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Disabled people and social estrangement: Facilitating connection in counselling

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PhD Thesis

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Abstract

In this thesis I explore why disabled people often feel socially estranged and how this issue might be worked with in counselling. Disability has a very low profile in the counselling literature and research in this field is often conducted from a counsellors' perspective. As a disabled person myself, I have based my research on a reflexive narrative approach that draws on interviews with disabled people who have been clients in counselling. From a person-centred perspective, I understand the impact of estrangement on the self-concept and interpersonal relationships in terms of societal conditions of worth. Counselling is considered by some writers in the field of Disability Studies to be an oppressive pursuit. Others who align themselves with a feminist approach argue that the psycho-emotional and lived experience of disability should not be excluded in research. I draw on these writings as well as on participants' experiences to critique the theory and practice of counselling disabled people. Finally, I formulate a framework for understanding disability in counselling and offer some recommendations for practice.

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Declaration

I declare that this thesis was composed by myself, that the work contained herein is my own except where explicitly stated otherwise in the text, and that this work has not been submitted for any other degree or professional qualification except as specified.

A handwritten signature in cursive script that reads "Connie Johnson".

Connie Johnson
30 April 2019

“It is when we feel separate from others and from the flow of life that we are at most risk”

(Jordan, 2004b:36)

“All I ever wanted was to be accepted for who I am and not for others’ perceptions of me”

(Corker, 1994:241)

“Understanding is not just a case of putting up a ramp”

(Reeve 2006:103)

“It is about a different way of looking, and about a different way of responding to what we see”

(Cameron, 2012:245)

Chapter 1: Introduction

The starting point for this research came from the realisation that I am not the only disabled person to feel a pervasive sense of being different from other people as I go about my everyday living. That sense of difference never leaves me and it permeates every aspect of my relationships with others. I was always aware of this feeling, even and perhaps most painfully as a child and young adult, but I did not talk about it with anyone. For the most part, I ignored this feeling but felt inhibited in social situations that extended beyond my relationships with family and friends. It was through being in counselling as a middle aged woman that I became aware of the extent of the emotional anguish that I often experienced in relationships, particularly with non-disabled people. I shunned any involvement with other disabled people because I wanted to be *“like everyone else”* (Michalko, 2002:171). I tried to distance myself psychologically and emotionally from my impairment so that I could take part in activities with friends and family without feeling different. I ignored the discomfort I felt acutely when I was unable to involve myself in strenuous physical activities like hill walking with my peers. Relationships were not easy for much of my childhood and early adult life because there was always an underlying anxiety. I could not find the words to say how I felt and I did not feel that anyone else would understand what I was experiencing.

As I moved on in my life, gaining a sense of belonging through being in close relationships with some friends, family members and my children, these feelings became less acute and more hidden until I experienced a life-changing crisis. It was then that I entered counselling for the first time. This enabled me to reflect on what was happening and eventually to regroup myself and to find a new way of living. A few years later, I decided to train as a counsellor because I realised how helpful this could be for other people as well as for me. What I did not realise at the time was that counselling training involved uncovering the hidden feelings that were having an effect on my capacity to be at ease in relationships with others. Part of my development was to become self-aware enough to make therapeutic use of the thoughts and feelings that arose in me as I listened to my clients. This was the next

stage in a long process of encountering the painful emotions, memories and anxieties that were associated with my interpersonal relationships. Counselling has been a highly beneficial pursuit for me and yet, in relation to the disabled part of me, it might not have been so. My counsellor was sufficiently skilled and self-aware to notice some of the crucial thoughts and feelings that I had not previously expressed to myself or to others. I realised that these qualities were highly important to my process.

I became aware of my counsellor's patience and skill when I reflected on my last lengthy period of counselling. I recalled one of the pivotal moments during that process that had a profound effect on me and that was so subtle that it could easily have been missed. I described this moment in the following extract from a published version of my story (Johnson, 2016a:109-110)

: *“During one session I found myself speaking in detail about the painful effects of one of the surgical procedures that I had endured and found highly distressing. [...] Whilst I was talking about the details of this procedure, I noticed my therapist take a sharp breath and her facial expression changed abruptly. Without realising what was happening, I immediately fell silent. My therapist asked me what was happening, and I was surprised that she noticed my silence because I hadn't been aware of it myself – I was too caught up in my memories. When my therapist spoke, I began to realise that I had withdrawn because I didn't think she would want to hear about my story. I didn't want to say any more about my memory because I thought that my vivid description was too much for her to bear. It had just become too much for me to bear in that moment. My therapist very gently said she realised that her expression had frightened me, and she explained that she was imagining how painful the procedure had been – she could feel the pain of it too. She said she wanted to hear my story – she knew I had always protected other people from hearing it, but she reminded me that this was my true story and that my feelings were real.*

She encouraged me to talk some more. I felt so touched by her care and warmth that I began to cry. My therapist gently took my hand and we sat

together feeling the horror of that time in hospital. I told her about the doctors, nurses, and visitors staring at [my leg] and about the questions they kept asking. But they never asked me about the pain or what it felt like to be stuck in a hospital bed when my sisters were at home or out in the sunshine playing with their friends. Even as I spoke with my therapist, I felt that I was making a fuss. I stopped talking again. I remembered that sometimes when people stared at me during that time I refused to speak to them or answer their questions. Becoming invisible was the only way to escape their intrusions”.

What interests me about this story now is that my counsellor’s skill and willingness to reach out and comment on what she was observing were crucial in helping me to experience and process the painful emotions that had always been with me. It was only after around four years of weekly therapy sessions that I began to realise that my disability had a profound effect on the way I saw myself and on the way I related to others. I was prompted to reflect on this when I was working with a client who was emotionally frozen and unable to relate to others at an intimate level as a result of prolonged trauma in childhood. I began to notice more acutely that I too, had a part of me that was emotionally frozen and to identify this as the part of me that was holding back from feeling free at an existential level in close relationships. I was able to address this frozen part through being with a warm, empathic counsellor but without this relationship, I might have continued to carry the stress, anxiety, depressed feelings and sense of being burdened by my increasingly degenerative condition. Because of this therapeutic process, I am now as comfortable as I can be with my impairment as a fundamental aspect of who I am as a person. I am able to be clear about how impairment and disability affect me in my relationships with others and to have more fulfilling relationships while recognising that my physical limitations can be frustrating at times.

Having explored this process for myself, I recognised that some relationships had been harmful to me in the past. As a child, I felt traumatised by the medical treatment I received because my emotional responses were not recognised or attended to (see Westbrook, 1996). I was often ridiculed in public places because I walked with a limp. It was through a healing relationship with my counsellor that I

became more at ease with myself and others (Natiello, 2001). I became curious to find out if other people encountered particular difficulties in their relationships that they felt were connected with being disabled and to find out if they were aware of difficulties in their relationships with their counsellors. I was interested to find out about moments where disabled clients and their counsellors missed being in connection with each other so that, as a counsellor, I could make a contribution to knowledge in my profession by seeking to understand this phenomenon. I realised that it is crucial for counsellors to understand how their disabled clients experience relationships with others, especially when they find some issues difficult to talk about.

As I embarked on this research, I did not have any enduring relationships with other disabled people. My first port of call in finding out more about how disabled people experience relationships was to delve into the literature of Disability Studies (DS). This is a discipline within the Social Sciences that has arisen from the disabled people's movement that began in the mid-twentieth century in the UK. According to Colin Barnes (2014:17), the literature from this group of writers in the academy *"has generated a radical critique of conventional thinking and research on disability related issues"*. I soon found myself aligning with feminist writers in DS. Jenny Morris (1991:8) was one of the first to touch a chord with me when I read the following words

"Disabled people – men and women – have little opportunity to portray our own experiences within the general culture, or within radical political movements. Our experience is isolated, individualised; the definitions which society places on us centre on judgements of individual capacities and personalities. This lack of a voice, of the representation of our subjective reality, means that it is difficult for non-disabled feminists to incorporate our reality into their research and their theories, unless it is in terms of the way the non-disabled world sees us".

I recognised that I had been isolated in being the only disabled person among my immediate community of friends and family and that I did not find anyone around me who understood how I felt. I suppressed my feelings of anger and frustration at not

being understood but I shunned any involvement with other polio survivors because I did not wish to see myself as a disabled person. The stress, anxiety and bouts of depression I experienced were exacerbated because I was unable to find a voice to speak about issues such as the negative attitudes that other people sometimes expressed to me about my impairment. I had no idea until I became engaged in counselling research that it would be possible, even desirable, to give voice to my feelings. In time, I became aware that both my experiences and those of other disabled clients could be made available in a way that might enhance counselling practice.

As a counsellor and counselling trainer, I was aware that, particularly from a person-centred perspective, very little has been written about counselling disabled people. I wanted to redress that balance by bringing the voices of disabled people into centre stage so that the “*knowledge*” that they have kept to themselves might come out from the “*underground*” (Michalko, 2002:174-175) by being brought into the domain of counselling practice. I wished to address the issue of social isolation that Tom Shakespeare (2006:170) writes about when he says

“Disabled people often have more difficulties than non-disabled people in dealing with both their bodies and health, and the environments and systems which they have to negotiate. They rely more on others to provide assistance on a day-to-day basis, and they may be more vulnerable to medical complications. [...] Yet while disabled people may have greater need of friends, they are less likely to be well-integrated into networks and friendship circles. Disabled people differ from most other disadvantaged groups because they experience significantly greater isolation and loneliness”.

Shakespeare does not include counselling as one of the ways of addressing this situation. For this reason, I decided to explore the issue by focusing on relationships as they are understood from a counselling perspective.

This research is essentially an ‘insider’ critique of counselling practice where the experiences of disabled clients take centre stage in order to inform counselling theory and practice. In a similar vein, it is a critique of the views about counselling that are expressed by DS writers, some of whom have had negative experiences of

counselling and consider it to be an oppressive activity. In chapter 2, I use some of the literature from DS to introduce sociological and historical perspectives on the issues that estrange disabled people in society and in their interpersonal relationships. I explore the main criticisms of counselling as expressed by writers in DS and I present an overview of the existing relevant literature in counselling that pertains to working with disabled clients. I explain that the person-centred approach can be used as an appropriate way of understanding and working with disabled people in counselling. Finally, I specify the overall research aim and questions that I seek to address. In chapter 3, I discuss some of the challenges of researching how disabled people experience relationships and why the narrative approach is an appropriate framework for this research. I explain how I went about conducting the research and analysing the data as well as the ethical issues that arose and how I resolved them.

In chapters 4-7, I present my research findings. In Chapter 4, I discuss the issues that participants encounter in their interpersonal relationships and that lead them to feel socially estranged and sometimes disconnected from others. In chapter 5, I discuss how these issues affect people psychologically and emotionally and in terms of their personal development and self-esteem. Both chapters 4 and 5 set the scene for the next two chapters (6 and 7) where I illustrate how the counselling process unfolds successfully for participants (chapter 6). In chapter 7, I illustrate how difficult it can be for disabled clients and their counsellors to understand each other. I present participants' experiences of difficult encounters that include missed opportunities and ruptures. I present an overall discussion of my findings in chapter 8 and I include a discussion of the main contributions that this research makes to knowledge in both DS and counselling. I discuss the implications that arise from this research for the development of counselling training and practice and reflect on how my findings might illuminate some aspects of person-centred counselling theory. In chapter 9, I conclude by formulating key principles for counselling disabled people. I discuss the limitations of this research and highlight some of the issues that are indicated for further exploration.

Chapter 2: The research in context

The overarching aim of this research is to explore the troublesome issues that routinely arise for disabled people in interpersonal relationships; to find out how these issues affect them psychologically and emotionally; to find out if and how they explore these issues in counselling and to discover how counselling can be used to improve their sense of connection with themselves and with others in their social spheres. In this chapter I examine the key issues and debates that form a background to this research. In section 2.2, I use literature from Disability Studies (DS) to examine the issues that can contribute towards disabled people feeling isolated and different from others. I include an exploration of how disabled people address this issue collectively. In section 2.3, I use both DS and counselling literature to provide insight into the range of psycho-emotional and relational affects that people can experience as a result of living with disability. I address the different approaches to counselling disabled people in section 2.4. In 2.5 I identify the contribution that I make to the existing body of knowledge in counselling and DS. I begin the chapter by discussing why relationships are important aspects of daily living.

2.1. Relationships matter

Relationships matter because they are core aspects of human existence. They can be fulfilling, life sustaining and induce a sense of belonging but they can also be the cause of distress. They have a profound impact on the way that people grow and develop through different stages in their lives. It is through relationship that people develop a sense of their place in the social world and of how they view and experience themselves and others.

2.1.1. Relationships and wellbeing

Research suggests that *“close relationships are indeed vital to [...] well-being, including happiness, mental health, physical health, and even longevity”* (Perlman

and Vangelisti, 2006:4). Other research emphasises the quality of connection between people as a major indicator of wellbeing (Mearns and Cooper, 2018). As Goleman (2007) points out, research in neurobiology indicates that when two people are interacting, feelings are communicated, often unconsciously. When people are positively attuned, the relationship goes well. If they feel wary of each other, their relationship will be difficult. People who grow up in un-empathic or abusive relationships are more likely to experience psychological distress (Mearns and Cooper, 2005). The less stressed people are the more sociable they are able to be so they can feel good or bad through their communications with others (Goleman, 2007). Loneliness and disconnection from others is a further source of psychological distress (Jordan, 2004a; Mearns and Cooper, 2005).

Furthermore, the way that people relate to themselves can be a source of distress. Too much self-criticism can lead to low self-worth and contribute to poor mental health (Mearns and Cooper, 2005). Jordan (2004b:47) adds that

“disconnection from oneself, from the natural flow of one’s responses, needs, and yearnings creates distress, inauthenticity, and ultimately a sense of isolation in the world”.

She makes the point (2004c) that few researchers have explored the causes of disconnection and how to move from there into greater connection with themselves and others. Mearns and Cooper (2005, 2018) have investigated this aspect of human relating and my research takes some of their work forward by exploring what inhibits disabled people specifically from developing growth enhancing relationships.

2.2. Disabled people and social relationships

This work of writers in DS is not widely referenced in the field of counselling but as a body of knowledge, it provides an understanding of the social, cultural, historical and political forces that militate against disabled people feeling at home in their social worlds.

2.2.1. An oppressed social group

In sociological terms, disabled people are identified as a *“collection of persons differentiated from at least one other group by cultural forces, practices, or way of life”* (Young, 1990:43). The forces that differentiate and undermine disabled people centre on the notion of normality – a somewhat elusive, even mythical term (Lorde, 1984). This *“taken for granted, natural status”* (Shakespeare and Corker, 2002:7) is identified by Karen Parry (2004:65) when she states that

“The norm in the UK is to be white, British, male, young, straight, non-disabled. To deviate is to be classed as ‘other’. The more one deviates from this norm, the less power and privilege one is accorded. [...] Grand narratives sustain this hierarchy and division, by quantifying and labelling the ‘differences’ that separate people. This creates unequal power relations that then lead to oppression”.

This unequal power is demonstrated in the media and literature, where disabled people are often portrayed as either tragic or heroic figures (Cameron, 2010, Davis, 1997; Shakespeare, 1999).

When disabled people are considered to be absent of normal characteristics, they are vulnerable to oppression. Young (1990:41) points out that this term is used in political spheres to refer to the disadvantage and injustice some people suffer because of *“everyday practices of a well-intentioned liberal society”*. Oppression occurs when people are labelled by others as being part of a group that is identified for the purposes of exclusion or derision. Young identifies ‘five faces of oppression’ to uncover some of the practices that oppress people. ‘Exploitation’ is the unequal distribution of wealth and resources. ‘Marginalisation’ is the separation of people into those who are able to work and those who are not and who are therefore dependent on welfare systems. ‘Powerlessness’ occurs when some members of society, especially professionals, are given more respect than others in society. ‘Cultural imperialism’ occurs when dominant groups are considered to be the norm and people who do not embrace the cultural norms imposed on them are labelled as ‘other’. ‘Violence’ can occur when one group challenges the dominance of another group.

Disabled people can experience any of Young's forms of oppression in the form of stigma. Jennifer Colman Brown (2010) explains that this is a way of expressing the value judgements of the dominant culture. Scambler (2009:441) defines stigma as *"a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation"*. Colman Brown (ibid) identifies three aspects of stigma namely, fear, stereotyping and social control. She argues (ibid p 181) that stigma *"allows some individuals to feel superior over others"* and that *"stigmatised people are needed in order for the many non-stigmatised people to feel good about themselves"*. She continues her argument, saying that people use one particular characteristic of a person to overshadow all others in order to stigmatise. Disability is one of these characteristics and Gill (2001:366-367) sums up what this experience can feel like saying

"To be silently, smilingly dismissed as someone pathetic and strange and encounter dismissal even in cultural milieu you call your own is confusing and dispiriting. That is the standard social experience of disabled people in the non-disabled world they inhabit. [...] [The] problem of relations between disabled and non-disabled worlds is not a small rift of communication, it is a deep divide. It encompasses both intellectual and affective components, in that it is based on misconceptions about the experience of disability and conflicting values between disabled and non-disabled people about what constitutes a worthy life".

This 'deep divide' affects disabled people emotionally and psychologically (Johnson 2011; Morris, 1997; Odell, 2011; Portner, 2005). Living with disability can be a stressful experience and can affect interpersonal relationships in diverse and profound ways (Johnson, 2011) that are not generally understood by non-disabled people.

One of the consequences of stigmatisation is that disabled people can feel that they occupy a liminal place, or twilight zone in society (Murphy, Scheer, Murphy and Mack, 1988); *"in the community but not of the community"* (Shakespeare 2006:175); homeless (Michalko, 2002) and estranged (Gill, 2001). All of these terms indicate a lack of belonging at an existential level. For the purposes of this research, I use Gill's term 'estrangement' (2001) to indicate the sense of feeling separate from

others when difficulties arise in relationships because a person is disabled. As well as having a general sense of estrangement, the sense of being separate or different from others can appear directly through difficulties that arise in interpersonal relationships. A number of terms have been used to describe these difficulties. Jordan (2004b) writes about 'blockages' between people; DS writers use the word 'barriers'; Goffman (1963) refers to 'strain' in relationships and disabled writer Colin Cameron (2010) uses the term 'tensions'. These terms could be used interchangeably, since they refer to the issues that impede the quality of connection between people. Instead of using these terms, I veer towards counselling terminology by using Jordan's (2004b) word 'disconnection' to indicate the difficulties that arise in interpersonal relationships generally and the word 'rupture' as the commonly used term that refers to difficulties that arise in the counselling relationship.

2.2.2. Oppression at an interpersonal level

Estrangement and disconnection can be expressed towards disabled people openly at an interpersonal level, through hostility, abusive and violent behaviours and more subtly through rejection and undermining attitudes.

Overt hostility

Violence against individual disabled people is frequently reported in the media and Pam Thomas (2011) likens this to the hostility experienced by black, minority ethnic and lesbian, gay and transgender groups. This can take the form of 'hate crime' (perpetrated by people unknown to those they target) or 'mate crime' (violent acts of hostility, ridicule and targeted attacks on disabled people by friends or family members that can be associated with domestic violence) (ibid). Goodley and Runswick-Cole (2011) in their research on violence against disabled children find that this can be psycho-emotional (a form of verbal violence and dominance that can threaten the very existence of a person); systemic (perpetrated at an institutional or structural level) and cultural (fascination and fear of disability). Some research indicates that disabled people are more at risk of being sexually abused than non-

disabled people (Reeve, 2006). Martin, Neepa, Sotres-Alvarez, Kupper, Moracco, Dickens, Scandlin and Gizlice (2006) find that, in one particular geographical area, disabled women are at least four times more likely than non-disabled women to experience sexual assault. Margaret Kennedy (1996) provides an in-depth account of the prevalence of sexual abuse among disabled children. Negative attitudes to disability and the difficulties that disabled children and adults may have in disclosing abuse render these people particularly vulnerable.

Although acts of violence can be challenged through the judicial system, disabled people are still vulnerable to attack. Through political activism, disability is now regarded as an equal opportunities/human rights issue in the UK (Swain, French and Cameron, 2003). However, Colin Barnes (2010) points out that, despite changes in social policy and legislation, discrimination has not disappeared but instead has become more subtle.

Subtle exclusion

Disabled clinical psychologist Brian Watermeyer (2009:94) offers some understanding of subtle forms of oppression and the effects of these on disabled people. He points out that

“The anxiety which emerges within the observer upon exposure to disability may often lead him/her to [...] a ‘manic defence’ which draws him/her into unsolicited, anxiety ridden [...] defensive manoeuvres, including withdrawal”.

Mark Deal (2007) uses the term ‘aversive disablism’ to make the point that people who think of themselves as non-prejudiced may adopt attitudes that are not overtly anti-disabled but are ‘pro non-disabled’. He argues that these attitudes often drive policies and procedures by favouring non-disabled people and can be adopted by both disabled and non-disabled people, even those who are expected to be allies. This form of discrimination is particularly relevant to counsellors who, in their attempts to exercise anti-discriminatory practice may be unaware of the subtle attitudes they convey. Gill (2001) points out that where prejudice towards disabled people is not overtly expressed, it is harder to oppose but Deal argues that if these subtle forms of prejudice are not identified and challenged, they can easily become

entrenched. What is clear is that violence, hostility and abuse are relational issues that can be targeted towards disabled people in everyday life.

2.2.3. The medical approach to disability

In Western cultures in past decades, disabled people were often segregated in education by being placed in 'special schools' (see Goodley and Runswick-Cole, 2011) and by being excluded from employment so they became associated with sickness, poverty and oppressive dependency (Oliver, 1990). Advancements in medicine and technology have changed this situation in recent years so that in Western cultures, disabled people's lives have improved and more of them are able to gain employment (Marks, 1999a) and to live satisfying lives. Most disabled people are appreciative of these improvements (Shakespeare, 2006). However, activists argue that medical professionals, who are usually non-disabled, still *"have the power to assess disabled people, to define their needs, control the resources made available to them, specify solutions and evaluate outcomes"* (Swain, French and Cameron 2003:134). The argument is that these professionals do not always understand disabled people's needs, especially in terms of social involvement.

Medical language is used to categorise and identify people so that they can be given appropriate treatment but disabled activists object to this form of classification when it is used in social circles as a way of identifying people (Oliver, 1990). Part of the problem is that *"the workings of power are internalized, and we comply with what seem to be self-evident truths"* (Swain and French. 2004:58). The medical approach, as it is practised in the health sector in the UK, involves the 'self-evident' notion that people are offered treatment so that they can overcome their conditions and adapt to the existing social and physical environment (Reynolds 2004b:125). This supports the view that disabled people should try to live as far as possible like everyone else (Michalko, 2002) in order to fit in with societal norms. However, living in this way can be very stressful and can cause disabled people to feel that they are being forced to keep their struggles hidden in *"underground terrain"* (ibid p 175) where it is not known or visible to others. This means that disabled people can be left alone to deal

with the stress of trying to fit in with environments that do not take their bodily limitations into account.

Michalko (2002) argues that there are very few places where the experience of trying to live in this way can be voiced or heard. He suggests that disabled people are only welcomed in society under certain conditions – notably if non-disabled people do not feel too threatening by their impairments. He points out that this is in part due to the emphasis on healthy living and beauty as ways of viewing the body in Western cultures. This leaves many people, not just those who are disabled, feeling inadequate if they do not measure up to perceived standards. He suggests that non-disabled people who feel threatened by vulnerability and death often project their fears onto disabled people. They regard disability, illness and impairment as unnatural conditions that should be medicalised and where possible, fixed. Because of this, people whose bodies cannot be fixed are left with nowhere in society that they can call home. In order to feel accepted, some disabled people feel the need to pass, or mimic (ibid) non-disability.

2.2.4. Collective resistance

Swain and French (2004) draw on Foucault's idea that wherever there is power there is resistance and that power can be both constraining and enabling (see also Proctor, 2002). Colman Brown (2010) points out that fundamentally each stigmatised and non-stigmatised person chooses to feel superior or inferior over the other. By this argument, people can choose to ignore such attitudes but I argue that this not easily done at an individual level but that it can be done collectively through political activism.

Largely under the leadership of Mike Oliver (1990), the Social Model of Disability (SMD) has been devised as a way of changing the way that disability is regarded, moving from a medical to a social perspective. It challenges the dominance of medicine as the sole identifying marker of disabled people and it highlights the role that social, political and cultural environments play in disabling people's lives. The SMD uses language to differentiate between the medical model and the social model

of disability. The term 'impairment' indicates the *"functional limitation within the individual caused by physical, mental or sensory impairment"* (Oliver, 1996). The term 'impairment effects' refers to *"those restrictions of bodily activity and behaviour that are directly attributable to bodily variations"* (Thomas, 2007:136). In the SMD, the word 'disability' refers to

"The social disadvantages and exclusions that people with impairment face in all areas of life: employment, housing, education, civil rights, transportation, negotiation of the built environment" (Thomas, 1999:10).

The term 'disablism' refers to

"exclusionary and oppressive practices [...] like sexism or racism, it can operate consciously or unconsciously, directly or indirectly and may be acted out in social interactions between individuals or may be institutionalised and embedded in organisational structures and statutes" (ibid, p 40).

The distinction between disability and impairment is helpful in recognising that there are different levels of responsibility in managing disability – individual and social. However, the distinction is not always clear cut because *"impairments and impairment effects are thoroughly intermeshed with the social conditions that bring them into being and give them meaning"* (Thomas, 2007:153), This is particularly the case in research, where the impact of both experiences on individual disabled people's daily lives is not so easily separated (Shakespeare, 2010). In my view, recognising the reality of impairment effects is not tantamount to adopting a medical understanding of disability but it is about being prepared to acknowledge that disability and impairment affect disabled people in different ways.

The term 'disabled people' is widely used among disabled writers and activists (Linton, 2010) and I use it in this research. Some non-disabled people are uncomfortable with this term, preferring to speak of 'people with disabilities' in order to emphasise personhood over impairment (see Michalko, 2002). My use of the term 'disabled people' concurs with the dominant language in DS where the emphasis is on the environmental, social and political forces that marginalise people. The word disability is problematic because the prefix 'dis' means 'apart' or 'asunder' so 'disable' means to deprive of capability or effectiveness and the word therefore *"cleaves to ability and its absence"* (Linton, 2010:235). Using the term 'non-disabled'

is similarly limiting. The term 'ableism', most notably introduced by Campbell (2009), is often used in contemporary writing in DS. The emphasis here is on discrimination in favour of the 'able', turning attention to the notion of 'ability' as it is embedded in cultural assumptions of normality. Campbell (2008:2) states that

“Ableism refers to a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human”.

She argues (ibid p 1) that DS researchers should “*shift our gaze and concentrate on what the study of disability tells us about the production, operation and maintenance of ableism*”.

While there is enormous scope in attending to an ablest perspective, DS writers often use the term disability as a form of solidarity (Davis, 2010b). For the purposes of this research, I have chosen to use disability terminology and perspective for the most part because it is used in much of the literature that I draw on. However, I acknowledge philosopher and gender theorist Judith Butler's (1990) questioning of the need for broad, usually binary, categorisations of people because of the differences that exist within each category. This view is encapsulated in the idea of intersectionality, meaning the “*relationship of disability to other markers of gender, sexuality, race/ethnicity and social class*” (Goodley, 2011a:33). As Swain and French (2004:59) point out,

“Oppression cannot be understood solely within the relations between non-disabled and disabled people. This positions people in single categories, in this case disabled or non-disabled, and does not recognize the complex interplay of differences of age, race, religion, sexuality, gender and so on that is integral to the lives and identities of all disabled and non-disabled people”.

Mark Deal (2003) adds the point that there can be a perceived hierarchy of impairment within the broad category of disability. It may be, for example, that deaf people receive greater respect than wheelchair users because they do not look disabled.

Shakespeare (2014) suggests that disability could be thought of as a matter of inclusion and equal rights instead of as a group identity that is defined by its victimhood. Butler (1990) suggests that, rather than being caught up in the nature of identity and labelling, it is more meaningful to address the power dimensions between binaries such as disabled/non-disabled. That does not need to involve refraining from categorising people since, as disabled writer Tobin Siebers (2008) points out, the notion of 'disabled' as a social group is needed in order to question it. He sees it as an identifying marker that *represents* something, rather than as something that is intrinsic in itself in the same way as 'black' is used to identify a political position rather than a skin colour. In a similar vein, Goodley and Runswick-Cole (2014:5) argue that sometimes it is necessary to accept the use of the terms 'able' and 'normal', saying "*after all, like them or loathe them, these phenomena undergird the language of citizenship, law and humanity*". They turn the use of the prefix 'dis' to negate the term 'normal' – to 'dis', they say, is to trouble "*and the dis/ability complex does some troubling work to the register of the normal and the condition of the human*". They point out that to be human and to be disabled are often regarded in oppositional terms but "*we want to move to a time when thinking about the human will always involve thinking about disability*". (ibid p 13).

Tobin Siebers (2008) takes the view that disability is a normal human state and Rhoda Olkin (1999: vii) points out that for disabled people "*our world abnormal is normal*". Others note the conventional view of what is normal belies the fact that bodies decay; that people die (Wilton, 2003) and that disability cannot be conceptualised as a fixed state (Cameron, 2010; Garland Thomson, 2010a; Priestley, 2003; Reeve, 2002). Butler (2009:25) notes that "*lives are by definition precarious: they can be expunged at will or by accident; their persistence is in no sense guaranteed*". People can become disabled at any time in their lives and this occurs regardless of race, gender, sexual orientation class, geographical situation or culture (Priestley, 2003).

Accepting that there are divergent views about terminology, for the purposes of this research, I use the disability term to highlight the sense of difference and social estrangement that some people who self-define as disabled share.

2.2.5. Deaf people and disability

Although I argue that social estrangement is a common experience among disabled people, it is important to point out that deaf people do not necessarily consider themselves to be disabled. Some regard themselves as a linguistic minority where the use of sign language is a marker of their identity and culture (Corker, 1998). This group is widely referred to as the 'Deaf' community, where language such as British Sign Language (BSL) is commonly used with its divergent forms according to geographic location. In this research, I use 'deaf' as a generic term because the emphasis here is on deaf people who are comfortable enough to be thought of as disabled and who may or may not consider themselves to belong to the Deaf community. Following Corker's terminology and for the purposes of this research, I refer to 'deaf people' and use 'deaf', deafness 'and 'hard of hearing' as terms that refer to these particular forms of impairment. I use the term 'deaf' community to refer to the wider community of those who consider themselves to be deaf and/or those who associate themselves with Deaf culture.

Corker takes the view that deaf people are marginalised within the disability movement where those who regard themselves as disabled may expect to be supported. Writing as Scott-Hill (1993), she argues that this is because the language difference between deaf and hearing people does not fit with the materialist framework of DS which she considers to be a phonocentric group. She argues that deaf people are more inclined to feel a sense of difference between themselves and hearing people than between themselves and non-disabled people, so the emphasis is on the capacity to hear or not to hear. Corker's personal stance is that she chooses whether or not to identify herself as a disabled person. She feels herself to be disabled because this helps her to make sense of her experience but she struggles with the fact that she does not look disabled (Corker and French, 1999). This inner dilemma can also be experienced by other disabled people whose impairments are not immediately obvious to others.

2.3. Social estrangement and conditions of worth

The language and writings in DS provide an informative understanding of how and why some disabled people feel socially estranged. As a counsellor, part of my contribution to knowledge in both DS and counselling is to formulate this understanding in a person-centred framework. I do this because it is my own professional perspective and because there is a dearth of literature on person-centred counselling in the context of working with disabled clients. The word 'therapy' is often used in person-centred language but because I intend to discover how disabled people experience counselling that may or may not be person-centred, I use 'counselling' as a generic term throughout the thesis.

2.3.1. Conditions of worth

The person-centred approach derives from the work of Carl Rogers and his theory of personality (see Rogers, 1961). I draw on the work of Mearns and Thorne (2013) to give an overview of this theory. The key concept of 'conditions of worth' can be defined as "*internalised attitudes or beliefs*" (Warner, 2009:119). The attitudes and beliefs that people internalise derive from a person's need to survive the early years of their lives. The assumption is that people need the acceptance and approval of others who care for them. They need this in order to develop positive self-regard which involves the capacity to trust that the way they experience themselves, others and the world around them is accurate and reliable. This state is defined as an 'internal locus of evaluation' but this state is always in danger of being disrupted by other people's negative judgements. If people rely too much on other people's judgements, they are liable to develop an 'external locus of evaluation', where they are heavily influenced by others in making choices and decisions.

The process of growing from child to adult involves the development of a sense of 'self', which is described in this approach as the 'self-concept'. The theory of conditions of worth involves the idea that, in order to maintain a positive self-concept and to gain the acceptance of others, people may tend to deny or distort their

experiences. To use myself as an example, I might say that I do not have a physical impairment and that I am just like everybody else (denial). Alternatively, I might say that I sometimes feel a little tired (distortion). These are both states of incongruence that I might adopt when I feel that my impairments will not be considered acceptable to others. A congruent state would be for me to say that I have several impairments that affect the way I live my life and that affect me emotionally at times. In this way, I would be integrating my experience of impairment into my self-concept. If I were to repeatedly distort or deny this aspect of my experience, I might lose touch with these aspects of myself and be unable to recognise that my impairment and my experience of disability were driving my emotions and behaviours. I might experience a general sense of anxiety and feel threatened in some social situations without realising why that might be. My self-concept, of being just like everybody else, would be vulnerable to disruption when I encountered situations that felt threatening. I would be unable to see myself as a disabled person or to recognise the difference between impairment and disability so I would be likely to internalise my experience of the disabling physical and social environment and regard it as something that I would need to adjust to myself.

The care that people are given as they are growing up is usually offered with some conditions attached and these conditions can be exacerbated in adult relationships. People are always incongruent in the sense that their self-concepts are never wholly authentic. The important issue in counselling is that people can become psychologically distressed when they are unable to achieve a balance between the conflicting demands of self-actualisation, meaning the desire to become fully themselves, and the need to live in their social worlds (Mearns and Thorne, 2013). To follow my own example, I would feel anxious about revealing aspects of myself that I considered unacceptable to others and so constrained to make the most of my life as it is. Where people are criticised, undermined or rejected by others, they learn to become self-critical and this results in low self-esteem (Barrett-Lennard, 2013). When people are severely damaged by others, they may feel the need to withdraw and retreat into independence as a way of alleviating their distress but this can reinforce their sense of estrangement (Mearns and Cooper, 2005).

2.3.2. Social and cultural conditions of worth

I use the generic term 'conditions of worth' to refer to the internalised messages that disabled people receive from influential people in their lives, such as family members, partners, friends, colleagues, neighbours, teachers, care givers, personal assistants, healthcare and medical professionals. Taking into account the writings from DS that I have drawn on so far in this chapter, I extend this concept to include the experience of disabled people who often experience social and cultural conditioning. Person-centred psychologist Gillian Proctor (2002:1) argues along the lines of Young (1990) when she states that groups of people who "*differ from the norm are defined as 'other' and set up by society to have less access to power*". Rogers recognised that structural forces could be at play in oppressing and disempowering individuals and he sought to address these issues through individual and group work (Proctor, 2002). Person-centred practitioner Khatidja Chantler (2005) points out that Rogers developed his theory of personality from the perspective of a white heterosexual middle class non-disabled American male who grew up in a society that values autonomy and independence. For this reason, she argues, he did not give sufficient attention to the social disadvantages that people who are identified with minority groups encounter in their daily lives. She takes the view that person-centred counsellors most commonly consider the family to be "*the most influential arena where conditions of worth are framed*" (Chantler, 2005:250). She uses the term "*racialised and gendered conditions of worth*" (ibid) to incorporate an understanding of the cultural, social, historical and political forces that undermine people who experience these particular forms of difference.

Drawing on Chantler's work, I consider what Thomas (1999) defines as disability and disablism (see 2.2.4) to be forms of what I call "*social and cultural conditions of worth*". In order to take the notion of intersectionality into account, I use this as a broad term that incorporates disability as well as other identifying markers that derive from oppressive regimes and culturally embedded attitudes and values. As well as conditioning people to feel different and 'other' through limited access to public places and resources, social and cultural conditions of worth can be passed on to individuals as a set of attitudes through the media (McMillan, 2004) and literature

(Davis, 1997; Shakespeare, 1999; 2014) where disabled people are often portrayed as either tragic or heroic figures. Understanding that messages about the self (conditions of worth) derive from social and cultural attitudes as well as from relationships with influential people creates room for clients to re-evaluate how their self-concepts have been formed.

2.3.3. Caregivers, counsellors and conditions of worth

As I have said, conditions of worth can derive from the attitudes and values that professionals such as those involved in education and medical settings adopt. These spheres of influence can be particularly evident in the lives of disabled people, many of whom need specialist care. Additionally, as Jenny Morris (1997) points out, some disabled people are educated away from home in special schools, so for these people, teachers can be particularly influential. Although anti-discriminatory practice is the rhetoric in the provision of care, the reality is that disabled people are often subject to conditions of worth by the people that routinely attend to their needs. Mary Westbrook's research (1996) suggests that children who were treated for polio in the mid-twentieth century in Australia became significantly stressed, anxious and depressed as adults as a result of the attitudes and harsh routines imposed on them by medical professionals. Contemporary research in the UK suggests that conditions of worth may be a consequence of professionals in healthcare settings being unable to tailor treatment to the needs of individual patients because they are subject to the constraints of the working environment that make this difficult (Swain, Clark, French, Parry, and Reynolds, 2004). In this respect, Shakespeare (2014) adds that care, in whatever context it is offered, can be stressful for both care-givers and their clients.

It is not uncommon for counsellors to work with clients who have been in receipt of treatment in healthcare before they engage in counselling. This can be because the focus of counselling is on emotional and relational issues that cannot be explored adequately in medical and healthcare settings. Similarly, counsellors are often aware of relational issues that arise between clients and other care-givers such as family, friends, professional care workers and personal assistants. In her

rehabilitation work with clients who have Multiple Sclerosis (MS), psychoanalytic counsellor Julia Segal (2002) notes that they can sometimes cover up their frustrations by behaving in difficult and awkward ways. This, she says, can be so difficult for carers that some of them resort to responding in retaliatory ways by being violent or abusive. Person-centred counsellor Jan Hawkins (2002) finds that people with severe learning difficulties sometimes expect to be reprimanded for expressing themselves in behavioural ways because they cannot articulate their feelings. This behaviour is not always understood or tolerated by professionals as person-centred counsellor Suzanne Keys' (2006) discovered through her work with a physically disabled client who was reprimanded for his behaviour by teachers at his school.

Conditions of worth that derive from "*oppressive and controlling attitudes, behaviours and institutional regimes* (Hawkins, 2002:54) can be particularly painful for disabled people because they occur in settings that are in place to care for them. Hawkins (2002) feels so strongly about the ways in which carers can treat their service users that she urges counsellors to become involved in challenging these regimes and attitudes. Person-centred counsellor Marlis Portner (2000) takes a similar view. Through her therapeutic work with clients who have severe learning difficulties, she is aware that these people are confronted with discrimination in public places on an everyday basis. Because of this, they feel their differences acutely and can become highly sensitive to the reactions of other people. She argues that the attitude of the carers is of crucial importance because it is with them that people learn how to live with their impairments. Carers, she says, can counteract conditions of worth by offering supportive encouraging environments for their service users.

Person-centred counsellors and trainers Lorna Carrick and Sheila McKenzie (2011) designed and implemented a research programme in an attempt to support social and health care workers in their work with autistic people. Their research participants were care workers whose clients had communication difficulties and often presented with challenging behaviours. As a counter-balance to the behaviour-modifying approach that participants were accustomed to using, Carrick and McKenzie found participants who agreed to learn some techniques derived from a person-centred counselling approach and to put them into practice with their service

users. The result of this research was that where participants introduced the attitudes of empathy and acceptance instead of being corrective, their relationships with their service users became significantly less stressful. This concurs with Jan Hawkins' view that attempting to modify the behaviour of people with severe learning difficulties can inhibit their personal growth and be counter-productive.

Although counsellors can play their part in supporting both professionals and their clients to develop good working relationships, they are not immune from reinforcing disabled clients' conditions of worth. Humanistic researcher John McLeod (2009) points out that counsellors can be so keen to express acceptance of their clients that they may find it anathema to acknowledge, and therefore to reflect on, the prejudices that they might inadvertently project onto their clients. The counselling profession is situated within western culture and therefore within the cultural predisposition to think in terms of normalcy. Dan Goodley (2011a:80) refers to the 'ableist society' where we all judge ourselves and others according to what is considered collectively to be the normal human body. On this basis, it might be assumed that the theory and practice of counselling is based on the notion of ableism because of the culture in which it is embedded. To some extent, this is manifest in the published counselling literature where counselling practice is often written about in terms of 'different' client groups. The notion of different groups is by definition based on a perceived standard of normalcy – of who might be considered to be a normal client. Indeed, this research comes under such a category. The dilemma then becomes whether or not to write from within the culture in order to aid understanding of the experience of being different or whether to question the whole notion of difference. My approach to addressing this issue, as a researcher who is immersed in the counselling culture and in the broader western culture, is to acknowledge the issue; to notice it where possible and to reflect on how the culture might influence all aspects of this research. As a researcher in the counselling field, I am working within an ableist culture while questioning it at the same time. As such, this form of critical thinking is encouraged (Lago and Smith, 2010) while still being relatively innovative in the counselling literature and professional discourse.

The counsellor's sensitivity to these issues is expressed through the ethic of anti-discriminatory practice (see Lago and Smith, 2010).where the right to be recognised and heard regardless of difference is acknowledged and addressed. In this way, counselling as a profession is not intent on subordinating disabled people but "*whilst claiming 'inclusion', ableism simultaneously always restates and enshrines itself*" (Campbell, 2008:5). In other words, the term 'inclusion' indicates a group that has been excluded and while there are attempts at 'including' disabled people in the pursuit of counselling, in practice they often thought about as 'other'. Assumptions are often made such as that people can walk into a counselling room (premises are often not physically accessible to disabled people (see Johnson, 2010); that they can communicate with words, that they can read, hear, understand language and see. If clients do not have these characteristics, they may be considered as 'other' and therefore need 'special' conditions to enable them to take part and these may or may not be available.

2.3.4. Effects of conditions of worth

I turn now to an exploration of how all forms of conditions of worth can affect disabled people in terms of their relationships with themselves and others, drawing on literature from both DS and counselling. Referring to the effects of disablism, DS writer Carol Thomas (2007:72) states that "*the damage inflicted works along psychological and emotional pathways, impacting negatively on self-esteem, personal confidence and ontological security*".

Effects on the relationship with self

As I said in 2.3.1, where conditions of worth have been particularly damaging, a person is likely to be internally incongruent. In this state, a person is unable to symbolise their experience (Warner, 2007) or integrate experiences that have been denied or distorted into the self-concept. Disabled people who experience this state could be understood as "*persons who are suffering from inauthentic or alienated forms of being in the world*" (Schmid, 2005:75). DS writer Tom Shakespeare (1996) acknowledges that disabled people are socialised to think of themselves as inferior

to non-disabled people. This view concurs with the notion of conditions of worth and DS writers explain this through the idea of internalised oppression. Gail Pheterson (1986:148) defines this as the *“incorporation and acceptance by individuals within an oppressed group of the prejudices against them within the dominant society”*. The lived experience of internalised oppression is expressed evocatively by disabled writer Micheline Mason (1992: 27) who says that

“Once oppression has been internalised, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives”.

Susan Wendell (1997) encourages disabled women to speak about the impact of the social and cultural forces that oppress them in their daily lives. However, as she is well aware, internalised oppression can prevent disabled people from making the most of the care they are offered and from finding ways to communicate their needs. Research conducted by Carol Thomas (2001:259) on disabled women’s experiences of receiving health care in the UK is *“strongly suggestive of the presence of disablism and gender oppression in the health care system in the United Kingdom”*. Disabled writer Sally French (1994) attempts to combat this by educating professionals who work with disabled people. Internalised oppression can diminish a person’s capacity to trust in their own evaluations and can deprive them from developing skills and making meaningful choices which they feel may not be respected (McLeod and Sherwin, 2000).

Psycho-emotional effects

The psycho-emotional effects of disability are intrinsically connected with relationships. There is ample evidence to suggest that disabled people can feel rejected by the negative attitudes they encounter in their social spheres as well as by the more commonly understood issue of lack of physical accessibility to public places. These experiences can induce powerful emotional responses such as depression, anxiety, shame and loneliness.

DS writer and trained counsellor Donna Reeve (2006:98) makes the point that *“an important source of psycho-emotional disablism comes from interactions with other people in society; relationships which can be affected by prejudice and myths about disability”*. DS writer and clinical psychologist Brian Watermeyer (2009:94) states that *“It is persons with more readily apparent forms of impairment who will tend to evoke disability-related anxieties and stereotyping”*. Such anxieties can be experienced through the ‘gaze’ that disabled people with such impairments are frequently exposed to in public places. Rosemarie Garland-Thomson (2009:9) states that staring of this nature *“has been extensively defined as an oppressive act of disciplinary looking that subordinates its victim”*. Reeve (2002) notes that disabled people can feel worthless and unattractive when they are stared at in this way. Lois Keith (1996) and Jenny Morris (1991) write evocatively about the effects of this on disabled women.

One of the most potent psycho-emotional effects of the gaze of others is that it isolates people and engenders a sense of shame. According to Goleman (2007) social rejection and/or the fear of this is one of the most common causes of anxiety. He argues that feelings of inclusion depend not so much on frequent social contact or numerous relationships but on how accepted people feel, even in just a few key relationships. He explains that people are hardwired to be alert to the threat of abandonment, separation or rejection because these were once actual threats to life itself. Psychoanalyst Phil Mollon (2002:3) asserts that shame *“can powerfully inhibit communication of what is most important in a relationship”*. He writes (ibid, p 23) that this is experienced as

“a hole where our connection to others should be. [...] and in the deepest depths of shame we fall into a limbo where there are no words but only silence. In this no-place there are no eyes to see us, for the others have averted their gaze – no-one wishes to see the dread that has no name”.

The work of Thomas (1999; 2007), Reeve (2002; 2006) and Watermeyer and Swartz (2008) on the psycho-emotional effects of disability does not permeate into mainstream counselling literature but it is highly relevant to working with disabled clients in counselling. This work takes a fairly low profile in DS research as a whole,

despite emotions being a fundamental aspect of life (Donaldson and Prendergast, 2011). Watermeyer (2012) argues that there is an urgent need to explore what can happen internally for disabled people in response to the discrimination they experience.

Estrangement from the body

Thomas (2007:152) states that “*psycho-emotional disablism – both in enactment and its effects – should be thought about as fully embodied*”. In psychotherapist Susie Orbach’s (2010) experience, clients’ attitudes towards their bodies are intrinsically connected to the sense of self-worth that comes from cultural notions of the perfect body. Disabled women in particular experience the “*oppression of the body by society and its culture*” (Wendell, 1997:275), especially in relation to sexuality, dependence, self-determination and discrimination (Lonsdale, 1990). This has become something of a gendered issue in DS but Hughes and Paterson (1997) are among the few male DS writers that advocate the inclusion of this aspect of disability in research.

Research conducted by Esmail, Darry, Walter and Knupp (2010) suggests that one of the most distressing cultural assumptions made about disabled people’s bodily experience is that they are asexual. They found that some disabled people are inclined to internalise this view, resulting in low self-esteem and a lack of confidence in seeking and finding partners. Some feel the need to deny their sexuality because of the attitudes of parents and carers (McCabe, Cummins and Deeks, 2000) that can be overprotective, particularly in relation to young people (Porat, Heruti, Navon-Porat and Hardoff, 2012). Disabled people are not often given sex education, especially in segregated institutions (Shakespeare, 2000a) and this can result in stigmatisation (Esmail, Darry, Walter and Knupp, 2010) and sexual abuse (McCabe, Cummins and Deeks, 2000). While most people find sexual partners at college, work and other social networks, disabled people often do not have access to such places (Shakespeare, 2000a). The lack of suitable transportation can be an inhibiting factor (Porat, Heruti, Navon-Porat and Hardoff, 2012). On the other hand, despite the forces that militate against them, research on men with cerebral palsy indicates that

they can and do find ways of expressing themselves sexually and to have sexual experiences (Shuttleworth, 2002). In their research, Payne, Hickey, Nelson, Rees, Bollinger and Hartley (2016) found that disabled women's sexuality remains poorly understood. They found that body image is an issue, particularly for women with visible impairments because they are consistently identified by others as disabled so that *"who they were as young women, their talents and interests, were repeatedly disregarded"* (ibid, p 1047). These women tended to develop a *"low sense of body worth"* (ibid, p 1045). A significant number of them said they felt uncertain about mutual attraction and were afraid of being rejected by prospective sexual partners.

Sociologists Kelly and Field (1996) note that it is only when the body malfunctions that it ceases to be taken for granted because of the limits placed on people's activities. Howson and Inglis (2001) suggest that there is a move away from mind/body dualism within academic disciplines in the humanities. Person-centred writers Keith Tudor and Mike Worrall (2006) point out that the 'organism' is a term that incorporates the body and the self-concept. In this approach to counselling, the body is usually conceptualised as a source of knowledge and this is particularly evident in Gendlin's (1996) work on Focusing. As one of the 'tribes' of the person-centred approach (see Sanders, 2012), Focusing involves using a set of interventions that enable clients to become aware of what is happening for them experientially. It is described by Campbell Purton (2012:52) as a process of

"bringing awareness into the body, noticing the concerns which are troubling one, getting a felt sense of each trouble, finding a way of articulating or expressing that felt sense in words or images, noticing where a word or image brings some release, and receiving what has come from that experiential shift".

