of validity. While there are long established methods in quantitative research for this purpose such as inter-rater reliability, many believe that qualitative research should be evaluated against criteria recognised as more appropriate such as those suggested by Elliott, Fischer and Rennie (1999) and Yardley (2000). Smith, Flowers and Larkin (2009, p.183) suggest the concept of an independent audit where a trail is kept from initial notes to the final report and which aims to establish that *'.... the account produced is a credible one, not that it is the only credible one'*. This is a very different stance from inter-rater reliability. The transcript in Appendix J provides a trail as to how the analysis was constructed. A further check on validity is the reflexivity of the researcher which is discussed in the next section. Although traditionally, it was believed researchers could remain aloof and have no influence on the collected data, it is now widely advocated that such objectivity and neutrality i.e. the ‘God’s eye view’ (Haraway, 1988) is impossible. The researcher is intimately intertwined with the subject matter being studied.

9. ENSURING RIGOUR IN THE STUDY

9.1: Credibility of Qualitative Research

As in quantitative approaches, it is important that evaluation be built into qualitative research. Criteria particularly relevant to qualitative research are: owning one’s perspective, situating the sample, grounding in examples, providing credibility checks, coherence, accomplishing general versus specific research tasks and resonating with readers (Elliott, Fischer and Rennie, 1999). Smith (2011b, p24) provides seven guidelines on the characteristics of a good IPA study -

1) The paper should have a clear focus
2) The paper will have strong data
3) The paper should be rigorous
4) Sufficient space must be given to the elaboration of each theme
5) The analysis should be interpretative not just descriptive
6) The analysis should point to both convergence and divergence
7) The paper needs to be carefully written

I will return to these characteristics in the Discussion Chapter when evaluating the study.

In conducting the study I endeavoured to be aware of my own perspectives, pre-understandings and presuppositions from many years working in the learning disability field. I maintained a Reflexive Journal as a safeguard and way of tracking and critically evaluating my own evolving thoughts and ideas. In writing up the study I was cognisant of providing a detailed, transparent account of the analysis process and being open to how my own values and history may have influenced the research at different stages. I conducted a thorough examination of the extant literature on counselling and learning disability in order to give credibility and coherence to the study and critically compared my findings to establish if there was resonance with existing research and whether the findings would have credibility for other practitioners and researchers. Finally, I was careful to ensure that my analyses and interpretations were grounded in the data at all times.

Given my training and background in psychology, I needed constant vigilance to remain true to the spirit of qualitative research and not allow my thinking to veer into a quantitative mindset. This was difficult, as I had never previously used qualitative methods and several times became aware of slippage in my approach e.g. thinking in terms of 'variables' and 'representative samples' and then realising that this mindset was not appropriate for qualitative research and IPA.

The elements of surprise and discovery are a vital part of qualitative inquiry -

> *'Good qualitative research is a matter of imagination, creativity, courage, personal integrity, empathy and compassion. Method is just a means of channelling these qualities'.* (McLeod, 2001, p.160)

I wanted to do justice to the participants by listening and learning from them, becoming immersed in their 'stories', remaining open to the unexpected and being willing to be surprised. I was certainly surprised by some of the findings e.g. the level of anxiety participants experienced and their initial expectations of the therapeutic relationship.

9.2: Position of the Researcher

The researcher has a pivotal role in qualitative research. All research contains a subjective element and *'the results of psychological research reflects the researcher as much as the researched'* (Salmon, 2003, p.26). Reflexivity is crucial in acknowledging the position of the researcher and is given much attention in qualitative approaches -

> *'Reflexivity requires an awareness of the researcher's contribution to the construction of meanings throughout the research process and an acknowledgement of the impossibility of remaining 'outside of' one's subject matter when conducting research'* (Willig, 2008, p.10).

Willig (2008) discusses two types of reflexivity – **personal**, examining how the researcher's own beliefs, values and history influenced the research and **epistemological**, examining how the design and methods of the study constructed the data and conclusions reached but also limited what could be discovered and reflects on how other research methods might have configured the questions and thus the findings differently. From the outset, I was drawn to phenomenological approaches and phenomenological understanding which is *'....distinctly existential, emotive, enactive, embodied, situational and non-theoretic'* (van Manen and Adams, 2010, p.449) as I aimed to come to a deeper understanding of the lived experience of my participants and the phenomenological approach seemed very fitting to counselling research.

According to the NDA Guidelines, researchers -

> *'........need a level of personal insight that makes them aware of unintended manipulation and interpersonal dynamics that may arise in the course of a study'.* (NDA, 2009, p.43)

From my experience and the literature, I was very aware of the centrality of power dynamics in the lives of PWLD as others regularly assume positions of authority over them while the learning disabled person often portrays powerlessness (Parley, 2010). Their vulnerability can as often result from the imbalance of power in relationships with others as from their individual characteristics (Clare and Murphy, 2001). I wanted to ensure that all my interactions with participants would model a horizontal relationship, conveying a sense of equality and collaboration. At the same time I was aware of the covert nature of power dynamics (Gilbert, 2003) and the strong possibility that participants may not have experienced our relationship as equal. I spent time with participants emphasising that there was no right or wrong answers to interview questions, that my only interest was in hearing their experience. However, I cannot be completely sure that they believed me.

My personal reflections made me aware of my unfamiliarity with the research role. Given my long experience as a counsellor/psychotherapist, the role of the researcher was difficult at times. It was tempting to go down avenues leading into more therapeutic-type interactions. To the best of my ability I sought to stay focused on the research questions and not become diverted and I endeavoured to accurately and faithfully present the views of participants and their sense-making of their counselling experiences. This involved presence and attentive listening during the interviews and remaining grounded in the data during analysis and interpretation phases.

9.3: Reflexive Research Journal

Most qualitative approaches recommend maintaining a Reflexive Journal to reflect on practice, track the research process and capture the researcher's presuppositions, expectations, hunches and evolving ideas. 'Reflexivity' is a process where researchers place themselves under scrutiny and acknowledge the ethical dilemmas permeating the research process, impinging on the creation of knowledge (McGraw, Zvonkovic and Walker, 2000). Learning disability has a personal emotional resonance through my family experience and coupled with over 25 years experience as a psychologist/counsellor in learning disability services, it is inevitable that I would bring certain fore-understandings and ideas to the research topic. I have witnessed clients develop and blossom through counselling and needed to be mindful of not allowing my own preconceptions in favour of counselling and psychotherapy to bias the research findings. My Reflexive Journal supported me to maintain some neutrality in the interviews and during the analysis phase. I wanted participants' voices to be foregrounded with my role being to faithfully reflect and describe their experiences.

Moustakas (1990, 1975) introduced using the 'self' as a tool in psychological research and since the qualitative approach acknowledges that the research and the researcher are inevitably intertwined, it is important to have disciplined reflection on this phenomenon. According to Etherington (2004, p.19) *'....to be reflexive is to be aware of our personal responses and to be able to make choices about how we use them'.* This self-reflexive process acknowledges and attempts to capture the necessarily subjective component of qualitative research, incorporating it into the final work thus guarding against pre-existing beliefs and ideas over-influencing the interpretation of the data. A reflexive researcher is aware that the personal, social and cultural contexts in which we live and work inevitably influences how we interpret the research process at each stage (Etherington, 2004).

I was aware that my prior experiences of counselling work with this population and my positive views of the process could lead to my understandings being prioritized and privileged, albeit unintentionally, and the views of participants being insufficiently heard and downgraded. My Reflexive Journal showed how in early interviews I was too preoccupied with the research questions and missed important leads which needed following up. On other occasions I probed insufficiently, being fearful of straying into a therapy role. For example, Robert, my first interviewee, mentioned being sexually abused and I felt a dilemma as to whether to probe further. Having established that he had discussed the matter with his counsellor, I quickly moved away from it and missed the opportunity to hear his experience of this aspect of his counselling. I was more careful of this process in myself in subsequent interviews. Some participants were very revealing about their counselling content e.g. Mark spontaneously discussed his relationship difficulties and alcohol problems without my having to question specifically. From the specific we were able to move to a more abstract discussion about counselling. However, other participants were less forthcoming and posed a dilemma about how much to probe without being intrusive.

I felt anxious about the brief responses given by many participants in their struggle to verbalise their experiences. Not wanting to lead by putting words in their mouths, yet when listening back to interviews I realised I had occasionally done that. I worried about the paucity of the data until through reflection and discussion with my supervisors I realised that there is no ‘bad data’. What emerges is reflective of participants, providing a window into their lived experience. Through-out, the Reflexive Research Journal was helpful in capturing my presuppositions and expectations and debunking them. For example I realised that the term mild learning disability is not very helpful in knowing what to expect. Some participants e.g. Mark, Keith and Shane were very articulate and able to language their experience very evocatively while others like Robert and Denis really struggled. Yet all were labelled as having ‘mild learning disability’. Reflecting on Linda’s interview, I marvelled at her expressiveness when speaking on a topic having strong emotional significance for her, such as the deaths of her grandparents. This contrasted with brief replies when responding to more abstract questions about her counselling experience. Such reflections helped me in subsequent interviews to seek concrete examples as a way of getting at lived experience.

The Reflective Journal was an essential element in ensuring rigour in the research journey, helping to make the research process more transparent.

Chapter 4

Findings

1. INTRODUCTION

1.1: Chapter Outline

This chapter focuses on the four superordinate themes and corresponding themes identified from the ten interviews. Each superordinate theme and its themes are discussed in turn and I conclude by giving a synopsis of the main study findings.

1.2: Superordinate Themes

The superordinate themes are represented in the majority of interviews while the corresponding themes have greater variability and may not be present for some participants. Appendix I provides a detailed elaboration of the superordinate themes. The superordinate themes are:

1) **Overwhelming Emotions**
2) **Trepidation to Trust**
3) **Helpful Aspects of Counselling**
4) **The Shadow of Authority**

The first three superordinate themes are concerned with participants' experiences of individual counselling. Although still grounded in participants' experiences, the final theme involves a higher level of interpretation, with a wider lens taken to provide a context to their counselling experiences.

2. THE SUPERORDINATE THEMES AND CORRESPONDING THEMES

2.1: Superordinate Theme 1 - Overwhelming Emotions

Several participants indicated they were dealing with overwhelming emotions for which they lacked coping skills. Prior to counselling they felt stressed by various problems and struggled to regulate their feelings. Many depicted their emotions in an embodied way suggesting that articulating emotions was difficult for them. They discussed their referral to counselling and the role of staff in that journey.

2.1.1: Theme (i): 'At the time I was really stressed'

Feelings of stress and upset propelled most participants into counselling. Mark felt emotionally overwhelmed following his girlfriend disclosing sexual abuse to him. While trying to support her, memories of his past abuse were triggered -

> *'....I was trying to persuade her to go to counselling and stuff like' (30).................you know she was sharing her problems with me as well and it was bringing up an awful lot of memories for me like'. (33-34)*

He was 'the helper' while neglecting his own needs – *'That's kinda me....I just think of everyone else besides myself' (63).* Having angry outbursts and abusing alcohol, Mark knew he needed help - '*At the time I was really stressed out…' (24).* Overwhelmed and unable to manage his feelings, Mark had some awareness of underlying issues linked to his angry and depressed moods but could not articulate them – *'Sometimes you em...feel crap and you don't actually know why' (283).*

Alan felt stressed and isolated – *'...I was awful upset then like' (57).* He contemplated suicide following his girlfriend cheating on him with his best friend. He was aware *'I had to talk to somebody and I didn't have nobody to talk to....' (16).*

Keith, Linda and Shane were coping with grief around the deaths of significant people. Keith was aware of needing support following his aunt's death – *'....my aunt passed away and I felt that I needed someone to see, to see someone' (66-67).* She was his Godmother whom he had desperately wanted to visit in hospital when she was terminally ill but his request was refused by her family – *'I would have loved to have seen her before she died' (160).* Although not privy to the full story, I sensed Keith's wishes were disregarded by his family, perhaps due to his disability and he felt excluded. Following his aunt's death, he felt very alone despite living close by to his parents – *'I had no one to talk to up to that point' (99).* On returning to work following the funeral – *'I just felt I was in a bad way and that I needed to talk to someone' (170-171).* Feeling '*.....I was down, that there was something wrong with me...' (193),* he sought out the counsellor attached to his workplace. While empathizing with his sadness, I intuited that Keith was additionally very angry towards his family but not aware of and able to express this emotion. He presented as a timid, mild-mannered man for whom acknowledging and expressing anger would be difficult.

Although initially presenting with relationship issues, Linda additionally dealt with grief around the deaths of grandparents who had raised her – *'....they bring me up since I was a child, since a little baby' (168).* She very movingly and poignantly described their deaths and her desolation at their loss - *'Sad it'd be when I think back about my Granny and Grandad and the love that I lost' (349-350).* Shane also struggled with unresolved grief following multiple losses. He was bereaved of his father, mother and stepmother and separated from staff to whom he was deeply attached. He impressed as bearing an enormous burden of stress.

Initial issues brought to counselling were around bereavement (Keith and Shane), relationships problems (Mark, Linda and Alan), anger (Robert) and bullying (Tom and Jim). Two participants mentioned no particular stress prior to counselling. Denis was very evasive saying only that his reason for attending counselling *'was private' (53).* I wondered whether he had clarity and awareness about his referral, as apart from saying *'Yea, that's private....you don't mind, no?' (57),* he never revealed a problem. Paul was also reluctant to name his referral basis but indicated that it *'was something that shouldn't be happening' (21).* His secrecy, coupled with his highly supervised living situation made me suspicious that he had issues related to sexual offending.

Besides presenting problems, participants dealt with other challenging matters as counselling progressed. Robert's presenting anger issues around his housemates became secondary to disclosure of sexual abuse. Mark related a difficult upbringing with many family relationships problems. Although the painful break-up with his girlfriend mobilised Alan to counselling, he also dealt with other concerns. Alan's ambition was to work with his uncle in England. Unfortunately, his uncle died prior to beginning counselling so he was also coping with the loss of that dream – *'...that was pulling me down also like' (74).* Both Mark and Jim became conscious that their alcohol use was problematic. Jim, a victim of school bullying experienced social anxiety, used alcohol to cope with his social phobia and was developing dependency. Being referred for counselling was very important for these participants, presenting opportunity to deal with core problems which otherwise would continue to impact negatively on their lives.

Bereavement and loss were underlying themes for others who had lost important people - Tom, his parents and three brothers and Paul, his parents. Robert's parents were dead and although implying he had not discussed this in counselling, he became tearful when mentioning them during the interview. Loss of other significant relationships was a theme for Linda (her boyfriend), Alan and Mark (girlfriends) and Shane (staff members to whom he was deeply attached). Sadness, grief and loss were strongly represented in the interviews, were clearly difficult for some to process and caused significant stress. Participants indicated that they had 'held' these difficult emotions for a long time, suggesting that their losses were not processed with the significant people in their lives.

2.1.2: Theme (ii): 'They were like torrents flooding up and down your stomach'

Verbalising their emotions was difficult for many participants who used the language of embodiment to express their feelings. Shane described his emotions in a very somatic way. He had been reared by grandparents and yet never cried when they died –

> '*And my sister said 'I can't make you out, I can't understand it' she says. 'Nana and Granda reared you; you were with them 'til you were seventeen' says she 'and you never cried over them'' (8-10).*

Sometime later, Shane had the traumatic experience of finding his father dead –

> *'...'twas I found him dead...I did find.... I found him dead. I kissed him before he died'. (681, 683)* and *'That's when my crying started. I never cried in my life....after losing my grandparents, after losing Nan and Granda, I never cried' (685-687).*

Following his father's death, the floodgates opened and he cried incessantly and became incontinent - *'I was still crying and then...it started to wear off and I was wet...I was wetting for a long time.' (42-43).* His reaction suggests a repression of strong feelings and no confidante in whom to confide. Although the crying had abated somewhat, Shane still struggled with grief - *'Sometimes it comes on me, it's not quite gone yet. It still comes on me' (45-46).* He spoke at length about his many past losses. He had discussed these matters with a previous counsellor but not with his most recent counsellor. His mother died when he was young and his father remarried. He developed a close relationship with his stepmother who had also died. He mourned the loss of previous staff whom he regarded as like substitute parents - *'Twas the man I was working with in Southport, he was like a father to me' (118).* This man was his supervisor when Shane worked in open employment in a factory. He greatly missed a staff member from a previous Group Home – *'She was like a second step-mother and I...I often think of her' (165).* Shane's use of 'father' and 'mother' for his relationships with staff are suggestive of major attachment deficits in his life. In addition, he had been badly burned and suffered a stroke so there was loss around his health. Shane seemed a man consumed by deep grief which he felt in a bodily way –

> *'It took a long time before them pains...I couldn't stop the crying, 'twas coming from the stomach' (313-314).*

A psychiatrist he met grasped the depth of his pain. Shane felt comforted when the psychiatrist commented -

> *'And I know that you're not putting on the crying, I know for a fact that you're not putting it on, but you will get through it' says he' (332-333).*

From Shane's account of his most recent counselling there seemed a lack of understanding of the impact of these major life events on his mental health. Shane described bodily weakness due to his distress – *'I was so weak sometimes, my hands used to shake' (359)* and *'...my legs used to shake' (361).* He believed his distress was visible and comments from others reinforced his sense of changed identity -

> *'I was never happ... happy, you could see it in my ...People were stopping me in the street and saying 'You're not the same fellow I knew' (368-370).*

Shane coped with his overwhelming emotions by indulging in escapism such as imagining getting a job in Dublin. Another coping mechanism was comparing himself with Elvis Presley whom he believed also found it difficult to cope with loss - *'He lost his mother and he went off the singing for ten years' (487).* Like Elvis *'going back on the stage' (489)*, Shane held the hope, perhaps unrealistically, that he would recover from his grief and return to his previous life. Through-out the interview I sensed a sub-theme of unarticulated loneliness and I wondered whether Shane had been seeking an attachment relationship with his counsellor which did not materialise and contributed to his disillusionment with counselling.

Alan's distress following the break-up with his girlfriend was exacerbated because she went off with his *'best mate'* so he felt a double sense of betrayal - *'And then...then I was awful upset then like' (57).* He confided in no one and was *'....pretending you'd be happy and not happy' (79).* As well as sadness, Alan demonstrated unaware anger, manifested bodily through asthma attacks -

> *'......every time me and my girlfriend were fighting or arguing, my asthma would build up and I couldn't breathe or nothing like' (131-133).*

This physical embodiment of anger prevented him from dealing in more constructive ways with the inevitable hurt and distress of relationship break-up. He repressed his feelings but showed awareness that lacking a confidante could lead to serious consequences -

> *'Well I didn't talk to nobody 'cause ...something might have....might bad have happened to me if I didn't go and talk to anybody' (186-187).*

He admitted that prior to counselling he was *'...kinda down at the time' (120)* and in fact had contemplated suicide - *'I was thinking to kill myself at one stage' (189).* Although he spoke of having 'mates', it is significant that Alan did not confide his deep pain to them, suggesting he lacked close relationships and intimacy in his life.

Robert's emotions also caused him somatic distress. He had regular conflict with his fellow residents - *'About problems with the lads and all that……upset and all that' (26).* He had difficulty managing his anger - *'...shouting at the lads and all that...banging doors and all that...'(226).* He was aware that his 'acting out' was problematic and described it as '*The problem about ....aaam....anything.....about my mood, angry and all that' (154-155).* His anger caused physical sickness - *'terrible pain in my tummy' (171).* Later in the interview he revealed sexual abuse by a housemate which he had disclosed to his counsellor. Robert's anger appeared directly related to the hidden abuse, manifested in 'acting out' his anger and somatising his distress. Jim also showed his emotions somatically, experiencing high levels of bodily tension, possibly linked to childhood and adult bullying. He intimated a degree of sexual frustration which led to stalking – *'I followed a girl home once I did' (157-158).* He admitted using alcohol to deal with uncomfortable feelings, was aware his alcohol intake was impacting on his health and that it was essential for him to begin '*...cutting back on it right because I have diabetes' (67).* Although desiring a relationship, Jim was an anxious man with limited social skills and few opportunities of meeting potential girlfriends.

Tom was not as articulate as others and laboured to verbalise his feelings. However, he described distress at several incidents where he was bullied and his belongings stolen – *'They were at my bag....and I had fifty pounds there and I didn't ...you know' (71).* And again *'Other people took the ...took the hats...I told Judy* (his counsellor) *that' (79).* Tom was very proud of his collection of hats so their loss was significant. Tom hinted at physical bullying and perhaps sexual exploitation in the past. He felt safe going to a local Shopping Centre because *'They won't touch me up there 'cause they all know me' (118).* Later Tom spoke of sleeping problems - *'You see I'm a fairly bad sleeper you know' (280)* and his involvement with mental health services. He revealed spending several months in a psychiatric hospital and problems around medication -

> *'I was very dopey with the tablets....they were very you know....I was going to bed then about half five and I wasn't ...em...wasn't eating that much you know...' (304-305).*

He also was unable to dress himself – *'I wasn't able to wear my clothes you know' (309)* and was *'getting dizzy spells...'(313).* Tom did not link his mental health problems to life events but mentioned that his parents and three brothers had died. On telling his counsellor, she organised for him to attend a bereavement group where *'You know they talk about...about the dead people' (486).* He admitted to feeling *'very lonesome you know' (490).* I wondered whether his grief and loss and the mental health and somatic difficulties were related and whether he could articulate his feelings of loss and loneliness to his family.

Neither Paul nor Denis had sought counselling and revealed no particular troubling emotions. They regarded counselling as something external which was 'done' to them, displaying limited capacity to engage emotionally with the counselling process. However, Paul did indicate that he felt *'...maybe sometimes maybe a bit upset and ...things like that' (169)* when he spoke about *'...something what shouldn't be happening' (21).* That so many participants experienced their emotions in a bodily way suggested that it was a wrestle for them to verbalise emotions thus needing the alternative language of embodiment for expression.

2.1.3: Theme (iii): The Journey to Counselling

Although stressed and not coping, Keith was the sole participant who self-referred for counselling. Others, like Alan who felt emotionally distressed, confided in staff. He talked to his Manager who referred him for counselling. Likewise, all the others had counselling recommended by staff members. While anxious at the prospect, participants acquiesced when staff suggested counselling. None mentioned that they had thought of refusing the staffs' recommendation. However, most reported that ultimately it was their own decision to attend, according them some level of autonomy and self-determination. Feeling some degree of choice is helpful in establishing the counselling process on the right footing. Linda's view was - *'Felt I had a choice so decided 'Yes I'll go' (87).* Alan was initially ambivalent - '*Well at the time I said 'Will I go, will I not go, so I said that I might as well go' (88),* while for Mark *'Yea...it was only a suggestion like and I was glad I...to have a choice to go...'. (67).* For Jim *'I was a bit nervous about it, but I....you know agreed to it' (90).* Others such as Shane and Paul complied with their Managers' suggestion. Shane's Manager advised counselling and with a hint of submission he said *'I'm sure to God that he* (his Centre Manager) *wouldn't mind if I said 'No' (52)* while Paul indicated that -

> *'She* (his Manager) *said.....she just said to me 'Would you like to go in and see Carol* (the counsellor) *and talk about it to her'. I said 'I have no problem going in' (118-119).*

Paul had experienced counselling previously and this familiarity might explain his willingness to attend. Tom's referral process was unclear but he intimated his sister had requested the counselling through staff which fitted with his dependency on his family.

Denis's interview raised important issues around choice as he did not freely choose to attend counselling - *'I think I was asked to do it' (68).* On further probing, he indicated *'Sometimes she* (the counsellor) *might want to see me' (175).* When asked if he had choice, he seemed very surprised and responded *'Oh.....like it be up to yourself?' (186)* and *'.....it would be hard to say 'No', it would be yes' (198).* Denis appeared unaware that the option to voice an opinion or refuse was available to him. Being uninvolved in decision-making around referral could impact on subsequent willingness to fully engage in the counselling process. It was heartening to hear that most participants felt some level of choice around attending counselling.

2.2 Superordinate Theme 2: Trepidation to Trust

Running through transcripts is a distinct sense of participants' initial anxiety and trepidation towards counselling and of gradual movement to trust and comfort with the process. The themes outline participants' initial impressions of the counsellor as *'a stranger'*, the fears and apprehensions engendered and how over time they developed confidence and trust in their counsellors.