Body psychotherapist Nick Totton (2015: xvii-xx) moves this understanding of embodiment into the domain of interpersonal relationships, stating that *"our body is a relational resource"* and that *"speaking about embodied relating is both possible and valuable"*. However, this may be difficult for some disabled people, largely because in doing this work, they may be afraid of encountering shameful feelings about their bodies.

Diminished sense of agency

While conditions of worth affect disabled people in terms of their sense of self, they also have an impact on their relationships with other people. Writing more generally about people who have experienced oppression, Jordan (2004a:11) states that

“When our real experience is not heard or responded to by the other person, then we must falsify, detach from, or suppress our response. Under such circumstances we learn that we cannot have an impact on other people in the relationships that matter to us. A sense of isolation, immobilization, self-blame, and relational incompetence develops”.

I equate this lack of impact with a lack of agency, which in person-centred terms means that a person will struggle to make choices and decisions based on their own inner promptings. This means that they will have developed an external locus of evaluation (see section 2.3.1 and Rogers, 1961) and an inability to trust in their own personal power (Rogers, 1978). For DS writer Karen Parry (2004:63), *“empowerment is about people being facilitated to take control, make choices and exercise the power they have”*. Watermeyer (2009:95) argues that disabled people lack this sense of agency because they are positioned by society as *“insecure, conditional citizens in a misattuned physical world”*. He uses the term ‘access discrimination’, which leads to ‘constructed dependency’. He continues his argument saying that if resources that are not made available to disabled people by statutory institutions but are offered only by charitable organisations, disabled people can feel obliged to be grateful for the care they are offered. Watermeyer (ibid p 95) argues that, for disabled people, this *“erodes assertiveness and entitlement through feeling a responsibility to reciprocally protect and care for others”* so that they are *“precluded from being allowed to show or communicate universal aspects of human emotional life”* (ibid p 96).

Humiliation and shame can disrupt disabled people’s ability to be agentic by taking the initiative in relationships (Hartling, Rosen, Walker and Jordan, 2004). Some

“play a role that is fixed by the roles and identities of those around them, whether these are people who are closely connected to them, like family

members or professionals or others whose influence is more distant and impersonal” (Cameron, 2010:110).

Others might have a tendency to withdraw (Portner, 2000), become passive or compliant (Loja, Costa, Hughes and Menezes, 2013). Some of this can be attributed to what Seligman (1975) refers to as ‘learned helplessness’ where people who have been institutionalised, hospitalised or have been dependent on others for their care, learn to believe that they cannot exert any influence over the events that affect them. Emotionally, this can leave them feeling hopeless, lacking in self-worth and isolated from others (Jordan, 2004b).

Relational effects

Carol Gill (2001) suggests that for disabled people, social estrangement arises from their relationships with non-disabled people. I qualify this statement by noting that disabled people are not immune from having their own prejudices towards other disabled people, particularly where their impairments are different. Very little research in either DS or counselling has been conducted with a particular focus on the relational effects of disability. One of the few works with this emphasis has been carried out by psychologists Lyons, Sullivan and Ritvo (1995), who offer insight into what can happen in personal relationships when a person acquires a significant impairment. One key finding is that people find it difficult to talk about their emotions, notably with those who are responsible for their care. Other changes include the loss of ‘companionship activities’, meaning the roles they play in domestic, family and leisure activities. This loss contributes to their sense of loneliness and disempowerment. Unfortunately, these relational challenges *are “often left to individuals with the condition to sort out for themselves”* (ibid p 37).

Impairment effects can interfere with disabled people’s capacities to make satisfying connections with others and there is a small but wide-ranging body of research to support this view. For example, people with Asperger’s syndrome experience *“a lack of social or emotional reciprocity and failure to develop peer relationships appropriate to development level”* (Attwood, 2007:57) which leaves them at risk of being misunderstood and marginalised. Elderly people who have speech

impairments associated with cerebral palsy often feel more isolated than their non-disabled peers (Ballin and Balandin, 2007). People with dyslexia can be exposed to negative attitudes and discrimination because of misunderstandings that arise from difficulties in communication (Carawan, Nalavany and Jenkins, 2015).

2.4. Addressing conditions of worth in counselling

Shakespeare (2014) offers some suggestions that disabled people can follow to resolve their sense of isolation. He suggests that they may benefit from making friends with other disabled people and from using online discussion and friendship groups. Watson (1998) takes the view that social integration arises most effectively through seeking solidarity with disabled peers though he recognises that this is not every disabled person's preference. It has been noted (Michalko, 2002; Cameron, 2010) that disabled people have very few places where they can be listened to and understood emotionally. In theory, this is the work of the counsellor. Since psychological distress often has its roots in relational difficulties, the counselling relationship is regarded as a major source of repair (Mearns and Cooper, 2005; Natiello, 2001; Norcross and Lambert, 2011). Some disabled people report that they have valued their time in counselling (Swan, Griffiths and Heyman, 2003) but some disabled activists and writers remain sceptical. They take the view that *“any focus on ‘personal experience’ is only acceptable if it is in the service of galvanising the broader struggle for social change”* (Thomas, 2004:572). Added to this, many counselling services are not accessible to disabled people (Reeve, 2014) and very few counsellors are appropriately trained (Olkin, 2003). Another significant issue is that counselling disabled people is usually considered from the perspective of rehabilitation. While this setting may be appropriate for those with acquired impairments, it is generally considered by disabled writers to be inappropriate (Reeve, 2014) since others have been disabled from birth and are not engaged in the rehabilitation process.

Disabled clients are very poorly represented in the counselling literature and it is a rather under researched, some say marginalised (Swain, Griffiths and Heyman,

2003) topic in counselling. This is confirmed in McLeod (2009) and in Cooper's (2008) meta-analysis of the counselling literature where there is no reference to disability.

2.4.1. The loss approach

Counselling in the context of rehabilitation has usually been practised from the perspective of a loss approach, as expressed in the work of Julia Segal (2002). The assumption is that when a person acquires a life-changing impairment, they go through a process of 'adapting' to the 'loss' of ability and of 'accepting' their conditions so that they can rebuild their lives. This approach is based on the now rather outdated theory used by counsellors to understand the bereavement process. The theory outlines four 'tasks' of mourning that a person may go through following the death of a significant person in their life. The tasks are first to accept the reality of the loss; second to work through the pain of grief; third to adjust to an environment in which the deceased is missing and fourth to emotionally relocate the deceased and move on with life (Worden, 1991:10-16). As a theory, this inevitably leads some people to "*hold strong assumptions about how others should respond to such losses*" (Wortman and Silver 1989:349-353). This theory is sometimes applied by counsellors to understand the process that people go through when they mourn other losses but disabled writers do not consider this to be a close enough representation of acquired impairment (Gill, 2001). Psychoanalytic writer Shula Wilson (2006) addresses this issue by reframing loss as 'eternal transition'.

Disabled writer and counsellor Donna Reeve (2014:256) asserts that this approach "*predicts the way that people are expected to adjust to disability*". Research indicates that some disabled clients have felt that this approach has been imposed on them by counsellors (Swain, Griffiths and Heyman, 2003). This persuades Lenny (1993:233) to state that disabled people "*unequivocally do not need counselling*". Watermeyer (2009) argues that the loss approach is constructed from a non-disabled person's perspective. Withers (1996) suggests that it is an unacknowledged projection where counsellors who use it are imagining what the onset of disability might mean for *them*. Psychoanalytic therapist Deborah Marks

(1999a) argues that counsellors may project such notions onto their clients if they are not sufficiently aware of their own defences and this may inhibit them from seeing the positive and powerful attributes their disabled clients may have.

A further argument against the use of the loss approach is that the process of adaptation can be understood in terms of normalisation where the person is expected to become as far as possible like everybody else (Michalko, 2002). Instead of acknowledging that the environment is not adapted to the needs of disabled people, for example to access to building and resources, this approach involves people adjusting to the environment as it is with no expectation that it will change. Watermeyer (2009) explains that in this approach, the focus of treatment is on mastering the newly acquired physical status and seeing disability as something that should be overcome. If the person does not overcome their impairment, they cannot pass as normal and they become isolated and silent about their struggles. This approach reflects the culturally driven fear of disability and does not involve building on strengths and capabilities or discovering new opportunities that can arise when a person becomes disabled. Shakespeare (1996) and Watermeyer (2009) therefore, view the loss approach as a deficiency model. John McLeod (2009:483) argues that the *“infantalization of disabled people”*, may stem from this approach and that highly significant aspects of disability namely *“issues around sexuality; loss; capacity to achieve life goals; challenge of being able to make a living or play a role in the community/workforce”* are not widely addressed.

To combat the pressure to become as normal as possible, many disabled people protect themselves by withdrawing socially and/or emotionally because they do not expect others to understand their experience and because they cannot be authentic in their relationships. As Jenny Morris (1991:70) points out,

“There are negative aspects of being disabled which would persist regardless of the kind of society in which we live. We should not be made to feel that we have to deny these negative things in order to assert that our lives have value”.

Watermeyer (2009:94) argues that disabled people should ‘reclaim’ the experience of loss but they point out that *“they are often simultaneously, culturally, forbidden*

from articulating this” because such feelings are not listened to or understood. Julia Segal (2002:58) makes the additional point that some disabled people may feel too raw to address the emotional aspect of becoming disabled. However, while recognising that this is a sensitive issue, she takes the view that *“protecting people from their own fears means leaving them alone with them”*.

What emerges from these debates is that disabled people are inclined to resist the assumptions that non-disabled counsellors may make about their internal processes. The loss approach does not incorporate experiences of disabled people who are not engaged in rehabilitation and does not recognise the role that the environment imposes on them and that contributes to their distress. This model tends to focus on ‘normalising’ deficiencies instead of discovering potentialities. Loss is a common everyday experience yet some disabled people feel constrained to remain silent about how they experience it in order to feel acceptable to others.

2.4.2. Psychoanalysis

Writing from the context of healthcare, DS writer Frances Reynolds (2004a:17) addresses some of the barriers that can inhibit the counselling relationship and process. She says that

“Enabling and therapeutic communications with clients are jeopardized by the prevalence of disabling models of care, unexamined assumptions about normality, long-standing organizational barriers to partnership approaches with clients, and pervasive notions of health and treatment that focus on pathology rather than quality of life”.

She argues that the factors that limit good communication are stereotyped attitudes; marginalising the client’s role in their treatment and lack of awareness of clients’ needs and goals. From the client’s perspective she says that lack of knowledge of medical conditions and the language used to describe them by medical professionals in this context can prevent clients from being sufficiently informed to make decisions about their treatment.

The psychoanalytic perspective to counselling has been criticised by some disabled writers because of its strong connection with the medical model (Marks, 1999a:13). One of the reasons is that it is the predominant therapeutic approach in psychiatry. Another is that it relies heavily on interpretation as a therapeutic intervention. This can be perceived by clients as authoritative, with the counsellor adopting the role of expert. Disabled people may sense this as a form of 'othering', where the counsellor distances themselves from their client by becoming uninvolved because the client's impairment may engender fear. Disabled people often experience this from people in their daily lives so it can be particularly painful if they experience this as rejection in the counselling relationship (Wilton, 2003). Susie Orbach (2014:22) picks up this argument, though not in relation to disabled people. She recognises that the traditional psychoanalytic idea of therapeutic neutrality, meaning that the therapist maintains a distant stance to avoid interfering with the client's material, could be troublesome for some clients. She explores this in the context of the new wave of relational psychoanalysis, taking the view that for a counsellor, to be in a therapeutic relationship involves being affected by the client. She says

"What the patient is struggling with is 'being' and [...] the process of being involves the engagement of an other, a thinking, feeling other with whom to explore the difficulties of being".

On the other hand, medical professional and psychoanalytic counselling practitioner, Shula Wilson (2002:131) aims to facilitate counsellors' understanding of disability by exploring *"the effects that disability has on non-disabled people, both as individuals and in the social context"*. The aim of Wilson's approach appears to be concerned with understanding the issues that disabled clients may encounter in their relationships through discovering the impact that these clients have on the counsellor. However, disabled people may take issue with this approach because it can emphasise the 'divide' (Gill, 2001) between them and non-disabled people without necessarily addressing how this situation might be addressed in the client's social world.

2.4.3. Social approaches

In their research on the experiences of disabled clients and their counsellors, Swain, Griffiths and Heyman (2003) found that, in the context of primary health care, counsellors tend to emphasise their client's impairments. In doing so, they do not give due recognition to the social, cultural and political contexts that disabled people often experience as hostile. For this reason, they suggest that the Social Model of Disability (SMD) should be incorporated into counselling practice. This would involve educating clients about the SMD so that they may appreciate that part of their distress arises from the social systems that undermine them. Disabled counsellor Joy Oliver (1995) also advocates this form of intervention. She notes that this approach may counterbalance the negative experiences that disabled clients may have had through being treated by professionals (for example, doctors, nurses and physical therapists) in healthcare settings (see Westbrook, 1996). However, Swain, Griffiths and Heyman (2003) found that clients and counsellors are reluctant to talk about disability because the label has negative connotations.

The message from the disabled writers that I have mentioned in this section is that counsellors who work with disabled clients should be aware of the SMD. This would enable them to understand that much of the distress their clients experience arises from systems that do not recognise or accommodate their needs. Counsellors who have this understanding could enable their clients to appreciate that their struggles are not always of their own making. In addition, encouraging disabled people to 'adjust' to social structures would be tantamount to colluding with the notion that disability is an individual instead of a societal issue.

2.4.4. Collaborative approaches

Disabled activist Mike Oliver (1996:61) asks the crucial question "*who should be in charge of the rehabilitation process, disabled people or the professionals?*" The message here is that disabled people should be involved in any form of care that they receive. Swain and French (2004:53) point out that

“To engage with questions of enabling relationships is to engage with questions of power, both between therapist and client, and within the social worlds of which both are a part”.

Mairian Corker (1998) argues that counselling should reflect the values of the client and not the counsellor. Contrary to the power that medical professionals still have to steer the process of rehabilitation, recent research indicates that in this context, counselling clients are sometimes being consulted about the support they require when they first become disabled (Crisp, 2011). In their research, Thurston, McLeod and Thurston (2010; 2013) adopt a collaborative approach as they seek to understand what helps people make the transition from sight to blindness.

Unlike most non-disabled counsellors who write about disability, Deborah Marks (1999a: xiii) identifies herself as a non-disabled person and adopts a reflexive approach where she recognises and values both the differences and points of connection between herself and her disabled clients. Kim Etherington (2002) explores her own position with regard to disability in the context of rehabilitation and recognises the significance of the social, cultural, historical and political impact on disabled people’s experiences of themselves and others. She demonstrates an understanding of the power issues involved in working with disabled clients in counselling. Like Marks, she acknowledges her position as a non-disabled person. Etherington’s narrative approach to writing and research (2002) offers space for disabled people to tell their own stories and to present their own experiences of becoming disabled. This approach is important because, as Watermeyer (2009:92) says, the *“loss discourse situates disabled people as vulnerable and incomplete, feeding and justifying segregation and other forms of social control”*.

What I gather from the issues I have discussed in this section so far is that social, collaborative and relational approaches to counselling are more likely to place the client’s perspective at the centre of therapeutic work than the medical approach. Having said this, Marks’ (1999a:1) points out each of the major approaches to counselling has their unique contribution to make in terms of working with disabled people. She notes that the SMD

“emphasises the social and environmental barriers that oppress some impaired people; psychoanalysis addresses intra psychic experiences of and defences against disability; post-structuralism focuses on discourses which constitute disability and phenomenology, which addresses interpersonal and experiential aspects of disability”

In her view, these approaches need not be exclusive of each other. Most of the objections that DS writers have about counselling stem from attitudes and interventions that disabled people have encountered in rehabilitation and healthcare settings or from approaches that are associated with these contexts.

2.5. Research contribution

One of the contributions that I make to knowledge is to formulate the process of counselling disabled clients using the person-centred approach. In doing so, I incorporate key insights from the work of some DS writers.

2.5.1. A person-centred approach to counselling disabled people

A person-centred understanding of the counselling relationship and process is expressed through Rogers' 'necessary and sufficient conditions for therapeutic change' (see Appendix A and Rogers, 1957). The theory is that people enter counselling because they feel anxious, vulnerable or distressed by conditions of worth. The messages they internalise about themselves may arise as a result of difficult relational experiences such as rejection, loss or trauma. Rogers' hypothesis (see Appendix A) is that if the counsellor is genuinely accepting and understanding of the client and the client perceives this, the client will feel safe enough to process their experiences so that the damaging effects of conditions of worth are minimised. Processing involves becoming aware of and sometimes re-experiencing emotional responses to distressing events and reflecting cognitively on these responses (see Greenberg and Paivio, 1997). By undergoing this process, clients may find that they alter their attitudes towards themselves by becoming less self-critical, less defensive and more self-respecting. They may find that their attitudes towards difficult issues

change and they may experience fewer symptoms of anxiety (Sanders, 2006). Changes of this nature enable people to feel more at ease in relationships with others and rather than denying or distorting problematic experiences, they allow them to become more integrated into the self-concept so they are less likely to be disturbed by them.

The person-centred approach (PCA) has been cited by disabled people as their preferred approach to counselling (Corker, 1994; Hodge, Barr, Bowen, Leeven and Knox, 2012; Lenny, 1993; Reeve, 2002; Swain, Griffiths and Heyman, 2003; Withers, 1996). I suggest that there are several reasons for this. The major strength of the PCA is that it is a social, collaborative, non-medical approach. Rogers (in Rogers and Sanford, 1989:1483) states that

“The single element that most sets client-centred psychotherapy apart from the other therapies is its insistence that the medical model - involving diagnosis of pathology, specificity of treatment, and desirability of cure - is a totally inadequate model for dealing with psychologically distressed persons”.

Instead of the counsellor offering interpretations, the client is considered to be the expert on their own experience (Sanders, 2005; Rogers, 1980). The counsellor's role is to enable the client to discover and act on their own inner promptings instead of relying on other people to guide them. It is an emancipatory approach where the counsellor seeks to minimise inequality by working collaboratively with the client (Natiello, 2001) and by facilitating the client's development of personal power (Rogers, 1978). It is intrinsically anti-oppressive (Proctor, 2002) and recognises the political dimensions of therapy (Proctor, 2002; Proctor, Cooper, Sanders and Malcolm, 2006; Rogers, 1978; Schmid, 2012). Whereas the medical model has impairment at its centre, the PCA is a holistic approach that seeks to encourage understanding of all aspects of a person's experience (emotional, embodied, cognitive and spiritual) with the awareness that the person is multi-faceted, having different configurations (Mearns and Thorne, 2000).

One of the significant connections between the PCA and the work of some DS writers concerns the notion of personal development. The PCA is essentially a process model where a central notion is that people's identities are shaped through

relationship. Identity formation is an ongoing process where people are always in a process of 'becoming' (Rogers, 1961), meaning that the self-concept moves and changes as the person encounters different life experiences and relationships. This process is verified from a neurobiological perspective, where there is evidence that people can reappraise what they perceive in others and respond accordingly (Goleman, 2007). Although they do not make the connection with the PCA, Sheila Riddell and disabled writer Nick Watson's work on disability (2003) suggests that through the interaction with other people, a person's identity can not only be formed, but also reformed and challenged. Watson (1998) explores how disabled people can change the way they view themselves by learning how to live with their impairments. His research demonstrates that this process often begins by the person denying their impairment and refusing to talk about that aspect of their lives. When they meet other disabled people, they develop an awareness of societal attitudes towards disability. Having this awareness enables them to challenge negative attitudes expressed by non-disabled people and to find their own unique ways of living creatively. Through this process, they become more self-accepting and learn to make satisfying relationships with other people. Watson's research indicates quite strongly that people can integrate their experience of disability into their self-concepts and that they can do this through being in relationship with other people.

Most of the literature and research on disability from a person-centred perspective involves working with clients who have severe learning difficulties (notably Hawkins, 2002 and Portner 2005) and who are 'contact impaired' (Prouty, Van Werde and Portner, 2002). Pete Sanders (2005) writes forcibly against the medicalisation of people who have psychiatric diagnosis such as schizophrenia and makes a case for a social understanding of their conditions. Richard Bryant-Jefferies (2004) writes about working with clients who have progressive conditions but he does not consult any work by disabled writers and focuses solely on the loss approach. None of these writers declare themselves to be disabled and although they all write sensitively about their client work, they write from the practitioner perspective. One of the key contributions to knowledge in this field is to offer a client perspective which is, by definition, in keeping with the PCA.

2.5.2. A client perspective

Mark Elliott and David Williams (2003:34) state that *“the mass of literature on counselling and psychotherapy invariably presents issues from the practitioner viewpoint”*. They argue that this perspective does not adequately portray the experience of being a client. In particular, it does not offer insight into how the client feels about the counsellor even though this can make or break the counselling relationship and process, especially at the early stages. Henkelman and Paulson’s research (2006:142) indicates that *“that much can be learned from clients’ assessments of counselling”* and that their *“viewpoints are critical to furthering understanding of hindering experiences”* (p139) because *“counsellors and clients make different judgments about what is of value in counselling and what is actually happening in counselling”*. With this in mind, my research focuses on learning about disabled clients’ experiences by exploring the disconnections that can occur in the counselling relationship.

Disconnection in the person-centred counselling relationship is usually understood in terms of the first and sixth of Rogers’ therapeutic conditions (see Appendix A). The clients must be in psychological connection with the counsellor and the client must perceive the counsellor’s genuine warmth and acceptance for counselling to be effective. Keith Tudor (2011:170) states that

“A co-creative relational perspective emphasizes the necessary dialogue between therapist and client about how the client experiences and perceives the therapist and, specifically, her or his acceptance and understanding. This is consistent with ideas about working with ruptures and repairs in the therapeutic relationship”.

Having argued about how crucial this process is, he goes on to say (ibid p 176) that this is *“the least researched or discussed of all of Rogers’ therapeutic conditions”*.

2.6. Summary

I have established that for disabled people, interpersonal relationships are often compromised at all levels of social living both by the constraints of the environment and by the effects of living with the limitations that arise from impairment. As an oppressed social group, disabled people can feel marginalised because of the powerful role that societal conditions of worth play in Western cultures. This can have a damaging effect on their personal development and the formation of their identities, which are often shaped by shame and internalised oppression. All of this can inhibit disabled and non-disabled people from talking about disability and impairment in ways that are value free. The disability movement in the UK, as represented by DS can be a forum for peer support but many disabled people do not choose to belong to groups of this nature. DS can be conditional in its acceptance of disabled people as there is resistance to supporting them emotionally and in their everyday struggles because of the emphasis on political action. Theoretically, counselling, and in particular the person-centred approach, is an appropriate forum for disabled people to talk about their everyday emotions and struggles but DS writers highlight many of the issues that militate against this.

DS writers have introduced debates and insights into understanding the lives of disabled people that can be useful in a counselling context. Counselling literature offers further insight into the potential relational effects of disability but there are significant gaps in knowledge of disability in this field. I hope to contribute to these debates and insights by bridging the gap between non-disabled writers in the field of counselling and disabled writers in DS by opening a dialogue between both perspectives. This is particularly important since, as disabled academic Colin Cameron (2010) points out, very few people have the knowledge, skill and motivation to help disabled people make sense of their experience. Disabled writer Tobin Siebers (2008:48) says

“We of the tender organs need to think about ways of telling our stories that will communicate the truth of our existence as a group facing prejudices and other barriers, often physical, put in place by society at large”.

Not only should these stories be told, but it is vital that they are told accurately and in their entirety so that they challenge the culturally assumed notion that disability is a tragic state. Jenny Morris (1991:71) sums this up saying

“In order that our lives can be seen in a balanced way, we must demand the right to be heard when we assert that there are wonderful things about being disabled. But we must also demand that it is we who define the negative things about the experience – and not the medical profession, health and social services professionals, parents or other non-disabled people”.

In a sense, this research is my story as it is informed by my own experience, by participants' experiences and by writers in the field of DS and counselling. I seek to generate knowledge and understanding of disability in the counselling field and to add substance to the dialogue about counselling within the field of disability. As I said at the beginning of this chapter, the overarching aim of the research is to do this by exploring the troublesome issues that routinely arise for disabled people in interpersonal relationships; to find out how these issues affect them psychologically and emotionally; to find out if and how they explore these issues in counselling and to discover how counselling can be used to improve their sense of connection with themselves and with others in their social spheres. In particular, I seek to address the following questions:

1. What difficulties do people experience in their relationships with others that they directly associate with being disabled?
2. How do these relational difficulties affect disabled people's emotions and behaviours?
3. How do these relational difficulties shape disabled people's self-concepts and sense of agency?
4. How do disabled people experience the counselling relationship and process?
5. What impact might counselling have on the way that disabled people relate to themselves and others?

In the next chapter, I outline how I plan to tackle the research aim and questions by discussing the way that I approach and conduct the research.

Chapter 3: Methodology

I turn now to the question of how I might address my research aim and questions. I intend to conduct the research in a way that is in keeping with my philosophical and theoretical approach to counselling. The line between conducting qualitative research and listening to others in the context of counselling can be quite blurred at times as the philosophical basis for both activities can be similar. There are significant overlaps between each activity so I need to address where they converge and where they differ. This will enable me to steer a path for the research and formulate an appropriate methodological approach. My research questions demand depth rather than breadth responses so they do not lend themselves to a measurement-based approach (Flyvbjerg, 2001). There are challenges in pursuing this form of qualitative research particularly as it involves exploring subjective experience, relationships and emotion that are by nature different for every individual.

My research questions are orientated towards the perspective of disabled people so it is possible to think of this as 'insider' research. I recognise there are problems in thinking of people as 'insiders' because everyone experiences disability differently. However, a disabled person's standpoint can offer insight to those who do not have this experience (Scully, 2010). Disabled people are more likely to be aware of the problematic issues that arise in their relationships with non-disabled people because they often find themselves managing social situations in order to appear as 'normal' as everyone else. Jodie Taylor (2011: 4) argues that an 'insider' researcher may offer practical advantages which, for this research might include having deeper levels of understanding, easier access to participants and rapport and trust between researcher and participants. On the other hand, Nancy Naples (1997:71) points out that the insider-outsider notion is a false one because of the issue of intersectionality. She suggests that

“The concept of “outsider phenomenon” highlights the processes through which different community members are created as “others” – a process in

which all members participate to varying degrees – and which findings of “otherness” are incorporated into self perceptions and social interactions”.

I plan to follow my research interest by capturing moments when the experience of being disabled matters to people – moments when they experience ‘outsider phenomenon’ in their relationships.

As a counsellor, my work involves listening and responding as people as they talk about difficult experiences but I understand what they tell me through a particular theoretical lens, namely the person-centred approach. As a researcher, I need to find a methodological framework that will enable me to pursue my interest in a robust and ethical manner. My research involves finding a way to make the intimacy of the client/counsellor relationship and process available to others for scrutiny and learning. That is a challenging task that has methodological and ethical implications.

3.1. The challenges of researching lived experience

As Catherine Riessman (1993:8) states, *“investigators do not have direct access to another’s experience. We deal with ambiguous representations of it – talk, text, interaction, and interpretation”.* Person-centred counsellors understand experience from a humanist, phenomenological perspective where an individual’s reality is understood to be the only reality that exists. From this viewpoint, there are no universal truths to be discovered about peoples’ experiences but instead, as Shake Toukmanian (2002:115) points out,

“People see what their experiential frameworks allow them to see and they make sense of what they see by developing ways of knowing and creating a version of reality that gives meaning, continuity, and coherence to their view of self, others and events in their everyday functioning”.

The only person who knows what they experience is the person who is having that experience.

It has been noted that person-centred counselling and phenomenological research are closely aligned since the fundamental premises are similar (Mearns and McLeod,

1984). It seems, therefore, that phenomenology is an appropriate way for me to approach this research. Psychologist Darren Langdrige (2007:9) states that

“A phenomenological approach offers a radical alternative to traditional understanding about what we believe we can know about the world and therefore, by implication, what we believe we can know about human nature”.

He argues (ibid) that human experience is a valid topic for research that can offer

“rich descriptions of people’s experiences, so that we can understand them in new, subtle and different ways and then use this new knowledge to make a difference to the lived world of ourselves and others”.

He points out that the focus of this approach to research is on first person accounts of life experience and that empathy is a crucial quality for researchers to adopt as they seek to discover and understand these accounts. However, there are limitations to this approach, since we can never completely understand what happens for other people internally let alone communicate that to others as a researcher seeks to do. Some of the ways of addressing this issue are to pay attention to the context in which the communication takes place; to address the issue of interpretation of what is being said and to listen to what is being communicated with an element of reflexivity. I discuss these issues in the following sections.

3.1.1. The significance of context

Perhaps the major problem involved in seeking to understand and communicate other people’s experiences is that normal human behaviour includes having preconceived ideas and assumptions about people and events (Langdrige, 2007).

Denzin and Lincoln (2000:18) note that the

“Individual researcher enters the research process from inside an interpretive community. This community has its own historical research traditions, which constitute a distinct point of view. This perspective leads the researcher to adopt particular views of the ‘other’ who is studied”.

Mark Aveline (2005:135) adds that *“the therapist shapes what happens by selective attention and inattention, filtering what is observed through personally held theory”.*

In a similar vein, Gergen and Gergen (2000) prompt me to acknowledge that as a

person-centred counsellor I am likely to favour the voice that suggests something that is in keeping with my theoretical bias.

Counsellors and researchers attempt to resolve this issue by continuously developing their awareness of personal biases by critically examining them so that they can be 'bracketed'. Otherwise known as 'epoche', this term is used in phenomenological research to mean *"the process by which we attempt to abstain from our presuppositions, those preconceived ideas we might have about the things we are investigating"* (Langdrige, 2007:17). Researchers aim to do this in order to attend to what is being said instead of what they *think* is being said. In person-centred counselling, bracketing takes the form of the 'as if' quality which is an integral aspect of empathy. Mearns and Thorne (2013:55) state that

"Empathy is a process whereby the counselor lays aside her own way of experiencing and perceiving reality, preferring to sense and respond to the experiencing and perceptions of the client. [...] with the counsellor actually experiencing the thoughts and feelings as powerfully as if they had originated in herself."

Bracketing in this sense involves the counsellor, or researcher, being fully present to the client, or participant's experience while maintaining a sense of what is happening experientially for him/herself. This involves a high degree of self-awareness and the capacity to distinguish the client's 'frame of reference', meaning their way of experiencing themselves and the world around them (see Mearns and Thorne, 2013). The counsellor, or researcher, is then able to listen fully while avoiding being overwhelmed by the client's or participant's material and capable of reflecting on the whole encounter. In this way, all of the material generated becomes available for analysis in the research.

What counsellors do not so easily recognise is that preconceived ideas and assumptions arise within social, historical and political contexts (Chantler, 2005). These contexts are fundamentally important in feminist research. Together with other feminist writers in DS, Barbara Fawcett (2000:108) recognises that

"Postmodern feminism(s) rejects objective standpoints, universal and rationally sanctioned positioning and emphasises the importance of viewing

all knowledge claims (including those of feminists and disabled people) as non-innocent, as privileged and as historically, socially and culturally located”.

Researching lived experience therefore involves recognising and identifying the prejudice and assumptions that are the basis for the interpretations we make about what other people are experiencing.

3.1.2. The issue of interpretation

Although researchers and counsellors may be able to bracket their assumptions and prejudices when they listen to others, however skilled they are, they can only understand another person through the lens of their own experience. A feminist approach to research offers the opportunity to become aware of, and to examine our own social, political, cultural and historical perspectives. This enables us to appreciate the impact of these forces on the way that we understand both ourselves and others who are involved in the research. Gergen and Gergen (2000:1096) explain that *“it is from our relationships within interpretive communities that our constructions of the world derive”*. As I have said, the quality of empathy is as essential in research as it is in counselling where there is an attempt to understand what another person is experiencing. A counsellor’s understanding involves both listening to what the person is saying and what they may be expressing non-verbally. Some sensations, emotions and thoughts are expressed subtly beneath the surface of what is said in words (Langdridge, 2007). In order to gain the fullest possible understanding of another person’s inner world in counselling research, it is helpful to read the signals that are not always expressed in words or that contradict what is being said. An obvious example of this is that people often smile when they talk about difficult experiences. Noticing this contradiction can prompt the enquirer to seek further information about what is happening for the person. In such a case, interpretations can be misleading unless further questions are asked.

One way of addressing the issue of interpretation is for the researcher to set aside the positivist approach of trying to be objective about human experience and to recognise that there is *“never a finally correct interpretation”* (Schwandt, 2000:195).

Flyvbjerg (2001) takes the view that context is an integral aspect of qualitative research. Instead of seeing this as a limitation, he argues that *all* research is context dependent, whether in the natural or the social sciences. He argues that no evidence is stable and that we are always working with the 'double hermeneutic' (Giddens, 1993). In other words, we are working not just with our interpretations but also with other peoples' interpretations of their own experiences. Schwandt (2000:195) states that

“Reaching an understanding is not a matter of setting aside, escaping, managing, or tracking one’s own standpoint, prejudgements, biases, or prejudices. On the contrary, understanding requires the engagement of one’s biases”.

This form of engagement points towards a reflexive approach.

3.1.3. Reflexivity

Writing about reflexivity, Marilyns Guillemin and Lynn Gilliam (2004:276) make the bold claim that *“the researcher’s practice is actually embodying his or her principles”*. In terms of both counselling and research, person-centred writers Pete Sanders and Paul Wilkins (2010:183) define reflexivity as

“The ability to stand back and assess aspects of your own behaviour, society, culture and other aspects of experience and upbringing in relation to such factors as [...] motivations, origins and meanings. Because we are all shaped by our environment, our thoughts, values and ideas are inevitably and inherently [...] shaped and coloured. In other words, as free and liberal as we may believe ourselves to be, we are all biased. Moreover, we carry this bias into all aspects of our lives including our research. Reflexivity is a deliberate attempt to acknowledge and take account of our biases and to act with awareness of them”.

Guillemin and Gilliam (2004:275) point out that acting on this awareness means *“to take a step back and take a critical look at his or her own role in the research process”*. They argue that this process of 'critical scrutiny' involves the researcher in self-searching and that it should be applied to every aspect of the research, from methodology context and data collection to the researcher's relationship with the

participants and to the participants themselves. Kim Etherington (2004:46) makes this approach more explicit, saying that it

“requires researchers to operate on multiple levels, being aware in the moment of what is influencing our internal and external responses, while also being aware of what influences our relationship to our topic”.

Gergen and Gergen (2000:1027) add that *“research reports are essentially exercises in interpretation”.*

Reflexivity is a necessary element in researching lived experience at all stages in the process. Social science researcher Linda Finlay (2003) examines how this can be applied, noting that the researcher’s personal history will always have an impact on the research. She suggests that transparency may include some discussion about the decisions, dilemmas and challenges that are encountered in the research process. My understanding is that these may be connected with the researcher’s own personal challenges. As Finlay suggests, it is important for the researcher to state their emotional investment in the research; to consider how power and the resultant tensions operate in the research process and to be transparent about how the researcher is situated within the project. Finlay (ibid p8) qualifies this by stating that personal experience can act as *“a springboard for interpretations and more general insight”.*

In chapter 1, I discussed the aspect of my personal history that acts as my particular ‘springboard’. I have accrued substantial life experience over the years and I developed the capacity to reflect on these experiences with a high degree of self-awareness through being a client in counselling. This has afforded me a degree of emotional distance from my experiences so that I can bracket them in order to attend to other people’s stories.

I discuss the issue of reflexivity further in 3.2.3 and 3.3.2 where I address my relationship to this research.

3.2. A narrative approach

A narrative approach to research is closely aligned with phenomenology and with counselling because it is a way of attending to people's experiences as they understand them at any given point in time. Donald Polkinghorne (1988:159) points out that *"a function of the human sciences is to read or hear and then interpret the texts of human experience"*. John McLeod (1997:34) uses the term 'narrative knowing' to describe how personal experience can be understood. He says that *"a story imparts information about the inner world of the storyteller or the person(s) about whom the story is being told"* and *"stories also convey direct and indirect information about the social and cultural location of the teller"* (ibid p38). As with phenomenology, Riessman (2008:187) points out

"A narrative is not simply a factual report of events but instead one articulation told from a point of view that seeks to persuade others to see the events in a similar way. Verifying the facts is less important than understanding the meanings".

A further point is that *"a narrator tells a story, but in doing so offers something over and above the bare story"* (McLeod, 1997:34). In counselling, this is about the meaning that a person makes about their experience but in research is also about communicating the meaning of people's experiences to others.

Riessman (2008:3) explains the basic premises of a narrative approach, saying that

"A speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story. Events perceived by the speaker as important are selected, organized, connected, and evaluated as meaningful for a particular audience".

This is essentially what clients do in counselling. In keeping with Riessman's work, I use the terms storytelling and narrative interchangeably.

A narrative approach is as an appropriate way of researching the lived experience of relating to others as a disabled person and of being a client in counselling for several reasons. Firstly, stories tend to have a structure where the narrator locates what

they are saying in the context of time and place (McLeod, 1997). Within that structure, stories express the meanings that the narrator makes of events and they are always shaped by their audience who in turn will make their own interpretations of what they read. Interpretation is an intrinsic aspect of storytelling and the interaction between the narrator and the audience, particularly in a one-to-one situation like counselling, means that the story is co-created. McLeod (1997:37) explains that *“the listener or audience may feed their own alternative accounts into the story that emerges, or may seek clarification by asking questions”*. Stories are told as pinpoints in time (Polkinghorne, 1988:121) where

“A person in the present can differ from her previous manifestations, and an early experience can now have a different meaning than it had when it occurred. The change in meaning comes from a reconfiguration that is possible in the narrative process”.

Telling a story is like painting a picture where the aim is to capture the essence of a moment as it is co-created, understood and interpreted at any given moment and to convey that moment to a particular audience.

3.2.1. Relationship narratives

A phenomenological perspective begins with the notion that human beings are born into and live their lives in relationship with others (Langdrige, 2007). A primary assumption is that when people become conscious, their consciousness always has an object – they are always conscious of something (intentionality). The object of study in phenomenology is the relationship between a person’s consciousness and the world they inhabit, which includes the relationships between people (intersubjectivity) (ibid p14). From a counselling perspective, this involves investigating the relationship that people have with themselves and others. Lyons, Sullivan, Ritvo and Coyne (1995:8) point out that when people tell stories about their relationships with others, they may be referring to what happens on several social levels. The first of these is ‘interactive networks’, meaning the relationships people make when they are in direct communication with other people. Mutual support is offered in ‘exchange networks’ and close relationships are formed with ‘significant others’. Perlman and Vangelisti (2006) use the term ‘personal relationships’ to

incorporate relationships that may or may not be exclusively intimate. I aim to find out about how disabled people experience relationships in any or all of these ways.

As I have said, people's consciousness is directed both outwards to others and inwards towards the self. McLeod (1997:39) states that as people tell their stories in counselling, they are at the same time formulating their own identities and that "*These new stories are then used back in the everyday world to construct different patterns of relationship and feeling*". Researching the lived experience of being disabled in the context of relationships involves considering embodied, psycho-emotional, cognitive (thoughts and beliefs) and behavioural (for example, Seligman's (1975) notion of '*learned helplessness*' where people become passive in relationships as a result of medical treatment and dependency on others). All of these elements are parts of the meaning-making process. According to Langdrige (2007), a phenomenological approach involves understanding that consciousness is embedded in the body and that people perceive their experiences in an embodied manner. As I have shown, this notion may be uncomfortable for the DS writers who prefer to leave bodily experience out of their research but it is intrinsic to a person-centred understanding of the person. This indicates the potential for tension in approaching issues that concern the body in this research and I address this in section 3.3.1 and 3.3.2.

As Polkinghorne (1988:112) points out "*when the story-making process is successful, it provides a coherent and plausible account of how and why something has happened*". As a story-making process, this research involves an exploration of the ways in which disabled people become disconnected from themselves and others. The process also involves finding out about the ruptures that might appear in the counselling relationship and process. I aim to find out if the sense of disconnection features in the form of ruptures in counselling and to find out how counselling might enable disabled clients to become more connected with themselves and others. As an investigation that is not measurable, there are questions about the validity and rigour of the research. .

3.2.2. Establishing validity in narrative research

Lucy Yardley (2000) asserts that there is a need for *“open-ended and flexible ways of assessing quality”* in qualitative research. She adds that if this does not happen, the research methods used are likely to be judged by the same criteria as culturally dominant quantitative research even though both approaches stem from radically different philosophical standpoints. She argues that the style and presentation of research should be meaningful to the people who are most likely to use it. As I have shown, counsellors and phenomenological researchers understand meaning through the co-construction of stories so this approach is likely to make sense to an audience that has an interest in counselling. It can be assumed that this kind of audience would be equipped to assess the quality of the stories that are presented albeit from their own personal and theoretical perspectives.

Along with attention to context and reflexivity in qualitative research Yardley (2000:221) stresses the importance of understanding language as the primary way of communicating whether this is in the form of text or speech. She states that *“linguistic and dialogic context of each utterance is crucial to interpreting its meaning and function”*. In a narrative approach, language is considered to be a resource that is used to tell the stories but it is not the subject of analysis itself (Riessman, 2008). Langdridge (2007:161) explains that *“language is fundamental in revealing the world and our relationship to it”* and as such, it depicts personal meanings within the confines of the linguistic and cultural structures that are available to people.

Riessman (2008) points out that recipients of narrative research may be sceptical about the stories they read and that they will make sense of them through their own perspectives. Given the negativity displayed by some disabled writers about counselling, it is important for me to present stories in such a way that they can be critically evaluated alongside each other. This means that I need to consider presenting a range of stories that are told by a fairly diverse group of participants thereby ensuring that I provide what Riessman (ibid) refers to as a ‘cumulation of evidence’.

A further way for the reader to assess the quality of the research is through what Gergen and Gergen (2000) call 'literary styling', where stories can be presented in such a way that they offer an informed point of view. Riessman suggests that the researcher aims to be persuasive by ensuring that stories are linked in a consistent manner and that gaps and inconsistencies are addressed. Following from that, stories are presented to evoke 'sympathetic resonance' (Anderson, 1998). This means that the reader will recognise what is being written because it resonates emotionally with their own experience, or with experiences they have witnessed in others. This form of validation provokes thought and offers opportunities for readers to think differently about a topic (Riessman, 2008).

3.2.3. Positioning myself within the research

I return to the matter of reflexivity as a way of validating the research. One important aspect of this, as Adriansen and Madsen (2009) suggest, is to reflect on my positionality in relation to the research in order to reveal something of my complex relationship with the project. I have already pointed out that we are all members of some groups and outsiders of others so we have multiple statuses in relation to other people (Naples, 1997). However, in this research, several of my roles conflate in ways that deserve attention. Breen (2007:163) notes that insider researchers are considered to be *"those who choose to study a group to which they belong, while outsider researchers do not belong to the group under study"*. To some extent this could be considered to be my position since I am a disabled woman and a counsellor. Adriansen and Madsen. (2009:145) note that the term *"double insider means being an insider both in relation to one's research matter [...] and in relation to one's interviewees"* and indeed, this depicts my position should I choose to conduct the research by engaging in interviews.

The literature on insider/outsider research suggests that, as an insider, there are both advantages and disadvantages. An insider may have some previous knowledge of the context of the research (Adriansen and Madsen, 2009). He or she may be aware of the culture of the group and the people who associate themselves with it and may be communicate more easily with others in the group (Breen, 2007).

On the other hand, disadvantages include a lack of distance from the research, meaning that the researcher is so involved with and immersed in the material that they cannot maintain a critical stance (Adriansen and Madsen, 2009). Assumptions may be made that may not be known to outsiders (Gair, 2012) and sometimes these assumptions may be erroneous (Breen, 2007). Gair (2013:137) states that

“The notion of insider/outsider status is understood to mean the degree to which a researcher is located either within or outside a group being researched, because of her or his common lived experience or status as a member of that group”.

This prompts me to reflect on the fact that I am far more immersed in the counselling culture and with the discourses that are embedded in the profession than I am in the disability culture. I have been a practising counsellor for over twenty-five years and a supervisor and trainer for much of that time. My work as a counselling trainer in an academic setting means that I have a wide knowledge of the counselling literature and that I engage with that literature on a regular basis. In addition, I have a wide range of personal relationships with other people in my profession. In terms of my engagement with the disabled community, however, it was only when I began this research that I encountered the culture and key discourses and met with other disabled academics and researchers. Before that, I had worked with several disabled clients and students and was aware of issues that arose from my own experience such as shame and disempowerment but I did not articulate those in terms of social and cultural conditions of worth and I was only dimly aware of the Social Model of Disability. Until then, I have not associated myself with a particular group of disabled people in the sense that I meet with peers on a regular basis. I have always experienced myself as the only disabled person in my social and familial groups. The disabled ‘community’ for me is simply a set of people who have similar experiences to mine and that I sometimes communicate with through personal networking and social media. From time-to-time, I engage with an international network of people through social media who have polio as I do. Here, we discuss issues of concern that are connected with our conditions. This helps me to understand my own condition more fully and to feel connected with others who share something of my experience. Members of this group do not discuss the politics of disability. My involvement with the disabled community could there be

considered to be either an insider or an outsider but I now think of myself as an insider who sits on the margins of the culture and a fully fledged insider in terms of the counselling community.

As Gair (2013), among others, points out, the insider/outsider dichotomy is rather simplistic. Gair (ibid, 138) argues that *“insider/outsider status might not automatically mean a critical awareness, accurate empathy or enhanced insight and understanding, or a lack thereof”*. As a disabled woman, I cannot assume that I am fully aware of the experience of other disabled people whose gender identities; sexual orientations; racial, cultural or social backgrounds or who have different impairments from mine. As a counsellor, I have a wealth of experience to draw on but I cannot ever assume a full understanding of another person’s experience. As Gair (2013:138) points out, *“a simplistic dualism of researcher as either an empathic insider or an ill-informed outsider”* can undermine the complexity of the research. Instead, the roles are more fluid than they may appear. This highlights something of the complexity of my position. For example, my experience of living as disabled woman enables me to appreciate the sense of estrangement that other disabled people often feel. It enables me to identify with many of the writings available to me in Disability Studies (DS). On the other hand, my experience as a counselling client and a counselling practitioner persuades me that counselling can have a positive role in disabled people’s lives, contrary to what I have read in some of the DS literature. .These two positions enable me to critically engage with both.

A further point is that the roles of counsellor and disabled woman are not static but instead, they play out in this research in a fluid d rather than a static manner. [Adriansen](#) and [Madsen](#) (2009:151) point out that *“the roles are dynamic and can be negotiated during the research process”*. For example, I evaluate the disabled literature from a counselling perspective and the counselling literature from the position of a disabled woman. Additionally, I can engage with both academic fields as either an insider or an outsider. If I choose to conduct interviews, I may use my counselling skills while maintaining the stance of researcher and I might be seen by participants, or indeed regard myself, as a peer. The roles are likely to be intertwined in many different ways. .

What the insider/outsider debate does highlight is that power dynamics play a significant part in qualitative research. My role as researcher is intrinsically one of outsider because I position myself at a degree of distance from the material. As [Adriansen](#) and [Madsen](#) (2009) point out, the researcher directs the whole research project and chooses how it will be presented; he or she selects interview participants and formulates the research questions. [Adriansen](#) and [Madsen](#) (ibid p 149) state,

“Even though the researcher and the researched may be placed in the same landscape of power, there is still a distance between them due to the analytical power of the researcher”.

Writing about research interviewing Finlay (2003:5) stresses the importance of attending to the *“power balance between researcher and participants”*. My research is located within the university where I teach counselling on professional programmes and in my other professional role I have my own private counselling and supervision practice. When I approach people to become involved in my research, I might expect that some will regard my position as relatively high in status and this might affect the way they respond to my questions. Indeed, my professional experience and interest in the topic strengthen my sense of legitimacy in the project. I am heavily involved in the counselling profession and I take a positive but realistic view of it. However, as Langdridge (2007:49) points out, as a researcher, it is vital that I retain a *“voice of ‘suspicion”* so that I can stand back and appreciate other experiences that are different from my own.

I do not always recognise my own power in relation to other people because I feel that other aspects of my experience undermine my sense of self. I live and work in a middle class environment but I was brought up in a family that had relatively low social status in the community. As a disabled person I often feel less powerful than others in relationships. The power that other people sometimes attribute to me does not always equate with my sense of self. I have engaged in several lengthy periods of counselling as an adult both because that is a prerequisite of my role as a counsellor and because I have experienced low self-esteem, depression and anxiety at different points in my life. It is possible that I will feel both powerful and powerless at different points in this research process and I may find that other disabled people share something of my experience. However, as a researcher, I will need to be

aware of where and when power is at play so that I can maintain this position. To an extent, I am predisposed to doing this since awareness of power is a key characteristic of person-centred counselling. In keeping with this approach, my aim is to work collaboratively with others who participate in my research as far as possible. .

Returning to the insider/outsider debate, it is notable that several qualitative researchers have pointed out that the quality of empathy surpasses this dichotomy. Gair (2013:139) points out that

“There appears to be agreement throughout the literature that qualitative researchers and research students need to listen intently to understand the lived reality of participants, whether those researchers are positioned as insiders or outsiders”.

Gill (ibid) goes on to say that

“This quest is to hear, feel, understand, and value the stories of others, and to convey that felt empathy and understanding back to the client/storyteller/participant. At times, this quest might extend to learning collective lessons from the stories and presenting that learning to readers in a way that preserves empathy.”

Qualitative researcher and counsellor, Liz Bondi (2003:73) notes that *“empathy enables people to engage in the work of communicating and understanding aspects of their experiences across a multiplicity of differences”*. She argues that as one of the counsellor’s key qualities, empathy can operate in the research context and particularly in the context of interviews. As a person-centred counsellor, I can listen to and reflect on what a participant is saying both overtly through their words and more subtly through their tone of voice and body language, while attending to my own thoughts and feelings in relation to what is said. This is what Carl Rogers refers to as the ‘as if’ quality (see Mearns and Thorne, 2013:55). Writing about research interviews, Bondi (ibid p 73) notes that *“the capacity to shift between immersion and reflection, or between participating and observing, creates space in which to manage the encounter openly and respectfully”*. This statement could equally refer to all aspects of engaging in qualitative research and as a counsellor it is an approach that enables me to apply an element of distance to this project.

It is becoming clear to me that, as Finlay (2003:5) points out, *“the boundary between the researcher and the research is blurred”*. This may continue to be evident as I move on to a discussion of how I put these principles into practice.

3.3. Conducting the research

Polkinghorne (1988:163) states that *“people strive to organize their temporal experience into meaningful wholes and to use the narrative form as a pattern for uniting the events of their lives into unfolding themes”*. One of the first questions that arose for me when I began to think about conducting the research was how to work from this premise. I identified several ways of finding out about other people’s experiences. I could communicate with people by inviting them to write their stories; through social media groups; through analysing documents that I could find in literature and social media or through conducting focus groups. While I could appreciate that writing about personal experience can be therapeutic (Couser, 2010; Frank 2000), this was not the specific aim of my research. I could have communicated with people in a similar way online through social media groups. While any of these methods would have been possible, *“for a researcher, the basic source of evidence about the narratives is the interview”* (Polkinghorne, 1988:163). Polkinghorne (ibid) asserts that questions elicit narrative explanations and I have several reasons for choosing to formulate this research as a direct question and answer inquiry.

3.3.1. Why interview?

The desire to connect with other disabled people drew me to this topic and I was motivated to find out how their experiences compared with my own. During my time in counselling, it was very difficult for me to talk about my impairment, partly because I had always kept my thoughts and feelings about that to myself, which was a lonely and anxiety-provoking experience. As I said in chapter 1, when I was finally able to talk about being disabled it evoked a sense of shame that was dissolved by the warmth and keen attention of my counsellor. My sense was that it would be easy for

counsellors to miss this kind of hidden experience so I wanted to highlight this issue by telling both my story and the stories of others.

This led me to conclude that I wanted to talk with clients and not counsellors because only disabled people themselves would know about how their experiences of disability and impairment would affect their relationships with themselves in others. This idea is validated by Elliott and Williams (2003:34), who note that *“the mass of literature on counselling and psychotherapy invariably presents issues from the practitioner viewpoint”*. They argue that this does not convey what it feels like to be on the receiving end of counselling and (ibid p36) *“success thus depends on how the therapist is viewed”*. Person-centred counsellor Keith Tudor (2011:177) adds that the *“radical emphasis on the client’s report and reality is, in practice, missing from most accounts of the therapeutic process and relationship, and in training”*. Henkelman and Paulson (2006:143) point out that *“the stories of hindering experiences”* can reveal what *“clients are not saying”* and that practitioners can learn from these stories because they are vital to the success or otherwise of the counselling endeavour.

I was persuaded to go ahead with interviewing people on a one-to-one basis because this was familiar territory for me as a counsellor and in this way I would be suitably equipped for the task. The skill of the counsellor is to enable the client to identify personal issues and to articulate and express them emotionally, cognitively and by means of tone of voice and embodied communication. The notion of ‘edge of awareness’ material, meaning communication that is un-symbolised and un-processed but close to the surface of a person’s internal experience (see Mearns and Thorne, 2013), is a further aspect of person-centred counselling that may be applied to being present with people in the context of interviews. This involves listening to what the client communicates in subtle ways that are not immediately apparent but that become clear through the process of talking and listening. The client becomes aware of what is happening internally but that is not yet symbolised into language. It would have been more difficult to engage in such full communication in any other way than through meeting in person. The use of empathy in a counselling approach involves listening. The client becomes aware of

what is happening internally but that is not yet symbolised into language. It would have been more difficult to engage in such full communication in any other way than through meeting in person.

The use of empathy in a counselling approach involves listening carefully and continually checking with the client that what is heard is understood accurately but this method in research could only be used if the researcher is in one-to-one spoken interactions. The challenge in using counselling skills in research interviews would be to be aware that both approaches are different. A researcher generates stories that arise as responses to direct questions rather than from the interviewee's chosen topic whereas in counselling, the client decides on the content of the interview. In a similar vein, my research does not have a direct therapeutic purpose for participants as I have said.

3.3.2. Preparing myself for the interviews

Before I began to conduct the interviews, I was aware that, in conducting 'insider' research, *"the central research instrument in this context is a fallible, real, sensitive, fearful, fearing, anxious person"* (Soobrayan, 2003:118). I was further reminded that, in seeking to avoid 'insider blindness', I would need to be *"reflexive and self-conscious in terms of positioning, to be both self-aware and researcher self-aware"* (Taylor, 2011:9). With this in mind, I recorded the thoughts and feelings I had about asking people how their impairments and their experience of disability affected them in their relationships. As I said in chapter 1, I did not think of myself as a disabled person until I was in my mid-fifties when my condition was deteriorating and I was experiencing pain and the types of surgery that I had not had since I was a child. I had long ago buried my feelings about my impairment and I thought of myself as being like everyone else in the way that I lived my life. It was after a few years of long-term counselling that my disabled self began to emerge but that emergence was a painful process not just because of the difficult memories that arose, but also because of the intense shame that had caused me to bury my feelings in the first place. I began this research just a few years after that experience so I was acutely aware of the sense of shame that might arise for other people if I questioned them

about being disabled. I felt uncomfortable about inviting people to talk openly about what I perceived to be a personal and sensitive subject. I was concerned that I might be shaming them for no reason other than my own interest.

Another immediate concern was that I wanted my research to make a useful contribution to the existing knowledge about counselling disabled people. Questions about that were raised in my mind when I realised that this was not a desirable focus of attention in Disability Studies. Surprisingly, although I had been a counsellor to a few disabled people; supervised disabled counsellors; been a tutor on courses for deaf counselling students, I was not aware of hearing how disability was affecting them in relationships. Perhaps I had not thought of disability in that way because my own everyday experiences were so similar that it was like paying attention to the air that I breathe. I listened to and responded to issues that arose without thinking of them in terms of social and conditions of worth though I did not attribute these issues to the individual alone. I was aware of environmental constraints but did not articulate them in the way that I would now, having become more aware of the Social Model of Disability and related issues. In short, I did not feel sure enough about my proposed project to launch into interviewing disabled people without some form of consultation to help me orientate to the research. Through discussion with my supervisors, I decided to draw on the expertise of some people from my personal networks who were involved in counselling disabled people and who had been clients themselves. I invited them to join me in a discussion group so that I could have some experience of talking about disability and relationships; ascertain whether or not my research topic resonated with them and formulate my research and interview questions in the light of our conversations.

I set up this discussion group somewhat formally which, in hindsight is symptomatic of the hesitance I felt in broaching the subject. I thought of this as an advisory group but I structured the discussion following the guidelines that were available for conducting a focus group. I recognised that this format was a useful way to involve vulnerable, stigmatised or marginalised people in research because being with others who share similar experiences could feel supportive and conducive to speaking out (Peek and Fothergill, 2009). It was a way of enabling people, including

myself, to articulate our subjective experiences and to share insights into wider discourses (Barbour, 2007) which in our case involved the discourse of disability. We would be able to describe and evaluate their experience through the spontaneous expression of opinion and the structure would provide a quick way of finding the perspectives of several individuals in a time efficient way (Puchta and Potter, 2004). I selected a set of individuals who were disabled themselves; had been clients in counselling and who had strong connections with both the disabled and the counselling communities. I aimed to find between four and six people for the group, as suggested by Peek and Fothergill (2009) and I managed to find five people who were interested in taking part. For logistical reasons, only three managed to meet but I arranged to meet the other two separately at a later date.

In accordance with guidelines offered by Puchta and Potter (2004), I prepared simple questions for the group discussion, allowing time and space for spontaneous contributions which is consistent with the narrative approach to interviewing (Mishler, 1986). I sent an information sheet (see Appendix B.1) to each of the participants prior to the group discussion, along with the set of discussion questions (Appendix B.2) and I issued consent forms (Appendix B.3) at the start of the discussion which each participant signed. The group met in a room at my university workplace and I recorded the session, which lasted an hour and a half. I transcribed it in full shortly after. I wrote process notes immediately after the session to record my initial thoughts and feelings. The whole process confirmed that my intended focus on relational issues and the effects of these on the counselling relationship and process was likely to be highly relevant to disabled people. I noticed that participants were very keen to talk and to help raise awareness of disability in the counselling community so I felt assured that I was researching a topic that had the potential to make an impact both in the counselling profession and among disabled people including activists and writers.

3.3.3. Formulating the interview questions

It is widely suggested (Barbour, 2007; Peek and Fothergill, 2009; Puchta and Potter, 2004) that focus groups complement one-to-one interviews very well and this was

the case for me following the group discussion. On examining the transcript of that discussion and reflecting on what was said, I felt able to refine my research questions (see section 2.6) and to formulate them into questions for the interviews (see Appendix 2.6). The next step was to set about finding participants.

3.3.4. Selecting and finding participants

Having gained confidence in talking with people about their experiences of disability and establishing that my project was a potentially fruitful contribution to knowledge in counselling and DS, I began to think about how I would proceed. After I met with the three people who formed the advisory group, it became apparent that they all had stories to tell that would make a good contribution to the research topic. At the end of the group session, I asked them if they would be prepared to take part in the individual interviews. They all agreed but one had to pull out due to bereavement. The advisory group was in effect a starting point to help me gain a focus for the research and to orientate myself emotionally and in practical terms to working closely with other disabled people. The stories I have used in the thesis all emerged from the interviews and not from the advisory group itself. I had still to meet with the two people who had agreed to take part in the advisory group but who were unable to attend on the day we met. I felt that I had gained enough from the group session to feel comfortable about pursuing the interviews, so the two remaining people became my first interviewees.

As it happened, each of the first four interviewees had a different type of impairment so I became aware that this diversity of experience was going to be essential to the research. Gill (2001:369) suggests that

“Research on the social experience of disability should examine impairment-related factors such as visibility, type of impairment (including those affecting communication, expression, control of movement), preventability, and age of acquisition”.

This concurs with what Langdrige (2007:57) refers to as ‘maximum variation sampling’, which he considers to be the key method used in a phenomenological approach to interview research. Drawing on Polkinghorne (1989), he describes this

method as a way of looking for participants who have *“a common experience but who vary on as wide a variety of demographic characteristics as possible”*. As such, this is a purposeful, rather than a random method of finding participants that, according to Riessman (2008), is usual in narrative inquiry. Participants' common experiences would be that they identified themselves as disabled and that they would have been clients in counselling. If I wanted the stories to be persuasive to counsellors and other interested parties by providing a ‘cumulation of evidence’ (Riessman, 2008), I would need to recruit participants who offered a range of experiences. This might involve finding participants who are different from one another in terms of *“race, gender, sexuality and age”* Gill (2001: 366). Through the advisory group, I was aware that people with different impairments experienced relationships differently and that the age of acquiring impairment had a bearing on how disabled people view themselves and others (Shakespeare, 2006).

Initially, I was unsure about the possibility of finding suitable participants because of the specialised and sensitive nature of the topic. I estimated that I would need at least six participants to begin with. I considered how many interviews I should conduct, bearing in mind that the amount of data I generated would need to fit the purpose of the research and allow time to analyse and present my findings. As I have said, counselling in the UK takes place in private practice, healthcare and the voluntary sector and I wanted to represent each of these in my sample range. It was clear from the advisory group that some people prefer to be counselled by other disabled people (peer counselling) and others do not, so I looked for both experiences in my range of participants. I wanted to hear about the experience of being counselled by non-disabled counsellors because many of the relational issues that I have identified stem from the disabled/non-disabled binary.

Johnson (2001:114) suggests that researchers should *“make their connections with particular research communities explicit [...] so that competent readers may assess how standards were created and embodied”*. I found participants through my personal and professional networks using a snowballing approach (Roulston, 2010: 82). In this way, I could control the number of people I interviewed. Some people in my professional networks offered to act as intermediaries in finding clients who

would be interested in taking part in my research. I informed them about what I was looking for so they were able to suggest people who identified themselves as disabled and who were able to talk about their experiences. I spoke at two conferences in the early stages of the research and I met some counsellors at these events who offered to help me in this way. I had access to some disabled people through my position as a counselling trainer at the University of Edinburgh and I found some participants from there.

I reasoned that it was important to interview disabled clients without including their counsellors' perceptions and my rationale was that disabled people's voices are not often heard and that most of the counselling literature is written by practitioners. As I have shown, disabled people often feel disempowered by medical professionals and the voice of the carer is often the one that speaks for them. There remained the issue that the first interviewees were counsellors from the advisory group who talked about their experiences of being clients. I chose these people because I was aware that, as trained counsellors, they would have been accustomed to reflecting on and articulating their own experiences. In addition, they would be familiar with seeking out sources of support if they became distressed.

Writing about using friends as research participants, Taylor (2001:15) advocates the use of a mixture of known and unknown participants in social research. She suggests that selecting participants from within and beyond friendship groups provides a checking mechanism, especially in terms of how a particular culture is understood. Too much insider data makes it difficult to have analytical distance and may result in what she calls 'insider blindness' where mundane everyday knowledge can be missed. I applied this principle to my research by extending the net of participants to include people who had no involvement in counselling other than being clients so that I could gain different perspectives on the counselling 'culture'. Equally, I thought it would be important to include people who had an involvement in the disability community as well as others who did not. Each group would have something to offer to the depth of the data generated as Johnson (2001:111) suggests when he says that the best participants are those *"who can provide a 'thick' description and who do not necessarily theorise or analyse"*.

There is an argument for considering mental illness as a subset of disability but this is an intrinsic element in the research because all participants would be talking about their experiences of being counselling clients. This does not mean they would be mentally ill but they would have been psychologically and emotionally distressed at some point in their lives.

I considered what I wanted to achieve through the range of people that I found (Mason, 2002). I was aware of the relative absence of literature in counselling about disability issues and the low profile this group of people have in the profession generally so I wanted to highlight the many and various relational issues that can occur for disabled people. I reasoned that this might provide an open door for counsellors who have fears and anxieties about working with disabled people and offer knowledge and insight that might enhance their work. I also wanted to offer insight into the counselling process for disabled people who have misgivings about entering counselling and sceptical DS writers who consider counselling to be unhelpful. Mason (2002) suggests that sampling across a range can increase the chances of generating rich, evocative and nuanced data that provides a 'flavour' of how things can be. She adds that this approach can offer a way of understanding how things work in specific contexts and how they work differently in different contexts.

I continued to interview participants until I felt that I had reached a point where I could cover the range that I was looking for as far as possible. I would like to have found at least one participant who identified with a racial or ethnic minority group or who was not white and British but I was unable to do so and had to leave that as a limitation of the research. After I had interviewed fourteen participants, I had enough data to think that I had maximised my sampling with as much variety as realistically possible for this piece of research. I reasoned that I had answered in the affirmative to the question "*is the sample adequate for the task?*" (Langdrige, 2007:155). The snowball effect flowed very easily and I was surprised to find that people were genuinely interested and keen to be involved. I introduce each of them in Table 1.

3.3.5. Conducting the interviews

Before I launched into the interviews, I thought about how I would conduct them. I was aware that one-to-one interviews would enable me to talk with people in-depth to find some detailed specific accounts (Riessman, 2008). Elliot Mishler (1986: vii) suggests that *“an interview is a joint product of what interviewees and interviewers talk about together and how they talk with each other”*. Interviewing was therefore a way for me as researcher and for participants as narrators to co-construct stories that arose from the questions I asked them. Langdrige (2007) points out that semi-structured interviews are the most common method of data collection in phenomenological research and Mishler (1986:53) clarifies this, saying that a question may be

“part of a circular process through which its meaning and that of its answer are created in the discourse between interviewer and respondent as they try to make continuing sense of what they are saying to each other”.

The aim of interviewing is to find out about individual views and to discover more about detailed and contextualised stories (Barbour, 2007). Following the advice I had uncovered, I constructed a few questions (Appendix B.6) to guide the conversation (Johnson, 2001); to pursue the implications of the questions and to seek clarification where necessary, while remaining as flexible as possible so that participants would feel free enough to tell their stories in their own ways (Mishler, 1986; Warren, 2001). I was aware that I needed to allow participants to tell their own stories without my interference but to guide them back to the interview questions if they veered too far from them (Johnson, 2001).

I intended to find a way of interviewing participants that would avoid imposing my ideas on them but I was aware that this might be difficult because we were likely to share similar experiences. As reflexivity and transparency are fundamental aspects of this research as a whole, it was unlikely to be completely absent from the interviewing process. I planned to work with my biases and assumptions by making them available to participants if necessary while encouraging them to feel free to express their own views. In this way, I expected that the style of interviewing could

be conversational at times (Ellis and Burgess, 2001). I followed Johnson's (2001) guidelines by taking notes about my thoughts and feelings prior to each interview and then writing reflective notes as soon as possible afterwards. These recordings became an integral part of my subsequent analysis and presentation of the stories. Narrative interviewing requires skill but the heart of it is to hear and represent the voice of each participant as clearly as possible while acknowledging that stories are co-constructed.

Table 1: The participants

Name	Age Range	Type of impairment	Onset of impairment	Counselling context	Presenting Issue(s)	Involvement in counselling	Involvement in Disabled community
Alastair	50+	Severe musculo-skeletal pain	Mid adult	Peer counselling for disabled; private practice	Personal development over a number of years with different counsellors	Previous peer counsellor for disabled	Volunteer work in disability sector
Amanda	30+	Visual	Birth	Rape crisis (voluntary sector); clinical psychology (NHS); Bereavement (voluntary sector)	Relationships Consequences of violence and abuse	Counselling student	Offers business support to other visually impaired people
Bill	60+	Mobility, Speech	Birth	Student; voluntary sector; peer group; Employment Assisted programme	Personal development over a number of years with different counsellors	Counsellor and counselling trainer	Previous consultancy work in disability sector
James	20+	Mild mobility, mild speech, mild cognitive	Birth	GP practice (NHS)	Relationship issue	Counselling student	None

Janet	50+	Chronic degenerative illness	Mid adult	Private practice; NHS rehabilitation (clinical psychologist) Private practice (pre impairment)	Not clear Relationship issue	Counselling student	Involved in a support group for people with MS
Kevin	50+	Severe dyslexia	Birth but late diagnosis	Voluntary sector agency; private practice	Personal development over a number of years with different counsellors	Counsellor and counselling trainer	Previous paid work in disability sector
Monica	30+	Deaf	Birth	Private practice	Feeling alone as parent of young children, having moved to a different community	Deaf counsellor	Paid work in deaf counselling service
Nancy	60+	Deaf	Infancy	Private practice; Deaf counselling (voluntary sector)	Childhood sexual abuse Relationship issue	None	Socialises within deaf community
Nick	30+	Mobility	Birth	Private practice	Personal development over a number of years with same counsellor	None	Previous interest
Pete	50+	Mobility	Mid adult	GP practice (NHS)	Childhood sexual abuse Impairment issue	None	None
Robert	50+	Mobility	Adult	Peer counselling for disabled (telephone)	Bereavement Relationship issue	None	None

Sandra	70+	Mobility, age related	Late adult	Peer counselling for disabled (telephone)	Bereavement Relationship issues	None	None
Sarah	30+	Asperger's syndrome	Birth but late diagnosis	Voluntary sector agency	Relationship issue	None	Paid work in disability sector
Shirley	40+	Visual	Mid adult	Voluntary sector agency	Onset of impairment	Counselling researcher	Involvement in disabled research

3.4. Ethical considerations

My ethical thinking about this research stems from the premise that however rigorous the process would be, I would need to be aware that the *“primary responsibility is always to our informants”* (Clark and Sharf, 2007:400).

3.4.1. Ethical approval

I sought ethical approval on three separate occasions during the process of conducting the research. Firstly, I applied for and gained approval from the ethics committee in the School of Health in Social Science at the University of Edinburgh to consult with the advisory group. The next application was to the same committee to conduct the interviews and again, I gained approval for this. I did not involve my own clients in the research in order to maintain the therapeutic space for them but I was less clear about interviewing people that I knew through my role as university tutor. I was aware that some of my students had expressed an interest in my research and that they would have useful contributions to make. I was concerned to avoid abusing my position as a tutor so I consulted with colleagues and made a separate ethics application to the same committee for the two people that I knew in this capacity. I gained approval to proceed. I invited these participants to take part after my university role with them was complete and discussed the situation with each participant before we made the decision to proceed. As Taylor (2011) points out, prior knowledge of participants undoubtedly influences the interview so I was careful to avoid including my prior knowledge of them in the thesis.

3.4.2. Responsibility to participants

My responsibility to participants is evident in the attitude expressed in my intention to conduct this research collaboratively, reflexively and transparently with empathy and acceptance of each participant's perspective. This means that *“the researcher is more likely to be trusted, seen as less threatening and admitted to the participant's experience”* (Mearns and McLeod, 1984:375). I aimed to work with my own personal

and professional skills, biases and assumptions throughout the research but however well intentioned, I did encounter some challenges in meeting these aims. One particular example is that before I met the participant who is dyslexic, I contacted him with a text message without realising that he would have difficulty reading it. This could have been received as insensitive and disrespectful by the participant and indeed, he did make a point of telling me about his difficulty. I have discussed examples such as this one in the next few chapters because they reveal some of the issues that disabled people encounter in a daily basis in relationships and that may appear in the counselling relationship.

As I said at the beginning of this chapter, there are some parallels between counselling and conducting qualitative research, some of which are useful and others that present dilemmas and challenges. One of the significant challenges is that as an 'insider' to this research, I was treading a fine line between my own experiences and those of participants in the process of co-constructing the stories. To give an example, as I listened to Nancy, I felt a strong connection with her story about being an infant in hospital. As I wrote in chapter 1, this was part of my own traumatic story. As Nancy talked, I assumed that her hospital experience was equally traumatic which it may have been. However, after a few moments I realised that this was not the focus of her story. Her concern was a different one and I had to make an internal adjustment in my responses to her to avoid guiding her in a direction that she had not intended.

Part of the process of working collaboratively is that I attend to the power dynamic between myself and research participants. I was hoping that the research would be emancipatory (Oliver, 1997) to some extent without following a particular template (Thomas, 1999). This would mean inviting participants to offer their knowledge and experience with a view to releasing others from oppressive practice in counselling (Reeve, 2000). Disabled people can feel exploited by researchers (Oliver, 1999) where there is no benefit of the research to the disabled community and their sensitivity may be connected to the feeling of being exploited by medical professionals. I have been aware of this issue throughout the research process but my fears were alleviated when I realised that I have already made a contribution to

the existing literature (Johnson, 2011; 2016a; 2016b) that is now used in a number of counselling training programmes in Scotland.

In their research with school children, Nairn, Munro and Smith (2005:228), make the point that *“the question-answer format reproduces relations of authority reminiscent of classrooms”*. This is an inevitable aspect of the power that is inherent in my role as researcher, however much I try to establish an equal relationship with participants. However, with some participants, notably Amanda, I found the interviews to be more reminiscent of the counselling room. My questions seemed to prompt Amanda to recall the issues she spoke about with her counsellors and she seemed to be caught up with these issues again as she spoke. After the interview, I was aware that she had more to say about the several intense periods of counselling she had, so I asked for a further interview. It was then that she was able to stand further back from her memories to reflect on the interview questions.

I was concerned that asking participants about their experiences of counselling could involve making judgements about people in my professional networks. I had contact with the counsellors who acted as intermediaries between me and their clients but for the most part, I did not know these individuals personally. I was aware of adopting an attitude of professional respect for them regardless of what I thought of the stories I was hearing. However I cannot be sure of the influence that this situation had on the participants that I interviewed. Some may have felt that the need to portray their counsellors in a favourable light out of a sense of loyalty so I need to take that into account. I was particularly concerned about this during my interviews with Amanda. She was very effusive about her counsellors and had very little to say about her relationships with them that could be construed as negative.

3.4.3. Confidentiality

The disabled community in Scotland, though disparate, is not large and the counselling community is equally small. As readers of this research are likely to have an interest in either or both of these areas, I am mindful of protecting participants' confidentiality as far as possible while bearing in mind that they have all agreed to take part in the project. With this in mind, I have changed the names of all

participants and avoided using background information that was not directly relevant to the topic. As my interview questions involved asking participants about their relationships with counsellors, it was important to extend confidentiality to them. I have not used counsellors' names or any other identifying information about them where possible.

3.4.4. Informed consent

I gave each participant an information sheet as well as the interview questions in advance of the advisory group (Appendix B.1 and B.2) and the one-to-one interviews (Appendix B.4 and B.6) to ensure that each person was aware of what was involved. This was particularly important for the participants who had difficulty in processing information and it gave every one of the participants time to think about their responses prior to the interviews. This may have helped to avoid eliciting shame and to achieve a reasonable depth to the interviews. I discussed what was involved at the start of the group discussion and each of the interviews, to ensure that each participant understood what they were agreeing to and how the material would be used before they signed the consent forms (Appendix B.2 and B.5). At the end of each session, I took time to ask participants if they had any questions about the process and to ask how they felt about the interview so that they could wind down from the intensity of the discussion and establish what they might need in order to debrief.

3.4.5. Attending to particular needs

Early in the interview stage it became apparent that the particular needs of participants and my own impairments and experience of disability were going to affect the research process. I knew that conducting one-to-one interviews would be a personal challenge because of my own inhibitions, sense of shame and not least the difficulties I was experiencing with transport and accessibility that could limit my capacity to meet with people. I had to make decisions about the location for each of the interviews. Initially this felt daunting because it hadn't been long since I had to stop driving because of an eyesight problem. I felt uncomfortable about asking

participants to travel to meet with me but some participants lived in Edinburgh and were mobile enough to meet in my office at work without incurring expenses or becoming too exhausted. I arranged to speak with two people on the telephone because they lived in places that were too far away or too difficult for me to get to using public transport. I arranged to meet wheelchair users in their own homes because that was more convenient for them. I was able to use public transport to interview a further two participants and I had to rely on family members and friends to drive me to interview several others. Relying on others meant that they were aware of the purpose of my visits but they did not meet the participants or know their names.

I trusted myself to be creative about managing my limitations and I was aware that prospective interviewees would also have limitations. I expected to encounter communication issues when interviewing deaf participants but I was aware of some of the protocols and methods of communication from my past work as a tutor on two separate counselling skills courses where all participants were deaf or hard of hearing. I was aware that I would need to think about how best to communicate with participants who had impairments that affected their speech or their capacity to process information. I knew that I would be able to discuss individual methods of communication through my own professional networks where necessary, while maintaining the confidentiality of prospective participants. Many clients find it difficult to express their innermost thoughts and feelings in research (Riessman, 1993) for a variety of reasons, such as lack of awareness, trauma or shame. If I discovered that this was the case during any of the interviews, I would be able to rely on my counselling skills and experience to be sensitive to participants while listening to their stories. I was aware that fatigue was likely to be an issue for participants who had physical impairments so I would need to monitor the length of the interviews and be aware of the time and energy needed for travelling. I discuss some of the other logistical issues involved in attending to particular needs in future chapters.

3.5. Thematic narrative analysis

Riessman (2008:53) explains that all forms of narrative inquiry are concerned with the content of what is said, written or visualised but in thematic narrative analysis “*content is the exclusive focus*”. She states (ibid p 54) that

“Data are interpreted in light of thematics developed by the investigator (influenced by prior and emergent theory, the concrete purpose of the investigation, the data themselves, political commitments, and other factors)”.

Following what could be termed a ‘case-centred’ method of narrative inquiry, I began by conducting each interview which I recorded on a digital voice recorder and then transcribed. I generated fourteen ‘cases’ that consisted of the stories that participants’ told in response to my interview questions (the concrete purpose of the investigation). I analysed each of the interview transcripts in detail so that I could understand each of the participants’ stories and the meanings they attached to them. I then analysed the entire volume of data that I generated using prior (person-centred) theory to interpret the stories. Finally, I presented my findings thematically, based on my interview questions, using a person-centred framework. This was a painstaking, at times problematic, process which I discuss in the following sections.

3.5.1. Transcribing the interviews

Transcribing the interviews required attention to detail and I did this in two stages. Firstly, I transcribed everything that I heard as I listened to the recording using some of the conventions from the Jefferson transcription system (see Hepburn and Bolden, 2013) such as underlining to indicate emphasis, capitals for loud speech; brackets to indicate pauses and other notes to indicate responses such as facial expressions, tone of voice, gasps, sighs, tears etc.. I used these conventions to highlight content rather than the finer details that would indicate *how* the content was communicated linguistically. Although as Yardley (2000) points out, it is important to attend to language as participants’ ways of expressing themselves, the purpose of thematic narrative analysis, according to Riessman (2008) is to bring attention to what is said in the form of events and cognitions to which language refers. In keeping with a phenomenological approach, this statement means that I am not analysing the

minutia of the language but that I am paying attention to embodied and verbal gestures that indicate the whole nature of what is being communicated. Each participant's narrative is their own way of symbolizing different aspects of their experience. An important element in this research, as it is in counseling, is not only to listen to what the participant/client is communicating, but also to what is happening for me in response to them. This provides insight into the relationship between us, which can shed light on how participants experience other relationships. Cooper (2001:228) points out that

“as with cognitive and affective experiencing, something of the client’s somatic experience will be invoked in the counsellor e.g. the physical nausea that goes with what the client is experiencing emotionally or the tears that are invoked when the client talks about something sad”

This is in keeping with what qualitative researcher Linda Finlay (2005) refers to as 'bodily empathy'; 'embodied self-awareness' and 'embodied inter-subjectivity'. To this end, as I transcribed each interview, I used my research journal to indicate the thoughts, emotions and bodily sensations that arose for me in response to each participant as I listened to the recordings.

The second stage of transcribing was to make legitimate decisions about how to capture the meaning of what was being said by clearing out 'messy' parts of speech (for example, minimal responders and utterances) to make the stories more readable. In the final presentation, I retained some of the conversational elements of the interviews where the co-construction process was in evidence. Although in the main, I did not include the 'messy' parts of speech, I left some of them where participants used interpreters because these parts indicated something of the process of interpretation.

I encountered several challenges in constructing the transcripts. When the interview with Bill was coming to an end, referring to his speech impairment, he jokingly wished me luck in transcribing it. I had to listen several times to some of his words and phrases, with the volume turned up full in some cases. I missed one or two of his words but I understood most of them by listening to the content of the whole sentences. Pete had a very strong accent that was unfamiliar to me, so I struggled

to hear some of his words. Again, the context of what he was saying helped me to fill in the gaps as best I could.

Transcribing Monica and Nancy's interviews was a particularly interesting process because I was transcribing the voices of their interpreters and not the participants directly. The audio recordings did not reveal participants' facial expressions or gestures which were important aspects of their ways of communicating. On reflection, video recordings may have been more revealing but my sense is that this would have been too intrusive for them to feel that they could talk freely. The interview with Nancy was a very emotional experience but the interpreter did not express herself emotionally in the way that Nancy did through the gestures that could not be recorded. As I transcribed the interview, I began to feel rather detached from Nancy and I felt I was losing touch with her emotionally. For each of the other recordings, I noted highly charged moments that I could hear through differences in tone of voice and I noted moments of laughter and silences because I thought of "*the body as text that can be read*" (Nairn, Munro and Smith, 2005:224). I noted some thoughts and feelings about the interviews in my journal while I was transcribing so that these could become part of the analysis. However, in Nancy's case, I felt distracted by the interpreter's lack of emotional expression that did not reflect Nancy's gestures and facial expressions. I did hear one or two of Nancy's vocal sounds and I noted them on the transcript descriptively (for example, 'Nancy groans'). I retrieved a greater feeling of involvement with Nancy when I analysed the transcript. The interview with Monica was less emotional but as I transcribed it, again I was aware of a feeling of detachment because I was hearing her story through the interpreter's voice. The focus in that interview was more on factual stories so I did not feel so perplexed though on reflection I wondered if Monica had learned to set her emotions aside in her interactions with others and not only with me.

3.5.2. Analysing the interviews

Riessman (2008) describes transcripts as interpreted conversations but I needed a framework for making these interpretations. I used the Listening Guide, also known

as the 'Voice-Centred Relational method' of analysis. The guide, as explained by Mauthner and Doucet (1998:126) is "*deeply rooted within the broader traditions of feminist research practice and the increasingly rich and wide field of qualitative research*". It is a reflexive method, requiring a deep level of self-awareness and it is a way of keeping "*respondents' voices and perspectives alive, while at the same time recognising the researcher's role in shaping the research process and product*" (ibid p 119). Carol Gilligan and colleagues (2005:253) state that this is

"a method of psychological analysis that draws on voice, resonance, and relationship as points of entry into the human psyche. It is designed to open a way to discovery when discovery hinges on coming to know the inner world of another person".

Mauthner and Doucet (1998) explain that the method works

"by exploring individuals' narrative accounts in terms of their relationships to the people around them and their relationships to the broader social, structural and cultural contexts within which they live".

Using the Listening Guide involves analysing each transcript, one at a time, following four detailed steps. I adapted the guidelines offered by Gilligan and colleagues (2005) and Mauthner and Doucet (1998) to suit the particular requirements for my research. In order to ensure consistency, I constructed a template that I followed to analyse each of the interview transcripts (see Appendix C). This was a lengthy process which I carried out for each participant. I will explain how I did the analysis using Nancy's transcript to illustrate the process.

The first step in the Listening Guide analysis involved reading the transcript to gain an initial sense of the narrative and to record my initial responses to the interview. Mauthner and Doucet (1998:127) explain that

"The underlying assumption here is that by trying to name how we are socially, emotionally and intellectually located in relation to our respondents we can retain some grasp over the blurred boundary between their narratives and our interpretations of these narratives".

This step is essentially an analysis of my own responses to the interview and my interpretation of the participant's narrative. It was an extensive reading where I recorded the stories

This step is essentially my own responses to the interview and my interpretation of the participant's narrative. It is an extensive reading where I recorded the stories that each participant told along with my first impressions of the interview. Using Nancy's transcript as an example, I first of all wrote down my immediate impressions, then I listed the individual stories that Nancy told. For example, she talked about becoming deaf through illness as a baby; being in hospital for an extended period at a very early age; going to boarding school at the age of three; being sexually abused as a child; having panic attacks. There were around a dozen individual stories within Nancy's overall narrative which was based on my interview questions. I followed this by noting the imagery that Nancy used. This was particularly interesting because as a deaf person using sign language, Nancy's range of words were limited so she often spoke in descriptive, visual terms. I noted dominant themes which, in Nancy's case largely involved issues about communication and abuse. Finally in this step, I noted contradictions and absences in the overall narrative. At this point, I included the comments I had made from my journal and from notes I had made on the transcript as additional material. The process enabled me to become aware of many of the assumptions and interpretations I was making as I read each transcript. At the end of this stage, I had produced a 'relational and reflexively constructed narrative' (Mauthner and Doucet, 1998) for each participant.

The focus of the second step in the analysis is on how the participant experiences, feels and speaks about herself. It involves writing down each of the participant's statements that began with a personal pronoun to produce an 'I' poem. A segment of Nancy's poem is as follows:

I had speech therapy

I had a voice

I could speak

I'm hard of hearing

I have speech

I'm a good speaker

I'm a good lip reader

I can cope

Compiling the 'I' poem was a process that was intended to give me, as the researcher, a strong impression of the way that each participant spoke about themselves. It was not intended to be used in the presentation of findings per se but more as a way of enabling me to separate myself from the participants as preparation for the next readings. The process helped me to listen carefully to what each participant was *actually* saying and to bracket what I might have *assumed* they were saying during the first step in the analysis.

Step three involved reading the transcripts to find out how participants related to themselves and how they experienced their relationships with other people. This step formed the basis for my investigation since it was all about relationship. Where guidelines for the Listening Guide suggest that the researcher reads the transcripts at least four times, I found myself reading them many more times so that I could find out about how participants experienced relationships with each of the characters in their stories, including themselves. In both Nancy and Monica's cases, I added a section on working with the interpreter. I did a reading for each participant's relationship with their counsellor at this stage and, in keeping with my reflexive approach, I added a reading to investigate participants' relationships with me. On reading Nancy's transcript for example, I copied and pasted everything from the interview that she said about herself and this revealed several dimensions to her character and personality. I did a reading to determine how Nancy related to her impairment. I then identified all of the (actual) people that Nancy mentioned in her stories and read the whole transcript to see what she said about them, one at a time. I copied segments of the transcript and pasted them under the heading for each person in her story. For example, I grouped together all of what she said about her relationship with her mother; her partner; her children; her friends; her counsellors and other minor characters in her stories. This process helped me to discover some of the responses to my first research question, namely what difficulties participants experienced in their relationships with others. It also revealed information about the power dynamics and differences between each participant and the other people in

their social worlds. In Nancy's case, it gave me a sense of how deafness affected her relationships with herself and others.

The second part of this stage consisted of collating each participant's responses to my interview questions and again, I copied segments of the transcripts and pasted them under the headings for each question. Each reading at this stage gave me a greater accuracy and understanding of what participants were saying through their stories. I discovered some of the misunderstandings that I had made during the first stage of the analysis. The readings that I carried out at this stage enabled me to form as accurate a picture as possible of each of the research participants and their relationships with themselves and others. This was the most substantial stage of the analysis and it gave me a data set for each participant that consisted of headings and transcript segments that laid the foundations for further analysis.

The fourth and final stage of the Listening Guide involved exploring participants' perceptions of the wider social world and of structural issues of power. This reading was particularly useful for identifying participants' relationships with disability discourses. Again, I grouped the segments that were relevant to this topic together. As Mauthner and Doucet (1998) point out, the whole process is very time-consuming and it was repetitive at times as some parts of the transcript were used several times under different headings. However, as Jane Ribbens (1998:37) points out, *"not only does it require much attention and care to hear my own voice, but it requires even more attentiveness to hear and represent the voices of others"*.

3.5.3. Creating an overall narrative

The whole process of analysing the interviews using the Listening Guide laid the foundations for the next stage in the analysis, which was to analyse the data thematically. Carol Warren (2001:87) states that *"The object of qualitative interviewing is to discern meaningful patterns within thick descriptions"*. Essentially, through the analysis of each interview, I generated a wealth of in-depth and contextualised responses to my interview questions. I developed a clear sense of participants' voices; my own role in the endeavour and a sense of participants'

conditions of worth. The next stage was to bring the data together in meaningful patterns to form an overall narrative that I could use to present the data. Riessman (2008:73) states that *“prior theory serves as a resource for interpretation of spoken and written narratives”*. I had given myself the remit of depicting a sense of what it can be like for a disabled person to be a client in counselling and of how the process of counselling can unfold. Haselberger and Hutterer (2013:319) argue that, from a person-centred perspective, the researcher tries to *“empathically grasp patterns in their research field not illuminated or appreciated before”*. With this in mind, each stage of the Listening Guide gave me specific data that I could use to form a meta-narrative that forms a unique contribution to research in counselling and to the way in which a person-centred process of change can be understood. The way that I chose to depict the counselling process is rarely seen in the person-centred counselling literature. I chose this depiction to serve as an aid to counselling students, supervisees and anyone who has an interest in how counselling works. I thought of it as a teaching tool that illuminates the whole issue of counselling disabled clients for interested readers, including Disability Studies writers who have adopted negative views of counselling. My analysis revealed the importance of presenting not only successful aspects of the counselling process but also the pitfalls that can occur and that here is much to learn from both. I now proceed to expand on the steps that led me to establish my meta-narrative.

Haselberger and Hutterer (2013:321) state that *“Researchers follow a personal vision encountering the phenomena that are most intriguing for them”*. This made sense to me as I have always been interested in the process of change in counselling. I began to formulate a meta-narrative that provided insight into the therapeutic process of change. As I reflected on my findings, I noted that some participants described the ways in which they related to disability and impairment as something akin to the notion of distortion and denial that I described in 2.3.1. As a result of conditions of worth, these participants were reluctant or unable to find a place in their self-concepts for these significant aspects of their lives. This was a striking finding for me. Additionally, I noted that participants’ experiences of counselling could be understood in terms of a process that played out over time – weeks for some and years for others. I had framed my research topic, questions and

interview questions in terms of discovering more about therapeutic change. From the outset, I was interested to find out if counselling could enable clients to develop fuller and more meaningful relationships with themselves and others.

As a counseling trainer and supervisor, I was aware that students and supervisees often have difficulty in conceptualizing and describing how a therapeutic process unfolds. My research findings as well as my professional experience suggested that it would be useful to formulate my findings in terms of a process over time, as described by Mearns and Thorne (2013). I reflected on the intensity with which participants talked about the difficulties they experienced in their social and personal relationships and I realized that most of these issues had been addressed in counselling. This led me to formulate their stories in terms of the beginning stages of counselling, where the client lays out the stories that are of immediate concern for them and that they wish to discuss further. Counsellors refer to this as the client's 'presenting issue(s)'. This was foundational information that led me to analyse the findings in terms of the effects of these difficulties on participants' self-concepts as they arose from conditions of worth that emerged from relational issues. From there, I chose to present participants' experiences of counselling in a way that both illustrated what it was like for a disabled client to experience counselling and to indicate what happened for them in terms of a process of change, particularly in terms of relationship. This meant that I could reflect on and present what I found in terms of the conditions of worth that were at play in participants' everyday relationships and in the counselling relationship so that parallels might emerge. My research questions prompted participants to talk about difficulties they experienced in their relationships with their counselors and I asked them this with a view to learning about how conditions of worth impacted the process. Including that as a separate chapter meant that I could separate positive experiences from those that were more difficult so that I could provide a balanced picture of how counselling can be experienced by disabled clients. The comments that Disability Studies writers have made about counselling were in my mind at this point because I took the view that in the main, they did not communicate an in-depth understanding of the counselling relationship or process.

Steps one and two of The Listening Guide enabled me to differentiate between my interpretations of participants' stories from their own narrations. This gave me a structure for noticing my own assumptions, emotions, bodily sensations and interpretations so that I could lay them aside and thereby depict participants' voices as clearly as possible. I was aware at this stage of how participants presented themselves to me. Step three gave me a sense of how each participant related to themselves and others as well as their responses to my interview questions. Step four gave me a sense of how participants related to the disabling environment, including the social and cultural conditions of worth that affected them.

Using the data I had generated from each participant, I began to consider how to analyse the data in a way that would fit with my remit. Thinking about a counselling process, I first of all copied and pasted segments from each of the transcripts that had a bearing on the difficulties that participants experienced in their relationships. This would serve to illustrate the issues that disabled people might bring to counselling. I examined the issues that participants raised and listed them under the heading 'relationship issues' with brief words such as 'misunderstandings' and 'rejection' and I put the initials of each participant alongside the issue they had mentioned. I then had a range of issues that I grouped together by their similarities (for example, stories of loss) and created further headings which I have used in chapter 4. This provided me with a range of issues along with participants' different experiences of these issues. Every participant is represented in chapter 4 since they all had stories to tell that pertained to this question.

I used the same system to gather together participants' experiences of themselves that were derived from conditions of worth, some of which arose from the relationship issues they described in chapter 4. Although this was not a specific interview question, I had generated data from the Listening Guide and from some participants' stories to formulate my understanding of how each participant came to form their own self-concept. The person-centred counselling process is based on listening and responding to the client's distress that has arisen as a result of conditions of worth and that appears in the form of incongruence. This set of stories

is therefore illustrative of how disabled people can become distressed and incongruent and I have presented these stories in chapter 5.

I continued to follow the system of grouping the data from my analysis of each interview to form my meta-narrative of the counselling relationship and process. I have presented participants' experiences of counselling in chapters 6 and 7.

3.6. Summary

As Langdrige (2007:157) points out, it is not possible to make "*grand truth claims*" from this research. What I can do is to present my findings as though it were to a judicial court where it would be available for scrutiny (Langdrige, 2007). In this way, "*the goal of the research becomes one of inviting dialogue that may undergo continuous change as it moves through an extended network*" (Gergen and Gergen, 2000:1042). Flyvbjerg (2006:237) points out that "*good narratives typically approach the complexities and contradictions of real life*". This is one of the many strategies, considerations and reflections that I have examined in this chapter to ensure that the stories that I present reflect participants' voices as accurately as possible; that the overall narrative is plausible, coherent and persuasive and that all aspects of the process are transparent and ethically sound.

Chapter 4: Estrangement from others

This chapter focuses on the first of my research questions namely: 'What difficulties do people experience in their relationships with others that they directly associate with being disabled?' Four major relational themes that illustrate the sense of estrangement that participants experience emerge from my analysis. These themes are disconnection through loss of relationship (4.1); disconnection through strain, tension and misunderstanding (4.2); estrangement through rejection and abuse (4.3) and disconnection in helping relationships (4.4).

The stories that I present in this chapter illustrate what can hinder disabled people from making meaningful connections with others and the nature of the issues they might discuss in counselling. Before I present these stories, it is pertinent to say from the outset that every participant expressed a desire to feel connected with others. The amount of contact they wish to have depends on their personal preferences and dispositions – almost half describe themselves as outgoing and a few prefer the company of a limited number of people. Most place themselves somewhere in the middle of that range. It is also important to point out the words that participants use to indicate their sense of separateness from other people. They spoke about 'others'; 'normal people'; 'hearing people'; 'everyone else'; 'society'; 'culture'; 'the world'. This is indicative of the division between disabled and non-disabled people, which is the cause of many forms of tension in relationships (Cameron, 2010). This binary language is inevitably derived from my interview questions where, as a researcher, I asked participants specifically about their experiences of being disabled. It would have been difficult for them to have spoken about their experiences without somehow separating themselves from other people in some way. Although relationships between disabled people are not without their tensions, it is fair to say that this was less in my experience or in my mind when I began this project because my awareness of the disability literature led me to highlight the disabled/non-disabled binary. However, as I was questioning participants, some offered their experiences of these particular tensions as I will show.

In this chapter and for the rest of the thesis, it is important to note that both Nancy and Monica's words were spoken by their interpreters.

4.1. Disconnection through loss of relationship

Every human being experiences loss at some point in their life (Watermeyer, 2009) but some losses can be particularly painful for disabled people and I illustrate some of these in this section.

4.1.1. Losing all that is familiar

When an adult suddenly becomes disabled, their loss is not only physical and emotional, but also relational and Shirley's story indicates how catastrophic and traumatising this can be. She describes it as an "*annihilation of my social niche*". She adds that

"When you move from an able bodied world into a disabled world, its brutal [...] I feel I've lived in a very able-bodied world and I am now living in a disabled world".

She explains that "*Within a very short space of time I wasn't working, so I didn't have my colleagues*". This meant that she lost her financial income

S *[I was] no longer working and then having to move to a different neighbourhood because we were moving to a smaller house, because we didn't have the income. So it's this huge chasm. It was this massive shut down of relationships*

C and a lot of loss

S *lots of loss, yeah. I think it's like a nuclear bomb. So there was nothing left.*

Shirley became so overwhelmed by this experience that she lost a sense of connection with her partner and young children. Disability is identified as a risk factor for marriage breakdown because one partner becomes dependent on the

other, domestic duties are no longer shared and the quality of companionship can diminish (Lyons, Sullivan, Ritvo and Coyne, 1995). Shirley says

“My marriage kept going. I think probably because my husband was so busy. We had three [children] under five at that time so it was really challenging for him. He picked up the slack. I don’t know how, I just kept on existing not really functioning so it was really, really dark days and that lasted a couple of years”.

She was afraid of being isolated from her young children

“All these things, all these emotive things that you fear associated with blindness about not seeing them grow up”.

Her sudden isolation was also acute because *“not being able to drive and get out and about”* isolated her from other people. She had to learn to negotiate the use of public transport with her newly acquired impairment and that, she says, was not easy.

Shirley didn’t talk about how she felt with her immediate family, perhaps as a way of preserving her relationship with them (Lyons, Sullivan, Ritvo and Coyne, 1995) so she became totally alone in her distress. She says *“so there was nothing left. I felt not even part of a broader society. I felt really alone and it was a terrible time, terrible decimation of relationships”.*

When a very young child becomes disabled, they may not understand or be able to articulate their sense of loss so their distress can become buried until later in life. As a counsellor, my experience of client work and my awareness of research in counselling and related fields indicate that separation from the main caregiver at an early age is traumatic for an infant. This is echoed in my own story of being a seriously ill baby in an isolation hospital (Johnson 2016a). Loss of this nature can have an adverse effect on an adult’s mental health (Parkes, 1991). In Nancy’s case, this was manifest in her periodic panic attacks and in my case it took the form of periods of depression and anxiety. For both of us, this came to crisis point in adult life at the point of losing a close family member through illness and death. Although our stories were different, we were both plunged into trauma, reflecting our early un-symbolised yet terrifying existential experiences of loss.