2.2.1: Theme (i): 'Like talking to a Stranger'

Participants described their first counselling session and how rapport was established with their counsellors. Mark likened his initial session to - *'She was a stranger like.......it's like meeting someone in the street...' (111).* He was acutely aware of the 'strangeness' of the counselling situation, that it was not a typical social encounter. Keith experienced it similarly - *'...and you know yourself, you wouldn't know what to say to a stranger' (190).* Linda was conscious of the unusualness of the situation, feeling *'Very nervous......'cause I didn't know her' (127, 129*), a sentiment echoed by both Jim and Keith -

> ***Jim:*** *'I was a bit nervous I was, meeting her the first time...so' (94)*
>
> ***Keith:*** *Em....I didn't really know what to say to her the first time I met her.......because she was a total stranger to me at the time.....' (186 -188)*

These participants are indicating they felt out of their comfort zone, uncertain how to behave. Counselling was experienced as a perplexing and unusual encounter with 'a stranger' which they were unsure how to deal with initially. Mark commented '*It was a bit strange seeing a new person' (98-99).* Conscious of the difference between counselling and ordinary social interactions, he was aware that trust-building needed time -

> *'It was kinda hard so it was' (111)* and *'....it's going to take a while for you to get to know them and you wouldn't start giving out your life story straightaway, you know what I mean' (112-113).*

Others also indicated that trusting their counsellor took time before they felt comfortable in relating their problems. Linda stated that – *'...it took me a few days to get used to her and then I got used to her and I found her really good' (116-117).* Jim revealed his initial anxiety saying *'I was nervous at first going but then I got the gist of it then like...' (44),* suggesting a relaxation as he learned 'the ropes' of counselling and what to expect. Keith was keenly aware of not revealing himself too quickly before he felt sufficient trust in the counsellor, admitting *'It took a bit of time, yea' (207)* to feel at ease. Mark discussed his process as follows -

> *'It was ...it was kinda hard like, but it took me a while but I... ..then I got to know her and then....you know I was able to kinda say what's on my mind like you know' (115-116).*

Mark drew on familiar ground by likening the ‘getting to know’ process to another experience of relationship building -

> *‘It’s like anything....if a new support worker came in here and ...you know it was her...you know...the person’s first day...I’m not going to be giving them my life story like, unless I really knew them...you know what I mean.....it’s going to take a while like’ (120-123).*

Yet, despite the perceived strangeness of the encounter, all participants returned for further counselling.

2.2.2: Theme (ii): Fear and Apprehension

The initial meeting held a level of anxiety and sense of trepidation. Participants felt unsure and lost for words. Those prone to somatisation approached the encounter with even greater apprehension, with their anxiety being manifested bodily. Physical sensations felt by Robert, Alan and Jim were palpable. Robert was so apprehensive and fearful that *‘I felt sick...........that she might give out’ (78, 82).* Alan also felt bodily tension *‘Am.....kind of like butterflies in the stomach* (laughs) *(115),* while Jim revealed *‘I remember when I first went that I used to be very, very, tense actually’ (104-105),* fearing that *‘...she might be a bit strict like’ (98).* Although adult men, they approached counselling with feelings of dread. Robert felt ‘sick to his stomach’ as though he had done something wrong and feared being chastised while Alan and Jim were highly anxious. Although nervous, Alan was curious about counselling - *‘It was the only way to find out what was going on, so I said ‘I’d meet you today’ (94).* Alan was the only participant who reported suicidal feelings and his level of desperation most probably over-rode his fear. The three men conveyed that their acute anxiety distracted them from their problems. They were initially more focussed on the counsellor and the anticipated interaction than on themselves. Alan found difficulty in opening up – *‘It was awkward what to say like...’ (173).* His counsellor obviously sensed this and *'He told me that whatever was on my mind to say it out like' (128),* while Jim's counsellor equally took an active role in helping him to articulate his problems - *'She did ask me questions you know....' (107)*. Robert's counsellor did some relaxation prior to discussion his presenting problem. All of them needed considerable counsellor support to open up.

Despite their unease, Mark and Shane had reflected on the problems they wanted to discuss. Shane, preoccupied with the hope of obtaining some relief, had little focus on the counsellor -

> *'I think there was so many things on my mind I didn't know who I was meeting. Just wanted somebody....wondering would you....would I get anyplace' (144-145).*

Mark, who impressed as very self-aware, although concentrated on himself and his problems was conscious of meeting someone new -

> *'I was a bit nervous 'cause she was a stranger you know but I felt upset myself. Em......I wasn't crying or anything...I was just.....felt upset in myself and ....It was a bit strange seeing a new person' (97-99).*

Fearing the 'stranger' counsellor might be authoritarian concerned Robert and Jim who worried they might be reprimanded. By contrast, Paul approached counselling in a more cavalier fashion, with no expressed anxiety. He expected his counsellor to be someone monitoring his behaviour and checking up on him - *'Am....she'd ....probably Carol* (his counsellor) *would say......'Is Paul behaving his self'.....and things like that' (454-455).* Through-out his interview Paul indicated a strong awareness of the role difference between him and his counsellor, seeing her in a supervisor-like role. He had attended several counsellors before Carol, his current counsellor, and seemed relaxed about their initial meeting – *'I felt alright' (242).* He appeared happy to be monitored and contained, as though it was a security for him. Neither Denis nor Tom indicated any initial anxiety, perhaps because the counsellor was known to them from weekly visits to their sheltered factory. It is also possible that both were less able to articulate their internal states as they seemed less intellectually able than other participants.

2.2.3: Theme (iii): 'She's Very Nice'

Most participants expressed positive feelings towards their counsellor despite diffident and uneasy starts and the counselling relationship was strongly linked to their overall satisfaction with counselling. Perhaps recognising the high anxiety levels of Robert and Jim, their counsellors took the lead in building rapport and creating the relationship. It seemed critical that the counsellor was proficient at putting people at ease by appearing *'a normal person'* and engaging in initial neutral chit-chat. This was important for Keith -

> *'Well I thought she was very chatty like and you know….and I just felt she was a normal person in the end to talk to' (365-366).*

Linda's counsellor helped her feel comfortable *'By talking to me….by getting to know her' (131)* while for Mark the fact that *'She just talked to me' (101)* created a relaxed climate. Keith was relieved that '*I found that overall that she was.... she was a nice person' (230).* That participants attached the word 'nice' to their counsellor seems significant, suggesting that the counsellor's skill in creating social comfort is important. This 'ordinariness' of their counsellor was central to participants' relaxing and feeling ready to engage in the counselling process. 'Normality' is communicated in subtle ways such as clothing, demeanour, tone of voice and ability to engage in social 'small talk'. Undoubtedly these cues were intuited by participants, contributing to their positive evaluations.

Although not commenting explicitly on his counsellor, Tom mentioned them laughing and joking together and clearly enjoyed their regular meetings – *'Me and Judy have a laugh' (212).* Tom presented as a hearty jovial man, and was very open about matters which concerned him suggesting practice and comfort with engaging in social relationships. Robert struggled with verbal expression, and presented as an extremely anxious man. However, he conveyed he could communicate his feelings and troubling matters to his counsellor. Poignantly, he linked his fear of talking with being *'….afraid told 'shut up'…..being nervous and all that…' (202),* suggesting past experiences of not being listened to and even being ridiculed. However, he was relieved to *'...give your problem out to….to the counsellor' (273)* which was surely a great support for him. Although unable to articulate how he bonded with his counsellor, he was clearly attached to her and very reluctant to finish counselling despite attending for some years. Jim was also disinclined to finish counselling - *'I'm hoping that won't be for a while yet (298)* and indicated positive regard for his counsellor *'Because it's very good like...go to Helen and she's very good' (311).*

Participants who made no specific comments about their counsellor did not appear to have established a strong relationship. It was difficult to ascertain what Denis had gained from counselling as the counsellor seemed in charge of the process. Paul was focused on the counsellor getting him *'back on track'* and regarded her as someone to monitor/control his behaviour rather than showing concern with relationship factors. When asked what the counsellor had done to put him at ease, Paul replied -

> *'She just went to the Files and …and she just had them there in front of her and taking all the information in' (146-147).*

Paul preferred that the counsellor had background information prior to meeting him rather than him 'telling his story', which is an important part of building the therapeutic relationship. Paul gave no sense of seeing counselling as a collaborative relationship.

2.3 Superordinate Theme 3: Helpful Aspects of Counselling

Participants' experience of helpful aspects of counselling has six themes. Participants valued being supported to tell their stories and feeling understood by the counsellor. Advice and guidance emerged as beneficial as well as the opportunity to explore feelings. Participants valued the educational component in counselling and finally discuss their overall evaluations of the experience.

2.3.1: Theme (i): 'We got them out between us'

Tom expressed a sense of collaboration when he said *'I like to see Judy come and talk to me and talk to Judy you know' (509).* His presenting problem was bullying and *'I told her about the robbing and ....the few things Judy be asking me' (194).* Tom implied that Judy helped him relate his problem by asking him questions. Jim also mentioned his counsellor's questions -

> *'Well, she did ask me questions you know, I forget how...you know how she asked them like but she did ask me questions....' (107-108).*

When Jim disclosed his presenting problem, also of bullying, he experienced relief, *'It was yes, it was good to get it out' (189).* Without his counsellor's active participation it would have been difficult to articulate his problem. Participants needed to 'tell their stories', to communicate their concerns, as counsellors are not mind readers. For many with difficulties in verbalising and articulating, this proved a formidable challenge requiring the counsellors' active involvement. Robert, who had very indistinct speech, felt sick with anxiety at the prospect of counselling. In the interview he responded mainly with single words and truncated speech. His counsellor taught him relaxation as a prelude to verbal interaction - '*Exercise and deep breaths and all that' (87)* which helped him feel *'quiet' (94)* and more able to engage verbally. Her sensitivity to his needs supported him to communicate his problems.

Keith, although able and competent, struggled to verbalise his story - *'Em....I didn't really know what to say to her the first time I met her' (186).* He needed support to express what were bothering him – *'...we got them out between us' (296).* This sense of collaboration also comes through in Linda's experience - '*...she'd be there and she'd try and help you' (32).* Linda was aware of needing to play her role in the counselling process - *'I told her what was bothering me...she helped me out' (137).* Alan felt *'awkward' (173)* at first but pent-up pressure propelled him to disclose -

> *'I had a lot on my mind and I told him what happened and ....he was happy for me to say it' (173-174).*

Although very articulate, Mark experienced difficulty in opening painful areas of his life and was aware that counselling was emotionally demanding -

> *'I felt...I felt...I felt tired because...counselling can take an awful lot out of you...you know...'cause you're....You're telling people your problems and stuff like that ...and it can take an awful lot out of you ...and stuff like that' (130-132).*

Paul felt no need to describe his problems to his counsellor as -

> *'Well she knew all about it....'cause she heard it from Tom Price, she heard it from Ann Smith...and she heard it from them all' (53-54).*

The names mentioned were former counsellors from time previously, so Paul knew his counsellor had access to their notes with background information prior to meeting him. He additionally indicated that his Manager ('the Boss') briefed his counsellor and saw no difficulty with her knowing his history – *'Oh yea....so she know them...that was fine there' (61).* However, when Carol requested his version of events at their initial session he struggled to tell his story - *'Ah well...some of it I was and some of it I wasn't' (156).* He experienced difficulty in disclosing his *'problem'* and his counsellor was sensitive to this – *'...she said...anything you don't know I'll help you out with it and things like...like that' (161).* It probably helped that Carol had some prior knowledge as otherwise Paul may not have been open about his difficulties. Perhaps he may have felt a sense of shame if his problems related to sexual offending.

Shane was very talkative and articulate and while not revealing how he initially told his story, he was unlikely to have experienced difficulty in relating his concerns. Denis did not discuss whether or how he told his story to his counsellor.

2.3.2: Theme (ii): 'She understands what you're going through'

Robert, initially so fearful, quickly grasped that *'I could talk about my....about anything at all about me' (75).* Mark commented that *'It was really helpful..em...that I was...that I was able to talk out to somebody who understood...like you know' (194-195).* Linda viewed her counsellor as *'Someone with whom you can discuss your problems' (72)* and valued that her counsellor *'...was always there....she understands what you're going through' (209-210).* Alan, having kept in his problems, found it helpful when his counsellor '*.....told me that whatever was on my mind to say it out like...' (128).* Jim perceived that *'I could tell her my problems like, what problems I had' (38).* Participants were relieved to have their problems taken seriously which led to feeling understood. Another dimension of feeling understood was their reported freedom to talk openly. The quality of counsellor listening was mentioned as contributing to feeling understood with Mark making the distinction between people who did not pay attention and the counsellor *'who was really listening' (197).* He noticed the qualitative difference in listening ability between the counsellor and others in whom he had tried to confide but *'they're not really listening like' (200).* Alan was conscious that his counsellor *'....was listening to me and he knew where I was coming from...' (121).* Some participants did not articulate these dimensions so clearly but my impression was they felt listened to and understood. Tom initially attended counselling to increase his independence, but in counselling sessions talked about bullying which deeply upset him. Although he disclosed this issue to others in the past, he perceived that they did not listen - *'I reported to Louise* (a frontline staff) *and Louise said 'I know nothing about it' (83).* Whereas, when Tom confided about the bullying (where his possessions were stolen) to his counsellor - *'She took all the details about what ...what was taken' (220),* which he interpreted as her understanding his distress. Her taking his concerns seriously possibly contributed to his growing sense of empowerment.

Although his counselling was short-term, Alan felt understood by his counsellor - *'He made me happy so he did' (181).* And *'....he's a good person to talk to like' (325).* After the initial session, his feeling was – *'The first thing I said was 'I have to go again like, you know' (176).* His enthusiasm to return contrasts sharply with the *'butterflies in the stomach' (115)* he felt originally. He commented that - '*He took notes down in his book' (270),* which may have communicated to him his counsellor's understanding and serious regard for his issues. Paul was also impressed that Carol took notes and understood the difficult issues he was trying to overcome. He believed she had goodwill towards him and wanted to help him –

> *'Am ....she said now.....this is going to be.....because I want you to get better....and to see the good side of you and things like that' (150-151)* and *'....anything you don't know I'll help you with it and things like.....like that' (160-161).*

Although Carol was monitoring his behaviour, he experienced her as caring, understanding and sensitive to his needs. She did not read the Staff Record Sheets in his presence (which contained *'all the bad things' (239)*) although he was aware she could do so if she chose. Paul perceived her as someone working hard to help him, as empathising with his difficulties. He was impressed by her persistence -

> *'....'cause she kept at it and at it and at it until she got...had me back' (220)* and *'I knew from the last session I knew she was getting me back on ....on the right way...' (403-404).*

Keith was very appreciative of his counsellor's ability to understand and support him. When earlier he had disclosed his desire to visit his dying aunt, she contacted a Social Worker on his behalf. Unlike his family, he felt heard and believed she was on his side which probably contributed to his confidence to seek her out following his aunt's death. Indicative of feeling understood by their counsellors, participants discussed personal and intimate matters. Both Mark and Robert disclosed sexual abuse, which had not been presenting issues. Jim discussed childhood bullying and a serious problem he previously had with stalking women while Keith was able to discuss other family issues. Linda regarded her counsellor as -

> *'...someone with whom you can discuss your problems and at least that person is able to help you then...out.... with your problems' (72-73).*

Jim experienced his counsellor as *'....very understanding' (99)* and trusted her to the extent that *'....I go to Helen for all my personal problems you see' (308).* Shane's perception of his counsellor's lack of understanding undoubtedly contributed to his dissatisfaction with counselling. Although not commenting directly on their relationship, he implied feeling more understood by previous residential staff - *'Ah, they were nice people and they understood me' (703)*. He went for counselling because *'...she was the only help I....I had at the moment' (54)* but never felt helped by the process. He mentioned a previous counsellor (Ann K) with whom he seemed to connect more positively. Shane discussed confiding his grief to Ann but had little faith that his recent counsellor (Teresa) would understand and terminated after five sessions. When I asked if he would like to meet with her again, he was very clear that *'No, no I wouldn't'. (596).* I surmised that Shane had not felt understood by Teresa and never formed a relationship with her. Yet, he discussed past relationships where he felt understood, indicating his ability to form close, confiding relationships. For some unarticulated reason the match with Teresa was unsatisfactory. This was most unfortunate for Shane. Feeling sad for him following the interview as his pain was so evident, I encouraged him to talk further with his Manager. When asked if he would consider further counselling he responded - *'It doesn't .....I ....it doesn't push me' (590)* suggesting a futile hopelessness. However, later he indicated a willingness to try counselling again indicating some hope that the help he needed might be sourced.

As mentioned, Denis seemed to feel no control over his counselling - *'Sometimes she might want to see me' (175)* and his engagement seemed minimal. This passive stance was also evident in the research interview. He had however attended 15 counselling sessions. Perhaps he experienced some benefits which he was unable to articulate or he may have been simply complying with the wishes of the counsellor or his staff.

2.3.3: Theme (iii): ‘He told me what to do and I tried it out’

Alan felt suicidal prior to counselling and indicated that he needed a directive approach from his counsellor - *‘The best part was like you sit down and he told me what to do and I was happy then and was more relaxed for myself’ (201-202).* He felt under immense pressure and his counsellor’s directive stance contained him and provided a sense of safety -

> *‘I told him that I was thinking to kill myself and all this but I didn’t actually do it like so he was talking to me and telling me what to do like and I said I had to go to him again...’cause for more relief.....out of the system’ (217-219).*

Feeling more relaxed and clear-headed, he subsequently dealt with other problems. Alan’s asthma attacks were related to anger with his ex-girlfriend and he appreciated the advice suggested by his counsellor to manage these episodes-

> *‘He told me to take deep breaths like and cool down and take a walk…maybe outside and come back in and talk to her….and maybe take your inhaler if you have to need it at the time’ (141-143).*

He obtained guidance from his counsellor on managing his anger - *‘Like if you’re fighting, just go outside and take deep breaths and cool down’ (227).* Alan’s counselling was short-term and solution focused and his counsellor dealt with immediate crisis issues. This approach was successful for Alan who reported at the conclusion of the contract that *‘I was more relieved...I was more happy for myself’ (307).*

Several participants valued the ‘advice’ given by their counsellors. Jim appreciated that his counsellor *‘....she always gives me very, very good advice on things like so...’ (227)* and related how she helped him to control his drinking and gave advice on managing bullying and diet around his diabetes. Later in the interview he reiterated the importance of a directive approach -

> *'That she'd be giving good...very good advice like... that she'd help you out with any problems you have ...that she'll help you out' (314-315).*

Jim presented at interview as a tense and anxious man who was dependent on his mother for decision-making. Not surprisingly, he transferred this attitude and regarded his counsellor as someone who would guide and direct him – *'She'll just give me helpful advice straight away' (234).*

Mark had more sophisticated understanding and commented that his counsellor- *'Well you know she kinda gave me options of what to do and stuff like that...' (103).* He was aware that although his counsellor may have provided suggestions, ultimately *'...everyone has a choice...you know...like people can only advise you' (139).* He perceived his counsellor as being tentative and not directive when she suggested that -

> *'..maybe you need to think of yourself....like you can't take everyone's problems on like....you've to ...you know what I mean....'cause eventually you're going to be getting stressed out with it and stuff like that...and you need to try and think of yourself, you know...' (178-180).*

For his alcohol abuse and anger outbursts he appreciated more specific help. He learned strategies around his overuse of alcohol -

> *'….things about alcohol and stuff like that …how to distract yourself….you know that if you say 'Today I want to go for a drink' or something…em….I kinda know how to distract myself and try and do something else…to try and take it out of my head and mind like you know what I mean' (366-369).*

Likewise, to deal with anger he learned-

> *'…to maybe go down into my room and count to 10 or something like that. Or go out of the house, just get out of the situation, maybe bring your walkman and…listen to a bit of music and just tune out of …where you are… like you know' (300-303).*

Mark's counselling experience was primarily non-directive but he valued specific coping strategies for certain problems. A balance of a non-directive approach with clear strategies for dealing with specific problems seemed valuable for the majority of participants.

Tom's counselling focused on practical matters towards increasing independence. He spoke of '*….talking about making sandwiches' (15)* and *'She was making me how to do …how to do the washing and all that…' (91).* His counsellor set him practical tasks to increase his independent living skills, which may have been a consequence of his psychiatric hospitalisation, as he related incidents of greater self-sufficiency in past times. As Tom was unable to provide a timeline this is only a supposition. He lived with his sister and indicated that Judy (his counsellor) worked *'with my sister Trish' (998)* around the independence tasks. In addition to dealing with issues such as bullying and family bereavements, Tom's counselling involved specific guidance and advice which he perceived as helpful -

> *'Judy would help you out with it, and help you advice and all that ...all that information you know' (512-513).*

Paul's counselling was primarily directive as his counsellor was monitoring and supervising his behaviour *'....back on the right track' (207).* Paul handed over all power to his counsellor, believing she had the total wisdom about the *'right track'*. Carol had advised him -

> *'When you think of the bad thing, go into the kitchen and do something....something else instead...forget about what happened' (250-252).*
>
> *'If you feel bad now in the evenings, go and do a bit of writing ...or go and do a bit of colouring ...or do a bit of this ..and that' (344-345).*

He followed her advice reporting that -

> *'Well I might go in here and do ...a bit of writing or something like that' (264).* And *'I've a whole pile of drawings in there...in the sitting room. I just ...I just throw them in there out of the way' (371-372).*

Through-out the interview Paul implied he appreciated the close monitoring and was happy to be given advice and direction which he clearly followed.

Although mainly non-directive, Linda reported her counsellor helped her to cope with *'a bad mood' (299)* through specific advice such as -

> *'...go up to my room and listen to some music and not try to take it out on other people' (300)* and also *'count to 10...I found that great' (303)* and *'...read a magazine ...or some colouring' (305).*

Linda followed the advice -

> *'I tried the music and the colouring....and the reading...I thought it was very good' (307-308).*

Keith's counselling, mainly around bereavement issues, was non-directive and he did not mention advice-giving from his counsellor. However, he found it helpful when she reframed matters in a way that provided a different perspective. When his mother reacted angrily to him breaking a glass, his counsellor reframed it by suggesting -

> *'Maybe it's the way that your mother's upset with ...with her sister died...when her sister died and she wanted someone to take it out on' so she...so she chose me to pick it on' (238-240).*

This enabled Keith to 'let go' of the incident.

Shane spoke of his previous counsellor – '*I found Dr. Ann K was very helpful to me' (37)* and related how she introduced him to computers as a distraction from his grief – *'to take my mind off of that….off of….off of his death' (155)* and *'That helped me….helped my mind' (153).* She also advised him to apply for a job.

Robert experienced the relaxation exercises used by his counsellor as helpful and also mentioned her advice about ways of interacting with his housemates. Denis made no reference to advice or guidance provided by his counsellor.

Although many participants spoke about the value of 'advice' from their counselors I wondered if this was due to vocabulary limitations. They may not have been familiar with words like 'options' or 'suggestions' which Mark understood. This may reflect my own bias towards non-directive counselling. It is important to consider that participants may have viewed 'directiveness' in a different and positive way. Perhaps it gave them a sense of safety and containment, which was certainly the case with Alan. It is possible that many participants experienced a directive approach as more beneficial than non-directive counselling which may have mirrored their experience of other relationships.

2.3.4: Theme (iv): 'Talking about my feelings'

The opportunity to describe and name feelings was important for most participants. Robert had difficulty managing his anger, compounded by poor communication and speech skills. He found it helpful to talk *'....about my mood....angry and all that' (154)* and in cryptic language described how the *'......terrible pain in my tummy go away' (171)* through *'talking about it' (168).* '*Talking about my feelings' (141)* along with *'write down what I feel and all that (223)* and specific anger management skills all helped to *'get my mood back to normal' (235).* Experiencing a high level of tension, he learned to cope with anxiety through relaxation training - *'Breathing in and....and out and all that....and putting my hands on the chair and all that' (245).* Learning to regulate emotions, particularly anger, was a theme in several interviews with anger emerging as a major issue for Mark and Alan and to a lesser extent with

Linda and Keith. Given the historical oppression of PWLD, anger may be a particularly difficult emotion for them to acknowledge and express.

Mark spoke of how *'I...I used to get very agitated and stuff like that (292)* and initially found it difficult to verbalise his feelings *'...sometimes you don't know how to explain something, you know' (282).* Gradually he learned through naming and identifying his feeling state to take appropriate action -

> *'If I'm really up in a rage, I give myself a few minutes because sometimes when you're talking to somebody if somebody says something wrong then you'd only get more agitated' (308-310).*

Recognising and naming anger was important learning for Alan – *'...sometimes I could wake up in the mornings and still I'd be mad like for no reason' (222-223).* Through '*Just talking.......and he asked me different questions about how things were going each day for me and I'd tell him...' (267-268)* Alan learned to control his temper and identify anger triggers. With his anger under control, he came to acknowledge and deal with underlying sadness around loss. At the end of counselling - '*Well I was more happy in myself than sad' (284).*

Linda and Keith, although dealing primarily with sadness and loss, also admitted to feelings of anger. Feelings talk helped Linda to deal with grief around her grandparents' deaths - '*...sad about different things…that has gone through my life'* (154). She learned that grief has many dimensions. Her counsellor helped her to verbalise different emotional states - *'She talked about your feelings…like there were different feelings like happy, sad, angry, mad...' (296-297).* Keith recognized his anger towards his deceased aunt's family and his mother, feelings initially out of his awareness.