Nancy's traumatic loss of relationship occurred when she became deaf as a two year old child. One of the ways of making the transition into disability bearable is to talk about it (Lyons, Sullivan, Ritvo and Coyne, 1995; Segal, 2002) and whereas this was difficult for Shirley because she felt depressed and traumatised, Nancy could not talk because, she says

"I was such a young child so I've no memory of it but I have been told I was able to speak very well and then when I became deaf I stopped talking".

She had to learn a whole new language and she remembers the moment when she first realised this. It happened when she was taken from hospital to a boarding school for deaf children at the age of three. She says

"There were lots of kids playing in this really large bright room and they were all signing and I was really in awe [...] then one boy approached me and he was like 'hi' waving and I waved and he looked at my shoes - the laces were out so he's like 'oh I'll help you'. He was signing and he tied my laces for me and that was when I realised I'm deaf. This is what I need in order to be able to communicate with people so I've been signing really since that day".

Nancy says *"because of my own home background there was a problem – for nine months to be staying in hospital"*. At that time it was fairly commonplace for children to be placed in hospital or in care when parents were unable to cope (Morris, 1997) but Nancy says

"It really didn't bother me. My uncle had gone and I was used to being dropped off in places and left. That had been part of my life so it didn't faze me".

Although she says this, she does remember feeling disorientated. She says *"I was thinking 'where am I going? what's gonna happen to me now?' "*

4.1.2. Losing a parent

Many disabled people rely on family and friends for care giving and emotional support (Lyons, Sullivan, Ritvo and Coyne, 1995) so the loss of a family member can be devastating and frightening. Nancy began to have panic attacks when her mother became seriously ill but she was not aware of why this was happening. This happened at a time when Nancy herself was unwell. She says her mother

“was going downhill. Her health was deteriorating. [...] I have relied on her so much through life and I started to get panic attacks. My mum did try to help and be supportive but [...] I was actually helping her because she was very old at the time and unwell so I was [...] crying and being really upset and I started taking anti depressants”.

Nancy’s story suggests that the lack of an individual caregiver in her early years could have caused her to feel anxious (Parkes, 1991). The impending loss of her mother raised her sense of anxiety to the point of panic. She did not make cognitive connections with her early loss at the time but her reactions suggest that her early distress may have been having an impact on her. She looked to her counsellor to help her make sense of her feelings during that time and I will return to her story in chapter 6.

Throughout her rather turbulent life, Amanda’s most consistent supporter was her father whom she loved deeply. She says *“I was a middle child, my dad’s favourite”*. She remembers that he took care of her as a very young child when she was

“screaming and screaming cos it was like my eyes were on fire and my dad sort of came rushing out and put me back inside”.

Her dad’s way of being supportive was to be her driver. He did this as much as he could throughout her life until he became ill when Amanda was in her thirties. When her dad died, Amanda says *“I was in shock, cos it happened over six weeks”*. She says *“it was about six months after and [her partner] was worried. She was scared for me ‘you need to talk to someone”*. Amanda had a history of self-harm and had tried to commit suicide at one point in her young adult life, so her partner had reason to be concerned.

Both Nancy and Amanda’s reactions to losing a parent became acute because of their reliance on these parents for support. Although theories of grief and loss make connections with early attachment (Bowlby, 1998), they do not commonly consider the impact of disability on this process but Amanda and Nancy’s stories illustrate how profoundly painful this can be. Nancy did not have a primary caregiver as an infant and Amanda had a very difficult and abusive mother and therefore relied on

her father for solace. The loss of these primary care givers caused them both to feel destabilised and frightened.

4.1.3. Too many losses

Becoming disabled is very stressful but when this is juxtaposed with several other losses, the whole set of circumstances can be overwhelming and extremely isolating. In his middle years, Robert found himself facing several distressing losses at around the same time. He explains

“My mother and father and brother died a few years ago. My mother and brother died very close to each other”.

He had a serious accident as a young man and made a good recovery at the time but his injuries led to him become “*significantly disabled*” later in life. Robert says

“A few years ago I had a fall and I twisted a ligament very badly and at that point I was quite thoroughly depressed. I think the knee injury was kind of the crisis”.

This happened around the same time as his family members died. He said

“That might have been a bit of a trigger for the depression cos it was all going on about the same time”.

It has been acknowledged that “*multiple deaths can cause traumatic bereavements even in individuals who are not already vulnerable for other reasons*” (Parkes, 1991:271). While Robert did not say he felt traumatised after these deaths, he did say “*I probably should have recognised that this was depression but I didn’t*”.

Around the same time, Robert became a wheelchair user. He says

R *I was doing it [work] virtually all from home [...] so I had video conferences with work colleagues and that changed the relationship*

C *you mean you didn’t see people?*

R *not really there was no banter [...]. What I should have done was not go to bed for two months. I should have probably sought some help earlier. [...] I realised that I wasn’t coping. I took long term sick leave from work and I had no motivation to do work. I used to work for [the financial sector] and this was around the time that everything was going belly up. I was quite senior and*

there were a lot of decisions being made around me which I didn't agree with. I wasn't important enough so work was rubbish, my home life was rubbish".

He explains that the relationship with his partner began to deteriorate because of the changes in his circumstances and his ensuing depression. He says

"She was not an uncaring person but I was now somebody different. I became aware that I was working every hour that God sent. There would be no food anywhere and the house was a mess - bed hadn't been changed in months. I think she had her own issues which I tried in my own ways to help with but whatever I tried didn't work".

Robert's life seemed to come crashing down as one loss occurred after another, leaving him feeling lonely and depressed. John Bowlby (1998:102) writes about the *"deep and persisting sense of loneliness that the bereaved so commonly suffer and which remains largely unalleviated by friendships"*. He (ibid) makes a distinction between 'social' and 'emotional' isolation. Robert appears to have experienced both so his sense of isolation was magnified by the combination of his experiences. Although I did not experience loss through a series of concurrent deaths, I did experience a sense of emotional and social isolation because of the combination of an early experience of loss in the form of isolation from my parents and the traumatic loss I experienced as an adult through the death of a loved that occurred some decades later. Both Robert and I experienced the overwhelming nature of accumulated loss in different ways and this led both of us to seek counselling. I will return to Robert's story in chapter 6.

4.1.4. Losing the quality of relationships

Disabled people often find it difficult to form relationships (Shakespeare, 2014) but Alastair and Pete had established social networks before they became disabled. The difficulties they face are more concerned with losing their social networks and with the deterioration in the quality of the relationships that they still have. This is arguably one of the least understood consequences of becoming disabled (Lyons, Sullivan, Ritvo and Coyne, 1995) but the experience can be extremely painful.

Both men became restricted in the activities they could do with their friends when they became disabled. Pete says *“I was aware of it when friends talked about going away to the bothy and hill walking. That used to get to me a bit”*. Alastair’s impairment became gradually disabling until he reached the point of having to stop work. He says

“I used to see people through the activities I did. I see none of these people now”. [...] I became much less active - I felt a lack of enthusiasm about life with the constant threat of pain and fear. I live with a level of anxiety all the time that’s hard for people to grasp”.

He began to lose the strength of connection he once had with people that he had been close to previously. He says that one person, for example

“wants to see me better [...] always greets me saying ‘you’re looking well’ or something like that and I have a lot less tolerance of that now”.

Talking about his family, he goes on to say

“I’m more distant from them because of my depression. I’m not the person I was and physical intimacy is very difficult now. It’s a bit of a disaster”.

Although accessibility was a factor in their estrangement, both Pete and Alastair appear to have been more distressed by the limitations and relational effects of their impairments to the point where they both became chronically depressed.

Janet experiences a subtle and ongoing deterioration in the quality of relationships with her friends and family because of her progressive illness and disability. Some people avoid contact with disabled people because they imagine, often without foundation, that all impairments are contagious (Gill, 2001). Others, like Janet’s daughter have some cause for concern because some conditions are inherited. Janet says *“she worries will she inherit the condition. I represent something quite scary.”* Although they are not overtly avoidant in their relationship, Janet and her daughter find the issue difficult to discuss, something that Segal (2002) confirms is a feature of living with MS. Janet says that there may be a further component to the distancing in their relationship and she illustrates this with a story of what happened when her daughter recently split up with her partner

“It’s the first time like there was a major emotional issue in her life that she didn’t bring to me and it coincided with me having a major relapse. I’m still not

clear whether she needed the distance from me in order to sort out her relationship or whether she felt she couldn't come to me because I was having my own difficulties".

On a further, more practical level, Janet says

"I babysat for her son and that sort of normalised things but I'm not as able to do that cos he's a lot more energetic now. It's tiring and it's hard for me to go to her flat. She's over on the other side of town".

Janet's relationship with her daughter and sense of subtle disconnection appears to be changing for several reasons namely her daughter's increasing independence, Janet's deteriorating condition that caused her to feel fatigued and the disabling environment that contributed towards her ability to travel to see her daughter and to gain entrance to her daughter's flat that could only be accessed via a flight of stairs.

In this section there are apparent differences between people who have acquired impairments and those who have been disabled from birth or early childhood or birth but for each one of us, disability has contributed to the emotional pain and social isolation that we have experienced. None of us found it easy to talk about these experiences because they were not yet symbolised into language; they were not in the person's full awareness they were experienced in general feelings of depression or anxiety; they threatened the sense of self; or they were too painful and therefore felt but not articulated. In the next section, I illustrate other ways in which relationships can be affected by disability.

4.2. Disconnection through strain, tension and misunderstanding

Relationships between disabled and non-disabled people are marked by strain, misunderstanding and tension (Gill, 2001) and dealing with these misconceptions can be more demanding than dealing with environmental obstacles (Keith, 1996). While the lack of access to public spaces is a major issue for disabled people, Robert indicates that this is not understood by non-disabled people. He says

“I think there’s a basic truism that unless you’ve either experienced it personally or had considerable involvement with someone who has, you don’t get the complications of things that simple stuff like loos brings to your world” .

4.2.1. Lack of understanding

Confusions can arise when a person’s impairment is hidden. Nancy says

“When I was younger, a lot of hearing people maybe thought I was just stupid. Boys for example they just thought I was stupid, but I wasn’t”.

She has a more empathic view of this as an adult as she says *“I think it’s hard for people to understand what it’s like to be deaf”*. Kevin was often considered to be stupid because his condition was hidden and people did not understand his behaviours. He responds to this by saying

“The world expects people to manage and process information so all my relationships are affected all the time and I cover it all up all the time”.

Sarah says

“ The scary thing is that you look at me I am completely normal and until I turn round and say ‘actually there’s this’, no one knows. [...] the biggest issue I can have at work is I cope too well and [...] forget that I’ve got [Asperger’s syndrome] and therefore then get a shock when I suddenly start not managing to cope”.

She deals with this by explaining the nature of her condition to people who she thinks need to know, such as her employers and college tutors. She tells them that

“It can take me a while to get used to crowded busy noisy situations. Generally given enough time I can handle them but I just need understanding and for people to know about it”.

Sometimes she forgets to do this but it is unrealistic for her to pre-empt any stress and misunderstanding that might occur with everyone she meets.

Like Kevin, Nancy and Sarah, James is sometimes considered to be ‘odd’ because people do not understand how his condition affects him socially. He says

“There are times when because my disability is so subtle, they think that I’m not normal. They think ‘oh is this guy on drugs?’ or ‘is this guy drunk?’ [...] They sense there’s something different about me and they keep trying to work it out. I stand out from the crowd in some way, and they’re not quite sure in what way I do”.

James has close friends who are more understanding but even with them there are limits to this because they can’t understand his sense of estrangement. He says

“People who really get me and know me as a person, they can’t understand. They don’t know what the problem is because it’s not a problem to them and they don’t see me in that way”.

He is left feeling rather perplexed, alone and stigmatised.

Kevin describes how other people at work respond to him. He says

“People attributed my misunderstandings to being a difficult person. [...] I was disciplined at work at least five times for insubordination and not following procedures and in fact I cognitively didn’t understand what was being said. [...] When I get emotional and there’s a big thing going on I use humour to try and cope with the frenetic thing that goes on in my head and that humour can almost be like Tourette’s syndrome so I’ll say what I shouldn’t say, and unfortunately that’s back to the relationships. In those moments a flippant comment breaks the relationship down”.

Even with her peers in the deaf community, Nancy sometimes feels different because, unlike most of the others, she has some speech. She says

“I’m not hard of hearing, I’m a deaf, profoundly deaf person and that sometimes causes a bit of friction, animosity with the deaf community. I am accepted but there is a clear division with profoundly deaf sign language users and hard of hearing. Some will refer to me as a hard of hearing person and I’ve told them repeatedly ‘I’m deaf, I’m profoundly deaf’. I think that certainly affected the relationships I was able to build with the deaf community”

Each of these different manifestations of the lack of understanding that participants experience resonates with me because I have both visible and hidden impairments.

The hidden impairments can elicit the feeling of being 'stupid', as they do with Nancy, Kevin and me because people do not understand why they ask questions such as 'can you say that again?' or 'could you read the price label on that item for me?' Like Sarah, I sometimes feel the need to explain to people that I have these impairments and like James, I am sometimes considered 'odd' because I do not hear or see as well as other people and they cannot understand my responses to certain situations. My feelings are exacerbated by a sense of shame when people find it difficult to believe that I have these impairments. As a counsellor, this enables me to identify with participants such as Kevin and Nancy and my empathy enables me to appreciate the ways in which our situations are different. It may be that because I could identify with these experiences as a disabled person and because I listened to them as a counsellor, I was more aware of how they responded to these situations internally and I did not always ask them how they responded outwardly to other people. In this case, I may have found out slightly less about their relationships that I would have hoped.

4.2.2. Expectations, assumptions and projections

One feature of living in a dominant, ableist (Campbell, 2009) culture is that disabled people can feel alienated from others because they cannot conform to social norms. James feels that he misses out on activities with some of his friends because they do not understand how to help him join in. He says

"There may be certain things I can do but I'm not given the techniques to do them. If I'm taught the way to do these things I can do them just as everyone else but it's just not innate. [...] Maybe I need someone to coach me".

This applies to practical activities but also to social situations, where he often feels awkward and anxious because he cannot easily read social cues. He explains

"All the life experiences like social interactions, you're not taught them. You're expected to learn them and that's the challenging thing. [...] I just go into social interactions as I am and sometimes people look at me a bit weird and I think 'what am I doing wrong? I'm just doing what I'm doing'. [...] Sometimes I go into social interactions with almost a brutal honesty and that means people are quite intimidated and quite frightened [...] and step back. [...] I try to learn

and pick up cues but sometimes it might not work like that. [...] It's a whole learning process. I'm still trying to learn it really".

The consequence for James is that *"on a day- to- day basis I'm almost so unaware of it, when I hit those social interactions that do make me think of it, that makes me feel really, really quite low"*.

Kevin often feels the pressure of other people's expectations. He gives an example of this, saying

"People say 'well put these things in your diary. Look up your diary and do this and do this and do this' and I just think 'oh God', that would be great' "

It's very frustrating for him to feel corrected and instructed to do something that he cannot do. He says *"it's at the most superficial level that I feel people grasp what it's like for me"* and he feels that *"it's not a hell of a way to be alive"*.

As a wheelchair user, Nick's impairment is visible to others so he is often the recipient of other people's projections (Watermeyer, 2009). He explains this, saying

"People make some weird assumptions. They think that there's some big major realisation that I have to make. If I said that I go through a day and I don't notice they would just think I was in denial. [...] People often think it must be terrible to be bound to a wheelchair. [...] I wasn't aware of any problem and I'm still not aware of a problem really. Other people seem to think there is".

As Nick says, the root of this attitude is that non-disabled people often think that it is tragic to depend on a wheelchair and it may be that this attitude lies behind the approach that some people have to Janet's progressive condition. She feels a pressure to be fighting her condition and to be looking for a cure. In her experience, this comes from both disabled and non-disabled people. She says

"There are people who feel that you should try whatever you can, that if there's a drug out there it's worth a try. I'm very drug averse and I look at the risk of taking the drug whereas they look at 'well you have to try whatever you can because suppose you didn't try it and it could have helped you?' I feel that I have accepted that my life has changed irrevocably because of this condition and I feel that there are other people who are fighting and they keep looking for a cure and will there be a cure in our lifetime is a huge question for

them and for me it's like 'nah I don't really think so'. I have no expectation of that and no hope of it but not in a hopeless way".

Janet says that one of her friends expects her to understand how a relapse occurs *"she always asks what brought it on. 'I don't know. These things are random' and she's desperate to find a reason for her illness and be cured and get better. She's fighting it and she expects me to fight mine too in a certain way"*.

While she feels frustrated with these people, Janet has become more empathic towards her father, as she says

"It's really hard for him to see his child disabled with a chronic illness and there's nothing he can do about it. He's 87 now and [...] he wants me to be cured before he dies [...]. I don't think he has a clue where I am with it. I don't think he wants to go there. It was too much work for him emotionally to try and understand".

Like Janet, Nick also felt a pressure from other disabled people. He grew up with family and friends who did not consider his impairment to be problematic so it came as something of a shock when he realised as a young adult that not everyone saw his condition in this way. He says *"I was completely innocent that people made assumptions. They're deeply ingrained and they're not just people without an impairment"*. Referring to one such person, he says

"I met a guy who is very politically active and he made quite a few assumptions about what was right and wrong and the social model. He worships that. You can't be disabled without the social model [...]. They weren't seeing me through my eyes and I would tell them and they wouldn't listen, they wouldn't hear me".

Because he felt the need to conform to a set of expectations, Nick did not feel that peer support was a valuable source of strength (Shakespeare, 2006; Watson, 2003), so he abandoned his involvement with the disabled movement.

Although I identify as a disabled woman, the issues raised in this section do not have particular resonance for me but as a researcher I was interested and curious to find

out if and how these people felt differently to me. I relied on my counselling skills to help me to understand these participants' experiences

4.2.3. Communication

As a counsellor and a burgeoning writer and researcher, I am aware that communication is one of my strengths although my limited hearing enables me to appreciate something of the impact of deafness on everyday relating. Some of what I was to find out about participants' experiences in this realm were unfamiliar to me previously, so I had to pay particular attention to the experiences of participants who have impairments that affect their capacities to speak and to listen. Because communication is a basic building block for establishing and maintaining relationships, people who are impaired in this way can feel estranged from others. This is the case for Nancy. She explains

"It's a different way of life. If you want to talk to me, to speak to me for example, I have to stop whatever I'm doing. I have to look at you. I have to face you to be able to communicate".

Her current partner has difficulty in remembering this. Nancy says

"I have known him for over twenty years and he still to this day is frustrating. [...] He may say 'oh let's go for a walk' and I think 'oh he wants to talk'. He wants to have a conversation when he's walking. I can't do that. I'd have to concentrate on the road or where I'm walking".

She feels frightened because she cannot hear when people are approaching her. Talking about her partner, she says

I* *I'm absorbed in my book and he'll come in abruptly and I get such a fright. I don't hear him coming [...] and it really irritates me. I think just*

N *bangs the table*

I* *flash the light, stamp your feet, do something so that I know you're approaching me. It's so frustrating. It's really rare that he remembers.*

* Interpreter

Monica explains that communication among deaf people is not necessarily easier than it is between deaf and hearing people because there are different types of

hearing loss that cover a range from mild to profound (Morgan-Jones, 2002). People who have mild hearing loss might use hearing aids while those who have been profoundly deaf are more likely to use sign language or interpreters. Even among those who sign there can be geographical differences in the language that can cause confusion. Monica has lived in different parts of the UK and she says

“Signs can be different like accents. [...] You can tell where people are from by the accent and it’s the same with sign language. We have different signs. So there are some barriers there for me. Sometimes people might think I understand fully what people are saying and vice versa but we don’t. We all have our own signs and we have to ask for clarification”.

One aspect of Bill’s condition is that his speech can be very indistinct and other people sometimes find it hard to follow what he is saying. He chooses to describe this experience obliquely by putting himself in the shoes of a listener, saying

“I’m working hard to understand what they’re saying so I have to find a way of relaxing and I realise that I’m getting the rhythm of their speech but if you have somebody who has speech disability it’s really quite noticeable where the words are not at all clear”.

While at university, Bill met a fellow student who had a similar condition to him. He says *“I felt so guilty but I didn’t have the emotional energy or the emotional imagination to find a way of engaging with her”.*

Kevin has difficulty managing and processing information and he illustrates this issue by referring to what happened when he and I were planning to meet for the research interview

“First of all I have to read your text and understand it, then I have to accept I make a mistake of the time because I don’t manage time. I put you in at ten o’clock, to make sure I was here on time because I’m always late and of course I forget and then think you’re coming at ten, so I got myself ready at half nine. [...] The next thing is, I am really looking forward to seeing you but I can’t remember at all why you were coming because I can’t access the words [...] so I just hope when you’re gonna come because of my warm feeling for you, it’s gonna be fine. That’s what it’s like in every single engagement with everybody all the time. [...] Part of my difficulty is understanding. [...] I think my

ability to understand complex issues is impaired by my ability to articulate that understanding, so I rarely say clearly what I know, because it's very difficult".

He explains that he muddles his words up and often misses out words when he is speaking, so people can find it difficult to follow what he is trying to say. This can lead to difficult situations at work because he becomes frustrated and tempers begin to run high. He says

"When I'm in a discussion, it's very difficult to be coherent about my trouble because I use the wrong words and we have a massive explosion in the team".

Another impairment effect is that he does not remember people's names. Referring to an accidental meeting with a friend in a public place, he says

"I will look at somebody like X. Now X is somebody I've worked with for 20 years and I'll look at her and go 'I know who you are'".

This can be awkward for him, especially when he is with people who do not know about his impairment. He lives with a constant awareness of being different which he finds very frustrating and this curtails his sense of belonging within his social spheres.

4.2.4. Managing the differences

Amanda has her own ways of managing her condition but these ways can sometimes alienate her from other people. She was taught how to manage her visual impairment at a young age at a boarding school for blind children. She says

"We were taught how to be confident and how to maximise our lack of vision and we were taught techniques. Making eye contact is obviously difficult, so we listened to where the voice comes from and we look up an inch and that's our way of making eye contact. A lot of people would walk along with their arms out feeling their way. We were taught to just put our little pinkie out so that you just brush against it".

She explains that she was taught these techniques *"because we would be going out and about in the world and not wanting to be vulnerable".*

As an adult, Amanda's learned confidence and her tendency to downplay her impairment misled other people at times. She says

"I was about thirty when I started to embrace the visual impairment. I couldn't deny it any longer cos of the pain [...] and the fact that for years I've been apologising to inanimate objects. I just thought, it's not safe to not use a stick or ultimately have a guide dog [...] and that's when I recognised other people's attitudes. [...] Complete strangers come up to me and say 'you don't need a guide dog'".

When she walks with a white stick, she hears people say

"'You don't need that' - a lot of bus drivers especially. I'd have the bus pass but they kept saying 'why does she have that stick?' Why has she got the bus pass? She doesn't need it'".

At one point, a friend intervened on her behalf saying

"She's very good at looking confident but, he explained to some of the drivers 'she can't see your face but, she acts confident, she just doesn't look so vulnerable and she's not a victim'".

Janet has made steps to ensure that she could still connect with people socially but she often has to explain how she manages her tiredness which she finds frustrating.

She says

"I'll tell a friend that I can't come to a certain event because I'm too tired and they'll ask 'oh you're too tired' and sympathise with me. It's like 'no, this is not an emotional conversation I'm having with you. I'm giving you information that you need to know, I'm fine with being too tired and missing this event cos that's how I manage my life'. I'm all right with it and I don't have the emotional energy. I have to manage my time, I have to miss a lot of events, I have to say I might be able to do something and then cancel it in order to have a social life. I deal with that emotionally in a sort of global way. I've accepted that's the way it is. I can't then go and grieve each loss of not being able to go out there and then and it's like the outside perspective is 'well she's cut off from her feelings'. It's like 'no I've dealt with that I've moved on I'm just telling you I can't come'".

Segal (2002) recognises that having MS can cause people to experience many kinds of loss and suggests that each of these has to be grieved separately but Janet's experience suggests that doing this can exacerbate her condition.

Unlike Nick, Monica and Nancy have good connections with their peers in the deaf community for the most part but there can be drawbacks. Monica says it is "a very *small community*" and that this is difficult for her because her work with deaf people obliges her to maintain confidentiality. She says

"Friends of friends might be friends of my husband, partner's friends or whatever, so there's a link – that's what I call a chain relationship. Everyone seems to be linked in some way".

Not only does her occupation impinge on her capacity to be part of the social community but this has an impact on her relationship with her husband. She says

"My husband's deaf and I never talk about work because of confidentiality but sometimes I know who the person is because of my job but I don't talk about that. [...] It's just being confidential and that can be like keeping secrets".

Eventually, Monica says "I had to withdraw from the community. I'm still a member of the community but I have my own circle of friends now".

4.3. Estrangement through rejection and abuse

As I indicated in chapter 2, disabled people are more likely to experience the violation of their boundaries and the exploitation of their vulnerability through abuse and violence than non-disabled people. Participants' stories illustrate some of the different ways in which this form of oppression can be experienced.

4.3.1. Patronising, staring, ridicule

Disabled people are often stigmatised and stared at in public places because they are seen to be different (Garland Thomson; 2009; Goffman, 1997; Reeve, 2002) and James, Amanda, Bill and Pete talked about this experience. For James, this began at an early age. He says

“In nursery I noticed my peers would treat me slightly differently. It took a bit of time to notice because initially you’re just a baby and you’re just doing whatever you’re doing but then suddenly people’s reactions to you. I remember strangers acting slightly more patronising to me when I was walking around”.

He felt different because of the limitations of his impairment. He says

“I was not great at balancing and bouncing on small beams. I was aware that I couldn’t do that but I was probably aware of it because everyone else could do it and I couldn’t and I didn’t think it was normal”.

This difference was emphasised in medical settings where he says *“I found that physiotherapists were sometimes quite patronising and talked to me a bit slower than I thought they needed to”.* He concludes that *“it was all these gradual things that kind of accumulated throughout my life”* that led him to feel disabled.

Amanda says *“it’s happened in the past where people have said ‘are you blind?’ and I’ve said ‘as a matter of fact, I am’ so it’s like ‘oh, oh sorry’”.* While she feels able to respond to this in a matter-of-fact manner, Pete sometimes responds with anger when other people stare at him. He says

“If I go shopping in the main street they stare and there have been a couple of times that I’ve turned around and lost my hand with them and sort of ‘why are you staring at me? I’m missing a leg but I’m still human’. They just back off. It’s adults that are the problem. [...] I give them my harsh tongue but it depends on how I’m feeling”.

Bill finds it more difficult to respond. He says

“I walk past a group of teenagers who might be aware of my walk and might be tempted to tease or say ‘Jimmy are you pissed?’ and I’m not relaxed enough to make a joke of it”.

He says that he is uncomfortable and self-conscious when people ridicule him so he seems to block out these experiences at times. He says

B *I can’t remember how I made sense of other people’s responses because even now my wife says ‘did you not notice that so and so responded to you in a certain way?’ I said ‘no’*

C what sort of things would she notice?

B *well you know the classical thing of people talking about you to somebody else or clearly being slightly awkward or that I surprised their expectations.*

Person-centred counsellor Marlis Portner (2000) points out that people with severe learning difficulties are often ridiculed in public places to the extent that they avoid being with their peers because they are more likely to be made fun of when they are in groups. The other side of this is that they are then denied a sense of solidarity with their peers.

As a disabled person and a woman, I was privately aware of the emotionally disturbing feelings that were aroused in me as I listened to these stories. Like Bill, I would have preferred to 'block out' any feelings of embarrassment and anger. Although it was emotionally challenging for me as a researcher to listen attentively to these participants' stories, I was able to draw on empathic skill to set aside my own discomfort without denying what I was feeling. In this way, I could hear and respond to what participants were communicating to me.

4.3.2. Rejection

Several participants spoke of being rejected by others in subtle and overt ways. Nancy says

I* *"In the past I think hearing people maybe took advantage of me because of my deafness. [...] I certainly felt at that time many times, many, many times that nobody listened to what I was saying. There was no acceptance of what I was saying it was just like 'och just go away'*

C so did you feel quite isolated from other people then?

I* *"Oh yes without a doubt".*

*I = Interpreter

This excluding behaviour made it difficult for Nancy to make friends in her young adult life, especially when she was at college.

As a child, James says

"People just assumed that I couldn't do a lot of things that I could do. I remember playing at one time a sport thing where you hit a ball against a wall

and I remember being excluded cos they said 'oh [James] won't be able to do that'".

He was able to do some activities if he had appropriate instruction but other people do not always understand this subtlety. He tells the story of another rejecting experience saying

"I am used to people, even close friends arranging to meet at certain times when we're going out for drinks and they come an hour late. [...] At this point in my life I don't want to be on my own but then when they don't come it reaffirms the idea that I should be on my own. I think they're almost worried that I'll feel hurt if they tell me the real time they will be there because it's such a long time after the deadline".

This awkwardness leads James to feel perplexed, angry and despondent. He says *"I think that's so disrespectful and that makes me think 'oh well I wasn't worth coming out for'".*

Like me, most of the participants in this research are the only disabled people in their families. As Gill (2001) points out, it is common for people in this situation to feel excluded. Monica offers an example of how this can be experienced. She says that

"90% of deaf people have a hearing family, so [...] they might feel left out from siblings and from the rest of the family. Just things like meal times, the family will be chatting away but a deaf person might feel left out and not included in that. Or, family might feel disappointed in them because they might not be improving in their speech or not doing well at school [...] and that can make them feel depressed".

Sandra began to feel rejected by some family members after a series of difficult circumstances. She became disabled shortly before the sudden death of her husband and as a consequence of both, she felt alone and depressed. Shortly after that, she experienced several losses through death and divorce and at the same time, she was losing her involvement in community life. She says *"I was always [...] involved with church, with gala, with the pensioners".* All of these losses left her feeling isolated. She says *"I had nobody to talk to. I had to store it all up so I had to cope with it".* For most of her adult life, she and some of her siblings lived in the

same village and she would see them most days but because of her loss of mobility, she had to move to a more accessible home. She was particularly close to one of her sisters but she says *“I was lost because of my disability. It was my disability that closed it for me. I couldn’t go down to see her”*.

Sandra was further isolated because after she developed her impairment and moved house, she felt that she was being left out of family events. One of her brothers lived a distance away and was dying so Sandra wanted to say her goodbyes but other siblings prevented her from doing so, saying *“there’s no room for you here. There’s nowhere for you to sleep”*. A similar situation happened when one of her sisters was dying. The same family members prevented her from visiting her sister in hospital. She was excluded from attending the funeral by her sister’s family and that, she says *“seemed to have been the end for me, the end of family”*. The sense of rejection combined with the losses through death, left Sandra feeling isolated and emotionally very low.

4.3.3. Abuse and violation

Participants stories add substance to the view that disabled people are vulnerable to abuse and violence (Goodley and Runswick-Cole, 2011). Jordan (2004c: 36-37) points out that

“Traumas, particularly those caused by other humans (e.g., sexual victimization, war, or physical violence), create major disruptions in our experience of relatedness”.

Kevin was physically abused as a young boy before he was diagnosed with dyslexia. Nancy was sexually abused as a child and being deaf meant that she felt unable to disclose what happened. Pete was sexually abused as a child before he became disabled in his middle years but other people’s stories of abuse in his boarding school brought the issue to a head so that he felt overwhelmed by his feelings about that and his impairment. Robert felt neglected and used by his partner towards the end of their relationship and he attributes this to being disabled.

Amanda was abused by her mother physically, emotionally and sexually. She says

“My mother humiliated me, hit me, made me go out into the garden naked. She’d make sure if I had a bath I had to go downstairs in front of certain uncles and she’d lift my nightie up. As a three year old knowing that’s wrong - it was sort of hyper uncomfortable and she used to do it constantly. [...] You feel that intense childlike horror or pain or humiliation or anger. She wouldn’t parade my brother or sister it was always me. My mother resented me cos I was my dad’s favourite”.

Amanda was abused later in life as an adult. She says

“When I was in my late twenties I was in an abusive relationship with a woman who was eighteen years my senior and it was mainly verbal and emotionally abusive and a couple of times physical and I spiralled into a very deep depression”.

She took an overdose as a consequence. She explains

A *I wanted to die, I’d had enough*

C You wanted to die because you wanted out of the relationship?

A *I wanted out*

C wanted out of the abuse?

A *I wanted out of the abuse and I was also getting my mum on the phone shouting at me and telling me how worthless and useless I was and when you’ve got that you just feel you have no support. [...] She [her ex partner] did used to pick on my eyes. The lower I got the more abuse I got because I wasn’t able to defend myself. She would say ‘nobody would want you because you’re ugly’. She would try to lay it on me that because of my visual impairment I was ugly and useless and she used the same words that mum used to say to me”.*

Amanda’s impairment was connected with being abused – she and her mother appeared to resent each other because they shared the same inherited impairment - but she felt less clear about the causes of the violent incident she endured shortly after she left school at the age of eighteen. She was with teachers, from the school that she had just left, on a trip abroad with several other visually impaired young people. She told me that one evening she was raped. As she was talking to me, she seemed to be inferring that the rapist may have been taking advantage of her lack of vision so I asked for clarification

C Can I just check, did you feel that your visual impairment anything to do with that?

A *I would think because I come across confidently. I was actually abroad as a volunteer with a girl and a boy who have visual impairments. I was also there with two teachers but they left about half an hour before me. I was talking to a group of people. I hadn't told anyone in this group [...] that I had a visual impairment and it wasn't any of them that ended up assaulting me but perhaps because I didn't have peripheral vision, I wasn't aware of what was going on. I was just looking around saying 'I've just got to get there' so my visual impairment may have led to me not being aware of someone approaching but I think it was just opportunistic to be honest".*

I did not wish to impose my understanding of what happened onto Amanda but my question seemed to prompt her to reflect further on the assault. She said

"Part of me blames my visual impairment on the situation I got myself in. I didn't want to be seen as vulnerable. [...] I don't want to have to watch my back all the time or have to go out with someone holding my hand".

While it was important for me not to jump to conclusions about the attack, it seems that learning to be confident and to avoid being seen as vulnerable, may have prevented Amanda from appreciating that other people might take advantage of her.

4.4. Disconnection in helping relationships

Disabled people often have difficult relationships with the people they depend on for refuge and support (Gill 2001) and there is an inherent tension between being dependent on others for personal care and wishing to be as independent as possible.

4.4.1. Protection

Because disabled people are often regarded as vulnerable socially (Shakespeare, 2014), it is inevitable that others may become protective of them but non-disabled people often find it difficult to know when to protect and when to enable a disabled

person to take control of their situation. My own parents were advised to raise me as though I was 'like everybody else' so they did not over-protect me but Bill tells the story of how his parents protected him from "*the rough and tumble of school*". He says

"My mother later tells me that the head teacher in the elementary school said to her 'we're not convinced that he'll do well in the next stage of education' so it gave them, unbeknown to me, incentive to look at alternatives".

He recalls feeling a 'dent in his ego' because he says

"It was only when I left that one of my pals said 'I can remember when you first came because we were all called in before you arrived and the headmaster told us that they had accepted a new student with [a physical condition]' and that people should look out for me".

In both cases, people who were responsible for Bill's care did not involve him in their discussions. This seems to have undermined the little confidence he had about making friends.

Amanda spent her young years at a boarding school for children with visual impairments and she says

"I'd been away from home since I was nearly eleven years old. [...] When you go to school and you've all got visual impairment you are cocooned from the rest of the world. [...] They do give you a lot but ultimately they take a bit of it away because you are going into the mainstream. It's like 'oh gosh'".

Although she was taught to feel confident about managing her impairment, she was not prepared for moving from the protective environment of school to living in an ableist world. Conversely, while I was not over-protected, the lack of acknowledgement of my difference in relation to other people meant that I was unprepared to meet the challenges of living in a world where my difference was noticed and responded to, often negatively, by others.

Nick's story about being protected was less overt. He did not feel different within his family, friendship and school environments as he was growing up. Even when he encountered difficulties in his childhood, he felt supported. Referring to his disability, he says "*there was never any 'it' basically, not for me, not for them*". As a

consequence, he says *“I was very naïve so I trusted people very easily because I’d never learned not to”*. As an adult in his late twenties, he became friends with an older man who *“made quite huge assumptions about maturity, about growing up and he thought I would remain a child”*. I asked Nick to clarify what his friend meant

C so he was talking about sexuality?

N *yeah things like that*

C and he made assumptions about you that way

N *yeah, and he seemed to me to be very convinced.*

Nick says *“I hadn’t spoken about sexuality, or about maturity growing up relationships with anyone and there was the thing about trusting an older man”*.

He says *“it was very damaging because I trusted him quite a lot”*. When this was said to Nick, the effect on him was profound and it launched him into an in-depth therapeutic process.

4.4.2. Inappropriate helping

Nick is one of the many disabled people that find healthcare professionals overbearing at times and his first experience of this was when he was six or seven years old. He chose to tell me his story by way of a TV programme he had seen

“There was this young girl, she was six or seven and she had some impairment and she used to go around - and I used to get around when I was young in a slightly odd, different way - so I would lean up against walls to move around. I would stand up in a way that I described. I found it fine. There was no problem for me and there was this young girl, she gets around in similar ways and then she used to go to have callipers put on. First of all - I have quite a problem with so called experts - so called experts put her mother in a different room. [...] They forced callipers on [the girl] and suddenly she can’t get around anymore. It takes a long time to learn how to use callipers, cos I used them and it was quite traumatic for the young girl. Suddenly this so called solution doctors were so proud of and think they’ll make her life better, makes it a lot worse. It’s still quite upsetting now to think about”.

Nick tells another story about his experience with a social worker

"I don't look at my wheelchair and go 'och I have to use that all the time' I'm actually quite attached to it [...] but it had to go in for repairs so I had to use a rented wheelchair. I suddenly realised it's like losing a limb. I say 'I can't do all the things that I used to be able to do. It's like one of my limbs is missing'. [...] everything in this environment is built to this wheelchair so [it] can go under that table. [...] So this is the really weird causal chain. Whether or not I can put my contact lenses in depends on the wheelchair I'm using cos it's something to put my elbow onto the table. [...] So if you say that to people 'what difference does your wheelchair make to your contact lenses?' well actually it's quite a long story. It's something I've never talked about. I find working with social workers to get support. The assessment process gets cocked up cos it doesn't work because the process can be very unsafe, unpredictable".

The point he makes is that social workers might do assessments but may easily miss the subtleties of his support needs so Nick feels disempowered and alone because he is not being heard by those who seek to help him.

Colin Cameron (2010:128) points out that

"The paradoxical nature of disability is reflected in the fact that, while the experience of isolation has been identified as a major source of tension, so also is unwanted interference".

This is evident in Janet's story of being helped by a friend. She says

"I get angry, irritated by a sudden flash of temper when she like does things for me. It's like 'get off'. What I feel is like physically violated, it's that strong a reaction. She does things like she'll lift my foot if I'm being too slow. I know that it's motivated by her desire to be helpful and kind because I know her well enough".

Janet is beginning to distance herself from this friend because she says *"I'm disabled first and her friend second, whereas with my other friend, we're friends first and part of the reality is that I'm disabled"*. Kevin often feels over-helped. He finds that people offer suggestions that they think will help him when he gets mixed up or has difficulty reading. They say *"oh I'll read it for you"* but he says, *"I think, well you can read it for me. I'm not gonna understand it cos that makes it even less accessible to*

me". He says *"I can get really angry"* or he makes jokes about it but he feels patronised and undermined when people do this. On the whole, Pete feels supported by family and friends but he says

"Sometimes they try to be too kind, too nice. [...] I'm glad they're there. They're all good friends. They're understanding. Sometimes they nurse me too much but on the flipside they're always there when I'm not able. [...] I'm not ungrateful".

These stories illustrate how the experience of being helped can elicit awkwardness for both the disabled person and carers and that the person being cared for may feel uncomfortable about disclosing how they feel for fear of seeming to be ungrateful.

4.4.3. Personal care

Nick employs personal assistants (PAs) to attend to his personal care and generally this works well for him but he has experienced some anxious moments with some of them. He says that one carer *"took the piss a bit and turned up two hours late a lot and was quite intimidating"*. Referring to some others, he says

"You get people who really want to talk about my problem as they would call it, you know 'what's wrong with you?' and they think they can understand me by understanding that".

He chooses his PAs very carefully and in doing so, he prioritises the relationship over their training and experience. He says that he sometimes makes mistakes in his choices and he gives an example of recruiting a new PA, saying

"I use a catheter and I had to explain to her, she had to be shown how to fit it. 'Right OK this is completely new. I've never had to negotiate these kind of issues before'. So I thought, 'OK I'd better be careful here', so I rang the district nurse and asked her to show her how attach it. I made sure there was another woman there just to keep her comfortable and she [...] completely freaked out".

Nick understandably felt vulnerable in this situation and this is echoed by Siebers (2008:52), who points out that *"people who rely on caregivers have to be diplomats"*. Nick discussed this at length with his counsellor and I will continue his story in chapter 6.

4.4.4. Hidden labour

Nick's situation illustrates how disabled people can feel the need to manage the *"cognitive and emotional aspects of their interactions with non disabled people"* in order to make the bridge between themselves and others (Scully, 2010:32). It was only when I was analysing the results of this research that I became aware of the full extent to which I engaged in this process. Scully uses the term *'hidden labor'* to refer to the work that disabled people do in order to *"bridge the divide"* (Gill, 2001:350) between themselves and non-disabled people and to *"set the record straight"* (ibid). This might involve *"regulating the encounter"* by *"evaluating what strategies are needed and implementing them"* and anticipating *"what the other person needs to know or wants to feel"* (Scully, 2010:31). Nancy, Kevin, James and Bill notice people's puzzlement at some of their behaviours so they sometimes choose to explain themselves. Bill says

"I'm more aware of having little interactions with shopkeepers or bankers and they are perfectly fine by me but feeling under pressure to say 'I'm respectable you know if you doubt me'. [...] I fear that they might be perceiving me in a certain way".

Nick and Janet feel the need to reassure others that they are competent people who manage their conditions in satisfactory ways. Pete resorts to gratitude to manage other people's tendency to over-help him. Monica has been socialised to take care of others from an early age because she says

"My mum and dad were deaf. My mum always relied on me when I was young asking me words and what they meant and when they received letters from the council or whatever. [...] I think at that age inside I was like a helping person. I'll support people so when things happen I do feel a responsibility".

In terms of managing other people's emotional responses, Janet talks about her relationship with her daughter. She says

"I have a difficulty in my relationship with her because it hurts her so much to see me vulnerable and she's said to me 'I find it hard to be with you, find it"

painful', I think it's her powerlessness to do anything about it. If she could fix it would be all right".

Janet tries to bridge the gap saying *"I babysat for her son and that sort of normalised things cos then I was the granny doing the granny type things"*. Her deteriorating condition means that she can no longer do this, so she says *"I'm just trying to think what would rebalance things"*. She also works hard emotionally to alleviate her father's anxiety about her condition but although taking care of the emotional responses of family members can be stressful and tiring, Janet's efforts can have rewards. She says

"I think he was able to see that there is something that he doesn't understand about my approach to my illness and to stop sending me all these articles but it was too much work for him emotionally to try and understand".

Amanda says *"my dad always felt very helpless when it came to us with a visual impairment"* and she was always conscious of this so consoling him was a strong element in her way of relating to him. She was more aware of doing this towards the end of his life and she cites one poignant moment when

"He just felt like 'I'm useless, I can't do anything. I can't offer you anything anymore'. That's when I turned round to my dad and it's like 'you were more than our eyes and our chauffeur'. I said 'you were my dad'".

Amanda's story suggests that hidden labour does not need to be one-sided and that a balance can be achieved when both parties can benefit and make different contributions to maintain the strength of their connection.

Scully (2010) points out that in general, people who feel stigmatised can be motivated to engage in hidden labour for several reasons, namely to get support; to maintain relationships and to maintain self-respect. In my experience, this can take the form of self-protection. I am aware that I engage in diminishing my own experience in order to avoid the discomfort of having to respond to the reactions of other people to my impairments. Gill (2001:60) points out that disabled people often tend to

"ignore other people's lack of tact; respond graciously to others' intrusive curiosity, and routinely sacrifice their interpersonal equality to accept

unsolicited help from others who need to feel superior through helping. In short, they expend considerable energy to help non-disabled persons feel positive about interacting with disabled people”.

She adds that they may do this not only to seek acceptance but also because they are afraid of being mistreated. It must be said that people are not always aware that they are engaging in hidden labour. In my case, even though I am now more aware of engaging in this behaviour than I was previously, I do not always notice that I am doing so. Whether or not people are aware of what they are doing, hidden labour can be physically and emotionally exhausting (Gill, 2001; Scully, 2010). It is not uncommon for disabled people to withdraw (Watermeyer, 2009) as a way of protecting themselves and conserving energy.

Kevin resents the fact that disabled people often feel obliged to educate others about their impairments in order to be understood. He says *“you don’t expect the black person or the gay person or why should the disabled person have to be the educator?”* He often loses the impetus to explain how his impairment affects him because even people who know about his condition don’t fully understand it. He says, *“I don’t bother talking about it because it’s such a huge thing”.* Scully (2010) argues that if people disclose their feelings about hidden labour, they would not achieve the goal of bridging the social gap but instead their sense of difference would increase. She maintains that it is not ‘morally right’ for disabled people to contribute disproportionately to enable social relationships to operate smoothly because they are already situated in Western cultures as a socially inferior group.

4.5. Summary

In this chapter, I have drawn on stories from all participants and I have added my own perspectives as a disabled woman with a view to illustrating the diverse range of difficulties that can occur in relationships where a person is disabled. Some of the stories resonate with me more than others so I have relied on my role as researcher to steer a way through the morass of difficult experiences and to hold a certain amount of distance from the experiences that are particularly resonant with my own

story. I have used my counselling skills to guide me through my tendency to identify closely with some participants' experiences so that I remain empathic to their frames of reference. I did this through the recognition that their individual situations as well as their responses to them are not the same as my own.

I have shown that all participants in this research, as well as me, feel a sense of isolation at times because of the limitations we experience as a result of impairment and/or disability. We have experienced estrangement from others at different social levels – from members of the public, professional carers, family, friends, colleagues and other disabled people. We have felt estranged in different ways, for example, through the trauma of acquiring a disabling condition; having an impairment that inhibits communication; the deaths of family members, especially those who act as carers; the deteriorating quality of existing relationships; pressures that arise from misunderstandings; the assumptions and expectations of others; being shamed because of their impairment; rejection; abuse and hostility. A further cause of estrangement was illustrated by some participants as well as me, where disability and impairment effects occurred alongside other stressful life experiences. Participants have illustrated some of the causes of estrangement namely, the disabling environment; impairment effects and a combination of circumstances that include difficult life experiences.

Through our stories, we have illustrated some of the ways in which we compromise ourselves in order to maintain connections with other people. Some of us have said that we do this by hiding our responses (hidden knowledge) by not talking about how we experience the attitudes and behaviours of other people that cause us to feel confused, uncomfortable, hurt or damaged. Some of us have said that we compromise ourselves by engaging in hidden labour.

Around half of the participants say they tend to withdraw from others because of the strains and stresses involved in being disabled. They have identified several reasons for doing this. Some experience communication difficulties; have inadequate access to public places; feel emotionally hurt; have difficulty in trusting other people; feel that they are not understood; feel pressure to meet the

expectations of others; need to recover energy; are afraid of burdening others; think of themselves as private, solitary people. Participants identified different ways of withdrawing from others. Some, like me, do this by avoiding social situations that feel overwhelming or exhausting; by avoiding being seen with other disabled people for fear of being stigmatised; by becoming emotionally distant or by presenting a public self and keeping other parts of themselves hidden.

The sense of isolation that we experience runs contrary to our desire for social contact and this corroborates with much of the literature in DS (see Cameron, 2010; Keith, 1996; Morris, 1991; Shakespeare, 2014; Watson, 1998, 2003). This is a strong indication that social and cultural conditions of worth, or ableism, may have been internalised by participants and by me. The gaps between disabled people and others can feel like chasms at times because conditions of **worth** can cause us to become the 'people that we are expected by others to be' (Cameron, 2010). In this way, we can become estranged not just from other people, but also from ourselves. I turn now to illustrate how disabled people may respond to these experiences internally.

Chapter 5: Estrangement from the self

In this chapter, I address the second and third of my research questions, namely 'How do these relational difficulties affect disabled people's emotions and behaviours?' and 'How do these relational difficulties shape disabled people's self-concepts and sense of agency?' Disabled people are like everyone else in the sense that they each respond differently to the stresses and strains of life and how they do this affects their relationships with others. However, as I have shown, DS literature suggests that disabled people are subject to the effects of powerful social and cultural conditions of worth that affect them psychologically and emotionally; in their attitudes towards themselves and in their ability to take control of their lives. Although these aspects were not specifically named in my list of research questions (see Appendix B6), as a researcher in counselling, these were very much in focus as I listened and responded to participants during the interviews. Inevitably, as participants talked about their experiences, they did so with different emotional nuances and often talked about the effects of these experiences on the ways in which they experienced themselves. As a counsellor, I am trained to focus on emotional content and on the consequences of conditions of worth on the concept that the person has formed about him/herself. Therefore, these were intrinsic to the responses and interventions that I made as I listened to participants during the interviews.