Shane recounted how his first counsellor Ann K. had done some 'feelings' work with him – *'Draw a happy face and a sad face' (451)* and used photographs of his deceased parents for grief work. Shane was very articulate at describing feelings, signaling his familiarity with such a skill. Tom provided detailed descriptions of distressing events in his life. His accounts were concrete and although emotions were evident, he was unable to verbalize them. He proudly spoke of past involvement with sports in his local community – *'I have the trophies for the …for the football you know...at home' (364-365)* and also of his prowess at boxing *'I was a great boxer…I was up in Dublin and a lot …lots of places…' (388).* Although unarticulated by Tom, I sensed a sadness underlying the loss of a previous, more independent self. Tom never made his feelings explicit and I wondered whether his high level of medication might have blunted his emotional responsiveness. His counselling work seemed concrete and practical rather than concerned with feelings.

Anxiety was the chief emotion dealt with by Jim and he expressed relief in discussing his worries around various issues in his life – *'Any problem I have, I can just tell her like' (232).* Denis made no reference to any feelings work in his counselling.

2.3.5: Theme (v): 'She discussed what a proper relationship should be like'

Partner relationships were important for some participants who valued their counsellors' input around relationships and sexuality. Such education was especially appreciated by Linda, Alan and Mark, who had broken up with partners. Linda stated that *'I had a lot of problems with my ex-boyfriend too and that was part of it as well' (95).* In addition to relationship work around her ex-boyfriend, Linda benefited from sex education work with her counselor -

> *'….she had a book before her and we were doing about body parts…we were learning about the body parts so I kinda liked that because it taught me right from wrong' (224-226). 'I was helped….it really helped me a lot' (231)*

Recovering from relationships break-ups, Mark and Alan welcomed the support counselling provided and valued input about relationships. Alan was angry and depressed following the split with his girlfriend but through counselling learnt that *'....you have to move on I suppose' (168)* and that it was possible for them to remain friends - *'...if I see her on the road I wave and talk to her and she talk to me' (162).* Mark had been supporting his ex-girlfriend at an enormous cost to himself and his counsellor discussed the nature of healthy relationships -

> *'She helped me ..em…realise my relationship was stressing me out and it was time to …kinda have a look at that and stuff like that and she discussed what a proper relationship should be like and stuff like that, that there should be a bit of give and take, that it's not all me giving and stuff like that' (232-235).*

Excessive use of alcohol concerned Jim and Mark. Through support and education provided in counselling, they learned to deal with alcohol cravings and better manage their drinking. Mark learned – *'…..things about alcohol and stuff like that ….' (366),* while Jim believed that the help he got around his drinking was the most valuable part of his counselling -

> *'My drinking was about the help…the most help….as even now I don't drink on a Sunday anymore…so' (141-142).*

There was a strong educational component to Tom's counselling as he learned practical skills such as how to make his own lunch and attend to his self-care at home - *'I'm very capable of myself at home, of washing myself...and going up...having a shower' (273-274).*

2.3.6: Theme (vi): 'I'm happy in myself'

All participants indicated their counselling was almost exclusively verbal and concerned with exploring and resolving their problems. At the time of the interviews, half had finished counselling while five were continuing. Linda, Alan and Keith had completed their counselling and positively evaluated their experience. It was Linda's own decision to end as *'I felt happy...I felt everything was going ok and great and good in myself...much happier in myself' (336-337).* However, she appreciated having access to her counsellor if required – *'Helen said I can always ring her again if I need to' (324-325).*

Alan's counselling had been short-term – *'When the six weeks was up it stopped that time' (282)* but he felt *'I can't really do more now, I'm happy in myself and if I need him again I'll use him again' (284-285).* He was positive about his counsellor *'I reckon he's.....he's a good person to talk to' (325)* and would seek further counselling if necessary.

Keith had been happy with his counselling experience and commented *'I was yea, satisfied yea' (597).* He welcomed his counsellor indicating '*...anytime I want to see her, she'd see me' (562).* He would recommend his counsellor to others - *'I'd tell them to go and see a nice girl and her name is Judy' (607).* Those who had finished counselling of their own accord felt enabled to contact their counsellors if necessary without having to go through staff. They were assuming ownership of the process rather than depending on staff to initiate as previously. Their counselling experience had empowered them to greater self-sufficiency.

Due to his counsellor taking a career break, Paul's counselling had temporarily finished but he looked forward to resuming on Carol's return. He considered he had progressed - *'I...I knew from the last session I knew she was getting me back on...on the right way' (403).* He *'felt good' (434)* when his Manager told him *'Carol now will be soon back and she'll be talking to you again' (430).* He anticipated that '*the Boss'* would give Carol a positive report – *'Oh she'd say 'Oh he's doing well' and things like that' (462),* suggesting Carol's good opinion mattered to him.

The frequency of Mark's ongoing sessions had changed to fortnightly at his request and he appreciated his counsellor's responsiveness to his needs. Feeling *'drained'* after his sessions, he renegotiated his session length -

> *'We just tried maybe to do a half an hour or 35 minutes at the most now because I just feel that it's too much doing an hour like' (210-211).*

Following the change in session frequency, his counsellor indicated that *'...If I ever needed her that I could ring her' (152).* He experienced this as reassuring and evidence that his counsellor cared about him. Mark clearly enjoyed his counselling and commented *'...counselling is brilliant' (385).*

Robert felt *'Good in myself' (281)* and counselling helped *'.... get my mood back to normal (235)* and he continued to attend regularly. Jim indicated *'I just love going to her. Any problems I have I can just tell her like' (232)* and showed reluctance to finish '*I'm hoping that won't be for a while yet like' (298).* His evaluation was - *'I really like going to counselling....it really helps me like along the way' (320).* I wondered if there was a risk of dependency with Jim, given his dependent relationship with his mother. Tom's evaluation was also positive. He enjoyed meeting his counsellor and had fun and *'laughs'* with her and seemed to have become more independent. Shane had some positive remarks about previous counselling *'I found Dr. Ann K was very helpful to me' (37)* but unfortunately had not benefitted from his most recent counselling experience.

Few participants had critical comments. Mark regarded an hour as too long and had agreed a shorter session length. While very positive about counselling, Keith indicated that occasionally he found the pace - *'....a bit slow' (326).* By terminating counselling, Shane clearly signalled his dissatisfaction with the process. Some would enthusiastically recommend counselling to their friends -

> ***Mark:*** *'....I think that everyone should go....that's just my way of thinking of it because they'd be less people stressed out... they'd have someone to talk to and stuff like that' (385-387.*
>
> ***Linda:*** *'I'd probably say to her...how about don't you go and see a psychologist and they'll try and help you...they're always on your side' (363-364).*
>
> ***Alan****: '....if you need to talk to somebody it's good like' (317).*

2.4 Superordinate Theme 4: The Shadow of Authority

All participants were associated with learning disability services for many years and had internalised a model of relationship where they had a subordinate role. The final superordinate theme takes a macro view of participants' lived experience with authority and examines how these experiences may inadvertently have impacted on their counselling experience. It details the relationship models to which participants have been exposed and considers the role of staff in participants' counselling. Finally, these two dimensions are appraised in terms of their influence on participants' expectations of and experiences in counselling.

2.4.1: Theme (i): 'I wasn't allowed...'

Prior to counselling, all participants were immersed in various webs of relationships to which they alluded in the interviews. Prior relationships were particularly highlighted by Shane who spoke of his deep unhappiness with his current living situation. Having happily lived for ten years in a community Group Home (Smithfield), for unspecified reasons he was transferred into a campus setting. Although he expressed his upset and desire to move back to the Group Home or even to visit he felt unheard. When he finally visited his old Group Home he became emotionally overwhelmed and with great angst spoke of the close bonds he had forged with the Smithfield staff and how devastated he felt by the transfer. Having lost his father, mother and stepmother, the Smithfield staff were like surrogate parents. These vitally important relationships in Shane’s life had been severed without seemingly any consultation. He exuded helplessness and seemed powerless to influence the course of his own life which he perceived as totally determined by the management of his service. Similar passivity permeated his counselling where he felt unable to assert his right to seek a change of counsellor.

Like Shane, participants’ lived experience of significant relationships formed their background familiarity about relationships in general. These perceptions accompanied them, impacting the counselling relationship. It becomes important therefore to examine the landscape of their relationship maps which provided a template for expectations of the counselling relationship. Participants’ significant relationships were primarily subordinate/dominant in tone, whether with staff or family. Six participants lived in residential settings and were answerable to staff. All attended staffed day services, and were keenly aware of the power differential between staff and service-users. Paul ascribed a lot of authority to *‘the Boss’* while others clearly regarded the managers of services as having indisputable power. There is a strong sense that these adults lacked control of their own lives and were in submissive positions.

Two of three participants living with family viewed themselves as still in a 'childlike' role although they were adult men. Tom, living with his married sister, spoke of *'not being allowed' (108)* to do certain activities and gave a general sense of being over-protected. He depended on his sister for help when he showered *'...she brings my clothes....takes my clothes out of the bathroom....' (277)* despite appearing capable of doing this for himself. Interestingly, the focus of counselling was on increasing his independence. The theme of *'making my own sandwiches' (26)* ran through the interview, seemingly Tom's code for growing self-sufficiency and independence. Denis lived with his widowed father and impressed as childlike in the relationship, with his father doing all the cooking and housekeeping. This passivity was very evident in his counselling relationship and in the research interview. Of those living at home, only Alan had transitioned to a more adult relationship with his parents. He owned a car, giving him a level of independence significantly different from other participants. He had not told his parents he was attending counselling - '*And even my parents didn't know about it, I never told them about it' (96).* He felt entitled to privacy and had a mainstream lifestyle of going to pubs and nightclubs with his *'mates'* at week-ends. He aspired to a normal life outside of specialist services.

Although living in a Group Home, Jim returned to his parents every week-end and deferred to them for all decisions. At the preliminary meeting about participation in the study, he indicated he could not decide on participation without consulting his mother. Jim was thirty three years old and although an anxious man, was articulate and capable and yet needed his mother's permission to make a decision. Keith, the sole participant living totally independently, still regarded family as authority figures. A man of fifty, he *'wasn't allowed'* visit his terminally ill aunt in hospital.

In another vignette, he described his mother's anger when he accidently broke a glass and his feeling that *'....if I said anything back that I'd make it worse' (255).* Although upset by their interaction, he became child-like and did not assert himself. In day-to-day relationships with significant others, participants' lived experience was of subordination, passivity and deference to those perceived as authority figures. Many participants' initial view of counselling mirrored such relationships, imagining the counsellor would be another authority figure.

2.4.2: Theme (ii): 'Well they can't really force you'

In the journey to counselling, staff played a major role in the referral process. Only Keith self-referred, with the others recommended for counselling by staff. In the general population people normally self-refer for counselling. Even if occasionally counselling is recommended, it is usually the person's own decision whether or not to follow up. Encouragingly, all except Paul and Denis felt the actual decision to attend was their own even if the initial seed was planted by staff. However, this does not negate the influence of staff who play such a key role in the lives of service-users. Given the power imbalance inherent in the service-user/staff relationship, it is questionable as to the felt ability of participants to refuse staff advice. Power dynamics are often very subtle, impacting out of awareness. That participants were heavily dependent on staff was evident and it was primarily their staff who arranged initial appointments. Keith was the exception and his level of autonomy and independence was striking compared to the others. He lived alone in his own house and previously worked in open employment for many years. Although shy and timid, he participated actively in his local community and church. His knowledge of counselling came from a television programme -

> *'….Well, I'll tell you where basically I got the idea of counselling. I used to watch the television and you know the people in 'Fair City' would...em…go for counselling' (373-375).*

Keith's ability to be self-determining and autonomous may link to his independent lifestyle and previous experience in 'the normal world'. His autonomy emerged in relation to parental knowledge of his counselling. Talking about keeping his counselling private, Keith said *'I mean, ah sure I'm fifty years of age* (laughs) *and I can make my own decisions' (271).*

Many initially confided their problems to familiar staff but none alluded to family members or friends as sources of support, information or referral. Participants brought serious issues to counselling such as bereavement, relationship problems, anger issues, problems with alcohol, sexual abuse, increasing independence, bullying and sexual offending which none mentioned discussing with their families or friends. Indeed, reference to friends as supports was conspicuous by its absence. Alan, who lived at home, describing his state of turmoil prior to counselling, talked of *'....coming in from work I'd be mad and I'd be telling what was in my head to nobody like...' (76-77)* and of *'...pretending you'd be happy and not happy' (79).* Tom, who lived with his sister, hinted at over protection and was struggling to assert his independence. He attended counselling at the instigation of family and staff. Tom's interview and that of Jim showed the struggles of people who were vulnerable and suffered past bullying and exploitation and yet were striving for more independence and autonomy in their lives. It is understandable how family may want to protect and shield them from the hurt which more independence might inevitably bring. Relationships with family members can have a history, emotionality and complexity absent from the more neutral relationship with staff which may make confiding problems in staff easier.

Counselling is a private matter. Yet once counselling had commenced some (Robert, Linda, Mark and Paul) relied on staff to transport them to their appointments putting them in a dependent position where staff were aware of the minutiae of their counselling arrangements. Three other participants (Denis, Keith and Tom) were seen in their workplace which raises issues as to privacy and confidentiality. Keith mentioned how one of his workmates was curious and questioned him about his counselling session -

> *'There was a fella here now and he asked me where was I on a Friday and I told him it was none of his business what I was doing, that it was my own business I was looking after' (276-278).*

Keith could protect his privacy to some degree but others may not be so assertive and might feel coerced into revealing their counselling details to workmates and staff. Shane walked to his counselling sessions on the campus where he lived. Only Alan and Jim travelled independently to counselling appointments in a separate location from other activities in their lives. This raises questions as to whether participants had the necessary privacy and safety essential for effective counselling.

Most participants had little awareness of the 'etiquette' of counselling and were not in a position to address such issues, having to accept whatever was provided. They lacked the knowledge and power to assertively seek more appropriate counselling settings. Similarly in choosing counsellors, only Mark had a level of choice in selecting his counsellor -

> *'Well I did have a good choice in that….and I picked the person I wanted to have…either a male or female …you know what I mean…some people might feel more comfortable with a man, being a man or some people might feel comfortable with a female …it depends…and so I told the person who I wanted and stuff like that' (46-49).*

Due to past negative experiences with men, Mark requested a female counsellor. Being supported by staff to have active involvement in counsellor selection may have contributed to the strong therapeutic alliance he formed. This alliance enabled Mark to engage at a depth level in counselling and he impressed as utilising his counselling to successfully address complex life issues. Other participants had no choice and attended whatever counsellor was provided. Fortunately for most, the client/counsellor match worked, as they built sufficient rapport with the allocated counsellor to engage in the counselling work. The client/counsellor match was unsuccessful for Shane who did not request an alternative counsellor.

Staff tended to make initial appointments, perhaps because sometimes participants did not have the requisite skills. Of necessity, Robert's initial session was arranged as his speech was very indistinct and he would have struggled on the phone with an unfamiliar person. Mark described how his staff had phoned a Counselling Centre but then included and supported him to discuss his needs and preference with regard to a female counsellor. For Linda - *'Probably one of the house parents I'd say who arranged it I think' (106).* Alan's Manager made the appointment for his initial session which he attended independently. In fact he drove himself to the session in his own car. Yet, both Linda and Alan struck me as fully capable of phoning for their own appointments, perhaps supported with some prior rehearsal. The complexity and multi-layered nature of the participant/staff relationship is evident. It can be difficult to navigate between unavoidable dependency due to learning disability and control by staff in areas where participants are competent. A general theme running through interviews was of staff always being there in the background. Sometimes their interventions were necessary and helpful but I did wonder if at times they were assuming too much control and not allowing sufficient autonomy.

The support of staff, particularly in suggesting counselling and supporting initial engagement was important for participants to avail of counselling but there is a fine line between support and control.

2.4.3: Theme (iii): 'Afraid told 'Shut Up'

Two participants were apprehensive at initially meeting their counsellors, fearing that *'She might give out to me'* (Robert) or that *'she might be a bit strict like'* (Jim). These adult men, one in his 30's, the other in his 40's had an internal map of relationship analogous to parent/child interaction. They did not envisage themselves as equal and embarking on an adult-to-adult relationship with their counsellor. Both luckily overcome their fears and formed strong therapeutic alliances.

Initially Keith wondered about his counsellor - *'I really thought she was some kind of doctor, that she was going to do something to me' (224-225).* He was equating counselling with another familiar professional relationship, the doctor/patient relationship which has strong overtones of authority. He was anxious about counselling but his felt need overrode his hesitancy -

> *'Well I felt myself that I was down, that there was something wrong with me, that I needed someone' (193-194).*

Reflecting on his feelings about the self-initiated initial session, Keith was apprehensive and had misgivings -

> *'What was I thinking? Oh God, I was beginning to think that I was in trouble with her or something' (227-228).*

These qualms were despite the fact that he had sought the appointment and was an able, competent man. His statement is a poignant reminder of how subservient and vulnerable people with learning disability feel in situations with professionals, even counsellors. Participants were starting counselling with an internalized hierarchical relationship model. Not surprisingly, they expected the counselling relationship to emulate a similar authoritarian style of relating. Subservience and compliance were their coping mechanisms in approaching such a relationship. Although most people beginning counselling may have some initial apprehensions (as Linda did, saying she felt *'very nervous' (127)*) it is unusual to expect being reprimanded by one's counsellor. Jim worried that his counsellor might be *'strict' (98)* while Robert was literally *'feeling sick' (78)* that his counsellor might *'give out' (82)* to him. Such extreme level of fear and anxiety creates a barrier to trusting a counsellor and expecting to be treated as an equal.

The expectations of counselling advanced by Paul and Denis were even further along the authoritarian spectrum. Both were 'sent' for counselling for unspecified problems which they declined to discuss. It is possible they were unaware of or did not recognize they had problem needing addressing which contrasted markedly with the other participants' consciousness of problematic areas in their lives. Denis was evasive and Paul did not name the reason for his prolonged counselling. As the interview proceeded, I was more convinced that Paul's problem was around sexual offending although never articulated. His highly supervised living situation added credence to my suspicion. I had a similar sense about Denis, but no definite evidence. Both Paul and Denis seemed less able (or perhaps less willing) than others to verbalise their experiences unless around concrete matters. Although he may have initially gone for counselling under duress, Paul appeared to value the counselling experiences as helping him to *'get back to normal' (43).* He regarded counselling as part of his routine and gave no hint that it was coercive for him. The Manager *('The Boss')* of his service loomed large for him as an authority figure and he accepted without question that his manager and his counsellor communicated about his behaviour. When asked about this, his response was *'Feels good' (449).* The implication seemed that knowing he was under surveillance helped him in managing his behaviour -

> *'I…I…I'd say she….She'd* (his counsellor) *wait now to see will she hear anything from the …the boss again …and get back to her then again maybe' (443-444).*

Paul was in his 60's and lived much of his life in a large hierarchical residential centre. Although now living in the community, his years of institutionalisation inevitably impacted on how he experienced all relationships including with his counsellor. Paul demonstrated no awareness of being an agent of change in his own life and handed over total responsibility to his counsellor. He viewed himself as having *'a bad side'* and perceived counselling as -

> *'I knew someone was going to get me …back to the good one' (216)* and later he said *'….cause she kept at it and at it and at it until she got …had me back' (220).*

It was as though Paul viewed himself as a passive object needing to be moulded into a different shape by his counsellor. Like most relationships in his life, he viewed his counsellor as an authority figure, albeit benign, and was very alert to her symbols of authority such as her Diary, her two offices, her having access to Files about him, attending meetings about him and her filling in behavioural records about him. He did not regard the relationship as in any sense equal or collaborative and had no expectations of such.

Passivity was the defining element in Denis' relationship to his counsellor and he did not seem aware of having choice about attendance. His staff had told him to attend and although aware *'Well they can't really force you' (194)* he handed over all authority to staff and counsellor. He seemed to have no sense of agency in his life

'....like it be up to yourself?' (186). When asked about continuing in counselling, his submissively replied *'Sometimes she might want to see me' (175)* implying he felt no power in the decision. Although agreeing to participate in the research interview, Denis was unwilling to talk or open up. I wondered if he attended counselling with the same attitude i.e. outwardly compliant but resistant which would make a therapeutic alliance impossible. Both Paul and Denis were positive about their counsellors and attended regularly, suggesting that for them such subordinate relationships were acceptable and perhaps the only type familiar to them.

I have focussed at length on Paul and Denis as extreme examples of how the therapeutic relationship is impacted by the hierarchical relationship model that PWLD have internalised. Elements of the 'authoritarian shadow' were also evident to a lesser extent for other participants. There was passivity about their expectations of counselling, accepting whatever was offered without perceiving any power to shape it. This was especially evident for Shane, whose way of protesting was passive-aggressive in failing his last two appointments, effectively cutting his access to counselling. His passivity is understandable in the light of previous protests about his residential placement going unheard. His powerlessness about his life situation is evident in his comment –

> *'Sometimes I feel like going away to England and getting a job over there and .....if I could and never coming back' (248-249).*

By contrast, some participants had positive expectations of counselling and showed awareness that counselling was concerned with 'problems', 'helping', 'the self' and 'talking' and was a special kind of relationship. Linda had been referred by a Psychologist in her Day Centre and felt very positive believing '.....*it helps you with* *a lot of problems you have' (31).* Robert knew that counselling was *'talking about things and all that' (16)* and although anxious was willing to attend. While comfortable discussing some problems with his support staff, Mark expected counselling to give him something additional that wasn't available from frontline staff - *'Having someone outside of my everyday life is kinda helpful you know' (327-328).* He was cognisant that confidentiality with his support staff was not total and was aware that staff working on different shifts shared information thus limiting what was private and confidential. He was clear that *'there are certain things that I probably wouldn't say to them' (325).* Keith, Jim, Alan and Denis all mentioned confidentiality and privacy in relation to counselling which was very important to them. Jim was particularly anxious about confidentiality and in the interview needed extra reassurance that our conversation was private – *'I'm very nervous today because I'm afraid this might be repeated' (146-147).* His reaction demonstrates awareness that staff share and have access to an amount of information about service-users. This issue also arose with Linda who expected her counsellor to talk with her Social Worker and residential staff about matters raised in counselling. She did not regard this as negative -

> *'She'd even talk to my...my social worker or else my key worker or the staff who works with me in the house who might be able to sort it out for me' (36-37).*

Linda saw no problem with this breech of counselling confidentiality which might be indicative of how deeply she had internalised a paternalistic model of relationships. Both Keith and Alan had not told their parents (to whom they were close) of their attendance. Through-out the interview both made several references about their struggles to achieve independence and autonomy in other areas of their lives.

Participants did not take a majorly critical stance on their counselling. Apart from remarks on session length and slow pacing, none had openly negative comments and seemed surprised to be asked such a question. It was almost as if they felt no entitlement to be critical. Linda responded that her counselling experience was *'Perfect' (280),* while Robert's view was *'….it all helped me' (183).* When asked if their counsellor could have done anything more to help them, some responses were:

> ***Paul:*** *'Am….no, nothing' (354).*
>
> ***Alan:*** *'I don't know what…he's good anyways…for me anyways' (260).*
>
> ***Mark:*** *'Well, maybe just em…..I can't think….sorry…' (254).*
>
> ***Keith:*** *'No, I found….I find her very good, I don't see anything wrong with her' (518).*

The belief that they were consumers of a service, entitled to evaluate it critically and make suggestions for change did not seem to occur to participants and may be a further indication of a sense of subservience and subordination. Their lack of criticism may also be due to lack of skills and experience of evaluation. Of course, it may be that participants genuinely did experience their counselling as completely positive but the suspicion of passivity and compliance stayed with me.

3. SYNOPSIS OF FINDINGS

All except one of the ten participants experienced their counselling as positive. Most were very open and honest about their difficulties and described the sometimes overwhelming problems and emotions they struggled with which formed the backdrop to their counselling referrals. Several described how they experienced their emotions in an embodied way, causing them much stress. The majority were referred for counselling by staff working with them, with only one person self-referring. Most felt anxious and apprehensive about the prospect of meeting a counsellor for the first time and experienced the initial meeting as ‘strange’. Some feared their counsellors would be reprimanding and stern and were relieved to experience her/him as a normal ‘ordinary person’ who was ‘nice’. They subsequently developed trust in their counsellors and were thus able to explore important issues which had not been obvious as presenting problems. Participants experienced support ‘to tell their stories’ and feeling understood as very beneficial aspects of counselling. They also valued advice and guidance, talking about feelings and the educational components. Some found a directive approach to be very beneficial but also highly valued a supportive, non-directive relationship. Most professed satisfaction with their counselling experience and apart from minor comments on session length and pacing had no other negative remarks. Most would return in the event of further problems and would recommend counselling to friends.

All participants were service-users in learning disability services where they experienced themselves as subordinate in relation to staff and also to family members. Initially they brought this shadow of authority to their expectations of counselling, anticipating a similar type of authoritarian relationship. However, with support from their counsellors, most encountered a different type of relationship through their counselling experience which they greatly valued.

Chapter 5

Discussion

1. INTRODUCTION

1.1: Chapter Outline

A brief summary of the study findings begins the chapter. In keeping with the phenomenological spirit, the discussion aims to convey *'...a fascination with the uniqueness, the particularity'* of the findings, (van Manen and Adams, 2010, p.449), while relating to the extant literature in counselling and learning disabilities. Inferences from the superordinate themes will be considered and I will reflect on their implications for counselling practice, training and policy. The significance of the findings for learning disability services will be discussed and the study evaluated and critiqued against criteria for high quality IPA research (Smith, 2011). Finally, further research directions will be signposted with concluding remarks.

1.2: Summary of Findings

The study aimed to gain an understanding of adults with mild learning disabilities' lived experience of individual counselling. Ten adults with mild learning disability were interviewed and the data analysed using Interpretative Phenomenonological Analysis (IPA). Four superordinate themes emerged - Overwhelming Emotions, Trepidation to Trust, Helpful Aspects of Counselling and the Shadow of Authority.

2. OVERWHELMING EMOTIONS

'At the time I was really stressed
'I was thinking to kill myself'
'I gets lonely and I starts crying....I'm very easy to upset'
'I couldn't stop the crying, it was coming from the stomach'

It was very poignant to hear the level of emotional upset and suffering participants described prior to attending counselling. Several experienced deep emotional anguish and while some expressed their distress in words, others used bodily symptoms to convey their misery. Shane very ably articulated the depth of his grief, while Robert, with a speech defect and limited verbal communication skills, described the *'terrible pain in my tummy'* as how his emotional distress manifested. This belies the 'happy, carefree lives' myth of people with learning disability (PWLD) (Fletcher, 1993), concurring with established opinion of their equal and perhaps greater susceptibility to emotional problems (Kellett et al., 2003; Bramston and Fogarty, 2000).

The scarcity of research on the emotional lives of PWLD (Arthur, 2003) limits comparisons between the depths of present participants' expressed emotion with other studies. However, the interviews provided insight into the emotional lives of people with mild learning disability and the issues and challenges they faced which led to counselling. Of particular note was the paucity of supports in participants' lives apart from paid staff (Widmer, 2008; Robertson et al., 2001) which left them fairly isolated in coping with difficult emotions.

2.1: Embodied Emotion

An important finding was participants' experience of embodied emotion both prior to and during counselling. They struggled to cope with and articulate feelings which manifested in somatic indicators such as tummy pain, feeling sick, breathing problems, bodily tension and sleeping difficulties. Psychosomatic symptoms are a well established medium for communicating emotional distress (Kinnunen, Laukkanen and Kylma, 2010; Coughlin Della Selva, 2006; Lang, 1995; Lesse, 1979) but little recent research focuses on learning disability and somatisation (Matson, 1984b). Anger was particularly linked to somatisation and underlying issues needing addressing, specifically sexual abuse, bullying and relationship difficulties e.g. Alan's asthma attacks when he argued with his girlfriend, where anger sensations closed his airways leaving him unable to breathe. Robert linked his *'pain in my tummy'* with '*arguing with the lads'*, one of whom had sexually abused him. Somatisation was a strong theme for Robert and has meaning given his limited verbal ability and undisclosed sexual abuse. It was also his preferred language for communicating anxiety, as he felt '*sick in my tummy'* on initially meeting his counsellor. Jim's physical tension was likely related to anger from childhood bullying and Tom, another victim of bullying, had sleeping problems. Understanding the context provides meaning for these emotional reactions. Anger control has been noted as problematic in PWLD (Willner, 2007; Lindsay et al., 2004; King et al., 1999) but although numerous studies address anger management mainly from a CBT perspective, (Lishman, 2008; Rose, Dodd and Rose, 2008; Hagiliassis et al., 2005; Rose et al., 2005; Willner, Brace and Phillips, 2005) few explore underlying causes. Participants experienced strong emotions but it was extremely difficult for most to articulate these feelings. Moore (2001) believes that the emotional insight and understanding of PWLD has been underestimated and participants welcomed their counsellors' support to language their emotions as a first step in mastering overpowering feelings and making sense of their emotional reactions.

2.1.1: Non-verbal Communication: Counselling is dependent on self-expression but Upton (2009, p.30) reminds us that PWLD -

> *'.....may be unable to express their difficulties verbally, but these difficulties are both experienced and expressed by how they live their lives'.*

Participants' bodily reactions reflected an unarticulated inner state of turmoil and distress. Even with mainstream clients, psychosomatic reactions can indicate *'substantial impairment of communication'* (Lang, 1995, p.223) where the body expresses what is out of awareness and unsayable. The findings highlight the importance of attending to somatic symptoms as non-verbal communication. With verbal communication difficulties more prevalent in learning disability, participants' physical reactions were their best attempt at expressing feelings they struggled to verbalize (Rohajn, Rabold and Schneiderl, 1995) and counsellors need to be alert to such meta-communication. Recognising, naming and processing emotion are central in humanistic and psychodynamic counselling (Beail and Jackson, 2009) and emotion recognition and naming are prerequisite skills for CBT work (Hatton, 2002). However, counsellors may need to do some preliminary work before PWLD acquire this facility. Freud (1915) emphasised that psychotherapy is always concerned with affect and participants experienced deep emotional lives which needed support to be fully articulated and processed.

2.1.2: Somatisation as Defence: Participants' somatic reactions may have defended against feelings too difficult to process. An exploratory study by Newman and

Beail (2010, p.580) examined the defence mechanisms (which they define as *'....mental operations that remove components of uncomfortable affects from conscious awareness'*) used in psychotherapy by adults with mild learning disability. Denial, acting out and hypochondriasis were most commonly used. Although limited by small sample size and the instrument used to identify defences not tested previously with this population, the findings are suggestive that physical symptoms often express emotions which cannot be labelled and are difficult to accept and understand. Non-verbal mechanisms allow for indirect communication of matters too psychologically painful to express directly (Upton, 2009) -

> *'...sometimes only a non-verbal approach can deliver the information in a way it can be used, particularly when there is no conscious awareness of the underlying concerns involved'.* (Chused, 2007, p.879)

Somatic expression may have served a similar function for participants e.g. providing meaning to Robert's *'tummy pains'*, as he was unable to talk about his sexual abuse prior to counselling.

2.1.3: Emotional Intelligence: Noting the depth of emotionality that many with learning disability demonstrated and their difficulties in verbally communicating feelings, Stokes (1987) drew an important distinction between cognitive and emotional intelligence. The present findings around emotion link with recent research by Allan Schore, a major figure in establishing a neurobiological association for psychotherapy effectiveness. He has shown that *'the left and right hemispheres process information in their own unique fashions...'* with the right hemisphere being key to non-verbal communication and affect regulation (Schore, 2010, p.178). After decades of neglect and dominance by cognitive approaches, motivational and emotional processes are now taking centre-stage (Ryan, 2007). Schore (2005, p.841) believes that *'...the psychotherapy process is best described not* *as 'the talking cure' but as 'the communicating cure'.* He argues that a paradigm shift is occurring in psychotherapy from analytical, verbal, rational left hemisphere to integrative, non-verbal bodily-based emotional right hemisphere (Schore, 2011). He considers that the core of psychotherapeutic change is expressed in affective-relational processes rather than through verbal, conscious, cognitive insight, according with earlier psychodynamic views (Corbett, Cottis and Morris, 1996; Sinason, 1994; Stokes, 1987). This perspective links with the present findings of the centrality of emotions for PWLD and is heartening for counselling work in learning disability, as cognitive ability assumes less importance. It provides an explanatory framework of participants' bodily reactions as emotional communication and of their benefitting from counselling despite verbal limitations.

2.1.4: Attachment-based Therapy: Schore and Schore (2008) highlight the importance of attachment and the pivotal role of the therapeutic relationship for therapy effectiveness. This links with the pioneering work of the Tavistock Clinic based on attachment theory (Simpson and Miller, 2004; Linington, 2002; Hernandez-Halton et al., 2000; Sinason, 1992). Schore (2011) provides solid neuro-scientific evidence for the impact of early emotional transactions with the primary carer on the development of psychic structures (Schore and Schore, 2008), supporting earlier theorising by Sinason and other Tavistock psychotherapists (Sinason, 1992; Stokes and Sinason, 1992). Schore (2011) has demonstrated how attachment experiences shape the early organisation of the right brain which is central for emotional regulation, appraising other's emotions and managing stress. Given that the attachment experiences of some PWLD may have been fractured and problematic both in their families and services (Hodges, 2003; Sinason, 1992; Stokes and Sinason, 1992), it is not surprising that like the present participants, they would experience difficulty in expressing and regulating emotions. In addition to emotion as a core issue for counselling work in learning disability, the present findings highlight the importance of the therapeutic relationship as an emotional container and‘re-parenting’ opportunity. These were major aspects of what participants valued in their counselling experience.

2.2: Lack of Natural Supports

A significant finding, connected to feeling emotionally overwhelmed, was that participants’ lives were bereft of friends and social supports apart from paid staff (Robertson et al., 2001). Prior to attending counselling, several participants had confided in staff who worked with them. None talked troubling matters over with family or friends and did not refer to family or friends as sources of support in their lives (Widmer et al., 2008), although several had close family. Notably, only Alan specifically alluded to having friends and an active social life. However, his *‘mates’* were not confidantes. Only Shane hinted at feeling lonely which I found surprising. Since nine of the ten participants were male, this may link with research findings that men with learning disability were less likely than women to describe themselves as lonely (McVilly et al., 2006). Disclosing and discussing problems with friends is an important emotional support for most people (Stanfeld, 1999) but those with learning disability have fewer friends thus lacking this critical social support (McVilly et al., 2006; Jobling, Moni and Nolan, 2000). Lacking friends as confidantes leaves participants more vulnerable to becoming emotionally overwhelmed and stressed by problems. Friends take on *‘a counselling role’* at times of stress (Jobling, Moni and Nolan, 2000, p.237) and participants had major relationship vacuums (Bayley, 1997). This deficiency of natural supports magnified their isolation, creating greater dependency on paid staff in times of crisis life events.

2.3: Impact of Life Events

The findings are striking in the extent to which participants experienced their emotional distress as relating to upsetting events in their lives, giving their overwhelming emotions validity and meaning. Most research into the emotional problems of PWLD has been from a medical, mental health perspective highlighting presenting symptoms and diagnostic issues (Hurley, 2008; Hatton, 2002) without taking situational and life circumstances into account. Accepting that learning disability of itself brings increased vulnerability to mental health problems (Grey et al., 2010; Cooper et al., 2007a; Richards et al., 2001), the present findings highlight the importance of participants' lived experience in terms of problematic life events leading to counselling. Overwhelming emotions had meaning in their lives as they struggled with stressful life events such as bereavement, sexual abuse, bullying, relationship break-up and change. Having a learning disability is but one risk factor for emotional problems and life events emerged as a predictor of psychological ill health when eight other variables, including level of disability, were controlled (Cooper et al., 2007a). Stressful events associate with higher levels of emotional upset and physical illness in the general population (Paykel, 2001; Holmes and Rahe, 1967) and recent research in life events and learning disability suggests that PWLD experience more problematic life events then their non-disabled peers (Hulbert-Williams and Hastings, 2008; Cooper et al., 2007a; Hastings et al., 2004; Hatton and Emerson, 2004).

Participants were additionally contending with past institutionalization, powerlessness, repeated episodes of failure, unemployment and reduced opportunities for forming friendships and intimate relationships (Hall, 2010) and had awareness of the stigma of learning disability (Olin and Jansson, 2009). These are familiar issues in the lives of PWLD, having adverse impacts on psychological well-being (Dagnan and Waring, 2004; Jahoda and Markova, 2004; Caine and Hatton, 1998). Shane's powerlessness at being relocated to a new residence with loss of familiar staff caused him great distress (Mattison and Pistrang, 2004). The refusal by Keith's family of his request to visit his dying aunt seemed linked directly to his learning disability. Jim and Tom were victims of childhood bullying, corroborating research that bullying is more likely in children with learning disability (Mepham, 2010; Mencap, 2007). Two participants were sexually abused, an event more likely for PWLD (McCormack et al., 2005). Themes of powerlessness and lack of control have been reported in other studies in learning disability (Hoole and Morgan, 2010; McNally, Beail and Kellett, 2007) and are added stressors for this population. It was sobering to consider the myriad of painful life events and consequent unmanageable emotions with which participants were dealing and which propelled them to counselling.

2.4: A Myriad of Emotional Problems

Participants had experienced wide ranging life events leading to multiple emotional problems which had detrimental effects on their well-being. Some problems paralleled those in the general population (Hatton, 2002) but participants had additional troubles linked to disability, less effective coping resources and fewer natural supports. Most entering therapy in the general population are aware of a difficulty i.e. ‘the presenting problem’ (Stiles et al., 1990) whereas PWLD may have limited awareness and only vague understanding of the referral reason (Newman and Beail, 2002). However, most participants in the present study were conscious of presenting problems and understood the reason for referral to counselling (Merriman and Beail, 2009). When unclear about the reason for referral, clients tend to feel a low level of involvement in the process (Kilbane and Jahoda, 2011) which may have applied in Denis’s case. Awareness of a ‘presenting problem’ may link to cognitive ability and the majority of participants in the study seemed at the upper end of the mild range of learning disability thus demonstrating higher levels of understanding.

Participants’ level of emotional distress was considerable, to the extent that one had contemplated suicide. Suicides in learning disability are rare and mostly among those with mild learning disability (Patja et al., 2001), showing Alan’s desperation and degree of emotional suffering. Although their problems mirrored those in the general population, difficulties were exacerbated by their disability and lack of natural supports. Many had not received appropriate early support which might have ameliorated their distress which applied particularly around bereavement as related by Linda, Shane and Tom.

2.4.1: Grief and Loss: Eight participants dealt to some extent with grief and loss during counselling whereas only one had reported grief as a presenting problem. Their grief had apparently gone unrecognised (Blackman, 2008, 2003; Conboy–Hill, 1992), and may have contributed to later emotional difficulties (Dodd, Dowling and Hollins, 2005). Both Tom and Shane were treated for psychiatric problems with seemingly little attention given to their multiple bereavements. Yet, loss of significant people can lead to increased risk of additional problems for PWLD (Read and Elliott, 2007). Emotional and behavioural reactions to grief are often attributed to mental health problems, with associated depression and anxiety frequently treated through drugs rather than counselling (Grey, 2010). Traditionally, grief and loss were neglected in PWLD as they were considered incapable of experiencing grief (Dodd and Guerin, 2009). Carers and staff underestimated or ignored the impact of loss (Bennett, 2003; Oswin, 1991; Bicknell, 1983). The lived experience of the present participants demonstrates the importance of awareness of and attention to grief for psychological well-being. A wealth of literature highlights the importance of providing timely appropriate interventions around bereavement to prevent the development of pathological grief and long-term emotional problems (Clute, 2010; Grey, 2010; Boyden, Freeman and Offen, 2009; Dowling et al., 2006; Summers and Witts, 2003). Encouragingly, an Irish study found staff to be very positive towards supporting PWLD who had been bereaved, perhaps related to cultural factors around death and dying (Dodd et al., 2005).

Keith's exclusion from his terminally ill aunt had potential to lead to problematic long-term reactions. However, he wisely sought counselling. Being excluded from events prior to death and even from the funeral was historically common for PWLD and could lead to 'atypical' responses to bereavement (Raji, Hollins and Drinnan, 2003; Summers and Witts, 2003). PWLD are vulnerable to complicated grief, as multiple losses often surround the death of the significant person e.g. loss of home and way of life (Brickell and Munir, 2008) which applied to Shane who had many losses, unresolved grief and little support. As noted previously, there are likely fewer friends and natural supports to lessen the loss around bereavement for PWLD.

2.4.2: Relationship Difficulties: Relationship problems caused emotional distress to several participants i.e. Linda, Alan and Mark who had all lost significant intimate relationships. Jim desired a significant relationship but lacking the social skills had resorted to stalking women. Such issues raise important questions about the relationship and sexual lives of PWLD (Yacoub and Hall, 2009; Hall and Yacoub, 2008) and the level of support available to those in relationships (Munro, 2011). Participants had little assistance with interpersonal and intimate relationship problems leading to significant emotional distress (Kellett, Beail and Newman, 2005). An Irish study found that PWLD expressed a strong desire to experience an intimate relationship, had limited sexual knowledge and many barriers existed to a full sexual life (Kelly, Crowley and Hamilton, 2009). The present participants mentioned all these issues as important matters discussed in their counselling.

2.4.3: Sexual Abuse: Mark was a survivor of childhood sexual abuse and Robert was sexually abused by a fellow service-user. Both courageously disclosed to their counsellors, having carried the secret burden for many years which undoubtedly contributed to the mood problems, anger and frustration they experienced (Peckham, 2007; Sequeria, 2006; Sequeira and Hollins, 2003; Sinason, 2002). Sexual abuse is associated with a range of psychological problems in PWLD (O’Callaghan, Murphy and Clare, 2003; Sequeria and Hollins, 2003). That 20% of present participants experienced sexual abuse confirms its high incidence among this population (McCormack et al., 2005; McCarthy and Thompson, 1997).

2.4.4: Bullying: Jim and Tom experienced childhood bullying which possibly linked to their current social, emotional and behavioural problems (Mencap, 2007; Mishna, 2003) which in their cases contributed to over dependency on family, high anxiety and alcohol abuse.

3. IMPACT OF PAST AND PRESENT POWER RELATIONS

> *'I felt sick that she might give out'*
> *'She might be strict like'*
> *'I'd only make it worse if I said anything back'*
> *'Probably one of the houseparents who arranged it I think'*

Participants experienced high anxiety at the prospect of counselling, expecting a counsellor who would be a type of authority figure. They brought to the counselling situation a model of previous and ongoing relationships where they were in subordinate positions. Discussing how people with disabilities adopt *'the client role'* Peter (1999, p.812) believes that such a role can circumscribe relationships with other people. The term 'learning disability' can *'....freeze the individual in a position of inferiority and dependency...'* (Lee and Nashat, 2004, p.113). Although living in community settings, participants' main contacts and supports were staff who exerted strong influence on their lives. Participants were aware of their subordinate position in their social world in relation to staff and their families. Their lived experience was of inferiority, therefore their dependent behaviour was adaptive and meaningful for the environment in which they lived (Peter, 1999).

None mentioned having non-disabled friends who might have advised or advocated for them in accessing counselling, linking with studies highlighting that PWLD have none or few non-disabled friends (Partington, 2005; Robertson et al., 2001). Additionally, being reluctant to confide in their families created dependency on staff. The lack of egalitarian relationships in their lives probably impacted on their expectations of counselling to which they brought a subordinate/dominant model of relating, initially being fearful of the counsellor. The social context of participants' lives impacted on their interpretation of their world (Dagnan and Jahoda 2006; Peter, 1999). Most lived confined lives with limited exposure to new people, few outlets to gain information on services such as counselling and lacking a network of friends as sources of information and support (McVilly et al., 2006) relied heavily on staff.

3.1: Influence of Staff

All participants attended learning disability services and paid staff played a major role in their lives, offering a variety of supports - some lived in residential accommodation with house parents and all were assisted to some degree by staff in day programmes.

3.1.1: Support vs. Control: Although all but one participant lived in community environments there were hints that staffs' manner of supporting them had a flavour of paternalism e.g. Barry feared staffs' disapproval of his drinking, Shane's staff believed they 'knew best' about him visiting his previous Group Home. Similar interaction patterns are reported where service-users' views went unrecognised (Peter, 1999; Rapley and Antaki, 1996) or where they were *'shepherded'* to wanted responses which affirmed service philosophies (Jingree, Finlay and Antaki, 2006, p.223). The rhetoric of promoting autonomy and choice often does not translate to actual lived experience. Analysing staff/resident meetings in a community group home, Jingree, Finlay and Antaki (2006) showed how staff controlled interactions and how final decisions rested with staff. Such covert use of power can go consciously unrecognised by service-users as it appears benevolent (Watermeyer and Swartz, 2008). Participants' lived experience was of dependence on and deference to staff and such mind-sets transferred to the counselling situation e.g. Linda took for granted that her counsellor might liaise with her house parents. Although technically living in the community, Paul's lived experience was of limits and control (perhaps for the protection of the community) and a similar pattern emerged in his counselling which caused me to reflect on how counsellors sometimes collude with services in maintaining powerlessness. Even when community based, staff can bring the *'discourses of the institution'* with them, characterised by themes of protection, power and humanity (Hamlin and Oakes, 2008, p.49). In the institution, protection was for the person with disability but also the wider society which seemed the case with Paul. Power was one-sided, residing with staff, which was how Shane experienced his life. In terms of humanity, PWLD were not regarded as possessing the rich emotional life of ordinary people, a view debunked by the present findings. These same discourses can creep into community services where PWLD are protected from ordinary risks and staff struggle to find a balance between empowerment and protection (Hamlin and Oakes, 2008).

The present findings resonate with Peter's (2000) observation that PWLD are disenfranchised and lack choice, control and autonomy over their lives. They live in a world of power imbalance where they are *'...firmly under the control of professionals and other paid staff'* (Peter, 2000, p.354). A study of depression in PWLD found lack of control over their lives as the main concern raised by those interviewed (Lindsay, Howells and Pitcaithly, 1993). Feelings of unfairness and inequality were voiced by participants in a focus-group conducted by Hoole and Morgan (2010), resonating with Shane's feelings. In another focus-group study of service-users' views on mental health services, choice and control over their lives were voiced as what people desired (O'Brien and Rose, 2010). The present findings reiterate the importance for PWLD of having choice, control and autonomy in their lives, the lack of which impacts on their counselling experience.

3.1.2: The role of staff in counselling: Most participants were referred for counselling by staff, not having the requisite information themselves. Only one had self-referred, receiving his knowledge of counselling from a TV soap opera. Questions arise whether the ownership of problems rested with the staff rather than the person with learning disability (Willner, 2006) as sometimes the values and aspirations of the client can conflict with those of the referring party (Adams and Boyd, 2010). Whether the counselling process was explained sufficiently to participants to enable informed choice is questionable. The therapy role was not explained to 50% of PWLD referred to a psychologist (Willner, 2003). Some of the present participants attended involuntarily and we cannot assume the remainder were well informed as to what to expect (Willner, 2006). Denis and Paul were 'sent' to counselling by staff and although acquiescing, it was not their own initial choice. Staff organised initial counselling appointments, transport and accompanied some to all their counselling sessions. Perhaps this support level may have been necessary as *'...professional power can be exercised not only to people's detriment but also to their benefit'* (Gelb, 2000, p. 372). However, some participants were well capable of more active involvement suggesting staff may have assumed more responsibility than necessary (Peter, 1999).

3.2: Impact of Experienced Power Relationships on Counselling

Some participants brought a subordinate outlook to counselling, being fearful of the counsellor being stern and judgemental. In order to imagine and effect change, we need to know how power works (Watermeyer, 2012). Several participants were older men, who were long socialised into disability services, with the oldest, Paul and Shane, in their 60's. They knew their subservient place from many years in various institutions, had internalised their subordinate role (Danforth, 2000) and lacked an alternative model of egalitarian relationships to bring to counselling.