Drawing on person-centred counselling theory and practice, I consider the impact of conditions of worth on participants. Before I do this, I must point out that participants have all been counselling clients and that experience may have enhanced their self-esteem. They are all looking back at past experiences from their current positions so the effects that I discuss arise from a combination of how these participants regarded themselves in the past and how they view themselves now. In the following sections, I discuss the emotional effects of conditions of worth (5.1) and the effects of condition of worth on the self-concept (5.2). From there, in 5.3, I discuss what participants have said about how the different aspects of themselves (configurations of the self) shape the self-concept. Finally in 5.4, I elaborate on the effects that conditions of worth have on participants in terms of their sense of agency, meaning

to become self-directed, able to take control of their lives and have a sense of personal power.

5.1. Emotional effects

As counselling clients, all participants report that they have experienced vulnerability (see condition 2, Appendix A) that is manifest in depression, stress or anxiety at some point in their lives. I have shown that this can be attributed to conditions of worth; impairment effects or to a combination of both. Participants talk about their emotional responses to these issues and these can be summarised as exhaustion, frustration, envy; self doubt, sadness and anger and despair. Kevin, Amanda, Shirley and Robert say that they sometimes blame themselves when relationships became difficult. Robert says

“At a stroke virtually every relationship changed and it was a large part my mismanagement of the situation had caused it. What I should have done was not go to bed for two months. I should have probably sought some help earlier”.

Kevin sometimes feels low and despairing because of other people’s attitudes to his condition. He says

“I went through all of my education in absolute despair because anything I did that would take one hour would take me sixteen hours to do, to read, to write something, to spell it. I can get really angry. [...] It has a profound effect every day, all the time and its exhausting and I don’t have any choice”.

When Shirley first became visually impaired, she says

“I closed off as you do in a depression. You put your shell around you so your world shrinks and I became very isolated even within my family because I was just trapped in this shock and devastation”.

Pete lives with sadness, anger and frustration about his amputation and about being sexually abused. As a counsellor and a disabled person, I understand that both situations will have elicited shame in Pete and that this feeling becomes acute when he is ridiculed in public.

James says that being considered odd *“makes me feel that I should be very independent and on my own all the time. It makes me feel that I’ve got to be very strong for myself and just look after myself”*. As a disabled woman and a counsellor, I understand that *defensive withdrawal* can be uncomfortable when it comes with a desire for connection and can lead to a painful sense of estrangement as it did with James. Sandra attempted suicide because she felt isolated and Pete was one of several participants who had suicidal thoughts because he was so emotionally overwhelmed. Nancy says

“I think I was a happy child, always looked happy, had a good personality, always laughing but as soon as I’m on my own it’s like the walls are closing in again. [...] It was like I’m a gonna commit suicide if I don’t do something I mean it was just I couldn’t carry on like that I think my past had just caught up with me”.

Amanda attempted suicide whilst in an abusive relationship and Jordan (2004c:38) explains that

“In instances of trauma involving violation by another person, we lose our trust in the goodness of others. [...] It is not simply that what they do is beyond our control. [...] In abuse, there is a profound disconnection”,

One of Amanda’s pervading responses to being abused as a visually impaired child has been to maintain an emotional distance from other people with the possible exception of her father. She became wary of other people as she grew into adulthood because of her fear of abuse and violent behaviour. She says

A *I never really let anyone get close to me and a lot of that is the childhood difficulties and also if you remember, the main female in my life was very violent*

C *your mum*

A *yeah*

C *I suppose you closed in on yourself and just got very independent*

A *independent I had friends but they were sort of acquaintances.*

Lack of trust in other people

Nick felt protected in his early life so when he came across people who undermined him as an adult, he says *“I’m still very cautious it was such a shock”* from which, he says he is still recovering. He says *“you learn very quickly to become defensive about certain subjects, to keep some things away from other people to for safety. [...] For a while the only person who I could trust was my therapist”*.

5.2. Conditions of worth and the self-concept

The person-centred theory of personal development involves understanding that when people are exposed to damaging conditions of worth, they may distort, deny or hide aspects of themselves in order to maintain the self-concept they have developed as a result of trying to please others (2.3.1). For disabled people, this might involve attempting to pass as ‘normals’ (Goffman, 1997) by hiding their impairments where possible. In this way, they may *“bridge the divide”* between themselves and non disabled people (Gill, 2001:360). When they do this, they may help relationships with others to run smoothly but they can be left with the feeling of estrangement because significant aspects of their everyday experience cannot be known to others. These aspects may then be *“rendered less admissible or possibly banished entirely from view under the host of moral imperatives”* (Watermeyer, 2009:98). Ultimately, people may lose the capacity to identify their own thoughts and feelings; to trust in their own evaluations and to take control of their lives instead of allowing others to overpower them.

5.2.1. Resisting the label

The disability label carries negative associations about being a *“social burden, object of charity, perpetual dependent or quasi-human”* (Gill 2001:363) and these associations can have a profound effect on disabled people’s self-esteem (Shakespeare, 2014). While some may use the label for political purposes (see 2.2.4), others are resistant to being classified. Shirley and Amanda are keen to avoid

the stigma associated with disability. Shirley says very clearly *“I don’t want to be a blind person”* and Amanda says *“I didn’t want to be seen as blind. [...] I didn’t want a label”*. Although Bill is acutely aware of his condition, he chooses not to associate himself with groups that carry the disability label which for him is associated with shame. As a disabled woman, I resonate strongly with this stance, which I felt most acutely as I grew up as the only disabled child in a family with three non-disabled sisters. I felt very connected with Bill’s experience though we have different gender identities. Both of us are middle aged and have had extensive experience of being clients in counselling so I think these connections enabled us to talk freely about the shame that we have experienced and that we still encounter at times. As an only child Bill, too, was the only disabled person in his family. He says *“I was born with a disability. [...] I didn’t think of myself in any specific group to begin with”*. He recognises the political value of disabled activism but he says

“I chose not to identify myself with the disability community even now. [...] I feel kind of uncomfortable and ashamed of it. [...] There’s a bit of me that wanted to be non-disabled”.

Janet sometimes feels exhausted by other people’s assumptions. She says

“There are other people that I knew that were making assumptions about me. There’s a challenge that I could rise to but I can’t be bothered. I’ll never see them again, doesn’t matter, let them make their assumptions. I don’t care”.

Although she is making a clear choice, she is allowing herself to be seen in ways that do not feel comfortable to her. She feels that the disability label is too all encompassing so she ‘troubles’ (Butler, 1990) the notion. She says

“It’s like the model of race where there are people and then there’s the add-on of being black, or the add-on of being Asian, or the model of gender where there are people and then there’s the add-on of being female. It’s not that you can take me and talk about ‘me who has these characteristics and then there’s her disability’, there’s just me and I am who I am”.

She goes on to say

“If I’m in the kitchen and I drop a bowl and it breaks and I get pissed off with that cos I have to clear it up and it’s difficult for me to clear it up, is that an

issue to do with my disability? Did I drop it cos I'm clumsy? Did I drop it cos I'm disabled? Am I pissed off cos I just bought the bowl or because it's actually quite difficult? You can't say".

Bill has a similar attitude when he says *"I didn't fit in but again adolescents can go through that with their parents anyway [...] any statement I make, how do I know? Because we all have our ways of comparing ourselves to other people and that's part of our narratives"*. Bill and Janet seem to be distancing themselves from the label because it does not fit with their experience of themselves.

When the disability label is imposed on people they become conditioned to regard themselves through the eyes of others and this can overshadow any element of self-regard they may have. Shakespeare (2014) makes a distinction between the label that is imposed on disabled people by others and the 'badges' that they choose to wear themselves. In person-centred terms, labels can be associated with an external locus of evaluation (see 2.3.1) and 'badges' with an internal locus of evaluation. This distinction is useful because it indicates that choices can be made about how people respond to conditions of worth. The problem is that disabled people often wear badges that are not authentic reflections of their inner selves. As Gill (2001) notes, the contradictions that occur between personal and public identities can be burdensome and damaging to the development of authentic relationships with self and others.

5.2.2. Presenting a public self

Developing authentic relationships with others involves becoming congruent internally. A *"congruent person is in a process of understanding and accepting each of their perceptions and reactions as they occur."* (Cornelius-White, 2013:199). Most people are incongruent to some extent and that is a necessary aspect of social relating because different people and different situations demand that we present in ways that reflect the context (Mearns and Thorne, 2013). In my experience as a disabled woman and on listening to participants, I understand that as disabled people and because of conditions of worth, we consistently feel the need to

compromise the parts of ourselves that are connected with disability and impairment. This involves presenting a 'public self' to a greater or lesser extent, depending on the situation. Nancy is aware that she does this. She says

"I try to put on this façade and say that I'm fine and everything's OK. [...] I give the impression that I'm a lot of fun [...] so I cover up my insecurities by my humour and my personality".

Shirley says *"there's the external coping self and when the internal self can't cope it's like just collapse"*. She does not allow others to see the collapse because she does not wish to be seen as vulnerable but she struggles to maintain the facade of the 'coping self' because of the depth of her feelings. Kevin has a similar struggle when he says

"Usually people say 'oh you're very organised' and 'you're very quiet' and 'you're very calm'. It's because I'm all the time trying to manage information. [...] People say 'you talk really clearly' but actually what I'm doing is dragging the right words out and it can be exhausting".

Kevin works hard to compensate for this by using humour. However, he says *"it's not a hell of a way to be alive that you get away with it because people like you. It's heartbreaking"*.

Some disabled people manage their social interactions by performing like a stereotypical disabled person. Cameron (2010) suggests that they often feel forced to do this but Janet sometimes chooses this way of relating to others. She says

"I used my disability as an excuse not to be involved in family gatherings that I don't want to be involved in. It's only recently that I realised I was doing that. I present myself as much more disabled to my family than I do to my [friends]. I don't enjoy spending time with my family because of the amount of alcohol that's consumed and it's much easier for me to say to them 'I don't want to come cos it would be too much for me because of my illness' rather than cos they'll all be drunk and I'll have a miserable time".

She goes on to say *"we have a more comfortable relationship now that I'm disabled not a better healthier relationship"*. She explains

"It's a better position than I was in before where I was the weird one and didn't make any sense. I'd rather be in this position than the position I was in

before cos I always felt I was battling that position. It was a lie, whereas this is [she sighs] the truth but not the right truth”.

Janet is playing on culturally perceived notions of disability and she knowingly undermines her power. Although this form of incongruence alleviates her situation, it also involves her experiencing a degree of inner tension.

The above examples illustrate the high internal price that disabled people can pay in order to integrate into society (Gill, 2001). If they compromise themselves to avoid feeling the discomfort and distress of being labelled, they can feel “*forced to lead dual lives*” (ibid p 362).

5.2.3. Hidden emotional experience

Many people feel it is too risky to allow others to know about how disability affects them emotionally so they engage in “*downplaying the difference*” (Scully, 2010:29). This means that they “*submerge their spontaneous reactions and authentic feelings to smooth over relations with others*” (Gill 2001:362). Bill keeps quiet about the strains and stresses he endures in order to keep up with other people. He says

“I always put it down to my slight depression and or sometimes I’d disengage I feel very embarrassed by it but most people who have worked with me all laugh and say ‘that’s what [Bill] does’”.

He says that he experiences low self-esteem because of the limitations imposed on him by his impairment but he is keener to attribute his disappointment to depression, which is a family trait. He describes how he once felt about his parents’ lifestyle,

“I was brought up in a very middle class environment. My father was an intellectual snob in some ways. They went skiing and they were part of the beautiful crowd and I was slightly aware that I wasn’t a skier. It was never traumatic but it was something that I was aware of and in this [...] intense conversational society, I didn’t fit in. [...] My father’s family were all musicians and I would have loved to be a musician and of course that was difficult for me. [...] There’s a bit of me that can be envious”.

As a student, Bill did not recognise that his emotions could be connected with being disabled. He says

“I found university tough. [...] I found the work very stressful and keeping up with it dreadful but it never occurred to me that it was a physical problem. [...] I found the whole social scene quite difficult but I always managed to make one or two good friends so that in itself was never a big hassle but looking back on it, that was when I experienced my first depression”.

It is difficult for him to make the connection because his mother had a chronic mental health condition and he tends to attribute his depression to that inherited condition. He does not consider that his depression could be both inherited and acquired because he is disabled. That is the way he copes in his social world but it also prevents him from symbolising his emotional and embodied experience accurately.

Pete lives with constant physical pain and this causes him to retreat into himself at times and to withdraw from other people. In doing so, he feels very alone and, like Bill, he is prone to feeling depressed. He feels angry about being abused as a child and about being disabled. Because he does not talk about his feelings, it is unlikely that other people will understand him or be able to offer emotional support. His experience of abuse causes him to feel cautious and wary of people so when he is at his most vulnerable, he protects himself by maintaining a distance. This is very distressing for him and he says he often feels overwhelmed with emotion. He does not deny his embodied experience but he has developed strong feelings about it. He says

“I detest my body. I don’t feel like a man anymore. [...] People in general don’t understand how downgrading it can be. Just simple things like not being able to get to public toilets because they’ve got steps and in the shops you can’t get down the aisles. That does get to me”.

5.2.4. Hidden embodied experience

As well as keeping their emotions hidden, some disabled people deal with conditions of worth by internally denying their impairments – by keeping them separate from the image they have of themselves (self-concept). Bill was encouraged to do this at an early age. He says

“I think it was denial but the way it was done it was totally sublimated by treating me as super intelligent. I remember my father used to say ‘you know you’re going to be a philosopher’. [...] it’s all to do with being sophisticated and intellectual and [...] what I took, that I was a head and my body didn’t matter”.

Once again, I resonate with Bill’s experience. When I was a child, my mother took the view that if I could not engage fully in physical activities, I might benefit from using my creativity and my intellect to stimulate my interest. She encouraged me to develop these aspects of myself and to pay less attention to my limitations. It would be remiss of me to avoid mentioning that this may have led me to engage in this research. Like Bill, I denied my impairment internally and tried to ‘pass’ as normal where possible. Bill grew up with loving family but he still developed a sense of shame about his condition and he feels this most acutely when he encounters other people who have conditions similar to himself. He says *“I hate to admit it – I just didn’t want to be confronted by people similar to me. [...] that would confront me about how the world might see me”*. He says that this feeling has been with him in different forms throughout his life. He describes the way he felt about another pupil at his school

“There was another girl who had something far worse. I remember thinking as a kid I was obsessed with her because all her muscles were floppy. [...] I was pretty nervous of her and nervous of my nervousness of her”.

A further encounter took place when he was a young teenager on holiday with his parents. He says *“we met a very bright guy who had exactly the same disability as me and he wanted to form a friendship”*. Bill did not pursue this friendship but he says

“He got in touch with me thirty years later and I never responded to his letter partly because he had become very successful lawyer and I was ashamed because in my memory he had far more barriers yet he managed to do very sophisticated stuff whereas I was just a [names his profession] because I was brought up to think I would be some sort of academic”.

Not only did this encounter challenge Bill’s attitude towards his impairment, but it also challenged the self-concept he had formed as a ‘head’ and not a body. As an adult, he says *“I can think of people who I’m seeing now and their physical*

appearance does have an impact on me but I don't really talk about it". He still maintains the self-concept he formed in his early life.

Amanda says "*denial is a lovely safety blanket*". As a young adult, she wanted to be like everybody else and to go out and explore the world, which she did. She says

"I did love my first boarding school but I was needing to break away from that. When you go to school and you've all got visual impairments you are cocooned from the rest of the world. You go through your childhood and go through your special schools and they do give you a lot but ultimately they take a bit of it away. You are going into the mainstream and it's like 'oh gosh' but I've never let it stop me doing something. [...] When I was about eighteen till twenty-eight, twenty-nine, I completely denied that I had a visual impairment. I even attempted to have driving lessons [but] I suppose after the third crash and breaking my ankle I thought perhaps this isn't a good idea. It was about needing to be independent. [...] I did minimise it [her impairment] and just said 'oh, I can't see the bus' - the number of the bus all - but what I didn't say was that I couldn't see even if it was sort of two metres away. [...] My cocky confidence came out cos I couldn't see the lecture boards but I sort of bluffed my way through a lot of my life at that time. [...] I don't have full vision is what I would say to them. I just have a slight eye problem the sun just hurts my eyes. It's playing it down. [...] I want to come across as able-bodied with a little bit of a visual impairment, well quite a bit of a visual impairment. I just want to make people aware of what it's like to have a visual impairment that you're not just someone sat in a corner rocking, poking your eyes, which is an image a lot of people have".

Minimising her impairment caused some awkwardness in the way she related to other people. Her friends, for example, became puzzled at her behaviour, saying things like "*why does [Amanda] keep banging in that door frame?*" but, she says "*They respected my wish to not have a great big arrow over my head*".

Eventually, as her eyesight deteriorated, Amanda found that she could no longer ignore her impairment. She says "*I've about turned. I've done this ultimate denial for years then suddenly 'well I can't deny it any longer, the old orbs are getting*

worse". Shakespeare (2014:99) points out that *"the denial of disability is implicitly based on the rejection of the idea of an exclusive 'normality' and a refusal to be categorised"*. Amanda has not stopped reacting fiercely to being categorised and she now uses this determination to live life to the full as far as she can and in her attempts *"to show people that you can do things. You can abseil, you can rock climb, you can get to Everest base camp. I've travelled to Australia on my own. I went to Canada and the US on my own. You can just ask somebody or you can say 'show me where such and such is"*. Amanda's relationship with her impairment changed over time. She learned to be confident about managing the practicalities of her condition at school but she was not trained to manage emotionally or in her relationships with non-disabled people. For these aspects of her experience, she turned to counselling on several occasions.

Bill and Janet have developed attitudes towards their bodies that help them to maintain a sense of being normal. The both make a distinction between the 'self' and the body. Janet says

"When I became disabled it was like 'well I am a physical being and my physical system has malfunctioned so that I'm no longer operating smoothly. There's nothing wrong with me".

Bill says

"I often tell people that I used to have this fantasy game with myself and I was given an opportunity to go into a supermarket of disabilities and I was given the chance to swap my disability for any other disability and I always came out with my own disability. It's because it's my identity even though I would I have this fantasy that certain disabilities would allow me to do far more and I've spent a lifetime fantasising about it but ultimately it's who I am".

Bill, Janet and Pete seem to live with a certain amount of tension about their self-concepts. At times, they separate their minds from their bodies at in order to maintain self-concepts that do not incorporate their impairments while at other times they talk freely about their physical limitations. It is as though they keep their bodies separate from the other parts of themselves.

Like Bill, Nick sees himself as an intelligent man and he maintains this by minimising his emotional and embodied experience. All three of us have been disabled from birth or very early infancy. As a young adult, Nick says

N *“I was very cerebral, very stuck in my head. [...] I used to cope with relationships by being intelligent by being academic, so a lot of conversations would be academic conversations about a subject. I’d use a lot of terms like transcendence and neo Marxism and stuff like that. I said to this guy, I wish we didn’t have so many academic conversations and he said I know somebody who can help with that and that person was [his therapist]*

C and did she help to join up your head with your emotions?

N *yes, yeah that’s a good way of putting it*

He says *“for me a lot of it is to do with physical sensations just didn’t get taught after a certain age”*. He says

“I didn’t realise that my body was almost completely shut down. It’s hard to describe if you’ve never felt it but it’s like being right at the very top of your head, far out of any embodiment. [...] the way I’d always coped was like I say shutting down my body almost to the point where there were physical sensations that I just didn’t have or denied that I have”.

Nick talks about how he learned to suppress his sexual feelings- *“sort of sensuality or eroticism - you’re as far away from that as you can get”*. As I pointed out in chapter 2, sexuality and sexual expression are particularly distressing aspects of many disabled people’s lives. Nick couldn’t allow himself to have sexual feelings because he says

“There’s a lot of feelings of shame around. That’s why I grew to suppress them cos they’re shameful. You turn off. You don’t acknowledge any of it. You put it away in a box. [...] I still don’t understand quite where that comes from. My guess is that it’s to do with - I was constantly stripped down to my pants as a child by complete strangers - physiotherapists, doctors, strangers. [...] It probably carried on all through my life. It was normal even right up until in my twenties. I used to use an agency for PAs and they sent me complete strangers. They’d undress me and get me dressed and all the rest of it so I was perfectly used to it. I said to somebody once - this is a good way of describing it - I was sitting in a pub and I said to [friends]

somebody else in this pub may come into my bedroom tomorrow morning and strip me naked. That was the reality of my life. I had a slightly weird sensation that I could go out naked and I wouldn't notice you know, I was so used to being naked around strangers".

It is perhaps significant to point out that Amanda, Bill and Nick and I have all been disabled from birth or early infancy so that we have been inclined to try to 'pass' as normal where we can. Janet, on the other hand, acquired her condition as an adult and does not deny her experience of being disabled. Like the rest of us, she separates her 'head' from her 'body' but she is able to use her condition more flexibly to her advantage. Amanda was taught to be confident in managing her impairment with others, though not emotionally. I was able to seek support for my impairment in the workplace but only after I became more comfortable with the notion of being a disabled woman that, like Janet, I could 'play' with this role. Like Janet, Pete became disabled as an adult and he does not try to pass as normal. However, he is not comfortable with being disabled and he remains depressed and distant from his emotions. Extrapolating from these examples, as a researcher and a counsellor, I suggest that there may be a connection between being confident with the disabled role and being at ease in relationships with others, especially with non-disabled people. The notion of configurations of the self that I explore in the next section may shed some light on this issue.

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remains depressed and distant from his emotions. Extrapolating from these examples, as a researcher and a counsellor, I suggest that there may be a connection between being confident with the disabled role and being at ease in relationships with others, especially with non-disabled people. The notion of configurations of the self that I explore in the next section may shed some light on this issue.

What I have said so far in this chapter supports the view that disabled people, myself included, often find themselves working hard to be accepted in their social spheres and that this takes a toll on their already diminished energy (Gill, 2001). As a counsellor, I suggest that it is useful to understand how disabled people can respond to conditions of worth and that they may be conditioned to carry the burden of disability alone. Having said that, change is a bi-directional process and, although it is by no means easy, stigmatisation can sometimes be managed at a personal level (Garland Thomson, 2010b; Goffman, 1963). In person-centred terms, this involves developing an internal rather than an external locus of evaluation. What I am suggesting is that the forces that militate against disabled people can be so strong that they may need support to find their own ways of living fulfilling lives and this might involve collective and/or individual support.

5.3. Configurations of the self

One step in the direction of developing an internal locus of evaluation is to understand the dynamics that are at play within the self. The concept of configurations of the self can be an aid to self-understanding. Configurations are conceptualised by the client and heard by the counsellor as a “*dynamic complexity of ‘I’ positions*” (Mearns and Thorne, 2000:105), each having its own pattern of thoughts, beliefs and emotions. They are not fixed entities but they can be used as a way of understanding the ‘multidimensionality’ and fluidity (Mearns and Cooper, 2005) of the self. Kevin, for example, identifies several of his configurations - *‘the gay man’*, *‘a disabled man’*, *‘an English man from a working class background’*, *‘a*

middle class man now’, ‘ the terrified little boy’, ‘the angry teenager’, ‘the 20 year old who uses humour to defend’”.

Sometimes configurations are in conflict with each other and this is a way of understanding the inner tensions that take place in people’s internal worlds. The ‘public’ self is one of the configurations that are formed by conditions of worth and in this section I consider others that are in evidence from participants’ stories.

Dominant configurations

Some configurations can dominate the others, sometimes in the eyes of other people. This is evident in the statement made by Amanda, where she both acknowledges and resists the disability label

“Everyone is so quick to put you in a box and to put these labels on you but what I am is me who happens to have a visual impairment. That is a part of me but it doesn’t dictate who I am”.

The disability label is used by others as an identifying marker but a person’s other configurations can be recognised in this way in different contexts. Kevin, for example, might be identified as belonging to a ‘working class’ minority or a ‘gay’ minority but none of these define him as a whole person. His awareness of them, however, can help to make choices about which he allows others to see and which he keeps hidden, depending on the situation he is in at any given time. The problem for him is that he says

“I didn’t feel acceptable in the gay world because of my disability and I didn’t feel acceptable in the straight world because of my sexuality, so where did I belong?”

Socially acceptable configurations

Some disabled people are more tolerated socially than others because of compensatory factors’ which are defined as *“cultural advantages of race, gender or status, or resilient or gregarious personalities”* (Shakespeare, 2006:177). These could equally be described as socially acceptable configurations within the self.

Most participants in this research, as well as me, display several of these configurations in our stories. We are almost all white, middle class educated people and many of us hold socially acceptable roles in our work and family lives. Nancy and Kevin use their positive attributes to protect themselves and to distract others from their hidden configurations so that they feel more at ease in social situations.

Kevin says *“I’ve got these elaborate systems I’ve developed to compensate and I’ve had to teach myself”*. As I have said, he uses humour to divert people from focusing on his impairment but he adds that *“fortunately I’m really intelligent and very good at adapting”* and *“I’m popular”*. He says that these attributes enable people to *“put up with me and my needs cos they like me”*. While these aspects of his personality are advantageous in relationships, Kevin still says *“when you work in chaotic environments it’s very difficult and people attributed my misunderstandings to being a difficult person”*. Like Kevin, Nancy’s buoyant personality is very enabling in social situations. She says

“I didn’t really have a problem meeting people. I think they seem to like me. I get on OK because I have this speech so I think maybe I give the impression that I’m a lot of fun. I think that’s just my personality so I maybe cover up my insecurities by my humour and my personality”.

She has a good circle of friends who, she says are

“very supportive and they’re great in mixed company they keep me up-to-date with what’s going on. It’s not they don’t have to try hard to do it. It’s a natural thing and that’s what I like that’s what I need”.

While Nancy’s ‘good personality’ enables her to maintain satisfying friendships, like Amanda, her self-confidence has been undermined considerably because she was sexually abused as a child.

Tension between configurations

Pete lives with the tension between his private self and his impaired self. He wants to be alone but has a need to be cared for by friends and family. He says

“I’m quite a private person - keep a lot of things to myself. I rarely speak with friends about what issues I’m having. They know when I’m not feeling well but

I never really open myself to them. I prefer that. It's my own choice. I've always been like that even before things went wrong".

Pete can easily become irritated when people are over-attentive.

Amanda had better sight than most of her schoolmates so she often helped them. She says *"they would always go 'You can see. You do it. You do it'"*. She adopted the role of go-between with the other pupils and their teachers. She says

"After sixth year there ended up being two best girls – one who was very good academically which wasn't me, and one who was a good conduit between the students and the teachers".

This was a boost to her self-esteem and she still says rather proudly *"I've got forty-one years of experience with a visual impairment"*. While this aspect of Amanda's self-concept enables her to feel confident and to respond assertively to others in public places, her abused inner child was not confident and she did not learn to be emotionally resilient until she was much older and had several lengthy periods of time in counselling.

Watermeyer (2009:96) offers a powerful summary of the inner tensions that can arise from keeping emotional and embodied experience hidden from others and from displaying some configurations at the expense of others. He says

"A way of being which centrally involves trying to 'not be' aspects of a stereotype must inevitably draw individuals away from themselves, from what and who one is or may become or may discover about oneself. Disabled people are, at least incipiently viewed as 'victims', rendering the imperative to disprove or overturn this view. However, this necessarily places disabled people in an unreal and futile split, often expending efforts at disidentifying with one pole of a meaningless binary in order to avoid being forcibly attached to the other. What may emerge is a drama of constructs, rather than individuals, in which the politics of representations overwhelms the distinctness of unique lives and subjective struggles".

Even though most participants, as well as me, display characteristics that others view positively, we all feel the need to diminish our impairments and our experience of disability to some extent in some social situations. Keeping our knowledge to

ourselves can add to the stress we already experience in living with the physical, practical, cultural and environmental consequences of living with impairment. We often lack the freedom to become socially acceptable individuals in our own rights. This has inhibited the capacity of some participants to develop a sense of agency and personal power.

5.4. Conditions of worth and agency

The emotional effects of being disabled, and the impact that disability has on a person's sense of self, tend to undermine the capacity to develop what Shakespeare (2000b:20) describes as "*a life-giving sense of agency*". In person-centred theory, counselling can enable people to recognise, process and re-evaluate conditions of worth and so enhance their sense of agency (Warner, 2009). Bohart and Tallman (2010) elaborate on this, using the term 'self-righting'. This refers to the client's capacity to "*bounce back from adversity, to get things in order, and to find ways to move forward productively with life*" (ibid p 93). Their research demonstrates that clients can develop the capacity for "*creating new and more adaptive person-situation relationships*" (ibid) through counselling. Rogers' notion of autonomy is commonly understood by counsellors to mean a move towards individualism but Bohart (2013: 91-93) understands the term to mean the capacity to take control of one's life – in other ways to develop a sense of agency. Following this argument, he understands the concept of the fully functioning person to be a movement towards congruence, self-acceptance and self-directed behaviour. In keeping with Rogers' theory, Bohart and Tallman (2010) argue that clients become congruent when they reflect on their situations and find their own ways of moving forward. The actualising process is therefore "*the tendency to productively cope and grow in relationship to life's stresses [...] using one's capacities for learning and problem-solving in an optimal way*" (Bohart, 2013: 93).

Some research suggests that developing the capacity to take control of their own lives is one of the strengths of counselling for disabled people (Swain, Griffiths and Heyman, 2003). However, this must be balanced by understanding that people who

experience oppression can be inhibited from developing the competencies that are required for a person to act on their own desires and to make their own choices (Mackenzie and Stoljar, 2000). Gill (2001:362) explains that

“When individuals receive persistent messages that part of them is unacceptable they experience a sense of disintegration that can thwart self-determination”.

As well as the inhibitions brought about by conditions of worth, another of the stumbling blocks that is unique to disabled people in terms of their minority status in society, is that many of them need to rely on others to support them with the practicalities of everyday living. Although Nick is able to employ his own personal assistants, many others rely on family or friends to support them. This can be disempowering, especially for people who grow up being supported by parents and where it becomes difficult for them to break away and live independently (Swain, French and Cameron, 2003). Each of the participants that grew up as the only disabled child in their families managed to live independently as adults but Bill, James and Nick felt protected as they were growing up, so they did not feel well enough prepared for managing some of the difficulties brought on by exposure to the non-disabled world.

Another significant issue is that in healthcare in the UK, disabled people do not have the power to challenge the control that medical professionals have over their care so they are encouraged to be dependent in that setting (Watson, 2003). This was particularly damaging for Nick who has learned to manage his life according to his own preferences, but who grew up feeling disempowered by medical professionals and some care workers as I did (see Johnson, 2011; 2016a). . Pete offers a distressing example of another institutional setting that can be disempowering. His sense of agency is compromised because he was abused in a place that should have been caring for him (boarding school). One of the many damaging effects of this experience is that he finds it difficult when other people touch him, so he feels shamed and uncomfortable when others attend to his personal care. Because he does not like to talk about his emotions, his carers are unlikely to be aware of the full extent of his discomfort. He says he prefers to be left alone when he feels low but he is then left without anyone to soothe him in his distress. He remains in a situation

where he cannot easily make choices and decisions. Jordan (2004c: 36-37) describes such a situation saying,

“When in trauma, we are inflexible, stuck, bound to repetition. Little can be learned interpersonally; we cling to those patterns that are familiar. Withdrawal into mistrust and isolation is rampant”.

In more extreme cases, disempowerment in institutional care can lead to ‘learned helplessness’ (Seligman, 1975), where a person allows others to take complete ownership of their choices and decisions. Although Pete continues to feel despairing, he is not disempowered to that extent nor is any other participant in this research. However, participants offer further examples of the forces that can inhibit what Rogers’ (1978) refers to as personal power – a way of describing a sense of agency that is acquired through the development of an internal locus of evaluation.

5.4.1. Losing a sense of agency

Having been disabled from early infancy, I have not experienced the *loss* of a sense of agency, though I am limited in the activities that I can engage in and I have felt a sense of disempowerment in the past. My experience is therefore different from that of Sandra and Shirley, who both acquired impairments as adults. I drew on my counselling skills to listen to and to appreciate their experiences. Before Sandra became disabled, she was very involved in her local community. She ran a youth club; organised a self-help group for grandparents and lobbied parliament for their rights of access but she says *“I had to give that up. I couldn’t fight anymore”*. She explains

S *You’ve got to realise to a certain extent your capabilities but I still don’t accept my capabilities. It’s a very hard thing to accept*

C you mean doing all that organising and helping out?

S *yes with the grandparents. I know I can’t do that because my mind isn’t as active. Doing the books and with new information technology, I don’t seem to take that in the same but physically I still try.*

As well as the impairment that affects her mobility, the ageing process and the fact that she takes high doses of painkillers, is affecting Sandra’s cognitive capacities. Before she developed her impairment, she regularly walked five miles each way to

visit her sister. She says *“and then with something like [her sister] dying that I couldn’t do anything, I think that’s what broke me”*. Losing her independence and capacity to act from her own volition within her community was a blow to Sandra that still distresses her.

Shirley too, felt the loss of her usual way of managing her life. She says

“I’m so used to being a copier and to giving and to be at the stage, you’re a giver and you’ve nothing left to give, that’s a hell of a place to be in front of you because you don’t want to interact with people cos you can’t give anything. So it shuts down relationships”.

As a very active, coping and caring person, Shirley’s sudden loss of vision was devastating at an existential level and for a time, she lost all sense of agency.

5.4.2. Lack of knowledge and self-doubt

Self-awareness and self-assurance are necessary ingredients for developing a sense of agency. Some participants find that insufficient knowledge about their conditions and self-doubt inhibits their capacities to manage their lives fully.

Lack of knowledge

As a child and teenager, Kevin did not understand the nature of his condition and he says he felt disempowered by that. He did not always know what support he needed for his dyslexia or how to manage the difficulties he experienced in his relationships. When he received a diagnosis, the technicalities of his condition were explained to him but he did not understand what they meant. He says

“Nobody told me how to learn. [...] Nobody sat me down and said ‘that means it will be impossible for you because you don’t have any short term memory and somebody says something to you in a group and you’re meant to follow, you can’t do that cos you can’t hold information, you can’t retrieve information in the same way”.

One of the prevailing consequences of this lack of knowledge is that he lives in fear of being caught out. He says

“My little boy that can’t read and write and is terrified cos I went to a special school and the teacher at the special school in those days would punish you, would beat you, if you made a mistake and my little boy was being beaten at home, knew how to duck and dive and protect himself but was terrified. And so my little boy is always terrified of making mistakes”.

Being abused in this way has added fear to his lack of knowledge and that adds to his sense of disempowerment.

Self doubt

James has his own responses to being hurt by other people. He says

“it’s trying to work out the people who are interested in you and the people who are not cos sometimes in groups people who are just rude or not interested in someone and instantly I take that personally and link it to my disability and maybe it’s just because they’re got a problem and it’s nothing to do with me”.

Sarah has a similar response. She has a friend who lives abroad with whom she communicates regularly according to a routine that works well for both of them but when that routine is disturbed, she begins to doubt the friendship. She says

“I understand it on one level but there’s another level which after a certain amount of time seems to kick in and go ‘is she really on holiday or does she need a bit of space from [Sarah]?, and [Sarah] should therefore not be sending all these emails and maybe not volunteering stuff without being asked just so that she doesn’t find me too much”.

Sarah’s self-doubt leads her to think *“if the chat’s all about me and nothing about her I’m therefore a burden to her and therefore not good so should withdraw and not be in touch with her”.* She goes on to say

“There were times when I’d have been far happier just staying home. I really was depressed. I was scared that if I didn’t [go out] I’d eventually develop into a house hermit because ‘this is too much. I won’t go to this now, that’s getting too much’ till ‘I’m never out’ so it’s not a good place to be”.

She has learned to notice when this happens and to almost force herself to go out though she still finds that very difficult. Like Kevin, fear inhibits her from taking control of her life at times.

James appears to have internalised social and cultural conditions of worth that have affected his self-belief. He says *“I think people [...] change that mindset within my head which makes me think I can’t do things that I can do”*. He seems to be saying that, because other people regard him as disabled and therefore assume that he is unable to engage in certain activities, he finds it difficult to understand the effects of his impairment himself. He says

“It was the psychological possibility of not being able to do things that was the real inhibitor. [...] My physical disability made me feel that I had a mental disability that related to my brain and social interaction it’s very, very difficult to describe”.

Despite his parents encouraging him to try out new activities to build his confidence, the uncertainty about the limits to his physical and cognitive competencies seems to have curbed his internal sense of power and agency and that affects him in social relationships. He says *“I feel because I’ve got a disability that makes me more passive rather than active in terms of creating relationships with people”*. He wants to empower himself in relationships instead of being *“a couch potato who just goes along with everything”* but because he finds relationships difficult, he becomes anxious. He says

“I feel quite isolated sometimes when I feel that I have to be independent because of my disability. If I need someone around then I open myself up to vulnerability and then that vulnerability sometimes gets exploited by people but that’s probably an insecurity of mine because I feel that independence is like ‘oh yeah I can do everything on my own’”.

He is caught in a cycle of estrangement where he finds relationships difficult, so he retreats into *“vigorous independence”* (Watermeyer, 2009:95) but then feels he is to blame so he becomes more isolated and lonely.

A further inhibiting factor for James, Nick and Bill concerns the doubts they had as young men about their sexual attractiveness. This issue led James to enter

counselling. He says *“the act of being attracted to someone made me reinforce my own male identity”* but he felt very under-confident about how other people would respond to this. Nick says *“a part of me had incredibly low self esteem to do with sexuality in relationships”*. As a teenager, he says

“I had lots of emotional trauma about being attractive to people. I used to get extremely upset around it. My worst nightmare in a kind of angsty teenage way that I’d end up sad and lonely which is now not a problem but at the time it was very real thing”.

Bill says

“In adolescence issues of sexuality came up. That’s when I became properly aware of it. I became very self-conscious and kind of nervous and anxious”.

As a young man, he tried to test out whether or not he was attractive during a brief spell of working with disabled teenagers. He asked them to write down their impressions of him before and after his time with them. He says

“There was this lovely sixteen year old girl who said to me ‘I know what you were after but it didn’t work. My first comment was that you were an attractive man and my final comment is you’re still attractive’”.

He then comments *“but it wasn’t courageous because they were disabled people themselves”* Although Bill has had long-term relationships with women, he still says *“I’m very self conscious sexually”* and he says *“I’ve always had it in all my relationships”* and this causes ongoing distress both for himself and his partner. Having doubts about their sexual attractiveness is a major impediment to finding satisfying intimate relationships.

In terms of my analysis, I am interested to note that all participants mentioned in this section have been disabled from birth. The lack of knowledge about their conditions and the level of self-doubt they experience may be a result of never having the experience of being non-disabled and therefore having disability and impairment as integral, but not always recognised, aspects of themselves. In my case, until I engaged in my own counselling, I knew very little about polio and did not ask anyone about it because I was aware that it was shameful to carry this label as I grew up. I found out more as I began to engage in research and when I gained access to information that enabled me to understand more about the condition and about the

social context in which the illness took place. Living with this condition inevitably engendered a sense of self-doubt as I experienced myself as different from and inferior to others who were not disabled.

5.4.3. Receiving support

For some participants, the lack of agency is evident in their incapacity to recognise their need for support but perhaps because the emphasis in DS is on challenging the politics of medical treatment and care work, very little seems to be written about this in that field of study. At times, both Sarah and Amanda have relied on friends to point out their need for support. In the following example, I begin by reflecting on what Sarah said previously

C So you knew when you needed counselling because your friend said it?

S *essentially yes*

C your friends saw that you were behaving a wee bit differently

S *yeah*

C or a wee bit more upset or something like that but you couldn't quite get that yourself

S *I'm not good at understanding that. It's a bit like when I'm physically not well. I'm not always good at telling that I'm not well and often have to take the cues from others so when I was in uni I got very unwell and had to be sent home. [...] I learned at that point if people tell me that I'm looking pale and they keep on telling me that regularly, I have to take something on board and say 'well actually this needs checked out'. [...] A friend had begun to say to me 'look [Sarah] I think you probably need to consider counselling again. I'm getting this vibe sort of like I think you probably need to go back'. One of my friends turned round to me recently and said she thought that I do better when I have counselling so therefore maybe it would be a good idea for me to have counselling every two to three weeks.*

Amanda describes two occasions when she was not able to identify her need for support. She said that sometime after she was raped,

“I met friends in between the attack and then going for counselling and it was them that encouraged me to go for counselling because they would say ‘[Amanda], you’re not coping’”.

Around six months after the death of her dad, she says her partner “was worried. She was scared for me ‘you need to talk to someone’”. Amanda’s learned confidence and self-reliance seems to have masked her capacity to notice when she needed support.

Sarah sometimes forgets to tell people about her condition. She says

“I’d forgotten to say about the suspected dyspraxia. I think chiefly because with so much going on around me, to take a minute to say ‘by the way I’ve got X’ and by the time you’ve done the first meeting the fact that you’ve not said has completely slipped your memory”.

She describes one occasion when this became problematic. Before her manager knew about her condition, she reacted harshly to Sarah’s mistakes. When Sarah then told her manager about her condition, they were able to establish what support was needed for her to perform more effectively at work. Kevin said that he, too, has been disciplined at work before he learned about how his dyslexia was affecting him. It was only then that he could explain his behaviour.

Bill is aware that denying his impairment has sometimes affected his capacity to function well. He says

“There is something about impairment. I always attributed it to depression I can remember when I was a kid and that’s a very strong memory that I had a typewriter to do my work on and the ribbon got tangle up and I just broke the whole machine and I remember getting great satisfaction. You know the little bit where you put the ribbon where the keys hit the paper? I just took that out because that kind of anger is there at those little things. [...] That’s the kind of anger I remember the poor [Bill] though that it’s followed by a kind of victim bit”.

Later, while at university, he says

“I found the work very stressful and keeping up with it dreadful but it never occurred to me that it was a physical problem because typing with one finger,

and when I first went to university we had to submit two three thousand word essays a week”.

While growing up with impairment hindered him from recognising his need or accepting support, he says

“I have this niggling worry that I’ve just been lazy. My grandmother was the only person in the family that tried to get me to go to speech therapy [and] to physiotherapy because her argument was ‘but why not make the best of you?’ [...] My parents went to the specialist who had [the same impairment as Bill] and he said ‘look don’t hassle him, he’ll find his own way’ and that’s what I did and that has worked”.

He says that this was helpful advice but he appears to be left with a lingering sense that he could have pushed himself to do better. He says

“I think I’ve gotten away with murder. I’ve never had to work hard at adapting, whereas had I worked harder at adapting I would have been far more able to do things but somehow things were made easy for me”.

He tells the story of how this all came to a crunch point

“I thought I had finally been found out by a manager who said ‘that’s not good enough [Bill]. I spent my whole working life saying ‘God you know I’m a fraud’ and I’ve never been found out. My manager confronted me about my management skills and I was always worried that it would happen but when it happened it took me by surprise. He said ‘you know if we don’t find a way of working it out I might be forced to start thinking in terms of whether you are competent to do the job’ and I found myself under a lot of pressure. After that conversation, I was talking to [female family members] and they said ‘maybe you should go to the doctor’. ‘Yeah I might go to the GP’. I said ‘I think I’m depressed’. I got signed off and got put on anti-depressants and that was the start of something different for me. [...] My manager said ‘OK how can we become more supportive and take into account your disability and look at systems’ because I’ve had access to work but I’ve often made light of them or not quite made my needs explicit or worked out with people what were the implications”.

Bill feels self-conscious about his impairment and he can be angry at times but he feels confused about the connection between the bouts of depression he

experiences, the effects of his impairment and the effects of living in a disabling environment. All of these factors appear to have contributed towards his reluctance to seek the support he needed at work.

When Shirley suddenly became visually impaired, she too felt unable to accept offers of support. She says

“I wasn’t ready to talk to anybody. I didn’t want any specialist help so when the local blind society became involved and said ‘can we offer you anything’, I went ‘NO, I don’t want anything you can offer me. I don’t want to be in this world of blindness, of blind help’”.

It seems that she was still in shock at the trauma of becoming blind, so she says *“I wasn’t willing to engage with the services that were there”.*

Before Kevin understood the impact of his dyslexia, he did not think of himself as disabled and he resisted this notion initially. This changed when he took up employment in the disabled community. Talking about his colleagues at that time, he says

“They had to say to me ‘excuse me [Kevin], you’re disabled’ and I’m going ‘na, I’m just stupid’. [...] I’m not like you. I’d love to be like you. You people have got rights and there’s a movement and but I’m not one of you. [...] and they had to drag me kicking and screaming”.

Once he understood that he could receive support for his condition, he says *“gradually over five years I began to review all of what I’d internalised”.*

5.5. Summary

Several participants told stories about the emotional effects of living with impairment, disability and conditions of worth. These effects are negative in nature and stressful to live with and they range from frustration to attempted suicide. As a result of experiencing conditions of worth, whether expressed directly or indirectly, some participants felt the need to retreat into independence or to withdraw as a form of self-protection. Some have become distrustful and cautious of other people because

they have been judged, rejected, ridiculed or abused. Participants who adopted these forms of defensive withdrawal did not feel comfortable in doing so. While withdrawing protected them in some ways, it perpetuated their sense of estrangement. Very few participants were aware of the effects of ableism or social and cultural conditions of worth on their self-esteem.

Where people denied associating themselves with the disability label, they were unable to find an internal place for their experience of disability and impairment. They were then left with the inner tension of keeping their experiences at bay while they tried to appear like everybody else. Some, notably men, experienced conditions of worth about their sexuality and sexual attractiveness and found that they were unable to integrate these aspects of themselves comfortably. Some participants denied their emotions because recognising these feelings would have uncovered shame, envy or despair that they would find difficult to deal with. Some were able to deny their experiences for a time but could not continue to do this because impairment effects or the effects of conditions of worth began to intrude on their daily lives. Examples that were given were increased pain, fatigue and being confronted with other disabled people who have similar impairments.

The notion of configurations of the self serves to convey the dynamics that took place within the self-concept for some participants. Some spoke about keeping what they thought would be socially problematic configurations hidden. Instead, they emphasised other, more acceptable configurations to project a public image that they felt would be socially acceptable. Some marginalised their embodied experience, giving more prominence to their intellectual, playful or creative configurations in order to feel accepted. Other participants used their disabled configuration to play the stereotypical role of a disabled person in order to make social situations easier.

What is clear from these stories is that conditions of worth about disability and the experience of living with impairment is stressful for all of the participants mentioned in this chapter. They all live with different forms of strain and tension as a result of working hard to feel socially acceptable, for the most part without a sense of the

oppressive forces of ableism or social and cultural conditions of worth that were at play in their lives. Living in this way undoubtedly adds to the stress of living with impairment effects. Jordan (2004b:50) makes the point that

“In chronic disconnection, often brought about because the relational context is not mutual or growth-enhancing, there develops a deep sense of immobilization. [...] The pattern of immobilization, fear and self-blame leads to a heightened sense of isolation”.

I understand immobilization to mean a lack of agency. For some participants, this capacity was inhibited because they had been over-protected in their early years so they were not adequately prepared for managing difficult social situations as they grew into adulthood. For others, feeling disempowered by medical professionals, the limitations of impairment, overwhelming feelings engendered by loss or trauma led to difficulties in taking control of their lives. Other inhibiting factors indicated were low self-esteem, self-doubt, lack of knowledge about impairments, lack of awareness of the need for support and reluctance to seek support.

It must be said that all participants in this research have been clients in counselling at least once in their lives. Through that experience, they have learned to articulate their struggles but other disabled people may not be sufficiently aware of their internal processes to be able to do this. In the next chapter, I present stories about how counselling has helped participants to develop in terms of self-awareness and a sense of connection with others in order to illustrate how the counselling process can unfold.

Chapter 6: Making connections in counselling

In this chapter I explore the last two of my research questions namely ‘how do disabled people experience the counselling relationship and process?’ and ‘what impact might counselling have on the way that disabled people relate to themselves and others?’ A genuinely warm and empathic relationship with a counsellor is one way to counteract the negative effects of harmful relationships that derive from conditions of worth. While relationships can be harmful, they can also be the most effective healing agents (Natiello, 2001). Through counselling, disabled people can *“feel more whole and [...] foster self-compassion via having [...] authentic life predicaments held and accepted by another”* (Watermeyer, 2009:94). For some, the counselling relationship may offer qualities that are not available in other sources of care (Lyons, Sullivan, Ritvo and Coyne, 1995). Some participants corroborate these views but expand on them and I discuss their experiences of how counselling was helpful to them in this chapter.

6.1. The counsellor facilitates connection

The qualities that are widely acknowledged to be effective in counselling are outlined by Rogers (1959) in the six conditions that he identifies as being necessary and sufficient for therapeutic change (Appendix A). Research suggests that in the context of healthcare, disabled people value the expertise of professionals but they appreciate them more if they offer the interpersonal qualities of *“warmth, realism, flexibility, genuineness, honesty, kindness and the ability to share power and to work in partnership”*. (French, 2004:108). Further to this, disabled people are likely to feel at ease with people *“who seem devoid of disability prejudice but who know and despise it when they see it”*. (Gill, 2001:367). In this section, I discuss the qualities that participants identified as facilitative in their relationships with their counsellors.

6.1.1. Training and experience

Rhoda Olkin (2003) states that counselling professionals are not always suitably trained to work with disabled people. Donna Reeve (2000) suggests that counsellors should have specific disability training. As a trainer of counsellors, I agree with Reeve's statement though I qualify it by pointing out that in my experience, students are more likely to identify with disability issues if they are presented within the broad themes of difference, diversity and power. Without any intention to impose my views on participants, I found that they had their own views on the matter though my research questions as well as my identification as a disabled woman may well have influenced what they said to me in the interviews. Having been in counselling several times over his lifetime, and as a counselling tutor himself, Kevin says that he has only recently found a counsellor who 'gets him'. He says

"I feel understood by him. I feel valued by him. [...] It's working because he has done a huge amount of work on himself and he sees that as his responsibility. [...] He's done a huge amount of equality training. [...] He understands the social, political aspects of disablism, racism, sexism".

Kevin appears to adopt a similar view to myself in terms of the broader understanding of issues of difference but Monica's view as a deaf person is more specific. Her situation was initially less familiar to me as a counsellor embarking on this research so I had to learn from her experience.

Monica finds that deaf clients work best with counsellors who have an awareness of deaf issues because *"they would be more apprehensive about doing something like this because it's a new thing for them to do self-exploring"*. Nancy endorses this saying *"to be able to talk and to express myself, just to get it out"* is helpful. Monica notes that some deaf people like to talk to their counsellors about what it's like to live with deafness in a hearing world. She says

"The world is there and you have to live in that world and you have to find a way to cope so that probably opens lots of different avenues of how you can cope".

Monica suggests that counsellors can only help their clients to explore these avenues if they understand what it is like to be a deaf person living in a hearing

world. She has found to her own cost that there are very few counsellors who are proficient in sign language. The most suitable counsellor she could find was one who had some general disability awareness. Talking about this counsellor, Monica says *“she has ideas about barriers because of her son [who has learning disabilities] and what it’s like to feel frustrated so she had some prior knowledge about that”*.

Robert found it helpful to work with a counsellor who had an understanding of disability. He says

“I did discuss some practical problems. It was helpful as she was able to at least relate to the problem. She didn’t share the same disability but she knew people who did”.

It would seem from what Kevin, Monica and Robert are saying that in addition to their usual counselling training, counsellors will have a better understanding of disabled clients if they engage in relevant personal development; have knowledge of equality and disability issues and in the case of deaf clients, have an appropriate way of communicating. As a counsellor, I endorse this view because in my experience, social and cultural conditioning and the tendency to avoid involvement with other disabled people would have limited my understanding of disabled clients’ issues. By engaging in personal development through being a client in counselling, I became more able to involve myself with issues associated with disability with empathy, emotional engagement and a greater awareness of the impact of social issues on disabled clients.

6.1.2. Attitude and skill

Some participants find it helpful to talk in counselling about their relationships with the people who support them. Pete has been supported by friends, family members and professional carers in the past and he talks about his counsellor saying

“She was very kind and down to earth. She’s gentle. I’d seen CPNs, social workers and psychiatrists but never seen a counsellor. I felt more like a person and not a number”.

Alastair has worked with disabled people in the context of residential care and he is aware that they can sometimes have difficult relationships with their carers. He says *“just having somebody who’s nice to you, somebody who never gets pissed off with you helps”*.

Sarah and Nick make a distinction between talking with friends and talking with a counsellor. Nick says

“I have all this stuff in my head [...] and I have to get it out in some way. My friends don’t want to hear everything. There’s some stuff that is very personal and I think that wouldn’t be fair on them”.

Sarah says *“I think it’s a bit of a burden on someone to have that sort of thing to talk about”* and talking about friends, she says *“a lot of the things I want to talk about in counselling have to do with them”*. For example, on one occasion, she was prompted to see a counsellor because one of her friends was terminally ill. Amanda’s relationship with her counsellor was restorative because it helped to counteract her experience of abuse. She says

“She genuinely wanted to see me healthy. It was like a nurturing relationship but there was trust in her with what was then my current situation what had brought me to that brink”.

Kevin and Nick had experienced pressure from others so it was important that their counsellors did not reinforce that feeling. Kevin says that his most recent counsellor

“knew how not to create barriers - attitudinal barriers that made me feel patronised. [...] He never says to me ‘oh you’re so clever’ or ‘so intelligent’ cos my little boy goes, ‘yeah but if you really knew the truth’. He never says anything that sets me up to be [defensive] whereas a previous therapist would say ‘oh you should write’, whereas he doesn’t do that. [...] [This] helped those young vulnerable bits to articulate themselves”.

Since he often feels misunderstood and has been punished for making mistakes in the past, it is especially important that his counsellor does not repeat that pattern. Kevin says he

“would say ‘yeah I really got that wrong’ and I would go, ‘yeah’ but in that moment what he’s saying ‘did I get that right’ he doesn’t know intricately about dyslexia but he knows intricately how to find out from my experience”.

While he feels comfortable with his counsellor, Kevin has said that he resents the pressure to educate others about his condition but he does not seem to have felt that pressure from his counsellor, perhaps because they were both making an effort to connect with each other. Nick has been hurt by the assumptions that were made about him in the past, so it was important that his counsellor did not reinforce that feeling. He says

“She was a very good listener. I would talk and she would listen and I guess not make assumptions. It seems to me something slightly deeper than the listening”.

He continues saying *“it’s a gift that some people don’t put up walls”,* and that *“nothing was off the table”.*

6.1.3. Accommodating specific needs

Some participants indicate that counsellors may be more effective if they find ways of accommodating the needs of disabled clients in order to establish the therapeutic relationship. Robert and Sandra’s access issues were taken care of by being offered telephone counselling. Nancy said that her first counsellor was not deaf but that they were able to communicate through the use of rudimentary technical equipment. She said that it was much easier when she worked with a deaf counsellor sometime later who had suitable computerised equipment. Sarah feels anxious when meeting new people so initiating an appointment with a counsellor is daunting for her. She illustrates this by talking about planning a visit to the vet with her cat. She says

“Sometimes I put things off too long. The last time I had to make the appointment [...] I think that came through in May but it was June or July before I actually got [her cat] there so that’s a wee bit too long”.

Talking about meeting a counsellor for the first time, she says *“I’ve then got to try and form a new relationship with them and that’s a bit scary”.* She still managed to make the first step and talking about her counsellor, she can now say *“I know her, I trust her, she has an understanding of who I am and what works with me, what*

doesn't. [...] That makes things far simpler". Her counsellor understood that she finds it difficult to articulate her emotions and inner tensions so she said "OK we'll just go on until we're happier that [you are] in a place where stuff is OK".

The extent of Sarah's anxiety and the way that her counsellor and I managed the interview illustrates how much planning can be involved at the beginning of the counselling relationship. Sarah's counsellor had acted as an intermediary by inviting her to take part in my research, explaining what was involved from the information sheet I gave her (Appendix B4). The counsellor and I had a telephone conversation a few days before the interview so that I would understand the nature of Sarah's anxiety. Before this conversation, I consulted with a teacher who worked with young people with Asperger's syndrome and together we altered my interview questions to enable me to communicate with Sarah as effectively as possible (see Appendix B.7). The counsellor came with Sarah to meet me for the interview and we met in the agency where Sarah attended her counselling sessions so that she was familiar with the surroundings. Sarah's counsellor introduced us and she remained in the agency until the interview was over so that she could help Sarah to debrief if necessary. Although Sarah and her counsellor were at the end stages of their work together and were no longer meeting on a weekly basis, they met the week after the interview so that they could spend time debriefing again.

My approach to meeting Kevin for the interview was rather clumsy because I did not fully appreciate the extent of his dyslexia. This is illustrative of how it might be for a counsellor to meet with a disabled client for the first time. I first invited Kevin to take part in my research when we met face-to-face at a professional meeting. He agreed to take part so I texted him later to make arrangements about when and where we would meet. He replied by telephone and it was only then that I realised that he had difficulty in reading texts because he told me so as he spoke. I travelled by train to meet him at his home and when I arrived at the station, I received a phone call from him wondering where I was. He was confused about the timing of our meeting. During the interview, he said that this was typical of the way he and others made arrangements and from this I understood something of the extent to which his condition affected him in his daily life. I had to learn from Kevin and this was anxiety

provoking for him though this was alleviated when we finally met for the interview. Similarly, I had to learn about procedures from Nancy and Monica because I was not initially aware of some of the practicalities of arranging the interviews with them.

Interviewing deaf participants Nancy and Monica involved making arrangements for interpreters to be present. I understood that the protocol was for me to make the arrangements and pay the interpreters. Nancy chose her own interpreter and gave me contact details so that I could make the arrangements. We met in Nancy's home and the interpreter happened to arrive at the same time as I did. This meant that we could begin a conversation with ease from the outset. Monica chose to make her own arrangements and her workplace paid for the interpreter. We met in my office but the interpreter came from out of town and arrived very late, Monica and I were left trying to communicate with each other rather clumsily before the interview could begin. This was frustrating for both of us. In both cases it was fortunate that I had worked as a tutor with groups of deaf students teaching counselling skills so I was aware of how to work with interpreters. If this had not been the case, I may have had to rely on the participants and their interpreters to help me understand how the communication worked. My sense was that this would have been burdensome for the participant as it would be for a client in counselling.

6.2. Connecting with the self

Making contact with aspects of the self that have been denied, distorted or buried underground is an essential part of the counselling process. Bohart (2013:93) states that "*the biggest obstacle to the optimal operation of the actualizing process is defensiveness*" and that "*reducing defensiveness should lead to more effective pro-social behaviour*". Corker (1994:41) states that counselling is "*about allowing deaf people to be strong and secure in themselves*". For these and other disabled people, this involves becoming self-accepting and congruent. Participants offer some insights into how this can happen.

6.2.1. Configurations of the self

Kevin finds it helpful to talk about his different configurations with his counsellor because each configuration has its own characteristics and associated problematic issues. He says he can talk about

“what it’s like to come from a working class background and be a middle class man now and what it’s like to be a gay man in a heterosexual world, what it’s like to be a disabled man in a gay world. [...] I could move from being a gay man to being a disabled man to an English man to an abused man without having to worry about being misunderstood or having one thing contradict [another]. [...] So sometimes I’d be talking from my wounded abused child, sometimes I’d be talking from my child that was abused because of his inability to read, sometimes I’d be talking from the child that was terrified because he was gay. And my therapist now, has no difficulties working with [each]”.

Watermeyer (2009:98) points out that a client’s capacity to talk about difficult experiences *“incorporates a trust that the listener will hold onto the knowledge that ‘this is not all that I am’”*. If the counsellor understands that the client has many configurations, other characteristics of the client may emerge. Kevin’s ‘writer’ configuration became empowered while he worked with his counsellor. He says

“I have underestimated the impact that my dyslexia has on self learning and [...] my life is so busy to set aside the time and then cope with self learning it’s extraordinary and he is working with me on that [...] because he gets it, [...] He’s staying with my experience of what it’s like trying to do research and he’s not telling me what to do but at the same time, occasionally, he makes suggestions that are helpful”.

6.2.2. Connecting with emotional experience

Making contact with emotions is another integral aspect of the counselling process (McMillan, 2004). In person-centred terms, the client’s process involves learning to accurately symbolise the feelings and sensations that arise within them and finding words to express what is happening for them internally so that they are available for

reflection (Rogers, 1951). During that process, clients may be able to express the primary emotions that they have kept hidden previously. Primary emotions are *“the person’s initial or fundamental response to an event or experience”* (Greenberg and Paivio, 1997:36). When emotions are activated and expressed, they are available in the client’s awareness, making room for distressing experiences to be processed and assimilated into the self-concept. Research in neurobiology suggests that this process is important because emotional experience is an active agent in guiding behaviours and making decisions (Damasio, 2000).

Attaching words to emotions

Speaking from her professional experience of working with deaf clients, Monica confirms that they often use counselling to offload their otherwise hidden emotions. She says

“Talking about their frustrations, angers, any other emotional issues they might have, especially with the society we’re living in with everyday problems, it’s just, being able to offload to somebody. Offloading gives them the chance to manage better and to be able to cope a lot more easily”.

Deaf clients sometimes find it difficult to express their emotions in everyday life. Monica says

“I’m sure some families teach something about emotion but most of them don’t. It’s not their fault. Maybe because one of the children went to boarding school from a young age so they’ve grown up at school Things have changed because a lot of deaf children are in mainstream schools now. We’re talking about people my age who went to boarding schools meaning there was no relationship with their family, only the holiday times”.

Monica says *“it’s the counsellor’s place to give out new words and help them to understand themselves better”*. She speaks about helping the client to find words by a process that person-centred counsellors call ‘empathic conjecture’ (Watson 2001).

Monica describes how she does this

“I might say I feel this, this and this and they might say ‘yes’ but they didn’t know how to get that out and I feed them by giving words that I try to find and give them. Not all clients are like that but some have difficulty

expressing themselves. And then this helps them to build up their own knowledge and how to deal with the emotional behaviour better”.

Sarah is not deaf but she finds it difficult to express her feelings and her counsellor helps her with that. Sarah says

S *sometimes she does say ‘so what I’m getting from this is XYZ. Is this right?’*

C and can you say whether it’s right or not right?

S *normally I can. I can tell if it’s just about on or slightly off and what the differences are.*

Kevin sometimes finds it difficult to make contact with emotions that arise from his early life experience because, he says, his inner child is frightened. He says that his counsellor works best with these *“inarticulate parts”* and that he

“kept on saying to the little boy, not directly, but the little boy kept on looking at him and going ‘he’s not gonna get us into trouble for being wrong’ so he gradually helped that part begin to articulate itself”.

Like Kevin, I had my own frightened inner child who learned to hide her emotions. The story I told in Johnson (2011; 2016a) illustrates how my emotions were not heard or attended to when I was a child in hospital. I therefore learned that expressing emotion was not easily accepted by others, especially those in authority, so I was conditioned to keep them to myself, resulting in an inability to symbolise what was happening for me, resulting in what I now understand to be childhood depression.

Expressing emotions

Amanda says

“I’m quite open about the counselling I’ve had. The first time I was twenty-three and it was rape crisis counselling cos it had been five years since I’d been assaulted and I really hadn’t come to terms with it. I didn’t know what to expect. It was a very healing process but a very long process. [...] I was at university and I’d been away from home since I was eleven years old so it took quite a few sessions for me to start to trust this person and but also

equally for her to get to know me because you automatically put boundaries up and that barrier that has to be chipped away at”.

The barrier she is referring to is the distance she had formed between herself and others. She says that her counsellor was *“very warm, recognised my barrier and she was very, very patient. I got closer and closer to the hurt and to the pain”*. Although she has learned to portray confidence in some social situations, she had learned to shut down from her emotions because of the abuse she experienced from her mother. The process of encountering her emotions involved making contact with the anger that she had kept under wraps until she entered counselling.

Through counselling, Amanda discovered that she was afraid of revealing her anger because if she did, she would feel as though she was behaving like her mother. She says *“it’s like her [mother’s] anger and abusive tendencies are hereditary so I had to have this [...] very negative control.”* It took a while for her to make this connection and she recalls how it emerged

“The counsellor said ‘why can’t you tell your mum that this has happened?’ I said because she’d say I’d brought it on myself, being in a foreign country, walking back from the bar to the villa at midnight. She would just say ‘you shouldn’t be doing things like that’”.

Recalling the counsellor’s words, she says

“What would you like to say to [her mother and the person who assaulted [her]?’ I said I couldn’t do it verbally I had no words to say to them so she ended up getting cushions and a baseball bat out and it took me about three sessions before I could use [them]. That was to do with my mother and her violence but it’s only now that I recognise that. She went at my pace and she didn’t force me or push. She got so far and she’d say ‘OK I can see that you’re uncomfortable you know we’ll go back to such and such’”.

Amanda became more able to express her anger but she struggled to speak with her mother about how she felt. She says

“I’m not a confrontational person. I’ve never been able to say ‘you made my childhood hell’. I didn’t want to confront my mother because my dad was still living with her”.

As a young adult, Amanda lived with an abusive partner and during that time she became very distressed and attempted suicide. She began to see a counsellor at that time and she says

“that’s when I had to start writing a journal when I remembered certain things and it went as far back as to when I was two years old. I was able to pinpoint all these areas where my mother humiliated me or hit me. Through the counselling, I had to bare my soul”.

She began to make connections between her partner’s and her mother’s abusive behaviour. She says

“I became aware that I was trapped in this cycle and it all revolved round my mother but then my first relationship was with a woman very like my mother and my second relationship was very manipulative, very verbal, very mentally and emotionally abusive and veering onto the side of physical. The psychologist was wonderful but sometimes she did have to say ‘what is the worst thing to happen if you confronted your mother and what is the best thing that can happen if you confronted your mother?’ and I said ‘the worst thing is that she could disown me the best thing is that she could disown me’”.

Once again, Amanda’s anger came to the surface. She says

“I was in a safe environment where I could express my anger and it wasn’t expressed in a typical way. It was verbal, non aggressive but you can still say how angry you are. [...] I just had to write my blasted journal”.

Bohart and Tallman (2010) argue that counselling is about activating the client’s self-healing capacities and Amanda’s determination to survive corroborates with that statement. She says

“It took me about a year to recover from the suicidal ideation and I was self-harming at the time as well but I knew if I wanted to survive and wanted to stay aware I knew I had a long way to go and I knew I had a lot of work to do”.

One aspect of this work was to attend to her embodied experience.

Talking about abuse

Abuse is a well documented feature of many disabled people’s lives as I have shown in chapter 2 but because of shame and/or difficulties in communication, this

distressing experience can be difficult to talk about. Some research indicates that disabled people can learn to co-construct their own narratives following such disturbing experiences (Hawkins, 2002; Palmer, 2007; Van Nunatten and Heestermans, 2012). I have come to understand my own narrative to be one of medical abuse, where as a child and young adult, I was overpowered by medical professionals who did not acknowledge or seek to understand my emotional disturbance. Nancy and Amanda have their own particular narratives and, perhaps because of my own story, I felt emotionally connected with them. However, my self-awareness and counselling skill enabled me to avoid any confluence between their stories and my own. This is reminiscent of Rogers' 'as if' quality - an aspect of the counsellor's empathy (Mearns and Thorne, 2013:55).

Nancy says *"I had a really bad childhood. I felt betrayed as a child. I was sexually abused. I'd been betrayed twice by my own family and then my adopted family"*. For much of her adult life she internalised this highly distressing experience and kept it to herself. She says

"Before the counselling I didn't think about the bad things that happened. It was very rare that it came up. I guess it's just like the shutters came down and it took the counselling to move this away and then move on".

Nancy was advised to go for counselling because she was having panic attacks at the time when her mother, who was her main source of support, was unwell. She tells her story

"When I first went to that counsellor we spoke about my mother. [...] She was growing old and it might have been the time was near for her to pass away. We spoke through that issue and I felt OK but other things came up like a can of worms. [...] I don't think I'd addressed that yet because I was really fond of my adopted father. I loved him and I hated him as well. [...] He died when I was nineteen. [...] When I first told the counsellor what had happened it just came out and I had never told a soul, not even my next door neighbour who I'd grown up with from age nine. She never knew about what was happening to me. I just kept it to myself. It was something I locked away inside and I just got on with life. [...] I think it catches up with you because it's there under the surface. [...] I thought it was my fault and I learned a lot about myself. I

knew that it wasn't my responsibility, it was the family. It happened in both families. I thought it was normal. I didn't like it of course. I wanted to be loved, to be cuddled, to have affection".

Marian Corker (1994:26) says

"The experience of abuse, whether it is psychological, emotional, or sexual, is often more complex for deaf children and young people because deafness adds its own dimension of power, through denial, stigma, self-blame, self-esteem, confusion, body perception, helplessness and loss. The sexual offender must choose a victim who will remain silent or who will not be believed in the event that she or he tells".

Nancy has some sense of this but she says remains unsure. She says *"I wonder, I'm thinking is that a taking advantage of me? [...] I don't know".*

Grieving

Disability can be a complicating factor when a person experiences the loss of someone they love. When, as a young adult, someone that I loved with all my heart died after a brief illness, I was finding it difficult to articulate and express my emotions. My conditioning as a disabled person was woven into my sense of self and it was an aspect of the paralysis I experienced as I grieved for this painful loss. Much of my time as a client in counselling was spent on this issue and the intertwining of that with my experience of disability.

Sandra talks about how she worked with her painful experiences of grief and loss during her time in counselling. She experienced many losses in the later part of her life so her grief was complex. She used counselling to unravel what was happening to her emotionally. Sandra was close to one of her sisters (who also had a physical impairment) and they were able to offload their feelings as they shared time together. Talking about this sister, she says

"She gave me the support. She understood when I was suffering pain. I could talk to her about going to the doctors and after when I wasn't sure about things. [...] It was not accepting my limits and then with something like [her sister] dying that I couldn't do anything. I think that's what broke me".

Her distress was exacerbated by a further difficult relationship. Talking about the arrangements for her sister's funeral, she says

"It was hard to lose her but it was harder that her husband couldn't give her what she wanted, what she believed in life. She had to believe that there was something there [referring to her belief in God] because she wanted to know that she was going to see her son" [who had died previously].

After her sister died, Sandra felt cut off from the rest of her family and was left feeling alone and sad but she said it was "a case of *'just get on with it'*". Sometime later, she had several attempts at counselling but none of them worked for her. Eventually she was put in touch with a disabled people's peer counselling service and it was there that she felt able to express her feelings about being rejected by her family and about the loss of her dear sister. Talking about counselling, she says

"Phoning somebody and the manner they talk to you can make a difference for you to open up. The way she spoke to me was calming. I got out what I had to get out of my system". [...] I cried with [the counsellor]. I talked to them. They could understand that I couldn't do any more than I did. I couldn't accept that. I should have been able to go in and say cheerio to her. I should have been there. If I hadn't been disabled I wouldn't have moved from that house. After I got my crying out I did get that I was feeling lost because of my disability. It was my disability that closed it for me, that I couldn't see her. I couldn't go down to see her. I've had time to think about what it's all about. [counselling] has given me the opportunity to sit back about how I felt and why I felt like that. I think that's the history of me because I'd to deal with it all and whether this is all built up and I didn't get what I needed when I needed it".

She says "*it's an accumulation of things*" that caused her to feel distressed and to talk with a counsellor. She felt relieved in doing so because she had felt misunderstood by some family members throughout her life. Through counselling, she seems to have learned to 'self-right'. She says

"My older sister tries to control what the younger ones do but I don't take it so much to heart now. She's got her family. She looks after hers I look after mine".

She has finally found a way to be with the members of her family who are still alive and to develop a greater sense of inner peace about her present and past relationships.

6.2.3. Connecting with the embodied self

It has been argued that the medical approach leaves little room for connections to be made between psychological processes and the processes of the body (Marks, 1999a:59) but in counselling, “*psychological states of the body are simultaneously integrated by and integrated into an overall conception of the self*”. (Church, 1997:92). After her suicide attempt, Amanda was counselled in a healthcare setting and it seems that the process of making contact with her embodied experience was limited. She says

“We did talk at one stage about having a visual impairment but it was just touched upon because she didn’t see it as an issue and I didn’t see it as an issue”.

Amanda was still in what she calls her denial stage at the time but her impairment featured in her relationship with her abusive partner. She remembers that time saying

A *The lower I got the more abuse I got because I wasn’t able to defend myself*

C Did your impairment have anything to do with the low feelings?

A *I think sometimes it was. It’s funny because you put this to the back of your mind. [...] because of my visual impairment she would say ‘nobody would want you because you’re ugly, useless’ and she used the same words that Mum used to say to me.*

Hartling, Rosen, Walker and Jordan (2004:106) point out that “*A relational approach helps us recognize the many types of human interactions that may trigger feelings of shame or humiliation*”. Amanda may have put this memory to the ‘back of her mind’ because it was shameful and it may be that shame played a part in putting her visual impairment into the background of her work in counselling. It could equally be the case that the counsellor did not appreciate the effect that Amanda’s impairment had on the issues that they talked about or that she was unable to find a way to address

that. Amanda's impairment was a significant part of her experience, especially in relation to her mother, who shared the same condition.

James' counsellor did introduce the issue of his impairment and he told me how she did this. He says

"I was working out the way people responded to me and it may have been linked to the impairment. [...] I remember her saying 'in what way are you impaired?' and that was a very interesting thing to say because there aren't many things in my life that I'm physically unable to do that I want to do because of my disability but it's the psychological thing of having a disability is what inhibits me more than my physical disability itself".

This question opened a pathway for James to explore the part of his experience and to realise how difficult it is for him to assimilate his sense of agency alongside his bodily limitations. For him, the two do not sit easily together.

Research suggests that counsellors are often reluctant to acknowledge that clients who are wheelchair users might have issues around sexual intimacy (McLeod, 2009) but Nick was fortunate enough to have a different experience. He began to talk about his sexuality because he was directly challenged about that by a friend. Talking about his sexual feelings, he says *"there's a lot of feelings of shame around that and that's why I grew to suppress them"*. As counselling progressed, he says

"It's like thinking that you're complete and suddenly you realise that a whole chunk is missing or buried way back in your childhood. A part of the work I did was rediscovering what I forgot when I was six or seven".

Having buried any feelings he had about his body, he says that in counselling *"I had to open up that box. I mean it kind of blew open"*. He tells his own story

"I was able to talk to her about all the things that happened, all the sensations that I had in an environment where I wasn't shamed for the first time. How to describe it - it's like the first step so talking about them is always shameful, feeling them is always shameful and then I would sort of experiment in going in and out of my body and I would have certain sensations and go back to [his counsellor] and tell her about them and we would explore them. [...] Some of the things were wacked out. It's a bit like a sort of seven or eight year old

talking in a body of a thirty-four year old man a bit like that and [his counsellor] coped extremely well, there was never any shame”.

Nick talks about becoming highly distressed during this process. He says

“Basically the nature of therapy is that you look inside and discover things and I would imagine for everybody it could be quite a deep and difficult experience. [...] I had this faintly psychotic episode. I don’t know why exactly. I don’t know if therapy is to blame. I was smoking a lot of weed at the time which obviously contributed. I had a very severe emotional shock”.

Hartling, Rosen, Walker and Jordan (2004:103) say that

“To recount experiences of shame or humiliation, we risk revisiting painful images of being devalued, disempowered, or disgraced, perhaps triggering or reinforcing further feelings of shame”.

Shakespeare (2000a:160) says

“Talking about sex and love relates to acceptance on a very basic level - both acceptance of oneself, and acceptance by significant others – and forces people to confront things which are very threatening, given the abusive and isolated lives of many disabled people”.

Although the process was disturbing, Nick can now say *“my body’s, coming gradually back to life”.*

6.3. Connecting with others

Nick gradually began to feel more comfortable about having sexual feelings as he talked with his counsellor and the follow-through of this was to explore the impact this had on his relationships with personal carers.

6.3.1. Professional carers

Talking about counselling, Nick says

N *I would say the relationships it’s affected the most have probably been the PAs*

C *did you talk about that with [your therapist]?*

N *yeah I did, I talked about that a lot. One of your questions is if it helped with any relationships it certainly helped with PAs.*

He had been accustomed to emotionally detaching himself from his body when he was receiving personal care but he says

“There were sensations and feelings to do with personal care that were new to me. [...] I’ve had to learn a new language that I think for most people is normal. When I’m out of my body it feels like the fires go out so I learn [...] a whole new kind of sensation. [...] I guess shame is a big issue and [his counsellor] helped me put aside shame”.

Instead of feeling self-conscious, Nick was more able to acknowledge his sexual feelings with his personal assistants and he says *“fortunately they are very mature women so there’s never any shame from that.”* He says *‘it’s good. [...] I’m starting to become a bit more human’.*

6.3.2. Social relationships

In his late teens, James began to see a counsellor because he felt confused about his sexual attractiveness. Listening to James was reminiscent of my own experience as a young heterosexual woman who sought to find ways of relating to the opposite sex. I was acutely aware of my impairment as a student at that time and could not imagine that men would find me attractive. Unlike James, I did not talk about this with a counsellor because sadly, I was not aware of that as an option. I did, however, talk with a close friend about this and I found that enormously helpful and supportive. James spoke at length with his counsellor about the girl that he felt attracted to. He was unsure if his feelings were mutual. He says.....

“I was trying to unpick all these incidents that had happened in our relationship. [...] and I was in a state of not quite knowing. It’s hard to hear the stuff you don’t want to hear. [...] I wanted to distinguish between someone experiencing attraction for me but then maybe not acting on it. [...] Knowing that I was attractive would have given me more confidence as a person”.

James wanted his counsellor to confirm that he was attractive but she did not do this and he found that frustrating. Instead of answering his question, she made a space

available for him to process his own thoughts and feelings without her interference. Although this was uncomfortable for James, in retrospect, he says that

“It gave me the stark reality that maybe she [the girl he was attracted to] never thought of me in that way and maybe she thought of me purely in a platonic way. That gave me another thing to deal with because knowing you are attractive to someone who is quite attractive gives you more confidence but at the same time not knowing that they aren’t attracted to you may also give you ‘oh just forget about her and move on’. [...] I can’t blame the counsellor cos she didn’t know my relationship with this person. [...] It was more about how to move on from this and about how to take what I could from this experience and to develop as a person”.

He explains that while he was working with the counsellor, the girl he was interested in began a relationship with one of his best friends. Naturally this was extremely hurtful for him but it did seem to confirm his instinct that she was not looking for an intimate sexual relationship with him. He says *“after the sessions had finished I was at one with myself and I totally got over it”.*

While he talked about this with his counsellor, James began to explore how he related to other people. He says

“I remember talking to [her] about the reactions some people have to me. The counselling did help me to express myself and helped me realise that I can be who I want to be but it also made me realise that there may be times when people would appreciate someone who is not quite so brutally honest at times and to work out the relationships that are appropriate for you to fully express yourself and to work out the times when that isn’t so appropriate”.

Reflecting on his time in counselling, James says

“I certainly feel that I grew in confidence in that intimate relationship thing but then right after the counselling I felt [...] upbeat and going out of my way to be active and taking the lead in situations. [...] and about a month or so afterwards I did feel that but then I think it just faded”.

Although that was disappointing, James goes on to talk about what he achieved. He says

“I’m very aware of how other people have responded to me in the past and I think what helped was being aware of my body language and a bit more in terms of getting what I want out of relationships. [...] I think I gained a bit more self-awareness and self-belief and self-value. I learned to respect me and to think that I have got more value than I gave myself credit for”.

He learned to *“understand that it’s kind of normal for some people not to want to talk to other people”*. This enabled him to trust his own instincts in terms of intimacy

“I think it’s to believe myself, to trust my own instincts. I remember one good thing she said - ‘always acknowledge the intimate moments and the intimacy that is real for both of you regardless of what happened’. I was sensing that intimacy was a real thing and that helped”.

His experience confirms the point that

“Shame or humiliation - including experiences of being scorned, ridiculed, belittled, ostracized, or demeaned - can disrupt our ability to initiate and participate in the relationships that help us grow” (Hartling, Rosen, Walker and Jordan, 2004:104).

He now says *“Instead of being a victim of society I want to empower myself”*.

Kevin finds that counselling helps him to understand more about the conflict he gets into in relationships, especially in the context of work. He says

“It helps me unravel the emotional impact of misunderstanding and then I can see what’s theirs and what’s mine cos in the past I would completely lose it. [...] I have to be grounded and as a dyslexic person cos I can quickly get into chaotic thinking. What I realise is that this means listening to all the different parts of myself [...] when I’m in situations, then I can stay grounded. It’s an ongoing thing. I’m always gonna need it because until the world changes I’m always gonna need the therapy to keep me grounded”.

6.3.3. Close relationships

As I know for myself, shame is the ultimate silencing factor when talking about difficult sexual experiences and this is particularly the case when talking about childhood abuse. As a counsellor, I am aware that childhood sexual abuse is very

difficult to talk about because shame and powerful emotions are involved. It can be very frightening to reveal and unravel such experiences. Nancy adds another ingredient into this emotionally traumatic experience when she says *“I mean hearing children don’t tell either but I think more so for deaf kids”*. She did not talk about this until much later in life and as a result of her work in counselling. Talking about her experience of sexual abuse was a distressing experience for her at the time but I sensed that she felt comfortable in talking with me about this, even with the presence of her interpreter. I attribute this to the connection she and I had made through our the brief discussion we had about being new grandparents; through her perception of me as a disabled person; through the ease she felt with her interpreter; through the work she had done in counselling and her trust in me as a counsellor. As I have said, she chose her own interpreter because she knew that that she was aware of and sympathetic to her story. She tells the story of what happened, saying

“It’s there under the surface, it definitely catches up with you and when I told the counsellor I thought ‘that’s it I feel much better I’ve offloaded that’, but I didn’t. I was so ill. [...] every morning when I woke up I felt that it was just there. I was thinking about it. I was reliving it constantly. [...] I’d go to sleep thinking about it. It was just there constantly on my mind. [...] I needed to relive all that emotion and that abuse that happened”.

Her mother often asked Nancy what she talked about with her counsellor but Nancy says *“I didn’t know whether to speak to my mum about it because I thought I might hurt her and I didn’t want to do that”*. Eventually, she felt a need to disclose what happened

“That night I remember she’d been asking me. She was always talking about my father. She thought the world of him and I just said ‘do you know what mum? Enough. Dad was not a good man’ and she looked at me rather strangely and I said ‘you put him on a pedestal and he didn’t deserve that’ So she was like ‘what do you mean?’ I thought ‘oh no’ and I said ‘oh it doesn’t matter’ and she’s like ‘you have to tell me, please tell me’ and I was crying. I said ‘right I’ll tell you. Daddy molested me’ and her face was such a picture she said ‘oh [Nancy]’. I knelt on the floor beside her and I held her hand and she just kept repeating my name. I told her a little bit about what

had happened so I think that's why you know for two years I continued to go to this counsellor and express those feelings and we did hug each other and it really broke my heart. I'm sure her heart was broken as well. I went back in the morning because I was really worried about her. I felt I had really hurt her feelings and she just was like normal as if nothing had happened. I said 'oh I'm just come to make sure you're OK' and she's like 'yeah I'm fine'. We had another hug and I had a look around her house and she'd taken all the photos with my dad in them, they were all down and we never spoke about it again".

Although she felt guilty and concerned about her mother's feelings, Nancy felt relieved that she had told her mother what happened. The sense of relief seems to have prompted her to talk about her experience with other people that she felt close to. Talking about friends, she says

"They were heartbroken when I told them. They just couldn't understand it. I was worried about them. I would say I'm OK, don't worry but they were horrified. After I worked through things and they got through the initial shock, I feel that they know me better. [...]The counselling helped me to express myself. So as a full person they [...] understand me better. Maybe they understand why I was a bit of a rebel when I was young and partying and getting in trouble. [...] I think it's brought us closer as friends [...] I wouldn't tell everybody but I was able to tell them".

Nancy told her partner and he was shocked but very supportive. She wanted to tell her two adult children but she waited until the time felt right. She says

"I wanted to tell them together. They need that support when I tell them. So I sat them down and I said 'right OK. I promised you a year ago that there would be one day that I would tell you, so now is the time'. They were both crying and I'm getting upset thinking about it. They hugged me after I'd explained everything - told me they loved me. It was really hard. It was more difficult telling my children than it was telling my friends. It was good to be able to tell them. They love me anyway but I think they love me more".

Nancy was very emotional as she told me about this and I felt the impact of that as I listened attentively to her. At the end of the interview, I asked her how she was

feeling. She said that she felt emotional but that she would have a quiet evening at home, watching TV after I'd gone. She seems to have learned to 'self-right' and rather than deny her feelings, she was able to acknowledge how she felt. Her anger erupts when she hears stories about other children who have been abused. She says

"Anything that you see in the paper it makes me angry. I do feel anger. I think 'why is this happening?' Why are they taking young children, taking that young life away from them?"

Although she feels angry, her emotions do not overwhelm her in the way that they did previously. Through counselling, she has been able to release the stress and bodily tension that she carried silently for much of her life (Totton, 2015) and this opened the way for her to receive the warmth and love that her friends and family extended to her to. Her wounds were soothed. Judith Jordan (2004c:38) emphasises the importance of this, saying that *"Finding ways to re-establish the caring connection or the belief in the possibility of love as a response to vulnerability is essential"*.

Reflecting on her time in counselling, at the beginning, Nancy says "I was a bit sceptical about it but I was so glad I went. It was fantastic." She qualifies this by saying

"To tell you the truth I couldn't go through that again. Once I almost passed out because it was just too much. I had to lie down. I just felt everything was spinning, the room was spinning. It was really tough but the counsellor phoned my partner to come and pick me up at that time because I couldn't cope with it. For that short time because I had relived it again I felt raw. [...] Sometimes I wish I could have carried on the way I had been earlier. I was a strong woman. I was happy I had a good life and then these panic attacks started. I couldn't go on with that same lifestyle".

6.4. Choices and decisions

In the previous chapter, I noted that there may be connections between the ways that people respond to conditions of worth and their self-esteem, or self-confidence, and capacity to trust other people. In this chapter, I have shown that counselling can help some disabled people to develop more authentic relationships with themselves and that this can have positive effects on their relationships with other people. One of the major themes that emerge from participants' experiences is that the process of developing meaningful and satisfying relationships can involve making choices about the personal relationships that support them and give them strength (Shakespeare, 2006). Several participants talked about how counselling enabled them to do this.

6.4.1. Choosing relationships

A significant element in Nick's counselling process involved learning to differentiate his own thoughts and feelings from those of his friends. I associate this with my own learning whilst I was training to be a counsellor. It was there that I began to distinguish my thoughts and feelings from those of my clients. Nick says that his counsellor *"didn't break that trust"* and that this was *"why it was a positive experience"*. I asked him about that

C I wonder how she didn't break that trust

N *she was just a very good listener I would say so I would talk and she would listen and not make assumptions.*

It was the assumptions that other people made about his sexuality, about being a wheelchair user and about not being politically active that he found most difficult in relationships so that he says *"You learn very quickly to become very defensive about certain subjects, to keep away from other people for safety"*.

A significant element in Nick's counselling process involved learning to differentiate his own thoughts and feelings from those of his friends. I associate this with my own learning through counselling training, where I began to distinguish my own thoughts and feelings from those of my clients. Nick says

“If other people say ‘x’ I believe it because I have no sense of my own esteem in that way. [...] I had no idea I was naïve and innocent because I had this life with my friends and my family where it was all fine. My friends were extremely supportive when things got very difficult”.

The work he did in counselling enabled him to trust in his own thoughts and feelings instead of deferring to his friends. He talked at length with his counsellor about the friend who said he would never be a man and eventually, he says *“I decided that I didn’t want to be that person, what he thinks is a man”*. Another friend felt that the Social Model of Disability (SMD) would be helpful for him but after talking this through with his counsellor, he says

“I can now say the social model’s been next to useless for me. [...] Therapy’s been very helpful in understanding that the problem is not always mine. [...] Had I not been for therapy I would have probably been kind of indoctrinated. I would have had some kind of devastating personal realisation that I was in denial about [disability]”.

He found his own way of integrating his experience of disability into his self-concept by *“turning carefully to internal referents rather than external constraints”* (Watermeyer, 2009:99). He did retain the notion that his limitations were in part due to the disabling environment and he used some of the language of the disability movement when he talked with me.

As a self-declared quiet man, he remains close to his few good friends, saying

“There are not a whole lot of other people in my life at the moment. Rather than having ten friends I have one or two that are really very close. I say almost nothing to anybody outside these”.

He chooses to spend a lot of time on his own, often drawing and painting. He says *“I’ve always lived quite a small self-contained life so it’s not a huge problem”*. Nick says that he has more appreciation of these friends now.

Through counselling over several years, Amanda moved from being in a relationship with an abusive partner to being single and then to finding a new relationship. Reflecting on her time in counselling, she says

“I learned a lot about myself. I learned to forgive myself, my child self. You start learning to like yourself and that gives you the strength, no matter how hard, to follow something through and what was amazing was shortly after I was getting my confidence back. I was still on anti-depressants and still seeing my psychologist. I was isolated so I needed to make friends so I went on an internet chat room and met my now partner”.

She says her partner is

“strong and she has allowed me to get to know me and allowed me to nurture me and the child in me. I was also able to do that with the psychologist because if you had something that happened to you as a child, as an adult you still feel the emotional intensity as [though you were still] a child. [...] She doesn't wrap me in cotton wool but she can read me very well. She knows that my eyes are playing up but she doesn't pamper me, she doesn't baby me, smother me. She just says 'oh can I put some eye drops in for you?' and I say 'yeah that'll be good' or 'no'. It's not a big issue in the household but she knows if I go outside, I'm safe”.

This is significant progress for Amanda. Having held her distance from others in relationships for much of her life and survived abusive relationships as a child and an adult, she learned through counselling who she could trust. She moved from relentless independence to allowing herself to be nurtured and still to maintain control of her life.

All of the participants that I have mentioned so far in this chapter talk about having positive experiences of counselling, even if they felt that the process was painful before it became beneficial. An important element in my research was to find out some of the problematic aspects of counselling that participants attributed to being disabled. Alastair is one of the participants who felt ambivalent about the effects of counselling. He says that over the years, working with different counsellors was enjoyable but it has not benefited him in ways that he would have liked. What he can say about relationships is

“I'm even less tolerant of relationships where there is very little realness. Being a client gets you to expect a certain kind of interaction – you can enjoy it and the counsellor is prepared to hear about difficulties. Maybe I'm a bit

more tolerant of defences in other people – less tolerant in some ways and more in other ways. [...] Strangely I'm made a friend who is quite disabled. Within five minutes we were talking about pain and depression. He's in constant pain. We see quite a lot of each other. We meet for a pint, have lunch together. With people who are not disabled, there wouldn't be that whole discussion. The level of difficulties means that there is a freedom in talking to each other. There can be moaning but with others, you are constantly not telling them how you feel. You never give a straight answer but when I am with him I can be straight. It's nice and refreshing”.

It seems that the process of counselling has enabled him to have some clarity about the qualities he values in other people. Becoming disabled in his middle years has caused him to re-evaluate his friendships.

6.4.2. Leaving relationships

Part of the process of rehabilitation after a person becomes disabled can be 'network remodelling' and 'relationship adaptation' where some relationships may dissolve and new relationships and networks can be formed (Lyons, Sullivan, Ritvo and Coyne, 1995). For some participants, this has meant leaving relationships that no longer feel satisfying. Gill (2001:368) notes that

“An aspect of the disability experience that has received little attention is the decision of many disabled persons to renounce the struggle for acknowledgement and acceptance from others who consistently fail to understand them”.

Janet had an extensive period of counselling before she became disabled and at that time, she had concerns about her marriage. A few years later, when she became disabled, she says

“I decided to end my marriage because I didn't want to be married to that man as a disabled person. I felt too vulnerable and he had been abusive in the past. He had terrible anger issues. He had taken steps to address them with a great deal of success but I knew two things - that my disability would stress him and that he would not leave me because that was his value system. He couldn't leave a disabled wife - that would be wrong. The only way for the

marriage to end would be if I left him. I did not trust that he would be capable of continuing to address his anger issues and be with me as I became more disabled”.

Robert says that he became a different person after he endured several simultaneous losses. He says that his counsellor

“zeroed in on the fact that I was spending a lot of time worrying about if other people were OK and not spending enough time worrying if I was OK. I was still with my partner when the counselling was going on. I think she [his partner] had her own issues and what the counselling helped me to do was think about my needs too”.

While he was in counselling, Robert realised something about himself. He says *“I’ve always been quite caring I suppose”* and he connects this with supporting his mother before he became wheelchair bound. During the interview, he reflected *“I do seem to seek out needy people”* and to an extent he feels that his ex-partner was needy. He says that the relationship changed after he became a wheelchair user

“The relationship was poor but it had been at one time very good indeed. Her personality seemed to have changed from someone who was a real ‘up and out there’ to someone who was really withdrawn. I spent an awful lot of time and money trying to get her out of herself. [...] She’d always wanted to go to [an exotic location] so I bought her a pretty extravagant experience in the hope that she’d take herself out of the situation. It didn’t work. I’d say about a year ago, we called it a day on the relationship. She blamed the counselling for us splitting up. I started saying things like ‘no’. It was time for another very expensive car for her. I started going ‘make do with a less extravagant new car’ and so counselling did change that aspect of that relationship. The question is ‘was the break up necessary’? Perhaps it was. I wasn’t looking at it like that. I was just letting it steadily get worse and worse and if I had any objectivity I would have ended it before then”.

He reflects on his time in counselling saying

“I can only identify one thing, which was she [his counsellor] helped me realise it was important to put myself in the centre of my own picture. She [his partner] did very little around the house. She used to work and when she was

working we were both busy people and we had cleaners in but she ended up stopping work for some reason I wouldn't accept. She was self-employed and she just allowed it to stop. I couldn't help her and she wasn't helping me in the practical ways that I needed. As I say I was a very busy guy. It was so destructive that I couldn't tolerate being in it anymore. There was no great anger or hatred or anything. The break up happened just after the counselling. It's been unpleasant".

When I spoke with Robert, it had been over a year since the breakup of his relationship. He says that counselling "*certainly changed my view of the type of person that I go for*". He was actively making plans to leave the home he had shared with his partner. He says

"I've got two main options. I go back to my home area where I already have a social life and the other thing which has happened more recently is [I have been seeing] a girl that I met when I was at university. We met three years ago she's got on an aeroplane three times in the past year to come visit. It's going very well. So it's not all black you know, things are coming together But one thing, [she] isn't needy".

Through counselling, he learned about his compulsive caring for others and he had radically changed his way of forming relationships. It was a painful process but he is moving on with his life in ways that he hopes will be more fulfilling. He is allowing his new girlfriend to take care of him. He says "*she's independent, she's vigorous and she's a complete nag. We've stayed together for a while and well 'it's time to do your exercises, get up'*".

As a person who has had a visual impairment from birth, Amanda's experience of 'network remodelling' came about as a result of counselling. She made the decision to leave her abusive partner and her counsellor helped her to make the move. She says

"We did practice. She said 'what would you really like to say?' and I said 'this is what I'd really like to say AAAAAAAGH', but what I did say 'I can't live like this. I'm living in a hell if I stay here and I'm taking control back'. I eventually

managed. I had the strength to physically pull away and I walked out with a suitcase”.

The relationship with her mother was always a feature of counselling but until her father died, she remained in contact with her. After he died, Amanda went to bereavement counselling, prompted by the distress she felt from her mother’s behaviour. She says that her mother was

“going on that I wasn’t [her father’s] favourite and he was as bad as everyone else. He wasn’t the best father or husband in the world. I just thought ‘I don’t need this”.

She was able to express her feelings without these judgements in counselling. She says

“You’re in tears coos you’re so raw and there’s this hole and it is so fresh. Initially I thought I was angry at my dad for going but I was angry at the hospital staff, I was angry at the doctors because he’d been ill for so long and they’d misdiagnosed it. They hadn’t even looked for anything else so I was angry at them but ultimately I was angry at my mum and there was an element of anger at my dad. The last five years of his life could have been really good. He could have come and lived up here with me and [her partner]”.

Some years later, Amanda began a counselling skills course and she says “the *“course made me think ‘what do I want?’* It was then that she made the decision to let go of all contact with her mother. She says

“I’ve disowned my mum, sent her an email saying ‘I don’t want anything to do with you anymore. I don’t feel like a member of this family since my dad died coos me and my dad loved each other’ and ‘have a nice life’. I was anxious the first twenty-four hours after that but then I was just liberated and for the last five years I thought my dad would want me to stay in touch but I feel that actually my dad would just say [Amanda] don’t put yourself through it”.

As she reflects on the times she has spent in counselling over the years, Amanda says

“With each decade, pieces are chipped away at the foundations; you can get to the bottom of things. [...] You’ve progressed to a stage where you can talk

about things quite openly and it really did let me explore things. A lot of things”.

6.5. Summary

In this chapter, I have shown how some participants made use of counselling to make connections with aspects of their inner selves that had previously been lost. This could be described as an inner process of ‘coming home’ (Michalko, 2002) where participants were able to feel more comfortable with themselves. Some participants’ stories about the counselling process are reminiscent of my own though I did not disclose anything of my own experience of being a client. Their stories illustrate how the counselling process can involve encountering shame and painful memories as a pathway to making contact with the emotional aspects of their experience. For some, making connection with their embodied selves was significant. To a greater or lesser extent, the participants that I have discussed here have been able to dilute the effects of conditions of worth by listening to and relying on their own inner promptings to make choices and decisions that work for them. It could also be said that like me and in accordance with my person-centred understanding of the counselling process, some developed a degree of self-acceptance, which occurs when

“one is able to accept both the conflicting feelings and action tendencies, the beliefs and constructs involved and the negative self-judgements, listen to all of them respectfully and find the wisest synthesis” (Bohart, 2013:93)

I use this theoretical model to articulate what I think was happening for these participants. It could be argued that participants talked about their experiences of counselling in a positive light because they knew that I am a counsellor. However, I balance this thinking with the recognition that the stories they told have an authentic resonance in the sense that they are very individual, were told with emotion and that they were told in their own contexts.

Participants’ relationships with their disabled selves are very individual. For some impairment effects and disability were not at the forefront of their counselling work

because other issues were more pressing. Others discounted any connection that may have been present between disability, impairment effects and personal issues. A few were able to reflect on the impact that living with disability had on their everyday relationships as part of the process of counselling. It is notable that only Kevin and Nick made connections between their experiences and the disabling culture and environment in which they live. None of the participants made reference to internalised oppression, ableism or social and cultural conditions of worth. Kevin is the only participant who appears to have discussed the impact of social and cultural conditions on the developing self and relationships with others. Most participants' experiences therefore remained un-contextualised, confirming the work of Swain, Griffiths and Heyman (2003).