3.2.1: Expecting the Worst: Participants described high anxiety prior to their first session, perhaps reminiscent of previous relationships with those they perceived as 'professionals'. Underlying the anxiety may be fear of '*disablism'* by professionals where discriminative practices place further limits on psycho-emotional well-being (Reeve, 2004, p.85). They may have envisaged being treated less respectfully than the average adult (Chouinard, 1997) and lacking assertiveness skills may have feared complicity with *'oppressive relating'* (Watermeyer and Swartz, 2008, p.609). Unfamiliar with counselling and visualising the counsellor as an authority figure, some feared he/she would be reprimanding rather than benign. In an IPA study of six PWLD who underwent psychodynamic psychotherapy, clients were nervous and uncertain when they were unsure what therapy would involve (Merriman and Beail, 2009). Participants' anxiety in the present study might also link to PWLD generally having higher levels of anxiety (Reid, Smiley and Cooper, 2011; Douglas, Palmer and O'Connor, 2007; Dagnan and Jahoda 2006) which would likely manifest in new and alien situations such as counselling. Hagopian and Jennett (2008, p.468) define anxiety as *'...a constellation of responses that normally occur in the face of a potential threat'*. Participants experienced the counsellor as '*a stranger',* suggesting they viewed the counsellor and counselling as unknown and potentially threatening.

3.2.2: Lacking Self-Determination: Although 'oppression' may come from the social world, it has personal and psychological effects -

> *'Within the formative relationships of parenting and families, to institutional settings, cultural representations and interpersonal positionings, the disabled self is made'* (Watermeyer, 2012, p. 168).

Obviously, individual differences exist in how individuals configure their identity (Watson, 2002) and it is interesting to observe how the two oldest participants (i.e. Paul and Shane) presented as more lacking in self-determination than the younger ones in their 20's (i.e. Linda, Mark and Alan). This may reflect ideological changes in service philosophy with the embracing of self-advocacy and person-centred planning in recent years (Jukes and Bollard, 2003), which might impact more on younger service-users. Frosh (1991, p.2) sees the real persuasive power of the social environment as being the way *'....it enters unbidden and unnoticed into the foundation stones of our psychic structure'.* Paul lived for many years in a large institution and carried *'internalised oppression'* (Watermeyer, 2012, p.169) within him although now in a community setting. Shane described a circumscribed life where his wishes as to where to live and work seemed disregarded and *'...staff had the power to determine whose preference was legitimate'* (Jingree, Finlay and Antaki, 2006, p.224). Faced with such control, he adopted a passive orientation to his life and a similarly submissive stance towards counselling. Shane personified a *'personal experience of oppression'* (Reeve, 2004, p.84), leaving him docile towards his counselling thus undermining his emotional and social well-being.

4. COUNCELLING AS A SAFE SPACE

'She's very nice'
'I was able to talk to somebody who understood'
'She always gives me very, very good advice'
'She understands what you're going through'

Although normal to be apprehensive before engaging in counselling (Clarkson, 1989), participants needed to overcome intense anxiety to embark on the counselling journey. Initially they viewed the counsellor as *'a stranger'*, someone with whom they felt uncomfortable and needed time to trust. They accurately perceived the counsellor/client relationship as not being a usual social encounter, that although an intimate relationship, it was also artificial. It is enlightening to hear participants' views of what enabled them to feel safe in counselling.

4.1: The Therapeutic Relationship

The findings contradict past views that PWLD lack the emotional capacity to form a therapeutic relationship (O'Driscoll, 2009a) and conversely highlight participants' lived experience of the counselling relationship as the vital element to their satisfaction with counselling. As counselling progressed, all except one formed a therapeutic relationship, experiencing a space where they felt safe and free to confide their troubled selves. Perceiving their counsellors as *'nice'* and counselling as *'brilliant'* suggests positive evaluations of the counselling relationship and process. None reported difficulties around therapeutic boundaries, with none regarding the counsellor as 'a friend' as suggested by Jones and Donati (2009). The therapeutic relationship has been extensively researched in mainstream psychotherapy (Clarkson, 2003) where counsellor empathy, warmth and the therapeutic relationship consistently emerge as ‘the common factors’ correlating most highly with client satisfaction (Cutts, 2011; Lambert and Barley 2001). The therapeutic relationship has been virtually overlooked with the learning disability population (Jones and Donati, 2009) but some preliminary work suggests that similar therapist qualities and the therapeutic relationship are equally important for positive outcomes with PWLD (Strauser, Lustig and O’Donnell, 2004; Bihm and Leonard 1992). The experience of participants endorses this view. Indeed, for individuals having complex and long-term difficulties, such as PWLD, the therapeutic relationship may assume even more significance (Sanders and Wills, 2005).

4.1.1: Feeling Understood: Despite their anxiety and past experiences of subordination in relationships, participants persisted with counselling and highly valued ‘telling their stories’ and being understood by their counsellors. Since people with disabilities often live in *‘a world of unreal interactions’* (Watermeyer and Swartz, 2008, p.601), participants experienced great relief at being listened to and heard. They appreciated counsellors’ support in articulating their problems through judicious questioning and structuring of counselling sessions. ‘Talking as helpful’ similarly emerged as an important theme in another IPA study (Merriman and Beail, 2009). Similar to mainstream counselling, the present participants valued specific advice and guidance by the counsellor (Israel et al., 2008). However, it was vital that such guidance was given in the context of a supportive, empathic relationship. Counsellor interpersonal qualities and skills are major contributors to effective outcome (Bergin and Garfield, 1994) and similar to mainstream research (De Stefano, Mann-Feder and Gazzola, 2010), the present participants perceived their counsellors as embodying a threefold set of elements – human qualities, relational skills and technical ability.

4.1.2: Feelings Talk: Many participants expressed their emotional turmoil in an embodied way (Willner, 2005). They experienced it as helpful when counsellors assisted them to articulate their feelings and supported them to manage their emotions through directive means. While very helpful for clients to language emotions (McKenzie et al., 2000), itself therapeutic, some needed to learn specific skills to link emotions, events and thoughts (Joyce, Globe and Moody, 2006; Dagnan and Chadwick, 1997). The findings show that anger and anxiety were experienced as particularly difficult for participants and research indicates that PWLD may benefit from instruction in self-regulation techniques to manage such problematic feelings (Hagopian and Jennett, 2008; Rose, Dodd and Rose, 2008; Willner, 2007; Dagnam and Jahoda, 2006).

4.2: Absence of Criticism

The majority of participants positively evaluated their counselling experience and would recommend it to friends. They had few critical comments, similar to Merriman and Beail (2009) who reported a conspicuous absence of negativity by clients towards the therapy or therapist. They hypothesised that clients feared losing their therapy if they expressed negativity. My speculation from listening to the present participants is that lack of criticism connects to them having little familiarity with critical and appraising roles and believing that 'the professional' is above criticism which may relate with their experience of power relationships. Another possibility is since counselling provided experience of collaborative and egalitarian interaction, that they appreciated and enjoyed this novel and different relationship experience.

5. IMPLICATIONS FOR COUNSELLING PRACTICE

Participants' experience revealed several factors having importance for counselling practice with PWLD. Participants tended to somatise emotions, had difficulties articulating feelings and found affect regulation particularly problematic. They understood that counselling was about talking, experienced relief from relating their problems to a supportive, empathic counsellor and appreciated a level of guidance and direction. However, they had initial anxieties and apprehensions due to past experiences of power relationships. While participants' problems were similar to those of the rest of humanity (Jesper and Stapleton, 2005) they had added stressors due to disability issues of stigma, institutionalisation, restricted opportunities and dependency (O'Connor, 2001). In addition, they coped less effectively and lacked adequate social support networks (Jahoda et al., 2006). Five main implications for counsellors aspiring to work in learning disability emerged from participants' experience of counselling - the significance of emotion, the importance of the counselling relationship, awareness of power dynamics, recognition of the social context and flexibility of approach.

5.1: The Significance of Emotion

Participants revealed rich emotional lives but required their counsellors to facilitate their emotional expression and show awareness and sensitivity to the many non-verbal ways through which they communicated emotion. Counsellors working with PWLD need recognition of their own prejudices (Reeve, 2000) through regular supervision to ensure that they themselves do not underestimate the emotional lives of their clients. Arthur (2003, p.28) believes that reluctance to deal with emotional difficulties may -

> *'...throw up our own learning disability when confronted with complex behaviour that cannot be easily understood, communicated or treated in conventional ways'.*

PWLD are unlikely to spontaneously verbalise their emotions and will need encouragement from their counsellors to explore feelings. Counsellors should be comfortable and practiced in feelings work and competent in a variety of verbal and non-verbal means to explore emotional issues. Since somatisation was a strong theme for many, counsellors need alertness for physical manifestation of emotions. Psychosomatic symptoms may be the client's 'language' for emotions too complex or painful to express (Kinnunen, Laukkanen and Kylma, 2010; Newman and Beail, 2010; Lang, 1995). The counsellor may initially have to suggest appropriate words to model how emotions can be verbally expressed or alternatively use mediums such as art or drama. Many participants had difficulty in naming feelings and linking them to life situations implying that counsellors, irrespective of theoretical orientation, need to work specifically with PWLD in identifying and labelling feelings. Hatton (2002) identified ability to recognise different emotions as a prerequisite to engaging in CBT and specific training helping clients to link thoughts, feelings and behaviour has shown some success (Joyce, Globe and Moody, 2006; Oathamshaw and Haddock, 2006). The present participants experienced questioning as helpful and counsellors can facilitate linking events, thoughts and feelings through judicious questioning as a way *'to scaffold or structure sessions'* (Dagnan, Mellor and Jefferson, 2009, p.75). Participants particularly valued questioning in the early stages of counselling when they felt especially anxious. Supporting clients with reflection on events, considering alternative interpretations and taking account of wider contexts can also be helpful (Hebblethwaite, Jahoda and Dagnan, 2011).

As emotional regulation, particularly of anger and anxiety, was problematic for participants, counsellors need effective ways of helping clients with emotional self-regulation through knowledge of anger management approaches (Taylor, Novaco and Johnson, 2009; Rose, Dodd and Rose, 2008; Willner, 2007) and mindfulness techniques (Robertson, 2011; Kabat-Zinn et al., 1992). However, while techniques are helpful, participants' experience demonstrate that counsellors always need cognisance of underlying concerns impacting on clients' lives, rather than over concentration on symptoms and behaviours. Similar underlying issues such as low self-esteem, negative self-concept, negative social comparisons, feelings of hopelessness and poor social support found in people without learning disability can be identified in PWLD (Dagnan and Waring, 2004).

Issues particularly prevalent in disability such as stigma and discrimination (Jahoda and Markova, 2004) may underlie presenting symptoms and require naming by the counsellor. Hurley et al. (1996) consider that disability concerns inevitably arise during counselling work if the counsellor is sufficiently attuned and are likely to have strong emotional resonance. They believe that it is often through counselling that PWLD get their first opportunity to examine their disability and in fact that addressing the disability topic builds self-acceptance. Participants' experience reiterate previous research showing grief and loss as particularly salient issues for PWLD (McEvoy, MacHale and Tierney, 2012; Dodd et al., 2008). The findings strongly indicate that counsellors need vigilance to the possibility of other problems masking grief (Grey, 2010; Read, 1999, 1996) and be alert to somatic problems underlying grief and loss issues.

5.2: The Importance of the Counselling Relationship

Present findings support general psychotherapy research that irrespective of theoretical orientation, the counsellor/client relationship is central to a successful counselling experience (Elliott, 2008; Elliott and Friere, 2007; Clarkson, 2003; Lambert and Barley, 2001; Rogers, 1957). Participants were keenly aware of the interpersonal relationship between themselves and their counsellors, emphasising the importance of counsellors being *'friendly and nice'* and able to establish a collaborative relationship. Counsellor characteristics such as a friendly, empathic attitude, encouraging collaboration and ability to deal with hostility contributed to a positive working relationship in mainstream work (Roth and Fonagy, 1996) and participants' experience suggests are equally if not more important in learning disability work. The importance of a non-threatening, warm and relaxed demeanour cannot be over-emphasised and was reiterated several times by participants. This concurs with advice given in the Royal College of Psychiatrists Report (2004) on *Psychotherapy and Learning Disability.*

5.2.1: Awareness of the Non-Verbal: Counsellors need awareness that similar to mainstream counselling where clients scrutinize their counsellors and communication both verbal and non-verbal flows both ways (Manthei, 2007), a parallel scrutinisation was evident by participants in the present study. Therefore, counsellors need good interpersonal skills and awareness of their non-verbal presentation since non-verbal communication assumes even more importance when people are verbally challenged (Baikie, 2004). Considering Schore's (2010) research on the right hemisphere's centrality for psychotherapy work, impaired verbal communication assumes less relevance and counsellors need more attention to non-verbal communication, both the client's and their own. Non-verbal elements of counselling may be the most effective components and Linington (2002, p.412) regards *'attunement'* by the therapist as the fundamental part of effective working with PWLD. Building on the work of Stern et al. (1998), he asserts that the implicit non-verbal recognitions in the interplay between client and therapist *'....are the process of the therapeutic action'* (Linington, 2002, p.412).

5.2.2: Attachment Issues: Due to problematic early life experiences, such as non-acceptance or rejection, some PWLD may experience attachment difficulties and struggle with trust (Hodges, 2003; Sinason, 1992) and participants' experience reveals high apprehension at the prospect of attending counselling. Additionally, they had known the pain of stigma, ridicule, victimization and rejection (Willner, 2006). Counsellors must allow for these issues and the barriers they create in counselling work and be prepared to spend the necessary time in rapport-building. Accepting that some PWLD will have difficulties with trust and tend to compliance supports the counsellor in appropriate pacing and realistic expectations of rapport-building. In terms of trust-building, participants experienced initial structuring as supportive and helpful indicating that creating ambiguous opening moments through silence may be threatening and lead to increased anxiety.

5.3: Awareness of Power Dynamics

The counsellor/client relationship emerged as the most important element for participants' satisfaction with their counselling experience. Yet, several participants spoke of initially fearing that the counsellor would relate to them in a controlling and dictatorial manner. Given the pervasive authoritarian models of relationship experienced by many PWLD, it is imperative that counsellors not perpetuate such an interaction pattern. Counsellors need constant vigilance in their practice as Reeve (2000, p.682) warns that-

> *'Counsellors are subject to the same negative images and stereotypes of disabled people as the rest of society'.*

To engage in an egalitarian and authentic manner with clients, counsellors need a high level of self-awareness and constant scrutiny of their attitudes and behaviour towards their clients with learning disability. They need to reflect on their own reactions or in psychodynamic parlance, counter-transferences (Jones and Donati, 2009; Salvadori and Jackson, 2009; Simpson and Miller, 2004). Hodges (2003) cautions against the projecting onto the client of the counsellor's own weaknesses and disabilities and linking with this is the *'the disability transference'* where the client projects feelings onto the counsellor which are too unbearable to hold (Corbett, 2009, p.57). While present in all counselling work, these phenomena are likely to manifest to a greater degree in learning disability work due to the wealth of unexpressed feelings on both sides.

The findings indicate that counsellors need to be attentive to power issues which may be subtly at work in counselling sessions. The counselling process can be controlling as it is a *'social interaction'* which is *'rule-governed'* (Swain, Griffiths and Heyman, 2003, p.147). Counsellors should regularly check how the counselling session is being perceived by the client through seeking feedback. Shane was clearly unhappy with his counselling experience which seemingly went unnoticed by his counsellor. The lack of criticism of counselling in the study may signify that PWLD tend to compliance and passivity, acquiescing to those perceived as of higher social status (Heal and Sigelman, 1995) or they lack experience of their opinions being sought. The study highlights the ubiquitous presence of staff in the lives of

PWLD (Peter, 2000) and counsellors will need to reflect on its possible impact on the counselling process. Issues such as firm boundaries around confidentiality and self-determination will need discussion with clients to protect the integrity and privacy of the counselling space. Similar considerations are necessary where family members as caregivers are concerned. Counsellors additionally need regular supervision to examine their own motivations and reactions and develop awareness of their own power issues (Corbett, 2009).

The majority of participants felt satisfied with their counselling experience. They overcame their initial trepidations, felt heard and developed positive counselling relationships. This concurs with findings by Jahoda et al. (2009) where interactional analysis showed that verbal interactions in therapy with PWLD were not dominated by the therapist and power was evenly distributed. Although therapists asked more questions, questioning supported dialogue and encouraged the client to participate more actively in the therapy. According to McGowan et al. (2009, p.199), *'...power is relational, that is, power is constructed in social interchanges'*. Participants' experience suggests that counsellors in learning disability work bear the responsibility to create a climate of collaboration and equality in client/counsellor interaction.

5.4: Recognition of the Social Context

Findings support the importance of a social model approach as participants dealt with complex problems linked with their social situations which also connected to their disability e.g. Keith's experience around the death of his aunt and his lack of friends and social supports. In addition to relationship-building skills and effective strategies for particular problems, counsellors must be fully versed about the social context of the lives of PWLD (Jahoda et al., 2006; Reeve, 2004; Coles, 2001). The paucity of friends and other social supports emerged strongly in the study, similar to other research documenting the loneliness and isolation of PWLD (Lunsky and Benson, 2001; Robertson, 2001). Counsellors cannot assume their clients have outside support networks and may need to help clients address their relationship vacuums (Bayley, 1997). Being thoroughly grounded in the social model of disability is essential to provide depth of understanding (Barnes and Mercer, 2004) as the psycho-emotional impact of disability will need addressing in addition to specific 'presenting' problems' (Watermeyer and Swartz, 2008; Reeve, 2004, 2002; Hurley, Tomasula and Pfadt, 1998). Lacking this background, there is a danger of *'....oppression within the counselling room'* (Reeve, 2000, p.669). Ability to locate one's counselling theoretical perspective within the broader social and narrative lives of PWLD is critical for such work (Willner and Hatton, 2006). Hurley et al. (1996) believe that counsellors working with PWLD must adopt a strong rehabilitation approach, which involves acknowledging the disability while encouraging the client to appreciate and enhance strengths and positive attributes. Counsellors additionally require to be reflective practitioners and attend regular supervision so they acquire the -

> *'...capacity to process one's own complex, shameful and disavowed responses to disability.'* (Corbett, 2011, p. 285)

5.5: Flexibility of Approach

The findings intimate that flexibility in theoretical orientation and creativity in therapeutic technique are key factors to engaging participants and building rapport (Hurley, Tomasula and Pfadt, 1998). Counsellors need awareness that the cognitive and verbal resources of their clients must guide them at all times as the verbal skills of those with mild learning disability may range from very articulate to concrete and repetitive (Hurley et al., 1996). Participants valued structuring through specific questions in a supportive, non-confrontational atmosphere (Razza and Tomasula, 2005) and slower pacing, repetition of information and simplification of procedures were helpful (Dodd et al., 2011). Findings agree with the Royal College of Psychiatrists' Report (2004) advising counsellors to be friendlier and less rigid about boundaries. Participants valued counsellors who initially engaged in social chat as an overture to building rapport and whom they perceived as *'nice'*.

Counsellors need consciousness of their language use (Hurley, Tomasula and Pfadt, 1998). The verbal difficulties of some participants indicate that short sentences, simple language and *'checking back'* for understanding should be standard practice with this population (Razza and Tomasula, 2005, p.134). The intermittent checking for understanding is essential as PWLD tend to compliance, assume a false demeanour of understanding and are unlikely to interrupt or seek clarifications (Hurley, Tomasula and Pfadt, 1998). Bates (1992, p.83) recommends giving the initial stage of counselling plenty of time as engagement is *'....about finding the right level',* developing a dialogue and shared vocabulary of understanding. To summarise useful approaches: counsellors need to adapt their approach when working with PWLD through a friendly demeanour, using simple language, structuring initial sessions, having shorter sessions and pacing the session to the client's needs (Dodd et al., 2011). Aware of the primacy of the therapeutic relationship, counsellors need to regard a '*'tool-box of techniques and adaptations'* as a secondary means of enhancing the work (Hurley, Tomasula and Pfadt, 1998, p.374).

The findings indicate an advantage to an eclectic/integrative approach rather than a rigid, one-dimensional style. Many participants valued a directive style and appreciated at times being provided with advice, guidance and psycho-education, hence the requirement to tailor counselling approaches to fit clients' needs.

5.5.1: Non-Verbal Approaches: Participants' experience was that their counsellors used mainly verbal approaches, though they enjoyed non-verbal approaches such as drawing when used. Upton (2009, p.33) believes that counselling has become over dependent on verbal narrative and recommends incorporating more creative methods such as *'embodied expression'* which could involve whole person movement, dancing and music, art, acting, masks, role play and embodied games. Integrating such non-verbal approaches into their practice would be valuable for counsellors working with PWLD and expand their repertoire of tools. By placing less reliance on verbal articulation, non-verbal methods can provide greater flexibility and freedom for emotional expression.

5.5.2: Summary: Five major implications from participants' experience emerged which can usefully inform counselling practice:

- **The Significance of Emotions**
- **The Importance of the Counselling Relationship**
- **Awareness of Power Dynamics**
- **Recognition of the Social Context**
- **Flexibility of Approach**

6. IMPLICATIONS FOR COUNSELLOR TRAINING

Two participants obtained counselling from mainstream counsellors, the others were counselled by specialist clinicians in learning disability services. Yet, the majority of adults with mild learning disability live incognito in the community, suggesting that their counselling needs could best be met by mainstream counsellors. The findings reveal more similarities than differences between mainstream and learning disability counselling, especially for those within the mild range. However, Pattison (2005) reported that 62% of mainstream counsellors surveyed never counsel clients with learning disability and other authors indicate that mainstream counsellors feel inadequate in this area (Corbett, 2011; Mason, 2007).

> *'....becoming competent in treating people with ID should not be viewed as a prohibitively burdensome task'.* (Adams and Boyd, 2010, p.414)

From listening to participants' experience, indications are that a flexible, integrative approach is most helpful and elements from the main theoretical schools i.e. Humanistic, Psychodynamic and CBT have valuable contributions for this client group and need including in disability modules e.g. relationship building (Humanistic), attachment theory (Psychodynamic) and specific skills training (CBT). Since the counselling relationship emerged as a key element for successful counselling experiences, counsellor training needs to incorporate the newer findings in neuropsychology (Schore, 2010), as these provide a strong rationale for the use of counselling with this population, indicating that the affective elements of counselling are primary. The findings highlight how the context of participants' lives contributed to their problems, making it imperative that counsellors wishing to work with PWLD have knowledge of the social model of disability and disability issues (Coles, 2001). Additionally, the findings suggest that a systemic perspective could usefully be included in learning disability training modules, since many PWLD live and work in specialist services, are dependent on staff and are part of organisational systems which greatly impacts on their lives and well-being (Kaur and Scior, 2009; Baum and Lynggaard, 2006).

7. IMPLICATIONS FOR SERVICES

The study indicates that service-users valued counselling and recommend its availability for PWLD. In a British context -

> *'The reality remains however, that psychotherapy for people with intellectual disabilities is offered by a small and select group of clinicians......'*
> (Corbett, 2011, p.284)

Some Irish learning disability services provide a designated counselling service for service-users e.g. Brothers of Charity Services, Galway, while others provide some counselling as part of psychology or social work services. On the whole, generic counselling services do not provide for PWLD (Pattison, 2005) and many private mainstream counsellors regard themselves as neither knowledgeable nor adequately skilled in this area (Mason, 2007). Further research is needed on the optimal way of providing a counselling service to this population.

7.1: Access to Counselling

If we accept the opinions of PWLD as outlined in the present study, they perceive counselling as an important service which should be widely and easily available to them. Participants valued counselling which was user friendly and confidential. The Royal College of Psychiatrists' Report (2004, p.57-58) supports their views on accessibility, recommending counselling services in learning disability be needs based, focused on service-users, evidence based, co-ordinated, accessible, user friendly, safe and confidential.

In Britain, 'The Improving Access to Psychological Therapies' (IAPT, 2008) project is aimed at adults with anxiety and depression (Dodd et al., 2011; Beail, 2009) and in conjunction, the Positive Practice Guide for People with Intellectual Disabilities (IAPT, 2009) detailed how psychotherapy within this project should be adapted to PWLD. It recommended that their counselling/therapy needs be provided through primary health care facilities. However, there is little sign of implementation to date (Dodd et al., 2011). Irish services lag far behind in the inclusion of PWLD in mainstream counselling services. It is important that counsellors working with state-funded generic counselling services e.g. The National Counselling Service and other community-based counselling services develop the skills to recognise clients with mild learning disability and to up-skill on appropriate ways to work with them.

7.2: Provision of Information

Only one participant self-referred to counselling suggesting a lack of knowledge and information among service-users about counselling and its availability. Service-users should be provided with information and education about counselling through leaflets and brochures in easy-to-understand formats (Dodd et al., 2011). As many with learning disability attend education and training centres and sheltered workplaces, posters, informing of local counselling services should be displayed on Notice Boards. To counter literacy problems and increase familiarity, Information

Briefings about counselling services could be provided in these centres. Providing such information may encourage more independence in accessing services and less dependency on staff.