In terms of relationships with others, participants' stories indicate that counselling enabled them to be more in control of the choices they made about relationships. For many, this has come with the realisation that some relationships are more enriching than others. In this regard, the feeling of being understood and nurtured as disabled people seems to have been a strong element in the choices they made. As a researcher and a counsellor, I was surprised at how many participants felt the need to leave their current relationships as a result of counselling in order to find that sense of warmth and understanding. From my own experience as a counsellor and a counselling client, I suggest that this change can equally happen within existing relationships if both parties are prepared to make appropriate changes that may or may not be facilitated through couple counselling. The examples arising from participants in this chapter indicate that the capacity to be self-accepting can open the way for participants to receive the support of the people they have learned to trust though there is less indication of trust developing within existing relationships.

There is much to learn from these positive stories but there is arguably more to learn from the stumbling blocks that participants have encountered in counselling and I consider these in the next chapter.

Chapter 7: Difficult encounters in counselling

In this chapter, I continue to address the last two of my research questions namely 'how do disabled people experience the counselling relationship and process?' and 'what impact might counselling have on the way that disabled people relate to themselves and others?' Whereas in chapter 6, I presented participants more positive experiences of counselling, in this chapter I examine the difficult moments that participants experienced in the counselling relationship and process. As I said in chapter 1, I am particularly interested in this aspect of counselling because I experienced a significant potential rupture during my time in counselling that was pivotal to my growing awareness of the impact of disability on the relationship I had with myself and others. Hartling, Rosen, Walker and Jordan (2004:107) point out that

“encounters with the dynamics of shame and humiliation in therapy become almost inevitable” and that “all too often, shaming experiences have taught clients that safety lies in disconnection and separation” (ibid p105).

They go on to say (ibid p109) that

“if one cannot feel worthy of connection [...] within a therapeutic relationship, with whom can one feel worthy of connection? The fear generated from these types of ruptures may prompt a wide range of difficult reactions in our clients”.

Counselling is a relational pursuit and as Scully (2010:28) notes

“One of Goffman’s key insights is that while attribution of stigma is one way, both stigmatised and stigmatiser contribute to the ongoing management of the resulting spoiled identity”.

Unravelling participants’ attitudes towards themselves, their fears, anxieties and relational patterns as they occur in counselling are as relevant to the relationship as their counsellors’ self-awareness, skill and understanding of disability issues. In this research, most participants felt reasonably positive about their counselling experiences but a significant few felt a continued sense of estrangement after their sessions came to an end. Even those who felt the benefit of counselling experienced moments of rupture but this is common in counselling as it is in

everyday relationships. Where ruptures occur and they are worked with and repaired in the context of an empathic counselling relationship, clients can learn about how to negotiate their way through other everyday relationships (Wosket, 1999). This is delicate work, particularly where counsellors are working with disabled clients who may be susceptible to the feeling of disconnection and estrangement.

7.1. Attempting to connect

One of the major difficulties that participants identified in establishing a working relationship with their counsellors is that it is vital to find appropriate ways to communicate. This was an issue for Bill, Sarah, Nancy and Monica. Bill learned to be highly defended as a way of coping with the conditions of worth he experienced throughout his life so his process of making authentic connection with himself in counselling was very prolonged. As Maxine Aston (2011:28) states, *“to work with difference, there needs to be an understanding of exactly what the difference is, and how this will affect your interaction with your client”*. This process is not always straightforward. Although I identify as a disabled person, I did not have the insight or understanding to appreciate the extent of the complexities that can arise in communication until I worked as a tutor on a course for deaf students and until I interviewed participants’ in this research. This does not sit comfortably with me as a counsellor because through this research I have become aware that it can be frustrating for disabled people to be burdened with the task of educating others about their conditions.

7.1.1. Communication

Counsellors rely on the use of language to communicate with their clients but as I have shown in previous chapters, there are particular issues involved in counselling clients who have impairments that affect this basic element in social relationships.

Communicating with Sarah

As I have said, Sarah has been diagnosed with AS (Asperger's syndrome). People with AS generally have difficulty in reading social cues and in empathically relating to others (Aston, 2011). As a result, they tend to experience feelings of inadequacy, loneliness, social isolation or depression (ibid). It is for these reasons that they often seek counselling. Some research indicates that people with AS can learn ways of communicating effectively and that counsellors can develop specific skills to enable them to work with AS clients (Attwood, 2007; Aston, 2011; Woods, Mahdavi and Ryan, 2013). The issues that Sarah encounters on a daily basis were evident in the interview with me so I use our conversation to illustrate some of the issues that affect her in relationships.

I had limited skill in working with people with AS therapeutically but as I said in the previous chapter, Sarah and I were both prepared for our meeting. For the most part, the conversation went smoothly but as a counsellor, I am trained in empathic responding and reflective listening so I found it difficult to maintain the relational style I knew would be most effective in my brief relationship with Sarah. Difficulties in communication with people with AS are often derived from a failure to understand that they generally rely on a logical rather than empathic way of processing information (Aston, 2011). I was aware of this before I met Sarah so I tried to alter my approach by asking her what *happens* rather than *how she feels*. For example, we discussed what happened when she moved to a different office for work

C what happens when you stop managing to cope?

S *it depends. I mean most recently I had a big fall apart*

C did you

S *yeah they had to send me home from work in tears one day cos I just couldn't stop crying and each wing has at least 70 desks in it and [Sarah*] just was not handling*

C is that what made you cry?

S *Yeah I mean it must have it must have been going in every day for pretty well the whole day for a month or so.*

*Sarah often refers to herself in the third person

People often use double meanings, humour, innuendo and non-verbal language in communication and this will be difficult and anxiety provoking for clients with AS (Aston, 2011). They may not be able to put words to feelings (alexithymia) and I noticed that Sarah sometimes had trouble with this during the interview.

C Did you want him to be understanding of your feelings first?

S *I'm not sure it's hard to pin down*

C so it made you feel really upset?

S *I don't know.*

This does not mean that Sarah is lacking in emotion or that she is unaware of her feelings. There are many signs that she is very self-aware but, as Aston suggests, there are particular ways of finding out what is happening for her emotionally that are not in a counsellor's usual skill set. I realised that my skills were lacking at another point in the interview when I asked a question that Sarah found difficult to answer. I corrected this by reframing the question and she was then able to respond. We were discussing a previous counsellor's intervention and I said

C *It wasn't particularly helpful was it?*

S *I don't know it's hard to say. I find it very difficult to verbalise how this helped more than that. I don't know if I really recognise myself*

C what was helpful or not?

S *yeah*

C do you like coming to speak to [her current counsellor]. Was that helpful?

S *yeah it was good.*

Although Aston suggests that clients with AS do not reveal their feelings through their facial expressions and body language, I noticed that Sarah did indicate confusion when I made empathic interventions that she could not process. Perhaps that is a reminder that general trends and guidelines may not be applicable to all clients and that each person has their own individual range of capacities and limitations. Guidelines are useful as maps of the terrain that counsellors may find themselves working in but while each client may be somewhere on that map, it is only through relationship that they will find out where. As I listened to Sarah, I realised that she was inadvertently providing me with her own guidelines about how

she experiences relationships. For example, she says *“there are times I struggle with relationships but I’m not always very good at seeing it”* and *“some of the time I’ve really go to think about questions and what they mean”*. These statements inform me that she may not be able to recognise aspects of her relationship with her counsellor and she may need time to process some of the counsellor’s interventions. A further narrative indicates what it can be like for her to talk about emotional material in counselling. She tells a story about a difficult moment at work saying

“There was no way I was in the right place, after all that panic and stress at work, to deal with what I would describe as a purely social and emotional energy consuming task. If it had been a physical or mentally challenging task or thing to do that would have been fine but something that could place more demands on me in the social emotional range does no good”.

From that information, I learned that Sarah finds social situations both stressful and tiring so if I were her counsellor, I would be alerted to the possibility of that happening in our work together. Through this interview, I began to understand that disabled clients may not always need to educate the counsellor directly about the effects of their impairments on the counselling relationship and process because I could glean some information about Sarah’s communication style and the emotional and relational difficulties that she was experiencing indirectly. If I talked with her on further occasions, I would expect to discover more about the impact of her impairment on her relationships and so learn to converse with her more effectively while recognising that knowledge about how people with AS generally experience relationships is helpful.

Language proficiency and deaf clients

Some research suggests that deaf people can feel marginalised in counselling because of the scarcity of counsellors with appropriate skills. People who manage to engage in counselling might still feel anxious about their counsellor’s awareness of deaf culture to fully understand their experiences (Gill and Fox, 2012). Monica’s experience reflects this situation accurately. She says

“I was trying to find [a counsellor] who could sign because there aren’t many people who can do that. I went to counselling with a deafened person and

they could sign and that was helpful for me and when I went [back later] unfortunately she had passed away [...] so eventually I found a person who had level one sign language and it was very basic language skills [...]. The communication with her was a struggle because the level of her skills was quite low but we muddled through and it was fine”.

Although she recognised that this period of counselling enabled her to talk to some extent, Monica often had to educate her counsellor by helping her out with communication. She says

“Sometimes she asked me about things like deaf culture and what was the meaning of it and the definition of deaf culture [...] she used to ask me signs for certain words because she didn’t know them for herself”.

She felt frustrated about this because it interfered with her ability to relax and express herself freely. Earlier in the interview, Monica said

“Sometimes I do feel responsible. I think that’s how I was brought up. My mum and dad were deaf. My mum always relied on me when I was young asking me words and what they meant. When they received letters from the council or whatever and how to explain the words to them and I think at that age inside I was like a helping person. I’ll support people so when things happen I do feel a responsibility”.

When she talked about helping her counsellor sometime later in the interview, I said

C Did that have echoes with your sense of responsibility for helping your parents?

M Yeah

C Was that quite difficult for you?

M *I didn’t see it as a difficulty, just what happens from my life experience and things that you go through some barriers, they’re not barriers, that’s just life, that’s my life really and you just try to get through.*

Monica seems to have resigned herself to adopting the helping role but she adds

“It would have been easier if [the counsellor] had some knowledge about deafness and deaf culture and that would have made me feel less responsibility. She would already know about certain issues that I have - the culture, the community - and you could offload a little bit more. [...] She was not aware of what I was talking about or fully understood the implications”.

She found a counsellor some years later for a different reason but she encountered an unexpected issue there. She says

“It was a difficult time that I was going through about five years ago and I thought I would try to find somebody but I only found one person. She had level two sign language. [...] I met her twice and then I decided to stop with the sessions because she was struggling with me, not about the language. [...] We were talking about the problems with my family life. [...] I felt lost. I had lost my identity. I was concentrating on my children. At that time my children were quite young [...] and everybody had forgotten about me as a person. [The counsellor] was struggling with that herself because I think she thought my issues were related to the deafness but they weren't. She said things like, 'do you think that's because you are deaf?' 'No it's not because I'm deaf. [...] I'm the same as everybody else', but that's what she said. That was the point when I thought 'I can't carry on with the sessions' so I stopped”.

Monica retreated from counselling and fell back into her usual pattern of independence. She says

“I thought 'I just have to get through it by myself'. [...] I started to keep a journal which [...] was making me think what I want to do next, express my frustrations, my difficulties and that's how it helped. Over time things improved. [...] I thought I'll make the effort to go out and meet friends [...] go back to [her home town] to see friends [...] and leave the children with my husband. And that helped. It's something like self-help”.

Although she says that this worked for her to some extent, she was effectively denied the opportunity to work through her difficulties with the support of an empathic listener so she remained isolated in her plight. Fortunately she has a network of friends but this is not always the case for clients who find communication difficult (Shakespeare, 2006).

Working with interpreters

Monica is aware that she could have worked with an interpreter in counselling as she did with me in our interview. It has been argued that counsellors should be prepared

to work in this way and guidelines are available to support them in doing so (Corker, 1994). However, this is not a straightforward process as Monica points out

“Some deaf people have been to counsellors with interpreters. Then there’s three involved in the communication. Sometimes that can affect the dynamics and that can cause difficulties because the client is looking at the interpreter. So actually the development of the relationship between the client and the counsellor can be impeded. [...] I’m not saying all interpreters are rubbish - there’s some good interpreters out there but it’s how things are translated. [...] Sometimes it’s not the interpreter’s fault. Sometimes the deaf person might not be able to get out their emotional feelings very well and might be bottling them up. [...] The interpreter might think it means this and it might not. It might mean something completely different to what the person wants to say”.

A further issue is that the interpreter can be emotionally affected by the client’s material. In the context of her work in counselling, Monica says

“I was really surprised that clients were quite happy to use interpreters but I would meet the interpreter first and make sure everything’s OK and then [...] have a briefing session where I ask the interpreter how they felt – any issues, if they felt they made any mistakes. [...] I would encourage the client to decide where they wanted the interpreter to sit and get the room right and whatever made it easier for the clients. [...] I didn’t want to lose the importance of having eye contact with the client. [...] It seemed to work”.

She says that she would not choose this option for herself because she finds it inhibiting but it does work for some other deaf clients.

Nancy’s experience was somewhat different to Monica’s. She did not work with an interpreter in her counselling sessions but like Monica, she chose to use one for her interview with me. The way that we communicated is illustrative of the uniqueness of each deaf client’s style. The interview was full of intimate and emotional content. Nancy chose an interpreter that she knew and felt comfortable with for the interview so she was not inhibited in the way that Monica described. She has some speech which she says is unusual for profoundly deaf people so she feels different from other deaf people in that respect. She can lip read and she is emotionally

expressive so our conversation had a natural rhythm and flow. Nancy looked at me as I spoke to her, then we both paused while the interpreter translated my words to Nancy by signing. This meant that I could communicate directly with Nancy as she would read my lips and my facial expressions before the interpreter confirmed what I was saying. When Nancy responded to me, she signed to the interpreter and they both looked at each other while I watched and listened to the sounds and occasional words that Nancy used. I could see Nancy's non-verbal language as well her words as translated by the interpreter. When the interpreter repeated Nancy's responses to me, Nancy looked at me and we both expressed our emotional responses as the interpreter spoke. This meant that we had full communication and the strength of emotion that Nancy felt about her experience was communicated directly to me. I was reading her facial and emotional expressions very intently and she was communicating with me by mouthing and gesturing. I was aware that I was gesturing to Nancy and communicating my empathy by using facial expression more than I do with hearing people.

Given the relative ease of communication with Nancy and her highly skilled and attuned interpreter, it is salutary to note that there were limitations to the way that Nancy's material was translated. Perhaps this is inevitable when the language is not as sophisticated and nuanced as it can be between hearing people. There were many hesitations during the interpreter's speech where she used 'em', 'I mean', 'you knows' and I was not sure if these were Nancy's or the interpreters. On one or two occasions Nancy was astute enough to spot inaccuracies and correct them

[I = interpreter]

I *On the first day everybody that was there had to basically do a test and I thought well it was really to pass the time. I didn't know what it was for*

N Nancy gestures to correct

I *oh sorry - to pass at the time. I thought it was to pass the time.*

On another occasion, the interpreter realised her mistake and corrected it herself

I *because the subtitles so everybody else could read [sorry] eh could listen to the TV and iron.*

While these mistakes were relatively minor and correctable, there were moments when the use of present and past tenses were confusing to me and left room for misunderstanding.

I *em I think I was a happy child, always looked happy*

C yeah

I *had a good personality, always laughing but as soon as I'm on my own it's like the walls are closing in again em it's a very em I can't explain how I feel and I guess it's just like the shutters come down em and it took me the counselling to kinda move this away and then move on really.*

Nancy is moving from childhood, to the time she was in counselling, to the present 'I can't explain how I feel'. As a counsellor, I can appreciate that she may have become confused by going back into her childhood memories, which she was talking about in counselling and also to me, but it may be again that there's something lost in the translation. If she's moved away from the shutters coming down, the 'I feel' tense would not be accurate. It's a powerful image and it seems important to determine when that was actually happening – now or in the past. Maybe it does still happen for her now but she's largely moved on from the acuteness of the experience.

In the following extract, Nancy talks about her awareness of the sexual abuse she endured as a child being with her in only fleeting moments, but then she says this is still happening. I am not sure if this is a translation issue or if she's saying she's locked her experiences of abuse away again after opening it up in counselling some time ago.

"Before the counselling I didn't think about it. I didn't think about the bad things that happened. It was very rare that it came up. It was a fleeting moment that something would trigger it [...] but it goes away. [...] I have locked it away in my brain somewhere but now today it's all locked away".

In another moment, the interpreter missed the nuance of the word 'glad' that I was using

I *It was really hard it was more difficult telling my children than it was telling my friends of course*

C yeah

I *very hard*

C Are you glad now that you did?

I *yeah, of course. I mean happy is maybe not the right word but eh yeah I mean it was good to be able to tell them what had happened.*

Something will always be lost even when the communication is direct but working with interpreters creates another layer of potential misunderstanding. Working with a counsellor in this way would require a very high level of concentration to gain as much accuracy in listening as possible. as well as the capacity to notice mistakes and wrong assumptions.

7.1.2. Difficult beginnings

As I said in the previous chapter, Sandra had several attempts at finding a counsellor and here, she tells the story of the obstacles she encountered before she found a helpful peer counselling service.

“I needed help with what I was going through with the grandchildren. I couldn’t get it. [...] He [her husband] was dead so I went through a time of depression with that [...] so anything I had before I kept it into myself, it built up. [...] I got a form from the doctor for counselling because my sister died. [...] I’d seen two [counsellors]. The first one I got five minutes with her because she was overloaded or something. [...] The second one was a man and he sat back and I tried to talk to him, tried to put in words but I couldn’t put in words what I felt and what was bothering me and he says ‘there’s nothing wrong with you, nothing I can do with you’ and I only saw him the once. The doctor gave me a sheet for a counsellor in [a nearby village] but the cost of it was too much for me”.

Sandra has experienced multiple losses and has a sense of rejection because of her family experiences. It is possible that she felt further rejection and a reinforced sense of isolation from these failed attempts at engaging with a counsellor.

James worked for a ten week period with a counsellor in a GP practice. He said that he found counselling to be beneficial on the whole but when I prompted him to tell me about any ruptures he encountered, he said

“The first couple of times I was a little bit unsure. [...] When we were talking there was a bit of ‘hang on that’s not exactly what I meant’ but I don’t think I challenged her at that point because I was fairly new to the whole counselling thing and actually the idea of being given even more freedom to challenge your counsellor is really important to me”.

He seems to have deferred to his counsellor as something of an authority figure and felt that he could not tell her what he was feeling about the relationship. Not only that, he says *“I think I probably lightly brushed over it but I remember talking to my counsellor about the reactions some people have to me”*. One of the reasons for doing this was that he was afraid of becoming dependent on his counsellor. He says

“I was worried. [...] Your job as a client is to get as much from the counsellor as you possibly can and as much help as you can. By doing that you become utterly reliant on that one person for that time period but then it’s almost like the fear of ‘oh this person is in my life now and I can be totally reliant on them but I know that they’re gonna go away”.

James was sensitive to rejection and this seems to have interfered with his feelings about his counsellor but he did not tell his counsellor that he felt this way.

7.1.3. Confused agendas

Reynolds (2004a:17) notes that *“therapists need to recognize that clients/users of health services have a wide range of needs and goals, and do not always have agendas that coincide with those of health professionals”* and that there is often a tension between these different agendas. This may account for what happened with Janet. She was referred to a psychotherapy trained psychologist in a hospital rehabilitation unit and she recounts the story of what happened

“Looking back on, it I’m annoyed that they didn’t explain to me clearly what service it was that I was accessing. If they had told me I think I might have been able to make much better use of it. I was going with the expectation of one thing and he was offering something different. [...] I went there and it was like a counselling session and I thought I was gonna get eating management and physio and there was this guy who wanted to talk about my feelings of being disabled. I was just so pissed off with him. When I

twigged the fact that it was counselling he was offering me, I wanted to talk about other issues that had shifted because of my disability and in the end I told him I had no feelings about being disabled whatsoever because I got really, really frustrated. [...] That's how I felt with this guy, that he wanted me to process emotions that I no longer had and he just made me angry and of course my anger was a defence mechanism as far as he was concerned and it was like 'no you're putting me off because you're making assumptions about how I feel'".

This echoes the frustration that she feels when friends expect her to be upset when she is too tired to socialise. Janet continues her story about counselling saying

"I felt completely disempowered. There was no way in for me to challenge him. He was the rehabilitation expert and I was there to be rehabilitated. I was gonna be depressed about my illness. I should be depressed, 'no I don't have time to be depressed. I have other issues that are more important'. [...] There were a lot of issues that I wanted to revisit in the context of my disability like my career coming to an end; how I felt about what I'd achieved, what I hadn't achieved; the end of my marriage; lots of issues from my childhood that I hadn't resolved as an able-bodied person that shook me when I became disabled. I could have used a lot of help on these issues now I think about it and he just wasn't having it. I didn't really challenge him directly but I was in a space where I could have used help on these issues but I wasn't invested in it. My agenda was to be seen for the six sessions by this person so that would go on my medical and that was my main agenda and he sort of saw this other agenda of issues that I could have benefited from looking at but he didn't seem interested in them at all really".

At some point during this process, Janet says she *"retreated and didn't really say anything cos I wasn't invested in the relationship. [...] It was someone I didn't like"*.

She gave up on hoping that this period of counselling would help her so she did not tell her counsellor how she was feeling.

7.1.4. Role play

Nick had a very good relationship with his counsellor and he trusted her wholeheartedly. However, when I prompted him with the question of whether or not he encountered any ruptures in the relationship, he recalled one incident which he did not feel was important enough to question. Talking about his counsellor, he says

“She broke her leg and had to use a wheelchair and she was talking about how suddenly people were ignoring her, that her experience of other people was very negative in their attitudes. [His counsellor] seemed to assume she had some understanding. I never actually raised that with her. It never really became a problem partly because I’m undecided myself if the role playing helps or not. If you want to do role playing and tell them ‘you’re gonna use a wheelchair for a week’ they’d be well up for that cos they learn to understand but the accurate description is if you’re gonna use a wheelchair for the rest of your life”.

Nick is suggesting that his counsellor was trying to equalise the relationship by telling him about her experience. In doing so, she hoped that Nick would feel more understood as a wheelchair user in the social world. Disabled writer Sally French (1992: 257-260) gives clear guidance about the use of simulation as a way of understanding disabled people. She explains

“Simulating physical and sensory disabilities where, for example, people are blindfolded or obliged to use wheelchairs. [...] It is believed that the personal experience of ‘disability’ is vitally important in giving both children and adults an insight into the problems, difficulties and frustrations disabled people face, and that such activities have the potential to bring about positive attitudinal changes towards disabled people”.

She argues that such practices are misleading and potentially harmful to disabled people. She points out that

“There is little evidence that simulation exercises bring about positive attitude change [...] at best these exercises only simulate the onset of disability, but even that is not achieved because the people concerned know very well that at the end of the day, or at any time they choose, they can stop being ‘disabled’ and return to their able-bodied status”.

French points out that if non-disabled people try to imagine what it might be like to be disabled, they may be inclined to pay attention to the impairment more than the effects of the physical and attitudinal environment. She emphasises the importance of listening directly to disabled people themselves instead of making assumptions. In disability equality training, offered by disabled people, she explains (1992:265) that

“Participants explore how disability is defined, their own feelings and behaviour towards disabled people, the identity of disabled people, the oppression disabled people encounter and how to remove it through equal opportunities and empowerment. The voice of disabled people themselves is central at all times”.

7.2. Missing connections

Research confirms that *“the therapy relationship accounts for why clients improve (or fail to improve) at least as much as the particular treatment method”* (Norcross and Wampold, 2011:98) so it is important that counsellors acquire skills in establishing and maintaining the therapeutic alliance (Horvath, Del Re, Fluckiger and Symonds, 2011). Ruptures in the counselling relationship are not necessarily catastrophic if counsellors like my own have the skills to work with the client towards repairing them. It has been suggested that clients often have negative thoughts about the counselling process and/or about the counsellor and that client’s relational patterns can be present in the counselling relationship (Safran, Muran and Eubanks-Carter, 2011). In this section, I illustrate how ruptures to the therapeutic alliance can occur where the client is disabled.

7.2.1 Assumptions and misunderstandings

James says that he tried to gain his counsellor’s acceptance by minimising his experience and by emphasising what he saw as his positive qualities. As I listened to him, I recognised this pattern in myself as I worked with my counsellor. I now wonder if the desire to present myself in a positive light contributed to the length of

time it took me to talk about the effects of being disabled with my counsellor. James says that his desire for acceptance may have contributed to his counsellor's lack of understanding of the struggles he had in his social relationships. It is equally possible that his counsellor was keen to emphasise James' positive qualities because she was aware of his impairment and wished to compensate for his negative experiences. Talking about his relationship with the counsellor, James says

"She was very much aware of everything that I can do and it was almost like 'why do you have problems with social interactions, with the social things?'"

His counsellor was echoing a pattern that James noticed with his friends. He says

"When I talk to a lot of other people who do get on with me, they can't understand why I would feel I'm any different to anyone else. They don't know what the problem is because it's not a problem to them and they don't see me in that way."

He goes on to say that his counsellor

"didn't [...] see me in that way because she saw the positives but then she also accepted the negatives. She probably genuinely thought the negatives were so insignificant cos she genuinely was aware of so many of the positive attributes I have that it didn't quite come home in the way I thought it might have done".

James' counsellor was unable to break his sense of not being understood at that point.

Jenny Morris (1991:71) is aware of the sense of isolation that disabled people have when the totality of their experience is not understood. She says *"we need courage to say that there are awful things about being disabled, as well as the positive things in which we take pride"*. James struggled to be heard but he did manage eventually and his counsellor was able to understand the issue because of the incidents that he recounted. Although it was not James' responsibility to repair the rupture, in struggling to be understood, the indirect benefit of doing so appears to have helped him to articulate what was happening more clearly.

Kevin has had five periods of counselling over his lifetime so far. Talking about his second counsellor, he says *"lovely person, I loved him"*. He went to this counsellor

to talk about a family trauma and they seem to have worked well on this issue but Kevin says *“my self-concept was that I was stupid, and dyslexia was there but I’m stupid because that’s what I was always told”*. Talking about this counsellor, he says

“It was almost like ‘I don’t understand that, it’s got nothing to do with the work’. He was saying ‘I don’t understand that kind of thing. It’s not anything to do with me. That’s not what we’re here to deal with’ [...] and of course what it brought up for me was all of my inadequacy. I stopped after twelve sessions”.

Talking about his first two counsellors, he says *“neither of them did anything to demonstrate an understanding of the condition and the impact”*. He goes on to say

“For the first fifteen years of my life it was chaos and I needed to unravel it all and previous therapists couldn’t unravel it with me cos they couldn’t see the threads and where they came from. I think they didn’t understand, they weren’t properly able to have a social, political understanding of the themes, what’s it’s like to come from a working class background and be a middle class man now,. And what it’s like to be a gay man in a heterosexual world, what it’s like to be a disabled man in a gay world cos it’s hell. [...] We’re back to the very basic thing - if people don’t understand dyslexia, they don’t understand the impact that it has on the self-concept and then they mislabel and misdiagnose and treat you for things that are completely wrong”.

The previous examples in this section are of counsellors failing to understand aspects of the client’s experience but at one point, Robert made an assumption himself that stalled a potentially useful avenue for exploration. Having left his relationship with his partner, he wished to ‘move on’ but he found it difficult to decide how he might do this. He did not discuss this in counselling and seemed to assume that this would not be possible. When he spoke about entering counselling again, he said

“It’s not that I think it’s a bad idea, I don’t think I would directly benefit because my problems now are largely practical. For example to go out and make some friends now, I don’t really need to be advised unless the counsellor was really good at organising social diaries. My problem is really just re-engaging with stuff”.

Instead of managing this on his own, he may have been able to process his thoughts and feelings about his future in counselling so that he could make his decision but he did not raise this issue with his counsellor.

7.2.2. Power dynamics

Kevin says *“I’ve only ever had one counsellor that has understood and I’ve had five lots of counselling”*. While he acknowledges that he did some useful work with the first four counsellors, he told me about his first experience, saying

“[She] was lovely, we worked really well together. [...] She was overprotective when I told her about my condition and because I was in my twenties, I liked it but it disabled me. I felt patronised all the way through and I felt like a child with her cos what she kept on saying to me ‘it’s not your fault that you can’t read properly’. It’s the 1980s so, even though the [social] model was around, absolutely didn’t get it but it was benevolent, it wasn’t hostile, it wasn’t aggressive, it wasn’t intentional but I had a sense of helplessness”.

Kevin already felt undermined in relation to other people because of his dyslexia so a more enlightened understanding of this aspect of his life would have been beneficial though the full extent of dyslexia and the Social Model of Disability (SMD) were not widely known about at that time.

Some years later, Kevin began his fourth period of counselling when he felt at a low ebb emotionally. He worked with this counsellor for several years but he says

“It’s quite a damning thing to say of a therapist but he enjoyed my inability to function academically. He always enjoyed that he could point things out to me and because I was so vulnerable I was prepared to put up with the kind of slightly superior attitude that he had because I wanted the therapy to work”.

Once again, Kevin’s sense of powerlessness was reinforced. He recalls a particularly difficult moment

“He said I was narcissistic cos I would spend so much time talking. I think the pain that I carry I was obsessed about because I never got to articulate it and he interpreted it as narcissism. I now know it’s because I never ever got a chance to talk about years and years of being trapped in this world with being

gay, being dyslexic and having a very dysfunctional family. In the end I stopped therapy and I didn't go for therapy again for twelve years".

It was then that he found the counsellor who he liked and was still working with at the time of the interview.

7.2.3. Marginalising embodied experience

Whether or not participants in this research entered counselling to talk about disability, this was always a relevant feature of their experience though it was not always talked about. Some participants may have known that they were withholding their 'hidden knowledge' while others, like me, may not have been aware enough to articulate how they thought and felt about being disabled. Pete and James did manage to talk about their experiences of disability but they did not find this easy. Neither of them seems to have been aware of the social and cultural conditions of worth that were affecting them as disabled people.

Pete had two major issues that were troubling him when he entered counselling. It was five years since he had his leg amputated but he was still very troubled by pain and further surgeries as well as by how he managed his condition in relation to himself and other people. As I discussed in the last chapter, he had been sexually abused as a child and was feeling very distressed about this. He says

P *The disability side of it, we didn't go into that much [...] it wasn't that we never spoke about it, it was just about parents and how I was feeling - the depression side of things. I suffered from depression since I was seventeen but over the years it got a lot worse*

C would you say disability was part of your depression?

P *after the amputation I was in hospital and a psychiatrist was involved. I was in hospital for six months with it and when I was in hospital, because I was in for so long, I was really getting down on it but he was a male. I'm still coming to terms with what was going on with my leg and struggling.*

Talking about the amputation, he says

"It will always be an issue. The first thing I do when I wake up is hoping I'll see two feet and that I've been having a nightmare. [...] I'm down about the

amputation and starting to think about mum and dad and the abuse. I think [his counsellor] thought, and I agree with her, that the bigger issue was boarding school and mum and dad”.

He says his counsellor “*understood the cycle I was going through – being disabled and other things that were going on*” but making a choice to background his experience of disability seems to have left him alone to deal that very difficult aspect of his everyday life. Some of the feelings about both experiences were similar namely shame, anger, frustration and loneliness. It could be argued that his emotions rather than the events that caused them could have been the focus of Pete’s work in counselling. Part of the problem was that his time in counselling was curtailed because his counsellor left the GP practice where she and Pete met.

James felt confused about what was disabling him. He talks to me saying

J *The counsellor probably needed to realise that rather than me being disabled it was the psychological possibility of not being able to do things that was the real inhibitor*

C you were a bit worried that she might not understand?

J *because it’s such a subtle different thing so it’s like someone totally non-disabled and then someone who is handicapped and can’t do anything who is majorly disabled and can’t do a lot of things but then you’ve also got the person who thinks they’re disabled but they’re less disabled and think they can’t do things when actually they can.*

James is trying to explain to me that he couldn’t help the counsellor to understand that he found it hard to internalise both his disabled and his capable selves.

7.2.4. Hidden knowledge

None of the clients that I have discussed in this chapter so far talked with their counsellor about the ruptures they were experiencing. This seems to reflect the notion that disabled people are often conditioned to think of themselves as inferior (Shakespeare, 2006). While I did talk with my counsellor about some of the ruptures I experienced, especially after several years of working together, there are very few indications that participants’ counsellors had any sense of the conditioning that led

their clients to think of themselves in that way. My counsellor understood that I viewed myself as inferior in relation to others at times but I have no evidence to suggest that she realised that this may have been an aspect of disability. Talking about his first four counsellors, Kevin says *“I’ve never said anything to any of these people and I’m sure they would be horrified if I did”*. He has a self-declared tendency to please people and a feeling of being ‘helpless’ in his relationships with others at times. As a young adult, he did not understand the full implications of his impairment himself so he could not talk with his first counsellors about that. There is a developmental aspect to Kevin’s experiences of counselling in the sense that he gradually came to understand the impact that his condition was having on him. Once he saw himself as disabled, he learned more about his condition and he became familiar with the Social Model of Disability in the 1980s when the disabled movement was emerging.

7.2.5. A difficult ending

Pete found it difficult to talk about himself and to trust anyone else to listen to his vulnerable feelings so it took time for him to open up to his counsellor. As the work progressed, he found it increasingly difficult to internalise the warmth and empathy that his counsellor extended to him. He says

“It did help me but then I would get home in a state and be like that all weekend. I’d get a release after seeing [his counsellor]. I would get into a state with my body no matter who it was but it took the pressure off me, did help until I got home and I was alone again and the pain started working overtime. [...] She can’t be there twenty-four seven. It was partially my fault for not opening up”.

Pete continues his story saying

P *I was kinda knocked back when she [his counsellor] left. I saw her for six months but the GP practice never replaced her. I never got offered any other counsellor*

C would you like to have continued?

P *No. I didn’t want to start from scratch again. Trust is another problem. It takes me a long time to trust. It’s happened so many times in my life. Psychiatrists,*

social workers, CPNs. I can't work with males, can't cope with male figures, it just leads back to boarding school.

C so it's mostly men that were abusive?

P *yeah*

C so the fact that [his counsellor] was a woman made it easier?

P *it took a while but I felt more at ease*

C it sounds as though you managed to talk to some extent and that you felt she understood you?

P *yeah*

C but there was limits to that?

P *I've never been able to go into great detail about the abuse; I don't think that will ever happen. [His counsellor] knew so far but there's no point putting things into people's heads, making them think about it. The stuff they did to me I didn't like anyone to see it as well. I lived with it for years. It started when I was nine and finished when I was fourteen. I blame myself all the time for it but I learned to deal with it my own way*

C I guess that leaves you feeling lonely.

Pete was still in the middle stages of the counselling process, where he was still feeling emotionally overwhelmed and struggling to reveal the full extent of his feelings. Sadly, he seems to have blamed himself for slowing the process down so his self-esteem was still very low when counselling came to an end.

7.3. Continued estrangement

Alastair is very aware of feeling estranged in his everyday life. He lives with severe chronic pain and has a sense of being distant from most of the people around him. He has reached a point where medical intervention can no longer ease his suffering. He has had several periods of counselling over his adult life, some of this before he became disabled. He talked about his impairment in counselling, hoping that this would ease his depression and help him to manage his situation. I, too, have experienced chronic pain albeit not as debilitating as Alastair's and as part of my medical treatment, I was advised that there is a strong link between depression and

living with long-term pain. . I did not address the physical pain directly in counselling but I did find that counselling alleviated my depression and the sense of anxiety that derived from my relationships with self and others. Alastair appears to have placed more emphasis on his chronic pain during the periods of counselling that he discussed with me. He says....

“The difficult truth is that it was quite seductive having somewhere to unload but I’m not sure if it was helpful. I’ve been to five counsellors over the years and I’m not sure if any of them helped. [...] My last counsellor believed in the worth and value of sharing painful experiences and of sharing with other people not just here in the counselling room. But I never experienced that. Though I liked it, it didn’t change the pain. I hoped I would develop, change and find ways of handling it. [...] [His last counsellor] believed that the source of my difficulties was in my childhood sorrow. I often thought that the sadness was going to come back and that sent me on the road to counselling. [...] Sometimes an overt sense that how I deal with pain and distress comes from the past but if that were true, why didn’t counselling help? [...] My life situation is an intolerable one. If someone was to hammer my big toe every week, after a time would you cope better? I can’t say it’s about emotional behaviour why I can’t cope with it. I can’t say it’s not to do with my inner self but it feels that there are some things in life that are too hard and no talking or sharing with people can help. That’s why I am distant. Nobody can cope or relate to it and that’s why I feel so isolated and alone. I have tried anti-depressants several times but they always have side effects. I’m heading that way again”.

Talking about counselling, Alastair says *“I would look forward to it and enjoy it and I found it hard to leave”* but he still feels that his chronic pain cannot be understood by people who do not experience it themselves. He says *“You can’t counsel someone to cope with torture”*.

Shirley’s experience is different from my own or that of any other participants in the sense that she felt estranged consistently during and after her time in counselling. She began to see a counsellor some years after she suddenly lost her sight but it was not a good experience for her. She and her counsellor did not manage to connect with each other in meaningful ways. She says

"I guess that there was something about not understanding in counselling it's absolutely OK to not cope. [...] I didn't have any counselling knowledge and now of course I have and so it's difficult to look back with the same perspective but I remember there were some things in particular that made counselling difficult".

She had a very strong reaction on meeting the counsellor for the first time. She says
"I think I had a belief that counselling would make it better [...] this hope that a counsellor would sort it out. [...] I went with high hopes. [...] A last hope for me in some ways. [...] I went to a really nice lady but as soon as I walked in I was thinking 'this feels like my granny's front room', I thought 'you're not gonna get this, you won't understand. What do you know about despair and desolation? You look like you go to church and everything's rosy in your life [...]. You won't get it, with your china cups and your nice room and your clothes that are different from mine. You're really nice but you're really different from me [...] you don't speak to me on any level of similarity' and me thinking 'I don't fit here'. I didn't believe that person would understand the depth of my despair and the nuances. I guess I was desperate for her to prove me wrong".

Despite feeling that she and her counsellor were not well matched, she continued to attend. She explains

S *I could see she was a nice person and she meant well and that's why I didn't want to disappoint her. I didn't want to let her down, get her into trouble*

C *so you were taking a lot of responsibility for her then?*

S *yeah, I think that's my old theme*

C *you're the responsible one*

S *yes*

C *to allow her to see your vulnerability, was that difficult too?*

S *yeah that would be hard*

C *and did that mirror how you were in other relationships?*

S *I think it would because I'm so used to being a copier and I'm very much a giver and to be at the stage, you're a giver and you've nothing left to give,*

that's a hell of a place to be in front of you. You don't want to interact with people cos you can't give anything so it shuts down relationships

C and that was happening in your counselling relationship?

S *yeah I think it was*

C you had to give something to her?

S *yeah*

C to please her?

S *to please her. Absolutely yes. To make her feel that she's not disadvantaged*

C so in a way you're both paralysed - you couldn't give to her, she couldn't give to you

S *yeah.*

Shirley goes on to describe how she minimised her feelings with her counsellor. She says *"it was hard to let her see the pain that she was trying to pick at. I was going 'oh well, you know it's a bit of a pest having this'. [...] I couldn't share how much I'd collapsed because my own constructs are so tight about having to cope and having to be OK"*.

Shirley attributes some of these difficulties to the counsellor's lack of skill and understanding of disability. She says

"She didn't get how difficult it was to actually be there – what a challenge it was to sit down in that chair, to make space in a time where there was no energy, no life, to understand that struggle and then to try and hide, in some way to kind of pretend to the counsellor that I'm OK and then to face it all again. It was really terrible. [...] I think my counsellor thought she was doing me a favour to go over time but to get to counselling was really problematic for me, cos I would have to get a bus into town. I'd kids to collect and I had the babysitter looking after another. It was traumatic to get into town, to get to the place and then we'd go over time, so I'd be running for a bus".

Another example is that Shirley felt her non-disabled counsellor was being over careful about mentioning her impairment. She illustrates this saying

S *In hindsight I realise that there's a lot of taboo around disability and counsellors like to think they're not got any prejudices so they tiptoe around disability like it's 'don't mention the disability'. I think 'no! Mention it!'*

C What would you like her to have said?

S *What I find helpful is self-disclosure about how crap the environment is, the difficulties of it because it gives permission for a sharing of, you know, 'this is really crap [...] sometimes. Being blind is really shit'. It's really difficult whereas I think somebody who doesn't have that experience wouldn't in hell say that. Imagine saying to somebody 'how crap is it to be blind?' cos you would feel then that you were prejudiced or you were making assumptions".*

In the story that I described in chapter 1, my counsellor noticed a subtle point of disconnection in our relationship and when she pointed out what was happening, I was able to come back into connection with her. Sadly, Shirley's counsellor missed a moment when they could have made similar meaningful contact. She was in tears as she told me what happened

S *I remember one point that I was talking and it was the most poignant bit of it. It's emotional thinking about it. I remember describing to her about harnessing up the dog and I said, 'you know I feel like I'm putting a harness on me'. I think that was the whole crux of it, that it couldn't go further because I don't think she had the courage to really explore that. [...] The pain of not being able to live a normal life was really difficult, not to lead the life I lived. It was the huge loss of that freedom and for me the metaphor of harnessing up the dog - that my life was harnessed up and it was really powerful. That is my memory of how I felt at the time of counselling but, it didn't go anywhere*

C did she not respond in a way that was helpful?

S *I think she probably would be fearful to respond to that. She kind of made noises of like 'that's tough' but not in a way to 'look shall we pause here, would be OK to unpick this?'*

C it's really agonising to have actually got to that point and then not to feel received

S *yeah I think that's probably it Connie. I think you've read it. That's a lovely word for it I think for that to have been received and for me to have known that somebody understood.*

Person-centred counselling theory suggests that warm acceptance is the antidote to shame but that clients who have been shamed may find it difficult to receive a counsellor's acceptance (Greenberg and Paivio, 1997). This is evident from my own story (chapter 1 and Johnson 2011) where my counsellor worked hard to maintain connection with me and I struggled to come back into connection with her. This struggle to connect may be part of what was happening between Shirley and her counsellor though the result was very different. Jordan (2004c:28) notes that *"when people are unable to move from disconnection to connection, the resulting combination of immobilization and isolation may become a prison"*. At the time of entering counselling, Shirley did appear to be in a prison but counselling did not enable her to escape. As she spoke with me, she realised how much she was holding back from saying to her counsellor because she was so trapped in her own pain; trapped into a particular self-concept (carer) and feeling uncomfortable in the relationship with her counsellor. Shirley reflects on her experience saying

"Maybe it's two to do the relationship. Maybe I couldn't give you know, it's the client's ability to give you the other part of the relationship. I kind of think it's all about the counsellor doing the relationship but maybe it's the client, maybe I couldn't have been in a relationship with anyone. [...] It was the space between us, the chasm between us. No relationship".

Although Shirley's relational pattern may have had a part to play in the failure of counselling, the counsellor does not appear to have been sufficiently skilled or knowledgeable to help her address this pattern. The experience was very damaging for Shirley. She says

"I remember I was just feeling emotionally filleted, really opened wide and raw. It was so painful and it's not that we were doing work about the sight loss; it was the whole experience of going for counselling. She must have opened me enough for me to feel that raw way but I think what she did was opened the key to me looking at it, so that although I would put on a front for

her of, 'yeah you're doing a great job', privately I would be raw from hiding what was the real pain of feeling not understood and more isolated. [...] from having a deep hope that counselling would fix everything it compounded what was already a difficult situation. [...] There was a sense of me taking that blame on myself. I don't fit cos I don't fit anywhere. [...] I felt like I had failed this game. I felt I hadn't done really well in counselling. [...] It's left an imprint on me, not a nice one. [...] I guess it was a disaster and there's my part in it and how terrible would it be for her to know about how awful that was for me. Even now I carry a bit of shame about it, not having the guts to be 'this is shit'.

It may be that gender played a part in Shirley's inability to terminate counselling when it was not working for her. Miller (1986:13) suggests that

"Women's sense of self-worth is often based heavily in the sense that she is a caring person, and she hates to lose that sense. She may want at least to feel that about herself, even if care for her is not returned".

7.4. A lifelong process

Unlike Shirley, Bill managed to connect with his counsellors at some level but for most of his life he remained disconnected from the emotional effects of being disabled and from his embodied experience. He had several periods of counselling throughout his life mainly because he was prone to depression but for the most part he did not make a connection between that and his feelings about his impairment. It was not until his most recent set of counselling sessions that he began to express his emotional responses to being disabled. His story begins with the first two times he worked with a counsellor which he says were like *"intellectual conversations"* which is consistent with the way he had learned to function in relationships. During these early phases of counselling, Bill and his counsellors seem to have adopted a cognitive understanding of his depression. His wife was going through a period of depression when she and Bill attended counselling for Bill's second time. As he spoke about this, Bill says *"I don't think we ever talked about disability. I remember him talking about 'depression a deux'"*, a term he used to describe how couples can

become mutually depressed. The focus of their counselling was not disability so the impact of Bill's condition on their relationship was not discussed. This may have been difficult to unravel because his wife's brother was disabled. Although Bill says that she was comfortable with disability, she too would have grown up within the context of social and cultural conditions of worth that may have inhibited her from talking about the impact of her brother's, and by implication Bill's, experience on her.

Some years later, Bill attended a personal development group where his impairment was addressed by one of the group members who noticed that he was displaying a 'victim' side in his way of communicating with them. Bill reflects on what that person was seeing in him. He says

"I wonder if it was about the whole business of how I asked for help, whether it was manipulative [...] I could go into a kind of self pitying thing, you know 'the bastards, they don't know what it is like to be me'".

This moment depicts Bill's attitude towards himself and others at that time but he entered counselling some years later and he says

B *The work was more to do with my fight between sometimes feeling OK and engaged and sometimes feeling totally cut off. I went through periods of feeling very apathetic and then periods of feeling connected with people. It was not bipolar but I have a notion of myself as being depressed*

C *it sounds as though it might be connected with your mother and her being bipolar?*

B *I wonder and my sister certainly has it and it's a big issue. [...] I had this wonderful therapist - a woman. I don't know how it came but she supported me to look at my self- image and it was then that she picked up that I saw myself as [Bill] but I'm disabled'. That statement came out of a conversation we had. She heard that and [said] 'how does that impact on what we do together?' [...] She said 'you make it impossible for me to surprise you. You've got all the angles figured. [...] What she was trying to say was that something about me was sort of defended and she was concerned about that. [...] It was very much part of what was happening between us but even then I chose not to go with it.*

Bill reflects on this experience saying

“One of the important things that I’ve discovered through my therapy is that I had an image of myself that I was just a head [...] that somehow I denied who I was physically and that was a useful learning thing. [...] It’s a very personal insight but something about how you relate to yourself as a physical entity when you’re born with a disability”.

While Bill was beginning to acknowledge and understand more about the impact of his impairment on himself and others, he still felt the need to defend himself from exploring this any further in counselling. He finally encountered the primary emotion that had been dormant for most of his life in relation to his impairment. He tells his story

B *Three years ago I went through a crisis at work where [...] I got signed off and put on anti-depressants and somehow that was the start of something different for me. I [used] a telephone counselling service and the guy was lovely. We didn’t talk about disability, talked about work. What I discovered then and I didn’t talk to him about it, [was] that I am a terribly angry person and I’m furious about my disability. [...] Suddenly it occurred to me that it’s some sort of primal anger [...] about the limitations*

C I’m curious about how that came out with that particular counsellor

B *I don’t remember the process but it did come out of something that happened in that conversation. It was a wonderfully accepting conversation and I was no different with him than I am with you, but there’s something about me reflecting on what had happened in my thirty year career and him being very supportive and engaging that suddenly - I don’t know whether I even said it to him - but I came off the phone and I said ‘I’m fucking angry’*

C could it have been something the manager said that put two things together - your working career and your impairment. Was there a connection?

B *well there was a slight connection because he irritated me. [...] I suppose it did come from my manager because I think he was the first person that made it explicit. He was very conscious once we negotiated my return to work ‘OK how can we become more supportive and take into account your disability?’ I’ve had access to work but I’ve made light of [his impairment], not quite made my needs explicit or worked out with people what were the implications*

- C so he was attributing your performance partly to your impairment?
- B *no he wasn't but the next stage after the confronting was 'how can we enable you to do your job to the standards where we want you to do it?'*
 [...] *We went up to six sessions and [his counsellor] said 'if you want to have further sessions you can ask your manager' and actually I asked [his manager] for further sessions and I know he was rather busy and he never processed it so I just let it be*
- C did you ever get to talk with [his counsellor] about the rage then?
- B *not really, no.*

Although his view of himself was as something of an intellectual person for much of his life and he denied or minimised the impact of his impairment in order to maintain a sense of acceptance, Bill reached the point where he could recognise and express the rage and anger that had been buried deeply inside. He reflects on the process of counselling over many years saying

- B *My experience of counselling has been very circular.*
- C have you got any sense of why that might have been?
- B *don't think I know. I'm aware of how I find it really difficult. [...] I'm very good at thinking but with my emotions I'm not at all clear. [...] My self-development is more to do with the friendships I've had and my relationships. Ok I've had a lot of wonderful counselling support but I think the big difference to my way of relating has been my wife because she's such a wonderfully confronting person because of her own emotional needs. She can't bear any dishonesty so she pushes and pushes, not out of any actual need so she's the person that has confronted me the most effectively.*

He currently practices mindfulness which he finds useful. He says *"It sounds terribly facile but it seems to be supporting me to just accept me for who I am"*. The stories he tells illustrate the lengthy and quite difficult process of discovering and accepting himself as person and as a disabled person.