7.3: Raising Staff Awareness

Participants' experience highlights the important role played by staff in supporting access to counselling. Staff would benefit from education about counselling and its value and relevance in certain situations. Findings also indicate that the supports necessary around bereavement and the higher prevalence of issues such as bullying and sexual abuse need highlighting. Given their powerful position in the lives of service-users, it is important for staff to be reflective practitioners (Nugent et al., 2011; Finlay, Antaki and Walton, 2008) and have opportunities e.g. through supervision, process groups or training days, to consider their role in supporting service-users so as to encourage autonomy and self-determination and minimize control and dependency.

8. IMPLICATIONS FOR POLICY

The role of government is to ensure that sound policy and clear legislation is in place (Brown et al., 2011) and the 2008 United Nations Convention on the Rights of Persons with Disabilities places demands on governments to ensure equitable treatment for people with learning disabilities (Harpur, 2012). The findings of the present study have implications for policy in the area of learning disability. The findings show that counselling is clearly valued by people with mild learning disability and the evidence base is growing for its effectiveness (Willner, 2005).

The study findings indicate that counselling warrants inclusion in the array of services to meet the mental health needs of PWLD, particularly for those in the mild range. Given that the majority of people with mild learning disability are outside of specialist services, counselling needs to be more widely available and easily accessible through mainstream services. Indeed, *A Vision for Change* (2004), the most recent government policy document on mental health, recommends that the mental health needs of people with mild learning disability be provided through generic adult mental health teams. These teams are to be composed of a range of multidisciplinary professionals including counsellors. Counsellors on such proposed adult mental health teams would need up skilling in order to work effectively with PWLD and such services need to be more inclusive and accommodating to PWLD. The findings show the importance of seeking the views of PWLD and it is important that PWLD as consumers are consulted about all aspects of their service and have an input into government policy in the learning disability area (Royal College of Psychiatrists Report, 2004).

9. SOCIAL IMPLICATIONS

The study findings show that PWLD want above all, to live a normal life and be part of mainstream communities. They struggle to maintain positive social identities, sometimes at the cost of their mental health (Jahoda et al., 2011). Through self-advocacy movements they continue to fight to be treated with respect (McDonald, 2012) and to be heard when they say ‘Nothing about us, without us’ (Charlton, 1998). We need to continue to seek and listen to their opinions on all aspects of their lives.

10. STRENGTHS AND LIMITATIONS OF THE STUDY

The study set out to explore how people with mild learning disability experienced individual counselling and the meaning they constructed of it. It attempted to redress the balance in learning disability and counselling research by privileging the voices of service-users. As an advocate of right-based services I believe it is vital *'to ascertain the views, values and aspirations'* of PWLD to ensure services are responsive to their needs (Hoole and Morgan, 2010, p.6). The study succeeded in gathering the views of service-users, providing a valuable window into their lives and their counselling experiences. It counteracts the -

> *'...history of disabled people...* (which)... *is a history of being coerced into allowing others to define one's experience and hence oneself'* (Watermeyer and Swartz, 2008, p.609).

Few studies have been reported which sought the opinions of PWLD about their counselling provision. Therefore a strength of the study is its originality. Being based on a rigorous analysis of the experience of consumers, the nature of the study allows it to confidently advance ideas for improving the delivery of counselling to this population through the implications for counselling practice, counsellor training, services and policy outlined. Despite my 25 years working as a psychotherapist in learning disability, I was surprised at the centrality of emotion and how power relations impacted so majorly on participants' counselling experience. I found it sobering and humbling to hear the many difficulties with which participants struggled and have renewed admiration for their resilience and courage in the light of the adversities they face.

The study successfully utilised IPA showing its appropriateness as an approach for PWLD and adds to the body of qualitative work which is building in the area of learning disability. This phenomenological approach very powerfully accesses the experiences of peoples in their own words, treating them as experts on their own lives, something traditionally sadly lacking in the field of learning disability and accords well with the social model of disability. IPA also allowed for the social and cultural contexts of peoples' lives to be considered (Todorova, 2011), allowing a rich and nuanced account of participants' counselling experiences to be developed. Since IPA developed from psychology, it is more amenable to drawing on pertinent research and theory from psychology than some other methods (Howitt, 2010).

Although based on the experiences of people with mild learning disability, a further strength of the study is that the findings may apply to other marginalised and stigmatised groups such as those with long-term mental health problems, whose emotional lives are equally at risk of being discounted and whose dependency on services makes them also vulnerable to power relations issues. Further research is needed to confirm this view.

Participants felt free to express some negative comments on critical psychotherapy issues such as pacing of sessions, length of sessions and admittance of 'dropping out' of therapy which indicated that they felt comfortable in the interview. Given that the issue of power relations was a major superordinate theme, this is certainly an important strength of the present study.

As a small scale study with ten participants it is limited like all qualitative research as to generalisability. However, the aim was not to make generalisations but to open up this area to scrutiny and raise new questions, such as how the counselling needs of PWLD can better be met. A limitation is that the study sample were all associated with learning disability services yet the majority of people with mild learning disability do not access specialist services and there is no way of knowing whether a non-service community sample would yield a different viewpoint of counselling. However, such a group would be difficult to identify and source. The study sample had all engaged in counselling and so may have been more positive in their views than service-users who had dropped out or refused to attend in the first place. There is also the issue of using a 3rd party to make initial contacts with potential participants as they may have complied because of wanting to please the 3rd party. However, to counteract this difficulty, I reassured participants that it was totally their choice to participate and two potential participants did decline to continue. Six counsellors were involved with the ten participants which restricted the spread of counsellors involved, as two counsellors (Helen and Judy) worked with three participants each. It would have provided wider scope if more counsellors had been included. Counselling was defined in a broad manner, whereas focus on a particular counselling orientation may have provided different results. However, results from a recent IPA study on psychodynamic psychotherapy reported some similar findings to the present study (Merriman and Beail, 2009).

There is no guarantee that all participants were completely honest with me, as I had expected more critical comments about their counselling experience. They may have been compliant and pleasing and unwilling to relate unhelpful counselling aspects. Even Shane, clearly unhappy with his counsellor, found it difficult to express negativity towards her. Nine of the ten participants were male so the views of men are privileged in the study. Having a more balanced male to female ratio may provide a different overview of counselling experiences, although in mainstream counselling men and women respond similarly across different types of psychotherapy (Clarkin and Levy, 2004). The interviews were audio-recorded and given the finding of the importance of non-verbal communication in counselling work with PWLD, it would have greatly enriched the data if video recording had been used.

11. EVALUATION OF THE STUDY

For my overall evaluation, I will utilize quality criteria provided by Smith (2011b) who believes that issues of quality and validity need serious consideration by qualitative researchers and developed seven specific criteria against which IPA can be examined.

The study focused on a specific group of PWLD, those with mild learning disability and on one particular experience, that of individual counselling. There was specificity and **a clear focus** about the aim which allowed for clarity. All but one participant (Denis) clearly understood the purpose of the study.

Good quality IPA work is dependent on **strong data** derived from high quality interviews. From many years of working with PWLD, I had a familiarity with helping clients feel at ease and being a non-threatening presence. Despite my experience, I felt anxious at the initial interview which presented challenges due to the participant's severe speech defect. Overall, I believe that eight of the ten interviews were of high quality while I was less satisfied with my initial interview and the interview with Denis who was mostly monosyllabic. However, these interviews also illuminated a truth about counselling work with this client group which is often demanding and challenging due to communication problems and compliance issues.

I endeavoured in my analysis to have **rigour** through representing in the themes as many participants as possible and grounding themes in data from the interviews. Smith (2011) recommends that for samples greater than 8, there should be extracts from half the sample for each theme and my study meets that criterion with the superordinate themes as follows – Overwhelming Emotions (Robert, Linda, Mark, Alan, Jim, Keith, Shane), Trepidation to Trust (Robert, Linda, Mark, Alan, Jim, Keith), Helpful aspects of Counselling (Robert, Linda, Mark, Tony, Paul, Jim, Keith, Tom), the Shadow of Authority (Robert, Linda, Paul, Jim, Tom, Shane). I provided many extracts to illustrate superordinate and corresponding themes so as to demonstrate the richness of the data, its breadth and depth and also its representativeness. Extracts are given from every participant at some point in the analysis.

I provided a detailed **elaboration of each theme**. All four superordinate themes and the themes which are embedded in them are discussed at great length. I have constantly grounded all superordinate themes and corresponding themes in the data and indicated where I moved from descriptive to an interpretative stance. To ensure transparency, I provide a fully worked transcript of one interview (Alan) in Appendix J so that the reader can track the process of arriving at the superordinate themes and corresponding themes.

I endeavoured to be **interpretative not just descriptive**. Each superordinate theme has a level of description where I relayed participants' descriptions of their counselling experience and there is additionally an interpretative dimension where I have gone beyond the data to seek underlying but unarticulated meaning. In the Discussion Chapter, I have linked my interpretations to existing literature so as to minimize my own preconceptions. There was scope for a more interpretative stance in three of the superordinate themes, whereas one superordinate theme i.e. Helpful Aspects of Counselling has more of a descriptive flavour. In all interpretations I provided extracts from the data to support my explication thus providing transparency and plausibility.

My analysis includes both **convergence and divergence**. Initial analysis was immersed in each individual transcript before moving to consideration of the whole corpus of cases. Although common themes were identifiable, the individual was not lost and individual differences are highlighted throughout the study e.g. the difference in the perception of power relations between older and younger participants, the verbal eloquence of some participants and the struggle of others to verbalise, the negative counselling experience of Shane and the positive experience of others. I believe I remained faithful to the stories of participants and allowed their voices to be heard.

The analysis was **carefully written** with the goal at all times to faithfully report participants' views and meaning-making in a clear, concise and transparent manner which would make sense to the reader. My aim was to engage the reader so that he/she would connect with the lived experience of the participants and see the world through their eyes, emerging with an empathic and deeper understanding of the lives and counselling experience of people with mild learning disability.

12. FUTURE RESEARCH DIRECTIONS

The study showed that adults with mild learning disabilities' experience of individual counselling illuminate important facets about counselling with this population. The centrality of emotion and power relations emerged as key themes, and further research might usefully explore how power relations in counselling are experienced by PWLD. More qualitative research into the views of service-users is needed on e.g. life events, coping skills and perceptions of issues suitable for counselling. It would also be instructive to canvass their views on how counselling services could be more responsive to their needs perhaps through using focus groups. Other future directions for qualitative research in the area of counselling and learning disability might probe the experiences of counsellors who have worked with this population and compare their viewpoints with service-users' opinions. Although initially apprehensive at using IPA with PWLD due to their limited verbal repertoires, I feel it was ultimately very worthwhile, as it captured the reality of their verbal difficulties but allowed me to go beyond this limitation through its interpretative dimension. IPA has much to offer for research in learning disability and I would recommend further research using the approach.

More research is needed into the most appropriate styles of working psychotherapeutically with PWLD and it would be instructive to demonstrate the effectiveness of various approaches through randomised controlled trials (RCTs) though considerable obstacles exist to mounting such studies (Beail, 2010). It would also be valuable to ascertain the views on counselling of people with mild learning disability not associated with specialist services and the degree to which mainstream services and/or private counsellors could meet their needs. Accessing such a sample would prove challenging but might be possible through Employment Services such as FAS and health services such as GP's. The present study focused on people with mild learning disability but there is urgency to consider the counselling needs of those with a greater degree of disability through examining whether counselling services are appropriate and how best they could be provided to this population (Corbett, 2009; Hartland-Rowe, 2004; Simpson and Miller, 2004).

13. CONCLUSIONS

The present study explored the lived experience of individual counselling of adults with mild learning disability. Ten people were interviewed, told their stories with great poignancy and articulated, each in his/her way, how they experienced the counselling journey and the meaning they constructed of it. As all participants were associated with learning disability services, they had experienced a model of power relations where they were subordinate and they brought similar expectations that counselling would reflect such a dominant/subordinate model of relating. Starting from a place of fear and trepidation, they persisted with the voyage into the unknown and put their trust in the 'stranger' counsellor. They came to counselling with fears and anxieties, often expressed in an embodied way and struggled to articulate the difficult circumstances of their lives. They learned to navigate a different type of relationship as fortunately most encountered counsellors who were empathic and understanding and endeavoured to create egalitarian, collaborative relationships. Their counsellors supported them to tell their stories, affording great relief to most participants. The problems they presented were similar to those of the rest of humanity, but with additional stresses related to their disability. Having fewer friends and social supports and less effective coping resources left them heavily reliant on paid staff. Most participants were very positive about their counselling experience, would seek further counselling if necessary and would recommend it to their friends.

Participants' experience demonstrated that counselling is a valued and relevant service for PWLD and it is fitting that participants have the final words as their comments show empowerment, reflection, appreciation and impact resulting from their counselling experience -

Linda: *'I could see myself ringing her back and make an appointment to see her'*

Mark: *'It's always good to see someone outside of your own life like you know'*

Alan: *'It was good....if you need to talk to somebody....it's good like'*

Jim: *'I like going to counselling....it really helps me along the way.'*

Keith: *'I would have been upset if I didn't come...' (to counselling)*

It was indeed a privilege for me to hear about their journey and to be a witness to their empowerment, increasing confidence and growing sense of selves.

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APPENDICES

Appendix A: Interview Schedule

ID. Number: ________________

Gender: ____M _____F

Age: _________

Date started counselling: _______________________

Date finished counselling: ______________________

No. of Counselling Sessions: ___________________

Name of Counsellor: __________________________

Who referred for counselling: ____________________

Travel arrangements to counselling: ________________

Interview

Thank you very much for agreeing to take part. I would like to ask you about the experience that you had when you went for counselling.

Question 1: Could you tell me what it was like when you went for counselling?

Question 2: Who decided that it would be a good idea for you to go for counselling?
Prompts if necessary. (Was there something bothering you at that time? How much choice did you have? Who arranged the first session for you?)

Question 3: How did you find the first counselling session?
Prompts if necessary. (Do you remember how you felt when you met the counsellor for the first time? What did the counsellor do to make you feel at ease? Were you able to tell the counsellor what was bothering you? How did you feel at the end of the first session? Did you get a choice about whether to go back again or not?)

Question 4: What was the most helpful thing about going for counselling?
Prompts if necessary. (What parts of the counselling did you like best? What did the counsellor do that was most helpful?)

Question 5: Were there things about the counselling that you didn't like?
Prompts if necessary. (Did the counsellor do or say things that did not help you? Is there any advice you would give the counsellor about ways he/she could have helped you better?)

Question 6: Did the counsellor use drawing or anything else besides talking during the sessions?
Prompts if necessary. (Were these things helpful to you?)

Question 7: Could you tell me about the ending of the counselling?
Prompts if necessary. (Who decided when the counselling should stop? What do you remember about the last session? Do you remember what your feelings were at the end of the counselling?)

Question 8: When you look back now, what are your feelings about your counselling experience?
Prompts if necessary. (Would you go for counselling again if you had another problem? Is there anything else you would like to tell me about your experience in counselling?)

Thank you very much for talking to me. I very much appreciate it.

Appendix B: Initial Flyer

Research into experiences of Counselling

Volunteers Wanted

Have you been for counselling in the past year or two?

Would you like to talk in complete confidence to someone about what counselling was like for you and your views on counselling in general?

Kathleen FitzGerald, a Psychologist who has many years experience in learning disability is doing a Project and would be very interested in talking to you about your experiences of counselling.

Taking part in the project would involve a meeting of about an hour where you would be asked some questions about your experiences and views of counselling.

If you would be interested in taking part, please contact Kathleen on 087-3225812 and she will give you further information.

Appendix C: Information Sheet

Who I am

My name is Kathleen FitzGerald and I work as a Counsellor with people who have a learning disability. At the moment, I am doing a course at a University in Dublin called Dublin City University. I am doing a project on counselling and am hoping to talk to some people with a mild learning disability who have had counselling over the past year.

What this is about

I want to find out how people like yourself found counselling and whether you think it's a useful service. In this study I am trying to find out the things that make counselling a good experience for people like you, who have a learning disability and the things which didn't work so well. I hope to use the information gathered to make suggestions to Counsellors to help them to be able to give a better service. I would like to invite you to meet me to talk about your counselling experience. I am hoping to meet about 8 – 10 people altogether for the study.

I will go through this Information Sheet with you and then give you a copy to take away.

What taking part means

If you agree to take part in the study, you and I will meet privately for about an hour and I will ask you some questions. There are no right or wrong answers to these questions. What I am interested in hearing about is your experience of counselling. I will be using a tape recorder to record our interview so that I can listen to it afterwards and remember what we talked about. It will also help me to pick out the important points for my project. I will also take some notes while we are talking to make sure I really understand what you are telling me.

It's confidential

Our interview will be totally confidential in that no-one else will listen to the tapes or see the notes that I'll be writing. I will mind the tapes very carefully and lock them away so that no one else can listen to them. When the project is finished I will destroy all the information you have given me. I will destroy the tapes and all the notes.

Your name will not be written on the tape or on my notes. I will use a number so that I know which interview belongs to each person. When I am writing about the study your name will not be mentioned – I will use false names and change any information that might identify you so that it will not be possible to pick out what any particular person has said to me.

It's your decision

It is totally up to yourself whether you agree to take part in this study and even if you agree to be interviewed, you can change your mind at any time and decide not to go any further - you can just say 'I don't want to take part anymore'. Nobody will be annoyed or upset if you decide not to take part or to stop at any point. It is completely your decision as to whether you take part.

Support for you

In the interview I will be asking you to talk about your counselling experience and it may bring up some sad or upsetting memories. If this happens and you wish to have some extra support after the interview I will arrange for someone from your service to be available to talk to you. Before we start the interview, I will have worked out with you who you would like contacted if you get upset and need to talk to someone afterwards. For most people it is usually their Key Worker or a staff member that they know well and trust.

Staying Safe

If during the interview you tell me about bad things that have happened/are happening to you which mean you are not safe, I will need to pass this information on to the person in your Organisation who deals with safety issues for service-users. I will discuss this fully with you if it becomes necessary. This is because your safety is very important and I would want to be sure that you are safe.

Questions

If you would like to ask me any questions about this study I will be very happy to answer them.

I will contact you by phone in a few days to see whether you have decided to meet with me or not.

Appendix D: Consent Form 1

Do you understand what this study is about? ____________________________

Have you had a chance to ask questions and talk about this study? _____________________

Are you happy with the answers given to any questions you asked? ____________________

Are you happy to take part in this study? ______________________

Are you happy to have an interview about your counselling experience? ________________

Are you happy for this interview to be taped? _______________________

Are you happy for me to get some factual information from your counsellor if necessary (I have discussed with you exactly what information I need)? _________________________

Signing this form means that you are happy to take part in the Study with the above conditions and to be interviewed.

Participant's name: _____________________________

Participant's signature: _____________________________

Date: ________________

Witness: ______________________________

Appendix E: Initial Letter to Colleagues

Dear Colleague,

I am conducting Research into the knowledge and experiences of people with a mild learning disability of counselling, in part fulfillment for a Doctorate in Psychotherapy in Dublin City University.

I am seeking to interview adults with a mild learning disability who can communicate verbally and have undergone at least 5 sessions of counselling within the past 24 months. They may be in ongoing counselling or have finished their counselling.

I would be very grateful if you would pass on the enclosed Flyers to any person that you think might be eligible for the study. If a person has literacy difficulties I would appreciate if you would read the Flyer for them. It is important that people do not feel any coercion to participate.

If a person indicates an interest in participating in the Research, perhaps you might obtain their permission to pass on their contact details to me or suggest that they contact me directly on 087-3225812.

If you would like any further information please do not hesitate to contact me on the above number.

Thanking you for your co-operation,

Yours sincerely,

____

Kathleen FitzGerald

Appendix F: **Consent Form 2**

Research into Experiences of Counselling

I ________________ am participating in a Research Study on the experiences and knowledge of people with a mild learning disability of Counselling.

I give permission for the Researcher Kathleen FitzGerald to contact my counsellor _________________________ by letter to seek factual information on the six areas as outlined in the attached letter and I give permission for my counsellor to provide the information requested.

Signed: ______________________

Date: ______________

Witness:___________________

Appendix G: Letter to Psychotherapists/Counsellors

Dear __________

I am conducting Research into the knowledge and experiences of people with a mild learning disability of counselling, in part fulfillment for a Doctorate in Psychotherapy in Dublin City University. I am interviewing participants who have undergone at least 5 sessions of counselling within the past 24 months.

I have interviewed _______________ who has informed me that he/she attended you for counselling in the recent past. He/she has given me permission to contact you to seek some factual information which I require for the study. I would be very grateful if you would answer the following questions:

1) What is the theoretical model you use in your counselling/psychotherapy work?

   ____

2) Date when _____________ started counselling? __________________
3) Date when _____________ finished counselling? __________________
4) Number of Counselling Sessions attended? _______________________
5) Who referred ____________ for counselling? _____________________
6) How did _____________ travel to counselling? ___________________

I enclose a written Consent Form signed by ________________

Thanking you for your co-operation,

Yours sincerely,

____

Kathleen FitzGerald

Appendix H: Information about Participants' Counselling

Name	**Age**	**Length of interview**	**Number of counselling sessions**	**Name of counsellor**	**Theoretical orientation of counsellor**
Robert	42	18 mins.	11	Helen	Person-Centred +Anger Management
Linda	22	25 mins.	15	Helen	Person-Centred
Mark	27	31 mins.	28	Sheila	Humanistic
Paul	60	30 mins.	15	Carol	Person-Centre +CBT
Alan	23	18 mins.	6	Tony	Integrative
Jim	33	16 mins	68	Helen	Person-Centred
Keith	50	37 mins	12	Judy	Integrative
Denis	46	11 mins.	15	Judy	Integrative
Tom	47	27 mins.	25	Judy	Integrative
Shane	62	41 mins.	5 and 2 DNA's	Teresa	Positive Psychology + Mindfulness

Appendix I: Final List of Themes

Superordinate Theme 1: Overwhelming Emotions

Theme 1: 'At the time I was really stressed'

Robert: *'About problems with the lads and all that.....upset and all that..'* *(26)*

Linda: *'I had a lot of problems with my ex-boyfriend....'* *(95)*

Mark: *'I was having problems with my relationship and stuff like that with my girlfriend.....and there was a lot of stress in it'* *(9-10)*

Alan: *'I never felt like talking to nobody and then I started going for him a few times and then got mad and hit somebody at the end'* *(20-21)*

Jim: *'You see I have a drink problem.....I had a drink problem right..'* *(65)*

Keith: *'....my aunt passed away and I felt that I needed someone to see, to see someone'* *(66-67)*

Shane: *'I was really trying to sort out things. When he died I never cried in my life'* *(4 & 6)*

Tom: *'Somebody...years before Judy* (his counsellor) *came...someone was putting the knife into my dinner...yea' (62-63).* And *'...a lot of things was taken out of my bag'* *(67)*

Theme 2: 'They were like torrents flooding up and down your stomach'

Mark: *'Sometimes you em...feel crap and you don't actually know why ...'* *(283)*

Alan: *'I was just thinking to kill myself at one stage'* *(189)*

Robert: *'Terrible pain in my tummy'* *(26)*

Linda: *'Em....sad about different things.....that had gone through my life'* *(154)*

Keith*: 'Well I felt myself that I was down, that there was something wrong with me that I needed someone'* *(193-194)*

Jim: *'I followed a girl home once I did'* *(158)*

Shane: *'When I came in here, I was still crying'* *(40)*

Tom: *'You see I'm a fairly bad sleeper you know'* *(280)*

Paul: *'...maybe sometimes maybe a bit upset and ...things like that'* *(169)*

Theme 3: The Journey to Counselling

Keith: *'I didn't ring her, I saw her walking around the floor here...'* *(136)*

Alan: *'Yea, I had a choice about it'* *(90)*

Linda: *'Probably one of the houseparents I'd say who arranged it'* *(106)*

Jim: *'It was my own decision, I think:* *(74)*

Paul: *'The Boss said to me 'Would you like to go in and see Carol?'* *(118)*

Tom: *'...Mary D came down and asked us 'are you interested to see Judy'* *(46)*

Shane: *'....it was either Declan or someone around here'* *(23)*

Mark: *'Well I did have a good choice in that ...and I picked the person I wanted.. .'(46)*

Robert: *'The staff in the house'* *(29)*

Denis: *'Oh......* (long silence)*.....just asked to do it'* *(51)*

Superordinate Theme 2: Trepidation to Trust

Theme 1: 'Like talking to a Stranger'

Keith: *Em....I didn't really know what to say to her the first time I met her.. .she was a total stranger to me at the time...and you know yourself you wouldn't know what to say to a stranger' (186 -190)*

Linda: *'...it took me a few days to get used to her...'* *(116))*

Alan: *'Am.....kind of like butterflies in the stomach (laughs).* *(115)*

Robert: *'...........that she might give out'* *(82)*

Jim: *'I was a bit nervous I was, meeting her the first time...so'* *(94)*

Shane: *'I think there was so many things on my mind I didn't know who I was meeting. Just wanted somebody....wondering would you....would I get anyplace'.* *(144-145)*

Mark: *'I was a bit nervous 'cause she was a stranger you know but I felt upset myself. Em......I wasn't crying or anything...I was just.....felt upset in myself and ....It was a bit strange seeing a new person'.* *(97-99)*

Theme 2: Fear and Apprehension

Robert: *'I felt sick'* *(78)*

Linda: *'...very nervous.....cause I didn't know her'* *(127,129)*

Jim: *'I was a bit nervous I was, meeting her the first time...'* *(94)*

Mark: *'It was kinda hard like but it took me a while...'* *(115)*

Paul: *'....maybe a bit upset'* *(169)*

Alan: *'Well, I didn't like it at the time but...'* and *'Nervous I was'* *(14,117)*

Keith: *'I really thought she was some kind of doctor, that she was going to do something to me'* *(224-225)*

Theme 3: 'She's very nice'

Jim: *'……she's all right actually, like she's very nice, very understanding…so..'.* *(98-99)*

Alan: *'He made me happy so he did'* (181). And *'....he's a good person to talk to like'. (325)*

Linda: *'...she understands what you're going through'.* *(210)*

Mark: *'I'm not sticking up for her or anything…..it's just that I just found her really, really good like you know' (230-231).* And *'...I was able to talk out to somebody who understood like you know'.* *(194-195)*

Keith: *'Well I thought she was very chatty like and you know….and I just felt she was a normal person in the end to talk to'.* *(36)*

Tom: *'I like to see Judy'* *(431)*

Superordinate Theme 3: Helpful Aspects of Counselling

Theme 1: 'We got them out between us'

Tom: *'I told her about the robbing...'* *(194)*

Jim: *'It was good to get it out'* *(189)*

Linda: *'I told her what was bothering me'* *(137)*

Alan: *'I had a lot on my mind and I told him what happened'* *(173)*

Paul: *'Ah well.....some of it I was and some of it I wasn't'* *(156)*

Mark: *'...it can take an awful lot out of you'* *(132)*

Keith: *'....we got them out between us'* (296)

Shane: *'....'tis ruining your life....it's wrecking your life, crying like'* (58)

Theme 2: 'She understands what you're going through'

Robert: *'I could talk about my....about anything at all about me'* (75)

Mark: *'....I was able to talk out to somebody who understood'* (195)

Linda: *'She was...always there...she understands what you're going through'* (209)

Jim: *'Any problems I have, I can just tell her'* (232)

Alan: *'....was listening to me and he knew where I was coming from'* (121)

Keith: *'I found...I find her very good...'* (518)

Tom: *'I like...I like to see Judy'* (431)

Paul: *'...I knew she'd help to get me back..'* (204)

Theme 3: 'He told me what to do and I tried it out'

Alan: *'He told me to take deep breaths like and take a walk'* (218)

Jim: *'She'll just give me helpful advice straight away'* (234)

Mark: *'Well you know, she kinda gave me options of what to do and stuff like that'(103)*

Tom: *'Judy would help you out with it and help you advice and all that..'* (512)

Linda: *'...go up to my room and listen to some music ....'* (300)

Robert: *'Breathing in and out and all that...'* (245)

Paul: *'She said...' When you think of the bad thing, go into the kitchen and do something* (250)

Theme 4: Talking about my feelings'

Robert: *'...about my mood, angry and all that'* (154)

Mark: *'Sometimes you don't know how to explain something'* (282)

Alan: *'...sometimes I could wake up in the mornings and still I'd be mad like for no reason'* (222)

Linda: *'She talked about your feelings...'* (296)

Keith: *'I just felt I was in a bad way and that I needed to talk to someone'* (171)

Shane: *'Draw a happy face and a sad face'* *(451)*

Tom: *'Very lonesome you know'* *(490)*

Jim: *'Just to relax more I suppose and not be as tense like* *(107)*

Theme 5: 'She discussed what a proper relationship should be like'

Linda: *'...she had a book before her and we were doing about body parts..' (224)*

Alan: *'....you have to move on I suppose'* *(168)*

Mark: *'She helped me realise my relationship was stressing me out...'* *(232*

Jim: *'My drinking was about the most help...as even now I don't drink on a Sunday anymore'* *(141)*

Tom: *'About sandwiches and how to...how to do the house'* *(23)*

Theme 6: 'I'm happy in myself'

Linda: *'I felt happy...I felt everything was going ok and great and good in myself...'(336)*

Alan: *'....I'm happy in myself and if I need him again I'll use him again'* *(284)*

Keith: *'I was yea, satisfied yea'* *(597)*

Mark: *'...counselling is brilliant like. I think everyone should go'* *(385)*

Robert: *'Good...in myself'* *(281)*

Paul: *'I knew from the last session I knew she was getting me back on ..on the right way'* *(403)*

Tom: *'I like to see Judy come and talk to me and talk to Judy, you know...'* *(509)*

Jim: *'I really like going to counselling ...it really helps me along the way'* *(320)*

Shane: *'I found Dr. Ann Kelly was very helpful to me'* *(37)*

Superordinate Theme 4: The Shadow of Authority

Theme 1: 'I wasn't allowed...'

Jim: *'I'm very nervous today because I'm afraid this might be repeated'* *(146-147)*

Denis: *'Sometimes she might want to see me'* *(175)*

Robert: *'Afraid told 'shut up.....being nervous and all that'* *(202)*

Tom: *'I'm...I'm not sure with the cooker* (laughs)*....someone not allow me..'* *(108)*

Keith: *'....if I said anything back that I'd make it worse'* *(255)*

Linda: *'She'd even talk to my...my social worker or else my key worker or the staff who works with me in the house who might be able to sort it out for me'*
(36-37)

Alan: *'Well my boss said to go and talk about it.......and she arranged for me to go to a psychologist called Tony.* *(35-37)*

Paul: *'It had to come from Brenda'* (his Manager) *(69)*

Theme 2: 'Well they can't really force you'

Linda: *'Probably one of the house parents I'd say who arranged it I think'* *(106)*

Paul: *'She* (his Manager) *said.....she just said to me 'Would you like to go in and see Carol (*counsellor) *and talk about it to her'. I said 'I have no problem going in'.* *(118-119)*

Alan: *'I went to Mary* (a staff member in his Training Centre) *and we sat down and she arranged for me to go to a psychologist called Tony'.* *(36-37)*

Tom: *'Mary D* (a staff member) *came down and asked 'are you interested to see Judy* (his counsellor) *..........and I was interested to see her'.* *(46-47)*

Denis: *'Well they can't really force you'* *(194)*

Theme 3: 'Afraid told 'Shut up''

***Robert**: 'That she might give out'* *(82)*

Jim: *'Well I thought she might be a bit strict like...'* *(98)*

Keith: *'Oh, God, I was beginning to think that I was in trouble with her or something'* *(227-228)*

Paul: *'I knew when I was going to see her I knew she'd help to get me back.....back to the good side' (203-204)* and *'Am……I ...I...I knew she was going to get me back on the right track'* *(207)*

Denis: *'It would be hard to say 'No', it would be yes'* *(198)*

Mark: *'You're telling people your problems and stuff like that'* *(131)*

Linda: *'I decided....I thought it would be a great way of expressing your ..your problems'* *(66)*

Appendix J: Worked Example

Participant 4: 'Alan'

Date of Interview: 10/04/2011

Key: (As suggested by Smith, Flowers and Larkin, 2009 p.84).

Descriptive Comments = Normal text

Linguistic Comments = Italics

Conceptual/Interpretative Comments = Underlined

Emergent Themes	Original Transcript	Exploratory Comments
	1. I: Thank you very much Alan for agreeing to meet with me and as I explained to you, we are going to be talking about your experiences of counselling with Tony.	Setting the scene
	2. R: Yea.	
	3. I: And was it last year you saw him?	
	4. R: It was last year, yea.	Clarification of when Alan had his counselling
	5. I: And do you have any idea about how....how often you went?	

Short Term Counselling	**6. R: About 6 weekly sessions I think it was.**	Alan attended counselling for 6 sessions on a weekly basis.
	7. I: About 6 weeks....for 6 weekly sessions, right....and you're not going now?	
	8. R: No.	
	9. I: No...... you're finished your counselling now?	
	10. R: Yea.	He has now finished counselling.
	11. I: Ok. So........ maybe we'll start with me asking you what was it was like for you when you went.....you know, how were you feeling before you went for the counselling?	
Initial dislike	**12. R: Well, I didn't like it at the time but.......**	Indicates that he had a negative reaction initially to counselling.
	13. I: Yea?	
Need to talk Reluctance and ambivalence Counselling advised by staff No confidante	**14. R: .... I had to talk to somebody and I didn't have nobody to talk to so I guess...... so I talked to my counsellor from the course and she said 'Go and see what you like and think of it and you know see if**	Alan felt the need to talk to someone and went to his course advisor who suggested that he go for counselling. Alan appears to have been reluctant and ambivalent about going for counselling initially but was advised to do so by his course advisor. Alan was clearly feeling isolated as he indicates that he had no confidante.

	you're ok with it........see what the story is'.	Was Alan just being compliant by going to counselling to please his course advisor?
	15. I: Uh, uh. So there was something that was on your mind at the time?	
Withdrawn Anger and aggression Possible depression Bottling up feelings Physical violence	**16. R: Yea....I never feel like talking to nobody and then I started going for him a few times and then got mad and hit somebody at the end.**	Alan seems to have been quite withdrawn and angry at someone. He eventually hit someone (Was the 'someone' his best mate whom he talks about later). Was Alan depressed and what was his anger about? It sounds like he was bottling up some strong feelings and eventually exploded and hit someone. The word 'mad'is suggestive of a feeling of craziness and confusion in his head *Use of word 'mad' for anger*
	17. I: Yea, yea. So there were a good few problems that were building up for you........	
	18. R: Yea.	
	19. I: ......and you weren't talking to anybody at the time?	
	20. R: No.	
	21. I: Yea. And the counsellor up in..em.....up in em..... The Training Centre thought it would be good to meet with Tony?	
	22. R: Yea.	

	*23. **I:** And how did you feel when she said that to you..... do you remember how you felt?*	
Having a chat Sorting things out Relief got from talking Problems in his head Possible anxiety around counselling	**24. R: I felt good at the time so I went to see him to have a chat and he said 'Do you want to come again' and I said 'I might as well come again and sort out some things in my head'.**	Alan expresses relief at having someone to talk to and following the initial session he agreed to return to sort out some of the problems he was having. Alan is aware that some of his difficulties 'are in his head' and that he needs to talk them out with someone in order to 'sort out some things'. He shows awareness that talking is one way of dealing with problems. *'Having a chat' – is this how his Centre Advisor described counselling, as a way of making it less threatening for Alan who seemed reluctant and perhaps anxious at the prospect of counselling at first?*
	25. I: Uh, uh, great. So....em....and who decided it would be a good idea for you to go for counselling?	
Boss as authority figure Involvement of other staff Counselling suggested by others Staff control of referral process Passivity of Alan in referral	**26. R: Well, my boss X said to go and talk to Mary about it, if you had anything on your mind so I went to Mary and we sat down and she arranged for me to go to a psychologist called Tony.**	Alan's boss in the Training Centre was aware of his difficulties and suggested he meet with his Course Co-ordinator/Supervisor who referred him for counselling. How much involvement and choice did Alan have in deciding to attend counselling? From the way he describes it here, it would seem as if it was a decision made by the Supervisor who took the initiative in arranging the initial appointment.
	27. I: So it was Mary......	
	28. R: Yea, Mary Smith.	His Course Co-ordinator/Supervisor
	29. I: Yea, Mary who's the... .... she's your....Course Co-ordinator?	
	30. R: Yea.	

	31. I: So she was the person that thought it would be a good idea to see Tony?	
	32. R: Yea.	
	33. I: And you know when you think back, what was bothering you at the time Alan?	
Relationship problems Having a car – normal life Betrayal by best friend Confused telling of story may be indicative of anxiety	**34. R: Well I think the girlfriend and..... something that happened before like ....and I was looking out for her. We weren't going out at the time 'cause I met her once and the first time I kinda liked her and I was at home then and I had no car at the time...my car was in the garage and I went back to my mate.....and he was my best mate. And then we were going a week steady and they went up to the garage and then they got together like.......**	Alan indicates that it was a relationship problem that led to counselling. He gives a confused story that is difficult to follow. It seems that he met a girl and liked her for some time before he started 'going steady' with her and then his best friend went off with her. What is the relevance of Alan mentioning 'the car' and 'the garage'? Is the car a status symbol for him? There is no clear indication that issues such as the stigma of having a learning disability emerged in his counselling though they came up several times in the research interview. Alan's confusing telling of his reason for going to counselling may be an indication of anxiety at this early stage of the interview.
	35. I: Your best mate..... **(Yea)***...... went off with your girlfriend?*	
Excusing girlfriend Betrayal by best friend and girlfriend Suppression of feelings	**36. R: Yea. And he took advantage of her....she was drunk...** *(Yea)* **......and then my mate told me and I didn't believe her like and I**	Alan is describing being betrayed by both his best friend and his girlfriend which were issues he brought to counselling. Alcohol was involved. He did not attach any blame to his girlfriend but now finds it hard to trust her. He doesn't mention being angry at what happened. Does he suppress his feelings?

Breakdown of trust Query repressed anger	**didn’t want to cause trouble and I told her then and we had a chat and I took her back then. Anytime then she would go out with her friends and go out from college.....I didn’t trust her.**	Alan again used the term ‘a chat’ which may be a way of him minimizing his hurt and anger at her betrayal and his way of repressing his feelings. *‘College’ – Alan is implying that his girlfriend is in college. Does she have a learning disability?*
	37. I: Yea, yea....	
Upset and distressed Overwhelming emotion	**38. R: And then...then I was awful upset then like.**	Alan is now admitting to having been very upset by the double betrayal which undoubtedly contributed to his crisis leading to counselling. *‘awful’- strong word to indicate the depth of his distress.*
	39. I: So you were very bothered about all those things that were happening?	
	40. R: Yea.	
	41. I: Yea, they were difficult things.....	
Special girlfriend	**42. R: Yea....before like, any girls I didn’t mind but when you meet the right one......** (inaudible)..... **you know what I mean?**	Alan is saying he has had previous girlfriends but this girl was special. Alan is indicating a different type of attachment to this particular girl and his voice drops as he speaks suggesting a high emotional charge. *‘the right one’ – In Alan’s eyes there was something different about this girl. He is indicating that he is looking for a ‘special’ relationship.*
	43. I: So she was special......	
	44. R: Yea.	
	45. I: ....that particular girl?	

Accepted by girlfriend’s family Disappointment re future plan Going to England Death of uncle –grief and loss Distancing from learning disability	**46.** **R: I mean even the family liked me as well like. And then my uncle in England told me we’d be in England working together and he passed away then with cancer then like.**	Alan felt accepted by the girl’s family. He then brings in another issue: he had hoped to go to England to work with his uncle but he then died of cancer. The issue of ‘being accepted’ in the normal world seems important for him. Alan seems to be distancing himself from the world of learning disability and saw his future as being in England working with his uncle. Alan is describing a build-up of emotional problems which led to counselling.
	47. I: Oh, yea so that was another disappointment.....	
	48. R: It was yea.	Alan admits that his uncle dying was a blow to him.
	49. I: ......that you had. So you had your girlfriend letting you down **(Yea)** *and then your uncle dying* **(Yea)** *and that kinda was the end of that dream of going to England.*	
Dream of ordinary working life Grief re uncle’s death Normal social life Being pulled down Feeling overwhelmed	**50.** **R: Yea like, ‘cause we used to be working together and going out together and myself and my brother having a few drinks at the week-end and having the craic and everything so ..... that was pulling me down also like.**	Alan used to work with his uncle and then go out socialising with him and his brother at week-ends. He is grieving the loss of his uncle. *‘Craic’ – Alan is describing a normal social life for a young man of his age, going out drinking and having fun at week-ends.* Alan was feeling weighed down by the problems with his girlfriend and his uncle’s death. There is also the loss of his future dream of working in England. *‘pulling me down’ – is this Alan’s way of saying that he was feeling depressed?*
	51. I: Oh yea, so you were really feeling a bit down at the time **(Yea)** *before you went....*	

Continuing with usual life Bottling up distress Feelings of anger No confidante Sense of Isolation	**52.** **R: And then I wasn't.......I worked then like and coming in from work I'd be mad and I'd be telling what was in my head to nobody like......**	Alan had been keeping all his feelings of distress to himself. Alan was trying to continue with his usual routine but is admitting to feeling angry and bottling up his feelings. He is describing confusion and perhaps anger in his head but unable to confide in anyone which built up more pressure. *'mad' – Alan uses this word to indicate anger. Is he communicating that he felt out of control?*
	53. *I: So you were kinda going into yourself* **(Yea)** *and not talking to people at all?*	
Keeping up appearances Coping with major distress	**54.** **R: Yea, pretending you'd be happy and not happy.**	Prior to counselling Alan was trying to behave as normal, while in a lot of distress. 'Putting on a front' may be important for Alan in many areas of his life? Perhaps linked to his discomfort with a learning disability label.
	55. *I: Yea, Yea. That must have been hard.*	
Feeling better Life improving	**56.** **R: It's only....it's only lately it's only starting to getting good at work like, you know.**	Alan reports that it is only recently that he has begun to feel settled again at work. This suggests that he spent some time prior to attending counselling feeling very distressed.
	57. *I: Yea, yea. So that sounds like that you were really going through a lot of hard things at the time.*	
	58. **R: Yea.**	
	59. *I: Yea. And you know when Mary Smith said to you that it would be a good idea to go, did you feel you had choice, that you could say 'No', did*	

	you feel that you had a choice in the matter?	
Ambivalence re counselling Gave some thought to the matter Decision to attend counselling	**60.** **R: Well, at the time I said 'Will I go, will I not go' so I said that I might as well go.**	Alan gave the matter of whether to go for counselling some thought and finally decided that he would go. He sounded unsure as to whether he would try counselling. Ambivalence possibly linked to anxiety.
	61. *I: Uh, uh. So you had a choice?*	
His Choice to attend Counselling	**62.** **R: Yea, I had a choice about it.**	Alan is clear it was his choice to attend counselling.
	63. *I: You could have said 'No'.*	
Did not feel coerced	**64.** **R: I could have said 'No'.**	He is aware he could have declined counselling. Yet when recommended by his Manager and Supervisor, how free was he really to decline?
	65. *I: Yea, but you didn't you know...you took... that was a big step to take and you went.....*	
Awareness of needing help Sense of Desperation	**66.** **R: Yes, it was the only way to find out what was going on so I said 'I'd meet you today'.**	Alan was aware that he needed some help and decided to meet the counsellor. <u>Alan shows awareness that he was not able 'to find out what was going on' for him without the support of another and did not have friends in whom to confide.</u>
	67. *I: Ok.*	
Parents not told Possible stigma Privacy and issue	**68.** **R: And even my parents didn't know about it, I never told them about it.**	Alan kept the fact that he was attending counselling from his parents. <u>Did Alan feel a sense of shame or stigma about counselling? He clearly wanted to keep it very confidential and private.</u> <u>Was this him wanting to be an adult and have an independent, autonomous life?</u>
	69. *I: You never told your parents you were going?*	

	70. **R: No.**	
	71. *I: Right. And you know I mean, you're an adult so it's.....you can make your own decisions.*	
	72. **R: Yea.**	
	73. *I: Yea. So really this was kinda something you made up your own mind to do* **(Yea)** *without telling your family at all?*	
Importance of confidentiality Independent decision-making	**74.** **R: Yea.**	Alan made the decision to attend counselling himself and felt entitled to keep the matter entirely private.
	75. *I: Yea, so that was a really big decision wasn't it?*	Alan is showing a high level of independence in terms of decision- making. How usual is this in persons with learning disability? This seems to tie-in with other indications of how he wanted an independent life.
Sense of Autonomy	**76.** **R: It was, yea.**	
	77. *I: Yea. And who arranged the first session for you?*	
Involvement of staff – first appointment Staff control	**78.** **R: Mary, Mary Smith.**	Alan's first appointment was made for him by a staff member. Alan impressed as very capable and perhaps could have been supported to make his own initial appointment.
	79. *I: So she rang up the counsellor and arranged.........*	
	80. **R: Arranged to meet up.**	*'meet-up' has a flavour of casual, like as though it was a friend.* Is this Alan's way of 'normalising' or destigmatising counselling?

	81. I: .....the first session.	
	82. R: Yea.	
	83. I: An em...... did you go yourself.....for the first session or did somebody go with you?	
Independence and Autonomy	**84. R: I went myself.**	Alan went by himself for his first counselling appointment. Alan is demonstrating a high level of independence.
	85. I: And what was that like walking in the door?	
Initial Anxiety Physical sensations of anxiety	**86. R: Am....kinda like butterflies in the stomach** (laughs).	Alan felt anxiety prior to his first session. He describes his anxiety in an embodied way
	87. I: Yea, I can understand that..... so you were a bit nervous?	
Anxiety and Nervous	**88. R: Nervous, I was.**	He admits to being nervous.
	89. I: Yea, yea. And so you felt.....so when you met Tony for the first time, do you remember how you felt?	
Feeling Depressed Feeling Listened to Feeling Understood Advice and Guidance given	**90. R**: **I was kinda down at the time, when I was talking to him and he was listening to me and he know where I was coming from and he told me what to do and I tried it**	Alan felt ‘down’ when he went for his first session. He recalls the counsellor as listening to him and understanding him. He also indicates that he got some advice and guidance which he tried out. However, things did not improve immediately. Counselling does not provide instant solutions – is this what Alan is implying when he says that ‘things went downhill again’? Does Alan see the counsellor as someone

No immediate cure Ups and downs	**out...and I was working at the time and next thing things went downhill again....and so on like that.**	who provides advice and answers? Alan is showing a lot of insight about his mental state at the time.
	91. I: So.... you were a bit anxious at the beginning and when you went in you were a bit nervous, butterflies in your stomach and what did he do to make you feel at ease?	
	92. **R: He said that...**(inaudible)......	
	93. *I: Sorry, could you say that again.*	
Counsellor Support Counsellor Encouragement Anger management techniques	**94. R: He told me that whatever was on my mind to say it out like and ....he'd tell me what to do like if I got mad like........ and that.**	The counsellor invited Alan to talk about his concerns and that he, the counsellor would help him to learn to manage his anger. Support to 'tell his story'. The counsellor's support in helping him to open up was helpful and Alan seemed to value a directive approach.
	95. I: So he kind of gave you guidance?	
Embodied Emotion Asthma linked to anger Problem expressing anger	**96. R: Guidance yes, and plus I have asthma....and me and my girlfriend........and every time me and my girlfriend were fighting or arguing, my asthma would build up and I couldn't breathe or nothing like.**	Mentioning the word 'mad' brings Alan to talk about his asthma so he seems to be linking asthma and anger. Alan is linking his asthma attacks with arguing with his girlfriend. Alan seems to have had difficulties in expressing and managing his anger. It emerged in an embodied way through asthma attacks. Are people with learning disability more like to express feelings in a somatic way?
	97. I: Oh, gosh, so that was a big	

	problem then?	
	98. R: Yea	
	99. I: So it was almost like that it all became too much for you.	
Out of control Anger	**100. R: Yea, too much ....and I couldn’t breathe.**	When he would get angry, Alan was unable to breathe due to an asthma attack. Alan’s anger became ‘too much’ to handle cognitively and needed physical expression.
	101. I: And did Tony help you with that?	
Counsellor Support - Directive	**102. R: He did, yea.**	Indicates that his counsellor helped him to manage this problem.
	103. I: And what did he suggest for that?	
Anger management techniques Directive approach	**104. R: He told me to take deep breaths like and cool down and take a walk...maybe outside and come back in and talk to her..... and maybe take your inhaler if you have to need it at the time.**	Alan describes the techniques the counsellor suggested to manage his anger and thus control his asthma attacks. The counsellor also gave practical suggestions such as using his inhaler. Teaching simple practical techniques may be more effective with people with learning disability rather than a more non-directive, exploratory approach by the counsellor.
	105. I: So all that was helpful?	
Directive approach experienced as helpful	**106. R: Yea.**	Alan indicates that he found the counsellor’s approach helpful.
	107. I: You found that very helpful.	
Relationship Education	**108. R: And then if she was going with her mates......‘you go with your**	Alan learned to allow his girlfriend her space with her friends and for him to have time with his friends.

	mates and I go with my mates tonight' ...and that.....	The counsellor appeared to give Alan help with conducting a relationship and yet living his own life.
	109. *I: You'd say that to your girlfriend.....She go her way* **(Yea)***.....and you'd go your way....*	
Taking responsibility for others Difficulty staying with own feelings	**110. R: .....my way tonight and** (inaudible)**....and say 'Are you ok' and she'd say 'I'm ok' ......that's all .... and just you know be happy like.**	He seems to be taking responsibility for his girlfriend by checking if she is ok. Is Alan finding it difficult to focus on himself and his feelings? Regulating his own emotions seems problematic maybe due to his over involvement with his girlfriend.
	111. *I: Uh, uh.*	
Relationship Issues Frustration Relationship break-up	**112. R: So now I was happy for a few months and then says she... she wants to break up... she says there's too much on her mind ....and then broke up.... then she wants to get back together...... and to my telephone message if we're ever going to get back, she says 'maybe' so I felt I wasn't happy then........and we stayed friends then so we did.**	Alan's girlfriend broke up with him and then shortly afterwards wanted them to get back together. She then seemed to keep him on a string Alan's girlfriend seems to have her own issues ('too much on my mind'). Alan comes across as passive in the relationship and more focused on her needs then on his own needs and feelings. Alan never clearly indicates what he thought of this situation which must have been very frustrating for him and may have contributed to the problem with anger he brought to counselling.
	113. *I: So you stopped being boyfriend and girlfriend?*	

Anger Powerlessness	**114. R: Yea, we stayed friends and I was kinda... kinda mad then and I said ‘please get back’ and..... no and then......**	Alan wasn’t happy about them being ‘just friends’ and wanted to get back into a romantic relationship. Alan appeared to have little power in this relationship as his girlfriend is the one making all the decisions. *‘mad’ – Alan is here implying that he was angry the way things turned out with his girlfriend.*
	115. I: Um.....	He never articulates his feelings of powerlessness apart from briefly mentioning ‘being mad’.
Adjusting to relationship break-up	**116. R: And after a while then I was kind of....I seen her......if I see her on the road I wave to her and talk to her and she talk to me and ....**	It took some time for them to re-establish a friendship, where they can talk casually to each other. What Alan is describing is a very normal process of a relationship break-up where the decision to break up is not mutual.
	117. I: So you’re friends now **(Yea)***... but not boyfriend and girlfriend anymore?*	
	118. R: No, no.	
	119. I: So it’s finished.	
Relationship over	**120. R: Finished now, yea.**	Alan confirms that the relationship is now finished.
	121. I: And how are you about that now?	
Adjusting to relationship break-up	**122. R: I’m ok now....you have to move on I suppose.**	He indicates albeit reluctantly (‘I suppose’) that he is in the process of ‘getting over’ the break-up. The break-up was clearly not Alan’s choice was connected with his anger.
	123. I: Yea, so you’ve kind of adjusted to it.	

	124.	**R: Yea.**	
	125.	*I: And you know when you met Tony for the first time, how.....how easy or difficult was it for you to tell him what was bothering you.....you know when you sat down in the chair?*	
Awkwardness and embarrassment Coping with a lot of problems Encouraged and Supported Feeling heard	**126.**	**R: It was awkward what to say like and ...I had a lot on my mind and I told him what happened and..... he was happy for me to say it.....what I had to say.**	At his first counselling session Alan says he had a lot on his mind and perhaps was not sure where to start. *'awkward' – perhaps indicating unsureness, embarrassment at beginning to discuss his problems.* Alan indicates he felt heard by the counsellor, whom he perceives as supportive of what he had to say.
	127.	*I: Uh, uh ok. And how did you feel at the end of the first session?*	
Relief Enthusiastic to return	**128.**	**R: The first thing I said was 'I have to go again like', you know.**	Alan decided to go back again for further counselling sessions. Alan seems to be implying a strong sense of relief following his first session and a keenness to return. This is in marked contrast to his initial ambivalence around counselling.
	129.	*I: Yea, yea you wanted to go back.*	
Own choice to return	**130.**	**R: I wanted to go back, yea.**	He made the choice to return to counselling.
	131.	*I: And how did you feel.... say after telling Tony the things that were on your mind...say when you were walking out the door, how were you feeling?*	

Satisfaction with counselling Relieved and Happy	**132. R: He made me happy so he did.**	Alan was clearly very satisfied with his first counselling session and is implying that it was a great relief to finally talk to someone about what was 'in his head'.
	133. I: Yea, you feel a bit happier **(Yea)***.... walking out the door....and it was your own decision.....*	
Autonomy	**134. R: .....yea, my own decision.....**	Alan decided to return for further sessions.
	135. I: .....to go back again **(Yea)....***to go back again the next time. Ok. And Alan, what was the most helpful thing for you about going for counselling?*	
Dangers of not talking Bottling up feelings Feeling overwhelmed	**136. R: Well, I didn't talk to nobody 'cause..... something might have........might bad have happened to me if I didn't go and talk to anybody.**	Alan was keeping all his problems to himself and was aware that was not a very healthy thing to do. Being able to talk to the counsellor was very important for him. The link between bottling up problems and suicidal thoughts is clearly brought out by Alan here.
	137. I: Yea, what kind of bad thing might happen to you?	
Suicidal thoughts	**138. R: Well.... I was just thinking to kill myself at one stage.**	Alan admits to having had suicidal thoughts. He had felt so desperate that he had actually contemplated suicide.
	139. I: Were you?	
	140. R: Yea.	

	141. I: Oh gosh. So really you were feeling very down in yourself **(Yea)***.....so if you hadn't gone for counselling you think you might have done something.....*	
Suicide as an option	**142. R: .... Something wrong yea.....**	Alan admits that if he had not gone for counselling that he might have gone on to attempt suicide. This highlights the importance of a confidante, to talk over problems with.
	143. I: ......Something like that. So.... the most helpful thing was then that it helped you not to do that.	
Counselling as preventative	**144. R: Yea.**	
	145. I: So that was a great thing wasn't it?	
	146. R: It was, yea.	Counselling as a support during a crisis period. Alan was clearly going through a crisis period with overwhelming feelings which he was unable to process and having no confidante as a support.
	147. I: And what parts of the counselling did you like best?	
Sitting down talking Feeling comfortable Directive approach helpful Containment and structure	**148. R: The best part was like you sit down and he told me what to do and I was happy then and was more relaxed for myself.**	The actual sitting and talking was benificial and Alan found the directive approach used by the counsellor to be very helpful. Given that Alan felt suicidal and perhaps out of control, it was a relief to have had his counsellor contain and structure his painful feelings through a directive approach. Alan uses the words 'happy' and 'relaxed' to describe how he felt after counselling.
	149. I: So getting some kind of advice and guidance **(Yea)** *was helpful?*	

Support from girlfriend	**150. R: Yea and then...then the girlfriend phoned me as well at the time and says 'Well you must go to counselling to somebody and talk through things out and listen to what he'll say to you too like'.**	Alan indicates that his girlfriend was also encouraging him to go for counselling and telling him that he needed to talk to someone and get some guidance. How important is it that significant people are open to the troubled person seeking counselling? Although Alan had not told his parents of his counselling, he had confided in his girlfriend who strongly encouraged him to attend.
	151. I: Right. So your girlfriend knew you were going did she?	
Disclosed to girlfriend re attending counselling	**152. R: Yea, she kinda knew but then she had some feeling then like....and she said 'Don't lie to me' so then I couldn't lie so then I told her and she said 'Oh, that's good'.**	Alan initially did not tell his girlfriend he was going for counselling but she suspected and he then told her he was attending. She was very supportive of his decision.
	153. I: So she was encouraging you as well..... **(Yea)***...to go....she thought it was a good idea as well for you.*	
	154. R: Yea.	
	155. I: And what did the counsellor do that was most helpful to you?	
Talking as helpful Specific questioning helpful Checking on suicidality	**156. R: Am.....talking to me. He'd say 'How's your day today, how are things at work'. 'Good'. 'Anything bothering you'. 'No not really but apart from the girlfriend'. He said 'Tell me what**	Alan valued being invited by the counsellor to talk about his problems. It sounds like the counsellor asked him specific questions about different areas of his life which led Alan to disclose his suicidal thoughts and feelings. Alan indicates that he found it a great relief to talk about his suicidal thoughts and

Monitoring suicidal ideation Great sense of relief Enthusiasm to continue Clearing problems	**it's about and did you do anything stupid to yourself'. And I told that I was thinking to kill myself and all this but I didn't actually do it like so he was talking to me and telling me what to do like and I said I had to go to him again....'cause for more relief.... out of the system.**	feelings. The importance of talking for giving relief and clearing matters 'out of the system'. The relief Alan is feeling helps him to continue attending his counselling sessions.
	157. I: So it was kind of a relief **(Yea)***...so that was really helpful to you....to talk it out* **(Yea)***....and then you felt more relief, a sense of relief in yourself from that.*	
Angry feelings No awareness of anger triggers Feeling out of control	**158. R: Yea, and sometimes I could wake up in the mornings and still I'd be mad like for no reason.**	Alan would feel angry when he woke up and have no clear awareness of what was triggering it. Regulating his feelings was problematic for him. *Use of word 'mad' suggesting he felt no control or understanding of his feelings.*
	159. I: Yea. And did you learn how to manage.... how to cope with that.	
	160. R: Oh yea.	
	161. I: So what did he tell you how to cope with that?	
Anger management strategies	**162. R: Like if you're fighting just like to go outside and take deep breaths and cool down. And he'd say 'Are**	Alan learned anger management techniques to deal with his angry feelings. He also indicates that the counsellor kept monitoring his suicidal risk.

Suicide risk monitoring		**you all right inside, do you want to be dead'. 'No' so that was that then.**	Highlights the importance of containment and structure for clients who are a suicide risk.
	163.	*I: Uh, uh. So he gave you a lot of good ideas about what to do.*	
Advice and guidance	**164.**	**R: About what to do, yea.**	Alan valued the practical aspects and techniques he learned in counselling.
	165.	*I: Yea. And were there any things about the counselling that you didn't like.*	
Initial difficulties Privacy Issues Shame and stigma	***166.***	**R: When I was going in the start what I didn't like about it was people knowing about my business 'cause I'd try to avoid it from people like......**	Alan found counselling difficult initially mainly because he did not like others knowing his business. Did Alan feel a sense of shame about having to admit he was having problems? Image seems important to him so going to counselling may not have fitted with his idea of himself and may have been linked to his initial ambivalence.
	167.	*I: Yea....*	
Positive counselling experience	**168.**	**R: But apart from that then everything went on good for me.**	Alan reports positive feelings about his counselling experience.
	169.	*I: Yea. So at the beginning you were kind of a bit nervous about telling somebody your private business?*	
	170.	**R: Yea.**	
	171.	*I: But it sounds like after....after you*	

	had the first session over.... that things settled.....	
Improvement Feeling Settled Over-involvement with girlfriend	**172. R: ....things settled down for me and it went good for me for a few months and then she kinda got sick...**	Alan reports an improvement in himself and then talks of his girlfriend getting sick. Is this Alan again showing an over-involvement with his girlfriend?
	173. I: Who got sick?	
	174. R: My girlfriend.	
	175. I: Oh, your girlfriend.	
	176. R: Yea.	
	177. I: Ok. And did the counsellor say or do things that didn't help you, can you remember back now? Did Tony ever say something or do something that you kinda thought 'No, that doesn't help me'.	I knew that Alan had only been for 6 counselling sessions so as he spoke of his girlfriend getting sick some months later, I felt this was a move away from the focus of the interview and chose not to follow up on it.
No criticism of counselling	**178. R: no, he didn't say nothing like that at all, no.**	Alan has no memory of anything negative in his counselling experience.
	179. I: Everything he said......	
Positive view of counsellor	**180. R: .... It was right.**	Alan reports being very satisfied with his counsellor and his counselling experience.
	181. I: It was ...it was good.	

	182. **R: It was.**	
	183. *I: And say if you were going to give him advice, if you were going to give Tony advice about how he could help you better or help other people better, what would you say to him?*	
Positive views of his counsellor	**184.** **R:** (Long pause). **I'd say he'd be good. People who'd go to see him**.....(inaudible) **he's a person I'd say is good.**	Alan gives a positive recommendation of his counsellor.
	185. *I: Uh, uh. So is there anything you think he could do better?*	
No criticism	**186.** **R: I don't know what..... He's good anyways.... for me anyways.**	Alan has nothing critical to say about his counsellor or his counsellor's approach.
	187. *I: He was good for you* **(Yea)***....so it doesn't sound like you have any advice.*	
	188. **R: No.**	
	189. *I: You have nothing you'd like to tell him to do differently?*	
	190. **R: No.**	No negative comments

	191. I: Did he.....you know when you were meeting him over the 6 sessions Alan, did he use drawings.... or anything else besides talking?	
Verbal approach Directive Questions asked Note –taking by counsellor in session	**192. R: No. Just talking. He asked me different questions about how things were going each day for me and I'd tell him ......and he was writing down in his book....**	Alan's counsellor's approach was verbal. He did not use any non-verbal methods. Alan was conscious of the counsellor taking notes during the session. Is note-taking during sessions an interference in the counselling process? Does the client regard it as 'being taken seriously'? Alan does not indicate that he experienced it as distracting or problematic.
	193. I: So he took notes.	
	194. R: Yea, he took notes down in his book....	What is the significance of the note-taking for Alan? He seems to see it in a positive light rather than negatively.
	195. I: Yea.....	
Taking matters seriously	*196.* **R: In his black diary book.**	The counsellor took notes in his Diary. Alan noticed the colour of the counsellor's notebook so the note taking seemed significant for him.
	197. I: Uh, uh. And did he give you anything to write....did he give you any homework to do?	
No homework given	**198. R: No homework, nothing like that.**	Homework did not form part of the counselling.
	199. I: So there was nothing else in the counselling apart from going in and talk?	

Talking important	**200.**	**R: Going in and talk yea.**	Talking important
	201.	*I: Ok. Because sometimes counsellors would use drawings but he didn't use any drawings.*	
	202.	**R: No.**	No non-verbal mediums used by the counsellor.
	203.	*I: And then could you tell me about the ending of the counselling, Alan. Who decided when the counselling would stop?*	
6 Session Counselling contract Solution Focused Counselling not extended	**204.**	**R: When the 6 weeks was up it stopped that time.**	Alan had a 6 session contract with the counsellor which wasn't extended. (The service Alan attends pays for 6 counselling sessions for their trainees. In exceptional circumstances the counsellor can seek an additional allocation).
	205.	*I: Uh, uh. And who made......whose decision was that?*	
Client in happier place Satisfaction with 6 sessions Awareness he could return to counselling	**206.**	**R: Well I was more happy in myself than sad, I can't really do more now, I'm happy in myself and if I need him I'll use him again. 6 weeks was up.**	Alan felt happier in himself at the end of the 6 sessions and did not feel the need for extra sessions at that time. He is aware that he could return to counselling in the future if necessary. He accepted the counselling contract that was offered to him.
	207.	*I: So you....it was really you decided yourself* **(Yea)***....that you had ...you were happy?*	
Client's decision to finish Autonomy	*208.*	**R: I was happy enough in myself, yea.**	Although the 6 session contract was up, it was Alan's decision to finish his counselling and he did not indicate that he would have liked more sessionsat that time. The 6 sessions seemed sufficient for Alan's needs.

	209. *I: Yea, and that you didn't need....*	
	210. R: Anymore.	Alan felt he had sufficient counselling at that point.
	211. I: ...anymore, at that point. Ok.	Was Alan's counselling more like 'crisis counselling' and when the crisis was over he felt things were back to normal again?
	212. R: Yea.	
	213. I: And what do you remember about the last session you had with him?	
No memory of final counselling session	**214. R: (** Long Pause)......... **I don't know.**	Alan has difficulty recalling his final counselling session.
	215. I: You can't remember....	
	216. R: No.	
	217. I: It was last year.	
	218. R: Yea.	
	219. I: And do you remember anything he said to you or you said to him at the last session?	
Advice re girlfriend and anger	**220. R: He told me to work things out with the girlfriend and things like that....and not to be mad like....**	Alan remembers his counsellor advising him to sort out his relationship with his girlfriend and to work on his anger. These seemed the 2 key issues that Alan worked on during his counselling so the counsellor may have been reminding him of the essential points.

	221. I: Uh, uh.	
Memories of ending vague	**222. R: So..... that was the last thing I can remember.**	Alan's memory of the ending of his counselling is quite vague – however it was around a year ago.
	223. I: That's what you remember about the last session.	
	224. R: Yea.	
	225. I: And do you remember what your feelings were at the end....you know what were you feeling inside at the end?	
Sense of relief and well-being Feeling of happiness	**226. R: I was more relieved**........*(Yea)*......**I was more happy for myself.**	Alan felt a sense of relief at the end of his counselling sessions and was also happier in himself. Alan's immediate crisis was resolved but what about his underlying problems which led to the crisis in the first place? Is crisis work enough?
	227. I: Uh, uh. And how about the feeling.....the suicidal feelings......were they still there?	
Suicidal feelings diminished	**228. R: No, they were gone out.**	Alan's suicidal feelings had gone.
	229. I: They were gone.	
	230. R: Yea.	
	231. I: So it sounds like that you.....you made a lot of	

	*improvement***.......(Yea).....***in the 6 weeks. What do you think yourself?*	
Satisfaction with progress	**232. R: Oh, I did, yea. I did, yea.**	Alan indicates that he was happy with the progress he made in his 6 counselling sessions.
	233. I: Uh, uh. Yea. And say if you were to...em.....when you look back now, what are your feelings about the counselling experience?	How useful is a solution-focused approach with people with learning disability?
Talking as valuable aspect of counselling	**234. R: It was good....if you need to talk to somebody....it's good like.**	Alan sees being able to talk to someone as a valuable part of counselling.
	235. I: Uh, uh. And would you go for counselling again if you had another problem?	
Would return to same counsellor Relationship with counsellor	**236. R: Oh, if I had any problem, I'd probably go to him.**	Alan indicates that he would go back to the same counsellor if he had further problems. Suggestive that he had formed a therapeutic relationship with the counsellor
	237. I: So you would go back to Tony again?	
	238. R: Yea.	
	239. I: If something else.......	
Would return to counselling	**240. R: ......was bothering me or was on my mind, yea.**	Clear he would go back to counselling again if he had further problems.
	241. I: Yea, yea.	

Positive feelings about his counsellor Importance of being listened to	**242. R: Because I reckon he's....he's a good person to talk to like.**	Alan feels positive about the relationship he had with his counsellor.
	243. I: Uh, uh, ok. Is there anything else now Alan that you'd like to tell me about your experience in counselling.....anything else now maybe I haven't asked you.....that you think would be good for me to know?	
	244. R: (Long Pause)................**Don't know really.**	Nothing further to add.
	245. I: Can you think of anything else?	
	246. R: No.	
	247. I: It sounds like it was a good experience.....	
	248. R: Yea.	
	249. I: That you feel....felt much better at the end.	
Feelings of happiness and contentment	**250. R: Yea, it made me more happier like.**	Alan is clearly indicating that his counselling experience was a positive one for him and led him to feel happier and more content in himself.

	251. I: Yea, more happy in yourself.	
	252. R: Yea.	
	253. I: Ok. So there's nothing else then you want....you want to tell me?	
	254. R: No, no everything's good.	His life is now going well and he feels happy in himself. A year on from his counselling, Alan is feeling in a good place in his life.
	255. I: Ok. So will we finish there then Alan.	
	256. R: Ok.	
	257. I: So thank you very much for talking to me and I very much appreciate it.	
	258. R: Ok.	

Participant 4: ‘Alan’

Coding of Emergent Themes

Codes: OW= Overwhelmed Self

FA = Fear and Anxiety

AF = Authority Figures

HA = Helpful aspects of counselling

CA = Choice and Autonomy

Emergent Themes	**Code**
Initial dislike	FA
Need to talk	OW
Reluctance and ambivalence	FA
Counselling advised by staff	AF
Withdrawn	OW
Anger and aggression	OW
Possible depression	OW
Bottling up feelings	OW
Having a chat	HA
Sorting things out	HA
Relief got from talking	HA
Problems in my head	OW
Involvement of staff	AF
Counselling suggested by others	AF
Relationship problems	OW

Having a car	CA
Betrayal by best friend	OW
Excusing girlfriend	CA
Betrayal by best friend and girlfriend	OW
Suppression of feelings	OW
Breakdown of trust	OW
Girlfriend in college	CA
Upset and distressed	OW
Special girlfriend	CA
Accepted by girlfriend’s family	CA
Disappointment re future plan	OW
Going to England	CA
Death of uncle	OW
Distancing from learning disability	CA
Grief re uncle’s death	OW
Normal Social life	CA
Being pulled down	OW
Bottling up distress	OW
Feelings of anger	OW
No confidante	OW
Keeping up appearances	CA
Feeling better	HA
Ambivalence re counselling	FA
Decision to attend counselling	CA

Counselling his choice	CA
Awareness of needing help	CA
Possible stigma	FA
Parents not told	CA
Importance of confidentiality	CA
Independent decision-making	CA
Involvement of staff – first appointment	AF
First session – went alone	CA
Anxiety prior to first session	FA
Feeling down	OW
Felt listened to and understood by counsellor	HA
Advice and Guidance given	HA
Ups and downs	OW
Invited to talk by counsellor	HA
Anger management techniques	HA
Asthma linked to anger	OW
Problem expressing anger	OW
Impact of anger – breathing problems	OW
Anger management advice helped asthma	HA
Over-involvement with girlfriend	OW
Taking responsibility for others	OW
Difficulty staying with own feelings	OW
Girlfriend broke up with him	OW
Girlfriend having own issues	OW
Being ‘kept on a string’	OW

Staying friends	CA
Angry at break-up	OW
Trying to ‘get back’	OW
Powerlessness	OW
Re-establishing friendship	CA
Process of relationship break-up	OW
Relationship over	OW
Adjusting to break-up	OW
Awkwardness and embarrassment	FA
A lot on his mind	OW
Feeling heard by counsellor	HA
Keen to return for second session	CA
Own choice to return	CA
Satisfaction with counselling	HA
Dangers of not talking, of bottling up problems	OW
Suicidal thoughts	OW
Suicide as an option	OW
Directive approach helpful	HA
Containment and structure	HA
Girlfriend urging counselling	HA
Disclosed to girlfriend re attending counselling	CA
Talking as helpful	HA
Specific questioning helpful	HA
Monitoring suicidal ideation	HA
Relief at getting things ‘out of the system’	HA

Angry feelings	OW
No awareness of anger triggers	OW
Learned anger management strategies	HA
Valued practical guidance	HA
Initial difficulties with counselling linked to privacy issues	FA
Sense of shame and stigma	FA
Positive feelings about counselling experience	HA
Improvement in self	HA
Over-involvement with girlfriend	OW
No negative comments on counselling	—
Positive recommendation of his counsellor	HA
Verbal approach only used in counselling work	HA
Note –taking by counsellor in session	HA
No homework given	HA
Counselling contract was for 6 sessions	HA
Counselling not extended by client	CA
Client in happier place	HA
Client didn’t want to extend counselling	CA
Client aware he could return to counselling if necessary	CA
Client’s decision to finish counselling	CA
No memory of final counselling session	—
Advice re girlfriend and anger	HA
Sense of relief and well-being following counselling sessions	HA
Client happy with his progress in counselling	HA
Talking as valuable aspect of counselling	HA

Client would return if necessary to same counsellor	CA
Positive feelings about his counsellor	HA
Feelings of happiness and contentment	HA

Alan: Superordinate Themes

Overwhelmed Self	**Authority Figures and others involved**	**Fear and Anxiety**	**Choice and Autonomy**	**Helpful Aspects**
• Unmanageable feelings • Relationship problems • Disappointment and Loss • Suicidal thoughts • Anger issues • Bereavement	• Counselling advised by staff • Boss involved • Initial session organised by staff • Parents not involved • Girlfriend’s role	• Fear of Beginning • Initial Anxiety • Butterflies in stomach • Ambivalence • Stigma	• Making choices • Independent decision-making • Aspiring to a normal life	• Counselling Relationship • Advice and Guidance • Techniques • Rel. Education • Anger Management