Totton's (2015) work suggests that Bill may be starting to experience less of the stress and tension that were generated by holding his emotions to himself and experiencing periods of depression. Describing depression in terms of

hopelessness, Greenberg and Paivio (1997:191) shed some light on the process of working with clients who display such symptoms saying

“In accessing the hopeless state, one also accesses associated emotions such as sadness, fear or anger, pathogenic beliefs about self and others, unmet wants and needs, as well as fears or perceived barriers to getting needs met. Thus clients will have a better understanding of what is generating their hopelessness, as well as an awareness of their needs as providing healthy resources that can challenge or restructure their hopelessness in therapy”.

Over many years, Bill began to understand more about his depression by accessing the anger he feels about being disabled and by integrating this aspect into his self concept. This level of authenticity gave him the opportunity to discuss his needs with people at work so that he could function more effectively there. His family and friends enabled this process by nudging him in the direction of being more authentic about his emotions. This lifelong process is indicative of how deeply Bill felt about his condition and how alienating it was for him to keep his emotions hidden from himself and others. It is also indicative of the impact of social and cultural forces that undoubtedly led him to bury this whole experience underground.

7.5. Summary

Some of the ruptures that I have discussed in this chapter, like my own, were repaired and did not have enduring effects on participants' experiences of counselling. For others, the effects were more damaging. Some ruptures are indicative of their counsellors' lack of skill, awareness and understanding of the impact of disability and impairment effects on their clients. Others can be attributed to a lack of adequate resources, particularly in the case of deaf participants. However, counselling is a two-way relational process and it is evident from this chapter that the counsellors involved were faced with *“a layer of internal experience which is hidden from view”* (Watermeyer, 2009:94). As I discussed in the previous chapter, participants' knowledge is hidden through social withdrawal; hidden emotional and embodied feelings; minimising distress and maintaining a public face. Given what I have learned from some of the writings in Disability Studies and the

other findings that I have outlined, I have found that there are clear connections between what participants have experienced both in their everyday lives and in how they experience counselling. The effects of disablism, ableism, internalised oppression and social and cultural conditions of worth are evident in both. The events that are recounted in this chapter indicate that these forms of hidden knowledge were at play for participants in the counselling relationship. Very few were able to tell their counsellors about the ruptures they were experiencing. With the exception of some of Bill's counsellors, there are no reports of counsellors being able to address the client's hidden knowledge.

In previous chapters I have reflected on why participants may have kept their knowledge hidden and this is one of the findings that counsellors may be able to learn from. While clients may feel inhibited, it is the responsibility of the counsellor to help the client to reveal these hidden aspects if the time is right for them to do so. It is a delicate process but if the counsellor is unable to detect hidden knowledge, clients like Shirley, may blame themselves for the ruptures that occur in the relationship. Bill and Pete were able to see that counselling is a two-way relational process in the sense that they both recognised the inhibitions they experienced in making these inhibitions available to be worked with in counselling. Some ruptures were inhibiting for participants but not damaging to the overall process but for Shirley, the experience reinforced her sense of estrangement and distress. Unravelling hidden knowledge was particularly difficult for deaf participants, where basic communication is a major inhibiting factor and for participants who experienced physical or emotional trauma.

There are key messages from this and previous chapters in terms of counselling practice and indeed for anyone who has a relationship with a disabled person. I discuss these in the next chapter.

Chapter 8: Discussion

In this chapter, I provide a brief overview of my research findings (8.1). I elaborate on these findings in 8.2 by discussing the contributions that this research makes to knowledge in Disability Studies (8.2) and in Counselling (8.3). In 8.4, I examine the main implications for counselling training and practice and in 8.5, I reflect on person-centred counselling theory in the light of my findings.

8.1. Overview of research findings

In chapter 4, I discussed the responses I received to my first research question 'What difficulties do people experience in their relationships with others that they directly associate with being disabled? These questions arose from my own experience of being a disabled woman who enjoys the company of other people but who has felt awkward and anxious at times in social situations with associated feelings of being different and therefore estranged from others at different levels and in different situations over the course of my life. I was interested to find out if other disabled people had similar experiences. I found out that indeed all participants felt a similar sense of being different and at times socially estranged. As this was the focus of my questioning, I have inevitably presented a somewhat negative view of what it is like to be disabled in what I have outlined as largely un-conducive social and physical environments. This could have been balanced out by telling stories of positive relationships but my aim was to focus on issues that may arise in counselling so that these stories can be used to inform counselling practice. I found many similarities between my own experiences and those of my participants as well as many other stories that added extra layers to my own understanding.

All participants expressed a need to feel connected with other people to some extent. They have all experienced difficulties in relationships that they associated with being disabled. Most of the difficulties that participants spoke about were subtle in nature and rarely discussed within the relationships in which they occurred. The sense of estrangement was experienced through feeling different from others in

public settings and through disconnection with others in their everyday interpersonal relationships. These findings are indicative of an ableist culture. Becoming disconnected from others after acquiring a life-changing impairment was traumatic for some while others who had been disabled from birth lived with a chronic feeling of estrangement for the whole of their lives. Other difficult life circumstances, it could be argued, are not directly attributable to an ableist culture but more to life circumstances, such as the loss of a loved one through death or separation and childhood sexual abuse, can exacerbate a sense of estrangement. Similarly, living with impairment effects was a cause of social isolation for some, whether or not they felt the impact of the disabling environment.

Many participants found that they had to work hard to establish and maintain meaningful relationships and this is something that was not previously in my awareness though I recognised it as part of my experience as I analysed the interviews. The difficulties that participants identified and discussed were, for the most part, issues that they talked about with their counsellors. I qualify this by saying that some of them told me about these difficulties in the interview but they did not talk about them with their counsellors. I attribute this to my role as researcher who is asking people to recall past experiences with someone who has a less significant relationship with them; to my disabled status and to my counselling skill. My findings corroborate and elaborate on writings in Disability Studies but they are rarely evident in the counselling literature. I have used the theory of conditions of worth to depict the experiences of estrangement that derive from messages that participants have received from others directly through their relationships with others and indirectly through the social and cultural attitudes that are manifest in the disabling environment. Impairment effects engendered attitudes towards the self that were largely negative and these findings both resonate with me and add further insight into that experience.

In chapter 5, I addressed my second and third research questions 'How do these relational difficulties affect disabled people's emotions and behaviours?' and 'How do these relational difficulties affect disabled people's self-concepts and sense of agency?' These questions arose from my sense of self as a young disabled woman

who felt inferior from others in terms of my sexual attractiveness; from the experiences of participants in the advisory group that I set up at the initial stages of the research and from stories that I encountered in the literature on disability. My findings elaborated on and added insight into the issues that I had already discovered.

I found that most participants felt estranged from aspects of their inner experiences at least some of the time because of the messages they received from others (conditions of worth) about being disabled. Although these stories were not direct responses to my interview questions, as I said in chapter 3, I found out about them in my analysis. One of the major findings indicated in this chapter is the extent to which participants hid their feelings about being disabled from other people in their social circles. While I recognised this pattern in myself as I analysed the interviews, I was also aware that for the first half of my life, this lay at the edge of my awareness, only becoming apparent at the later stages of my time in counselling. I think that is what enabled me to ask participants if they talked with others about their feelings being disabled. Most if not all participants said they had not. This confirms Michalko's (2002) writing about hidden knowledge and indicates that it is something that non-disabled people including counsellors are often unaware of when they encounter disabled people. Like me, participants indicated that they carried their emotional and/or embodied experiences alone which for some caused inner tension, stress, anxiety, depression and for a few, suicidal ideation.

Some participants struggled to find an internal place for their experience of disability and impairment because they felt ashamed of these aspects of themselves. They were not able to symbolise these aspects accurately into their self-concepts and some lived with the tension of trying to pass as non-disabled people while internally disregarding their experiences of disability and impairment. For some participants, this reduced the capacity to negotiate their way through social situations because they were not fully aware of the effects that impairment and disability were having on them. Some found that they were passive in initiating relationships while others found that they were unable to say how they felt when other people undermined them. The notion of configurations of the self was evident from a few participants'

stories. Some participants were able to use their socially acceptable configurations to alleviate the effects of conditions of worth and to enjoy their relationships with others.

Several participants talked about their tendency to withdraw from others for self-protection because they felt hurt by the conditions of worth that they experienced because they were disabled. This was a striking finding and again, it resonated with my own experience of being a young disabled woman. It is illuminating to find the different ways that participants did this. Some withdrew from anxiety-provoking social situations; some retreated into independence and others kept parts of themselves that they considered to be unacceptable hidden while revealing only the socially acceptable parts of them. While withdrawal protected participants in some ways, it came with the cost of perpetuating their sense of estrangement and in my experience, this can be anxiety provoking and depressing.

In chapters 6 and 7, I presented participants' responses to the last two of my research questions, namely 'How do disabled people experience the counselling relationship and process?' and 'What impact might counselling have on the way that disabled people relate to themselves and others?' Contrary to Reeve's (2000) claim that counselling is an oppressive pursuit, and the negative experiences of some disabled writers (see chapter 2), participants stories in chapter 6 and my own as indicated in chapter 1, are illustrative of successful experiences of counselling. I found that several participants made contact with their embodied selves while others discovered more about their emotional responses to conditions of worth through counselling. For these participants, hidden knowledge, though not discussed in terms of ableism or internalised oppression, became available to them in such a way that they could talk about what they were experiencing. When hidden knowledge was brought into awareness and processed within the therapeutic relationship, these participants became more empathic towards themselves. Some made deeper connections with others in their social circles. Some developed a sense of trust in their own experience so that they could become more self-directing than they had been previously. Although these examples were found to be beneficial in terms of building self-esteem and personal relationships, they were not, in the main,

considered in terms of social and cultural conditions of worth. This may be indicative of counselling being at least in part, an ableist pursuit in the sense that the focus was on individual attainment rather than on how they were disempowered by their environments.

Another major finding is that a significant number of participants became more discerning about relationships. Some made choices to leave existing relationships in order to make room for new, more satisfying relationships. Although counselling was beneficial to several participants, the process was sometimes lengthy and some felt the need to engage in counselling on several occasions over the course of their lives. Some found the process difficult because they were exposed to overwhelmingly painful memories as I did (see Johnson, 2016a). Like me, others encountered shame as they began to make contact with the emotional aspects of their experience. All of this concurs with person-centred theory and practice where emotional expression is considered to be a way of developing authenticity in relation to self and others. How this occurs when clients are disabled is less familiar in counselling literature.

In chapter 7, I presented stories about difficult encounters in the counselling relationship and process. This is a pivotal question in my research since from the outset, I had a notion that it would be easy for counsellors to miss some of the thoughts and feelings that disabled people experience because they so often remain unspoken. I have a much greater insight into this question through my engagement in this research. The previous chapters provide background insight into this question but the stories in this chapter encapsulate some of the difficulties that I think could remain unnoticed and that I wished to highlight.

Most participants experienced ruptures, some of which could be attributed to hidden knowledge, client deference and hidden labour (where the client works hard to make the counselling relationship work). Ruptures appeared in the form of feeling misunderstood, ashamed, overwhelmed or disempowered in the counselling relationship. Some participants had strong enough relationships with their counsellors to sustain such ruptures while for others this was more of a struggle.

Some participants, such as Pete and Bill, were aware of resisting counselling because of their reluctance to make contact with difficult memories, emotions and embodied experience. Some participants felt that their counsellors were lacking in skill and understanding in terms of working with disabled clients. Other ruptures can be attributed to a lack of adequate resources, particularly in the case of deaf participants, particularly Monica. Several participants blamed themselves for the ruptures they experienced and they were left feeling inadequate, thus reinforcing conditions of worth. Unravelling hidden knowledge was particularly difficult for deaf participants and their counsellors, where basic communication is a major inhibiting factor.

My findings emphasise the point that I have sought to highlight, namely that hidden knowledge can be difficult to discern in the counselling relationship where the client is disabled. This can, in part, be an indication of the lack of awareness of ableist tendencies in counselling as I suggested in 2.3.3. For Shirley in particular, counselling did not work because the knowledge that she kept hidden, though partially in her awareness, was never revealed. Other participants' stories have illuminated this insight by uncovering some of the reasons for hiding aspects of their experience and by illustrating the ways in which hidden knowledge can remain hidden or be revealed in the counselling relationship and process. Having said this, I have found that it is possible for sensitive, understanding and skilful counsellors to.... enable clients to reveal and work with experiences that have previously been kept hidden. Through the experience of identifying and giving voice to their difficult experiences, some participants developed more authentic self-concepts and as a consequence, developed more meaningful relationships with others. Perhaps the most striking finding was that almost all participants expressed their sense of disempowerment through their reluctance to talk with their counsellors about the ruptures they experienced in the counselling relationship. I attribute this, at least in part, to the internalisation of social and cultural conditions of worth which they were not aware of. I discuss this issue further at various points in this chapter.

8.2. Disability Studies and Counselling

Most participants and their counsellors had little or no awareness of the social and cultural conditions of worth that can undermine disabled people and this was the case in my relationship with my counsellor though, as I have said (Johnson 2011), she was aware of issues of power in general as this affects her clients. It was through an examination of the debates in DS that I began to recognise and understand the influences that are not common knowledge in western cultures yet have a strong impact on social relationships. This applies to both disabled and non-disabled people and certainly to me before I began this research. In this section, I discuss this and other contributions that this research makes to these debates. My research sheds light on some of the issues raised by the literature in DS about counselling by offering a different perspective on debates about individual experience, hidden knowledge, oppression and social change.

8.2.1. Connection with disabled communities

For the purposes of this research, I engaged some participants who were aware of disability issues and the Social Model of Disability (SMD) through being employed or working in a voluntary capacity with disabled groups (see Table 1). However, most participants had ambivalent attitudes towards these groups. Janet was involved with a support group for people with MS but although she found that helpful to some extent, she felt judged for the decisions she made about resisting some of the drug treatment that was on offer. Alastair found solace with another disabled man where they could talk about the difficulties they encountered. They found each other independently and not through a disabled group. Nancy and Monica were very involved in the deaf community and both had friendships that emerged from there. Monica distanced herself from her local group for her own unique reasons but even though Nancy was actively involved in the community, she found that it did not support her at an emotional level when she was finding life difficult. With these exceptions, participants were not involved with other disabled people socially.

Watson (2003) suggests that involvement in the disability movement can create a sense of solidarity and confidence but this was not the case for most participants, none of whom were politically active at the time of the interviews. A few participants offered insight into why they distanced themselves from the disability movement. Nick felt that he was being pressured to become politically engaged and Bill, Amanda and Shirley did not wish to be associated with the disability label because of its negative associations. Shame was a factor in Bill's reluctance to be involved with other disabled people. Social and cultural conditions of worth underlie some of this resistance but it may be that the disability movement creates its own norms about how disabled people should live as Nick's experience suggests.

8.2.2. Connection with emotional and embodied experience

Feminist writers in DS have long argued that there is a place for addressing the burden that individuals carry from social and cultural conditions of worth and from the limitations imposed on them by their impairments (Crow, 1996; Morris, 1991, Thomas, 1999, 2007; Reeve, 2002). The psycho-emotional effects of disability have been identified by some DS writers (Reeve, 2002; Thomas, 1999, Watermeyer and Swartz, 2008), but there is still very little research that takes this issue forward. Reeve (2006:95) states that

“Whilst many disabled people have written about their experiences of disabling attitudes [...], there has been less discussion about the psychological consequences of being on the receiving end of prejudice and discrimination”.

My research contributes to this lack by exploring the impact of conditions of worth on disabled people psychologically in terms of the developing self-concept and emotionally in terms of their relationships with others. Thomas (1999; 2007) and Shakespeare (2010) consider impairment effects to be worthy of research but this still seems to be overshadowed by the current emphasis in DS on political processes. Swain, Griffiths and French (2006:168) state that *“the struggle to remove disabling barriers can have its own costs for disabled people”* and that *“they may need support to deal with their emotions after such events”*. Findings from this research confirm that both environmental barriers and impairment effects can

contribute to difficulties in interpersonal relationships. Alastair, Pete and Amanda's lives were dominated by physical pain and the consequences of that including ongoing depression. Alastair's pain was so severe that he could not engage meaningfully with most of the people he encountered in his everyday life. For these participants, the disabling environment has contributed towards their sense of isolation but impairment effects were equally limiting. Janet experienced tiredness and exhaustion and had to manage her life to accommodate this aspect of her condition. Transport issues and accessibility added to the limitations imposed on her by her impairment. Counsellors have long been aware of the impact of embodied and emotional experience on self-esteem, as psychotherapist Susie Orbach (2010) has pointed out but the link between this and the experience of disability has not been made clear in the counselling literature. Participants' experiences indicate that the psycho-emotional effects of both impairment and disability can undermine self-esteem and the capacity to engage in social situations. These experiences support Gill's view (2001:369) that DS academics should engage in "*honouring subjectivity and remaining closer to the experience of disabled persons in their research*". I argue that counselling should be acknowledged in DS as a way of supporting disabled people who struggle with these issues.

8.2.3. Counselling and oppression

As I said in chapter 2, some DS writers (notably Reeve, 2000) declare that counselling is an oppressive activity. I understand this to mean that disabled people are encouraged to fit into the social world as it exists without any consideration of social and cultural conditions of worth or of challenging detrimental societal norms. As I have shown, this attitude may arise from the way that counselling has been practised in rehabilitation and healthcare in the UK (see 2.4.1 and Reynolds 2004a). Janet's experience has echoes of this approach. While she was not expected to be grieving for the loss of her able-bodied self, she felt pressured to talk about her emotional response to becoming disabled to the exclusion of any other issues that she might have addressed and without any reference to the disabling environment. Some participants felt undermined by their counsellors in other settings than healthcare. Monica felt that one of her counsellors attributed her sense of isolation

to her deafness without understanding that she was struggling with being a mother of young children, which for her was the most pressing isolating experience at the time. Kevin's experience of working with his first two counsellors could be interpreted as oppressive in the sense that he felt disempowered by the patronising and undermining attitudes that they sometimes expressed.

Corker and French (1999:8) argue that

“The dominant discourse of some approaches to counselling can view a fully self-actualising person as someone who behaves in a ‘socially acceptable’ or ‘normal’ way and promotes this as the ‘solution’ to the client’s problem”.

While this may have been the experience of some disabled people, it was not a feature of any of the participants' experiences. In person-centred theory, self-actualisation involves the client becoming more fully functioning, meaning that they are more

“aware of their feelings, able to represent them symbolically, think about them in the context of their total experience [...] and are able to appropriately share their experience with others” (Watson, 2011:14).

This process involves clients developing the capacity to rely on their own inner promptings to discern what works best for them so that they can *“divine solutions for living that are optimal for each individual”* (ibid p18). The stories that I discussed in chapter 6 indicate that some participants were able to rely on their own promptings instead of following the expectations of others for making choices and decisions as a result of counselling. Their counsellors did not lead the way but instead, trusted that they would find their own ways of negotiating their social worlds. This concurs with Watermeyer's (2009) view that counsellors should enable disabled people to express their own subjectivity without interference.

Contemporary professional ethics in counselling are essentially about being client-led, anti-oppressive and collaborative (BACP, 2015). Ethically, counsellors are dissuaded from directing the changes that clients make in their lives although as in any profession, some individual practitioners may work in ways that are not consistent with the values they aspire to.

8.2.4. Counselling and social change

A further argument is expressed by Goodley and Runswick-Cole (2014:8) where they suggest that through the counselling process, the client becomes more “*psychologised, internalised, rational, autonomous and individualised [...] distinct, bounded and separated from others*”. Some person-centred writings contested this issue. McMillan (2004) points out that Rogers always considered his theory to be pro-social and that change involves the client becoming more connected with others rather than distanced. Like Kevin in this research, clients can become more skilled at negotiating their way through their social worlds. Gillian Proctor (2006) argues that through counselling, clients can become confident enough to make their own changes by re-evaluating the conditions of worth they have internalised and by challenging the power that others have over them. This was the case for Amanda, Janet, Nick and Robert who all used counselling to re-evaluate their relational patterns and to gain enough confidence to leave the relationships that were detrimental to them.

My focus on relationships in this research indicates that counselling has enabled some participants to function more effectively and meaningfully in their social worlds at a micro if not a macro level. Becoming more aware of embodied and emotional responses to living with disability enabled participants to integrate these experiences; to combat a sense of shame and therefore to be more skilled at talking with others about what was happening for them. In this way, disability and impairment could become a shared experience instead of one that participants continued to carry alone. This was particularly the case for Amanda, Nancy, Nick, Robert and eventually Bill, all of whom were able to bring their hidden knowledge of being disabled into the open in their interpersonal relationships.

Proctor (2002) acknowledges that individual work in counselling can be supported by collective action and that both approaches have their part to play in addressing the structural power that affects clients negatively. The problem is that with regard to disabled people, both approaches seem to operate separately and in tension with one another. This research indicates that there is scope for more connection

between DS and counselling since they both prioritise the wellbeing of people who feel oppressed. Person-centred counsellor Suzanne Keys (2006) illustrates how both client and counsellor can be changed in terms of their political awareness through the counselling process. In her work with a disabled young man, she became more aware of the social and cultural conditions of worth that affected him. The client became more articulate in his communications with others so that he had less need to express his anger through aggressive behaviour. Small changes of this nature in individuals can have a ripple effect on relationships outside of the counselling room, as Keys points out. Key's client's experience echoes Kevin's, where he became more articulate instead of reacting impulsively out of frustration in his meetings at work.

Dan Goodley (2011b) points out that psychoanalysis offers a way of understanding structural dynamics of disablism. Taking this idea forward, I argue that stories such as the one presented by Keys and those that I have presented in this research can offer insight into the dynamics of interpersonal relationships. If, as Cameron (2010) suggests, most disabled people would like to feel accepted just as they are and not as other people would like them to be, they may appreciate the kind of support that counselling can offer to enable them to see themselves in this way. Goodley (2011b:32) states that it is possible for DS to embrace disciplines that have previously been marginalised in order to "*promote the inclusion of all disabled people in mainstream life*". I argue, with Brian Watermeyer (2012), that there could be more collaboration and joint research between counsellors who have an interest in disability and DS writers who have an interest in counselling to address the issue of how disabled people might be more fully involved in their communities.

8.3. Counselling and disability

I turn now to a discussion of the contribution that this research makes to knowledge in counselling.

8.3.1. Disability and impairment effects

Although participants entered counselling for different reasons, they had differing experiences of talking with their counsellors about the impact of disability and impairment on their lives. Some discounted any connection that may have been present between being disabled and their other personal issues so disability was not discussed. Others did not feel that disability was at the foreground of their counselling work because other issues were more pressing. Shirley tried to talk about the traumatic experience of acquiring a life-changing impairment but she did not feel understood and the sense of disconnection with her counsellor reinforced her distress. One or two participants attributed their struggles in making connections with others to both impairment and the disabling environment but most others did not. Social and cultural conditions of worth in relation to disability were not aspects of many participants' experiences in counselling.

Participants varied in terms of their awareness and understanding of the difference between impairment effects and the disabling environment and almost all of their counsellors were unaware of the difference. James and Bill's counsellors seem to have understood that impairment had an effect on their clients' lives without understanding that the social and physical environments could be equally disabling. Sandra and Robert talked on the telephone with disabled counsellors through a peer counselling service but they do not appear to have spoken about disability and impairment as two different experiences. Nancy understood her impairment in terms of deafness rather than disability but that is explained by the different approaches that deaf people take to deafness as a language issue or a disability (see 2.2.5). Pete and Amanda appeared to be talking about impairments effects rather than disability when they and their counsellors decided to place this aspect of their experience into the background. They did this without any reference to the disabling social and physical environment. Amanda and Shirley resisted the disability label but there is no indication that they were able to discuss this with their counsellors. Alastair felt that his counsellor made connections between his feelings about impairment and his childhood experience of grief and there is no indication that she understood the wider implications of social and cultural conditions of worth in relation

to disability. Most of Kevin's counsellors did not differentiate between disability and impairment effects but he did eventually find a counsellor who had a keen awareness of equality issues.

In some cases, the lack of awareness of social and cultural conditions of worth may have led to an over-emphasis on impairment effects. In Janet's case, this may be attributed to the medical setting in which she received counselling. For others, the emphasis was more about internalising conditions of worth without awareness. Bill says

"I was born with a disability and I've discovered that there's quite a difference in the experiences between people that are born with a disability. [...] My experience is that the way we are brought up, I didn't actually think of myself in any specific group to begin with".

Amanda, James and Nick were also born with their impairments and like Bill, they seem to have internalised social and cultural conditions of worth to a greater extent than other participants. Amanda was taught to manage her impairment by appearing to be like everybody else in order to avoid looking vulnerable but she was not taught to manage the impact of conditions of worth on her emotionally or psychologically. She therefore became confident at some levels and in some situations and had low self-esteem because of other people's negative attitudes combined with her experience of sexual abuse. Bill, James and Nick have visible impairments and have had low self-esteem in relation to their body images. Nick internalised messages about his sexuality and of the three, he is the only one who resolved this issue in counselling. He had his own understanding of the disabling environment so his counsellor did not need to introduce that to him, though she did find it difficult to connect with this aspect of his experience. Bill was aware of disability issues but did not manage to shake off his sense of inferiority, perhaps because this was reinforced by his parents' approach to emphasising his 'head' over his embodied self. James may have understood his social anxieties more fully if he had more understanding of social and cultural conditions of worth and he may have felt less alone if he understood his situation in that context.

This research indicates that an understanding of the impact of impairment effects and disability would be beneficial in counselling disabled people. Disability Studies writer Fiona Kumara Cameron (2008) states that *“we cannot ‘know’ existence without being rooted to our bodies.* Person-centred writer Mia Leijssen (2006:127) points out that *“therapist and client are never just ‘talking’; they are always “bodies interacting.”* Equally, they are always influenced by social and cultural contexts. The capacity to differentiate between impairment effects, disability and impact of these on the issues that disabled clients bring to counselling may enable clients to find their own authentic internal spaces for their disabled selves. This could help to ease the embodied tension (Totten, 2015) involved in trying to be like everybody else

Accessibility

One of the most fundamental issues that isolate many disabled people and one that highlights their sense of difference is that of access to buildings and transport systems. It almost goes without saying this is a major issue for disabled people but this is commonly understood as a practical rather than a psycho-emotional issue. Siebers (2008: 51) says *“Let it be recognized that physical barriers are each and every one of them psychic barriers as well”.* This issue has gained prominence in Western cultures and it is ostensibly covered by current legislation in the UK. although much still needs to be done to enable disabled people to move freely in their social worlds. For this reason, I have not singled accessibility out as a separate issue but instead, I have addressed it where it has been a significant feature for participants. For example, Robert, Janet and Pete have restricted mobility and could not socialise with people as much as they would have liked because access to public places was difficult. Although the environment plays a major role in restricting their activities, impairment effects sometimes play a significant part in participants’ sense of isolation. Janet, Alastair and Pete for example were limited by their impairments because they experienced pain and fatigue regularly. Access was an issue for Kevin because information was not presented to him in readily accessible ways and for Monica and Nancy because most people are not deaf aware or can use sign language.

Although this is not the focus of my research, it is important to note that access to counselling remains a live issue. Despite the UK Equality Act of 2010, which means that legally counselling agencies should “*make reasonable adjustments to make their services more accessible*” (Reeve, 2014:259), many agencies cannot accommodate disabled clients. Some offer satellite services so that disabled clients can be seen in accessible premises. While this may be helpful to some, it is likely to emphasise their sense of estrangement and difference. As a deaf person who could not find a counsellor who had competent sign language in her locality, Monica’s response was to retreat into self-sufficiency. This took her out of relationship in her attempts to deal with the issue that she wished to discuss – that of feeling isolated as a young mother and a deaf person. Her sense of isolation was reinforced by being unable to find a suitable counsellor.

8.3.2. Hidden knowledge and client deference

As I have said, a striking finding in this research is the extent to which participants kept much of their experience of impairment effects and disability hidden from others in their social spheres. Some participants, who were accustomed to hiding their emotional and embodied experience like Bill for example, may have lost connection with these aspects of their own inner experience over time (see Mearns and Thorne, 2013). As Marks (1999b:615) points out

“Some experiences are so painful that they cannot be consciously experienced. Yet they continue to affect self-esteem, and shape thoughts and actions, even when the person has no conscious awareness of them”.

These strategies are put in place to help people to “*resist and survive [...] emotional oppression*” (ibid). Some participants identified shame as a major issue that prevented them from talking about their internal experience. Jordan (2004b:51) points out that shame is

“a major factor that takes us into isolation. When we feel it is unsafe to bring various aspects of ourselves directly into a relationship, profound disconnection results [...]. The belief that no empathic response will be available from another person leads to deep withdrawal and immobilization”.

Nick felt ashamed of his sexual feelings; Amanda, Bill and Kevin tried to pass as non-disabled people as far as they could and like them, Shirley was extremely uncomfortable about her vulnerability. James and Pete felt self-conscious of their impairments. Kevin and Sarah found it difficult to symbolise or articulate what they were sensing because of the limitations of their impairment and this, too, could feel shameful to them. Nancy said that she looked normal but felt different and that she could not talk about that experience with others. The sense of shame that these participants experienced can be attributed to conditions of worth because it is a direct result of feeling unworthy in relation to the messages they received from other people or from social and cultural attitudes towards disability.

Several participants, namely Alastair, Bill, Janet, Monica, Nancy, Nick, Pete, Robert and Shirley said that they did not routinely talk about their emotions with other people and particularly those emotions that concerned disability and impairment. They did this for several reasons. Sarah found it difficult to articulate her emotions because of her condition. Janet said she grieved for the losses incurred by her condition 'globally' but she chose not to talk about the emotional effects of being disabled with others. Bill was unable to acknowledge his authentic emotional experience for most of his life despite several prolonged periods of counselling. Some participants talked about having negative attitudes towards their bodies. Pete said that he hated it; Janet said it was like a machine that was not working properly; James and Bill were self-conscious about it; Shirley and Amanda experienced it as a source of stigma and Kevin found it disempowering because it prevented him from succeeding in his profession.

All of the participants said that they withdrew from others in one way or another because of their experiences of disability and impairment. Some withdrew by removing themselves from social situations when they felt overwhelmed. Others withdrew parts of themselves by presenting what they considered to be acceptable public images. All of these strategies meant that connections with others were inauthentic and distant. It is notable that there were times when impairment effects such as pain and fatigue caused participants to withdraw in order to recover their energies. This was the case for Janet, Pete and Alastair. Sarah retreated at times

because her condition caused her to feel stressed by being in the company of crowds of people. For others, a combination of disability, impairment and life circumstances caused them to retreat. Robert, for example, felt forced to retreat because it was logistically easier for him to work at home and he retreated emotionally because he was grieving. Sandra retreated not just because of her mobility issues but also because she had been ostracised by some family members and because she was grieving.

Client deference

If the pattern of estrangement and withdrawal becomes ingrained, authentic connection with others can become frightening at an existential level. Jordan (2004b:51) explains this by saying

“A state of disconnection [...] feels terribly unsafe. The tension between the yearning for connection and the terror of connection is exquisite and often paralyzing”.

This pattern was present for some participants in their counselling relationships and was demonstrated by their reluctance to tell their counsellors about the negative experiences they were encountering in the relationship. Person-centred counsellor David Rennie (1994) notes that in general, clients are inclined to defer to their counsellors for a variety of reasons. They might expect their counsellors to have more knowledge and expertise than they do and expect their counsellors to notice their non-verbal signals; they may wish to please their counsellors or be afraid of criticising them, fearing that conflict may disrupt the relationship. In the case of this research, participants may have refrained from expressing their views of counselling for these reasons. However, it is widely acknowledged that people who are associated with minority groups such as *“women, people of color, lesbians and gays, older people”* (Jordan, 2004b:48) and disabled people (Shakespeare, 1996) tend to feel silenced by authority figures (Proctor, 2002). This is a known phenomenon in healthcare settings (Reynolds, 2004a; Thomas, 2001). Following this trend, it is plausible to assume that this was happening for some participants. Although most of them were educated, middle class people and could be considered to be socially

advantaged in some respects, they all identified ways in which they felt inhibited in relationships as a consequence of being disabled.

Deference to counsellors and hiding negative experiences can lead to ruptures in the client/counsellor relationship (Henkelman and Paulson, 2006). While “*therapeutic ruptures are viewed as inevitable aspects of the therapeutic process*” (Safran and Muran, 2000:237), they “*are not always readily apparent to therapists*” (Watson and Greenberg, 2000:181). It is the responsibility of the counsellor to develop the awareness, attitudes and skills to work with this issue. If ruptures are not addressed, disabled clients may continue to feel disconnected and isolated. This was illustrated painfully in Shirley’s story, where she felt alone in the counselling room and blamed herself when counselling failed.

Nancy, Amanda, Nick, James, Sandra and Robert developed a more robust sense of self from counselling because they became more aware of their hidden knowledge. As a result, they were able to re-evaluate their thoughts, feelings and relational patterns but this outcome was less clear for others. James found that his counsellor tended to emphasise his positive emotions and experiences so he felt that his social anxieties were not fully heard. Janet worked hard to keep her emotions at bay so that she could preserve her energies and manage the stressful nature of her condition. That was her decision so it was not the counsellor’s responsibility to put pressure on her to think differently.

In Emotion-focused therapy – one of the ‘tribes’ of the person-centred approach (see Elliott, 2012) - counsellors take the view that change is most likely to happen when clients express their emotional responses to difficult life experiences. Pete, Nancy and Nick gained some relief from talking about and expressing their emotions directly with their counsellors and this was the primary benefit of being in counselling for Pete. The expression of emotion can enable clients to process their hidden knowledge so that they can “*build new images, and create new actions*” (Jordan, 2004b:53). While this was the case for Nancy and Nick, Pete did not have enough time in counselling to continue with this process.

Person-centred counsellor Natalie Rogers (2002) adds that embodied knowledge can be “*used to express, to create outer forms for the inner process, to let go, to gain insight, to provoke change, and to find new energy*”. Disabled writers Watermeyer and Swartz (2008) concur with this view, arguing that being ‘real’ in relationships involves bringing the struggles involved in being disabled into the public domain. This does not mean that disabled people should always talk about the difficulties they encounter. It does mean being aware of how disability and impairment affect them in their daily living so that they can talk about what is happening for them when doing so is likely to enhance their relationships. For Bill, Amanda and James, who have been immersed in social and cultural conditions of worth for the whole of their lives, this was hugely difficult. However, all three of them became less ashamed to talk about their impairments in their everyday relationships through counselling although the process could be lengthy.

8.3.3. Enhancing interpersonal relationships

The last of my research questions involved finding out about the impact of counselling on disabled clients’ capacities to form more meaning relationships with others. There are solid indications that several participants became more self-accepting and made more authentic relationships with others even though this may have been a difficult process. Nancy made deeper connections with friends and family when she became able to talk to them about her childhood experience of abuse; Sandra was able to grieve and find a way of responding to the family members who rejected her and Kevin was able to make more authentic relationships by developing empathy with himself and from there to be calmer in the presence of others. James was able to understand the impact he had on friends who sometimes found him overbearing. Nick was one of the few participants who addressed his embodied experience in counselling. He was able to connect with his personal assistants instead of distancing himself from them because of the shame he carried about his body.

As I have said, one of the most significant consequences of this process in terms of interpersonal relationships is that, through their new-found self-awareness and self-

esteem, some participants realised that their existing personal relationships were detrimental to their wellbeing. Several chose to terminate these relationships and this opened the way for them to make choices about the people they preferred to spend time with. Jordan (2004b:53) explains that this form of disconnection is different from protective withdrawal because it involves the need for other sustaining relationships to emerge. She states that

“One of the most important skills a person can develop is to be able to discern those relationships in which one is safe being open or vulnerable and those in which one should be appropriately self-protective”.

This was an issue for Nick and James, who both said they struggled to differentiate between people that were harmful to them and those that were not but both made significant progress in that respect through counselling. Nick, Amanda and Robert developed the courage to leave people that were harmful to them, making room for them to feel accepted and nurtured in new or existing relationships. They were acting not from fear, but from making self-aware considered choices where *“defensive patterns of “turning away” or “against” are transformed into turning “toward” and “moving with.”* (Jordan, 2004b:54).

Alastair’s story illustrates the additional point that it is possible to experience both withdrawal and connection at the same time. He withdrew emotionally from some of his close relationships and this remained problematic for him even after several lengthy periods of counselling. At the same time, he developed a stronger connection with a disabled friend because they were able to be mutually supportive because of their shared experience. Miller (1986:2) argues that ‘relationship authenticity’, which she describes as *“the need to be seen and recognized for who one is and the need to see and understand the other”* can provide the energy for personal growth. She adds that shared vulnerability enhances relationships because this enables people to gain *“what could be called courage: the ability to put forward [their] feelings and thoughts and to stand by them”* (ibid p 3). She follows this up by saying (ibid p 5-7) that *“in a basic sense, we must feel that others recognize our existence. [...] Otherwise, we cannot feel worthy at all.”* These writings are confirmed by some participants’ stories. Nancy, Kevin, Robert, Nick, Amanda and Alastair developed empathy towards themselves and the capacity to befriend their own

vulnerability through counselling. Alastair said that he became more tolerant of others; Kevin was more relaxed in conversations at work; Nick was more at ease with personal assistants; Amanda opened herself up to being cared for by her partner and Robert began to shed his compulsion to care for others while ignoring his own self-care.

It is significant to note that most participants tended to avoid talking with others about experiences that could potentially lead to conflict. From their experiences as practitioners working in community settings, (Miller,1996) and Jordan (2004a) argue that the capacity to encounter difference and tolerate conflict is a significant step towards making deeper connections with others. Jordan (ibid) argues that this is an important element in relationships and that healthy relationships make room for the different and sometimes conflicting thoughts and feelings of each person. She goes on to say that if people have the courage to talk about and tolerate their differences instead of retreating, the connection with others can become stronger.

The message from this section is that disabled people can develop fulfilling relationships if they engage with their emotional and embodied experience within the context of genuine accepting and empathic relationships with their counsellors. The process involves retrieving aspects of their inner experience that they have previously kept hidden. The process enables them to share these experiences with others and thereby to move from distant to more intimate relationships with the people they chose to be with. Relationships can be enhanced further if they are able to sustain connections where there are tolerable differences without retreating. This is by no means easy, especially given the social and cultural forces that militate against disabled people feeling accepted and at home in their social worlds.

8.4. Developing counselling training

I now offer recommendations for counselling training and practice that are indicated from this research. These can be addressed through the development of appropriate pre- and post-qualifying training, in supervision and through the

counsellor's engagement in their own personal counselling. They involve two main elements, firstly knowledge and understanding and secondly self-awareness and personal development. I highlight the issues to be addressed and offer examples of how these could be applied in practice. Some of these suggestions are based on my personal experience of working as a counselling trainer, supervisor and practitioner.

8.4.1. Knowledge and understanding

Throughout this thesis, I have emphasised the significance and importance of understanding what it is like for disabled people to live in environments that are often hostile to them. Social and cultural conditions of worth are not always evident to counsellors or to disabled people. In order to work effectively with disabled clients, this research suggests that counsellors should acquire relevant knowledge and understanding in order to avoid perpetuating the need for clients to '*set the record straight*' (Gill, 2001:364).

Jordan (2004b:49) states that "*any discussion of disconnections should include the societal factors that push us in the direction of disconnection*" and (2004a:22) that "*developing critical awareness of existing norms and practices is the first step to dismantling them*". Counsellors can acquire knowledge and understanding in several ways. Published guidelines such as those offered by Olkin (1999) and Swain, Clark, French, Parry, and Reynolds (2004) provide some general advice for working with disabled people in the context of social and cultural conditions of worth. Corker (1994) offers an understanding of deafness and deaf culture as well as offering some pointers for counselling deaf clients. In accordance with research offered by Oliver (1995); Reeve (2000) and Swain, Griffiths and Heyman (2003), I suggest that the Social Model of Disability could be used to introduce students to an alternative way of thinking about disability than the prevailing medical approach. Knowledge of the model can be provided by disabled people through Disability Equality Training (Reeve, 2000) or can be integrated into lectures and group discussions.

In my own experience of working with students of counselling, I have found that introducing disability (and the Social Model) as an aspect of difference, diversity and power can be an accessible way of enabling them to recognise social and cultural conditions of worth. It has to be said that coverage of disability in published works on equality and diversity in counselling training is sporadic and disability is not routinely addressed in this context (Reeve, 2000). However, inclusion of disability in this wider context can pave the way for counselling students to examine societal norms not just about disability but more generally about the myth of the normal and the power issues that are at play in society in terms of the oppression of minority groups. The issue of ableism in society has little or no coverage in counselling literature but this could be introduced as part of an exploration of social and cultural constructs that affect all of us, whether or not we are disabled. I have used Judith Butler's work to this end (see Butler, 2010 for example) to stimulate discussion about both disability and gender as social constructs. Writings such as Keith (1998) and Morris (1991) provide personal accounts of what it can be like to live in an ableist society as a disabled woman. These can be offered as background reading and referenced in group discussion. I have presented this research as a further resource for students of counselling. To date, I have published works that depict my personal experience of being a client in counselling (Johnson, 2011; 2016a). In addition I have written a basic introduction to counselling disabled clients (2016b).

Knowledge and understanding of this nature may be offered in the form of reading, seminars, group discussion and experientially in prompting students to make connections with personal experience. I elaborate on the latter in the next section.

8.4.2. Self-awareness and personal development

My research findings indicate that for counsellors to make meaningful connections with themselves and others, awareness of their own personal attitudes, experiences and prejudices about disability are invaluable (Reeve, 2002). This is particularly important because clients may not disclose or even be aware of their own negative feelings about disability and impairment. Mollon (2002:142) points out that "*the encounter with a therapist is fraught with potential shame*". This was a significant

inhibiting factor for Bill, Nick and James in relation to their impairments; Amanda and Nancy because of their experiences of childhood sexual abuse and Pete for both of these reasons. Counsellors need to be aware that shame engendered by these experiences can cause disabled clients to withdraw (Hartling, Rosen, Walker and Jordan, 2004). The counsellor's own feelings of shame may arise when working with their clients so it is essential that they attend to these feelings and the experiences that caused them so that their own issues do not interfere with their capacity to be fully present to their clients. Personal therapy or group work would be appropriate avenues for counsellors to address these issues.

This research has highlighted the importance of addressing personal issues in counselling training such as experiences of difference, positionality in relation to clients, body image and sexuality, vulnerability, attitudes towards disability, resilience in the face of conflict and robustness in seeking feedback from clients. These issues could be addressed in several ways throughout counselling training as well as in supervision, personal therapy and Continuing Professional Development. (CPD). I discuss these in the context of counselling training but these recommendations can equally be approached in the other contexts I have mentioned. The aim of this work would be to enable students to encounter experiences that *“will challenge assumptions and beliefs”* (Henkelman and Paulson, 2006:146).

Self-awareness and personal development are approached in counselling training through experiential work, stimulated by asking questions that prompt students to reflect on and discuss challenging issues. These can be addressed at any point during counselling training where relevant. Examples of such prompts are indicated in Figure 1. .

Figure 1

Questions to prompt the counsellor's self-awareness:

- a) Think about any experiences you have had of feeling different from others. Consider how you felt about this.
- b) How might your sense of difference affect you in terms of power in your social and personal relationships? When and how might you talk about the power dynamic in your relationship with a client?
- c) Think about experiences you have had of feeling vulnerable. What effect did these have in terms of your feelings about yourself and the way you present yourself to others? When and how might you talk about this with a client?
- d) How do you feel about giving and receiving feedback in counselling training and practice? How does this affect your work with clients? What might make it easier or more difficult for you to do this in practice?

Couser (1997; 2002) emphasises the benefits of writing personal accounts of living with disability and his approach could be used as a starting point for students to write stories about their thoughts, feelings and encounters of disability. This approach could be used to stimulate discussion about social and cultural conditions of worth. Other creative ways of addressing experiential issues may involve the use of art materials where students can make visual representations of their experiences. Creative approaches may be especially useful when addressing sensitive issues such as body image and sexuality – a notable element that is not usually addressed in counselling training (Tepper, 2000).

I have discovered that it is important for counsellors to enable disabled clients to explore their sexuality and to feel comfortable in doing so. However, as a counselling trainer, I have always been reluctant to take the lead on workshops and

seminars about this topic. Instead, I have tended to encourage my co-trainers to introduce the topic. This did not sit comfortably with me but engaging in this research has enabled me to reflect further on this issue. I have a clearer understanding that my lack of openness about my own sexuality is intrinsically bound up with being a disabled woman. My inhibitions undoubtedly stem from social and cultural conditions of worth. I now have a greater appreciation of the importance of addressing personal experience as a key aspect of working with sex and sexuality in counselling training. It may be helpful to invite students to find creative ways of depicting their own body images as a way of prompting discussion and self-reflection. Examples of how this might be done are outlined in Figure 2.

Figure 2

Questions to prompt the counsellor's embodied awareness

- a) How would you describe your attitude to your body? Are there aspects of it that you like and others that you find hard to accept? What might they be?
- b) Do you consider yourself to have any sort of bodily impairment? Do you think of yourself as 'able' or 'disabled'? How do you feel about that? How might this affect your work with clients?

I suggest that while disability can be addressed as a separate issue, it could also be incorporated into other aspects of counselling training. In the next section, I consider issues that are indicated by this research for counselling practice.

8.5. Developing counselling practice

This research highlights some aspects of counselling practice that are not commonly considered in relation to disability. Counsellors are required to adhere to professional

standards such as The BACP Ethical Framework (see BACP, 2015) and are therefore aware of general guidelines for good counselling practice. Some professional associations may provide general guidelines for working with disabled clients. One aspect of good practice is for counsellors to offer clients information about the services they have to offer. Perhaps the clearest way of doing this is to supply clients with written information that can be made in accessible form and issued to clients before or during the first session. Counsellors would then go over this information with clients on the first session to ensure that the information is understood and to allow time for clients to ask their own questions. Assuming that the service is accessible and that the client has agreed to the terms and conditions (as indicated in the introductory information) and decides to go ahead with counselling, I suggest that the following aspects should be attended to where the client is disabled.

8.5.1. Laying out the foundations

Much of this research points towards the importance of establishing trust in the counselling relationship. One of the ways of fostering trust is for the counsellor to lay out the groundwork, or the therapeutic frame (Gray, 2013), at the outset of their work together. Clarity about what is involved in the counselling process is essential to the effectiveness of the work. In this section, I discuss points that have emerged from participants' experiences.

It is good practice for counsellors to discover the main issues that clients wish to address in counselling (Watson and Greenberg, 2000:177-178) and from there to "*set out the tasks and responsibilities*" of both counsellor and client. This might involve asking disabled clients about any particular needs they have so that these can be met where possible. This may open the way for any further discussion about how the client's impairment affects their work in counselling. This was important for Sarah, who had to turn down the opportunity for telephone counselling because she could not comfortably carry out a conversation in that way because of her impairment. Asking about particular needs might have helped Shirley to explain how stressful it was for her to travel to and from sessions and how important it was for her

to finish her sessions promptly so that she could collect her children afterwards. Sarah could have explained that routine was important for her and that she found breaks and absences stressful. Her counsellor was aware of this, as her care and attention to Sarah about the interview with me demonstrated. Pete and James were counselled in the context of GP practices and both stated that they were not given long enough periods of time to address their issues fully. These are all issues that could be addressed and negotiated in introductory sessions and checked out from time-to-time in subsequent sessions. While it is not always possible to accommodate every need, conversations of this nature can at least help client and counsellor to establish a collaborative relationship. This is important because, as (Jordan 2004c:39) points out

“Where there has been doubt about the dependability of others, the therapist and client together try to build new relational images and expectations that include a sense of trust, commitment, and respect; we rebuild the broken empathic bridge”.

Sarah and James found social interactions difficult and Kevin found it hard to process information so they needed careful explanations about how to engage in counselling. Again, it is good practice for counsellors to explain what the counselling process might involve especially if the client has not been in counselling before. This paves the way for clients to develop their own therapeutic goals and to discuss any concerns they might have about the process (Watson and Greenberg, 2000). Attending to these issues would have enabled Janet to understand what was on offer from rehabilitation counselling and to feel that she and the counsellor could work to her agenda instead of her counsellor's. She, along with Nancy, Bill and Shirley experienced ambivalence about counselling so addressing this uncertainty would have enabled them to make choices about whether or not to engage in the process. Reynolds (2004b:115) points out that because clients often defer to their counsellors, they can be too inhibited to ask for clarification when information is presented to them in ways that are not straightforward or easy to understand. She explains

“For effective two-way communication to be achieved, the health professional needs to ‘step into the client’s shoes’, to anticipate what information may be most needed, and then take active steps to seek feedback from the client, for

example checking whether the client understands and is satisfied with the information given”.

Another important conversation that can be helpful in beginning sessions is to find out what networks of support are available to the client. Pete, for example, had great difficulty in processing his difficult emotions between sessions and he felt unable to talk with other people about this. Knowing this now, if I were Pete’s counsellor, I might disclose my concerns about his tendency to keep his emotions hidden so that together we might find ways for him to address his sense of being alone in his everyday relationships.

Taking all of this into consideration, I have outlined some of the questions and points that a counsellor might raise in a first session in Figure 3. Ideally, these would be addressed at the first session for every client so that any impairments and special needs could be addressed, whether or not they are visible and to avoid singling out disabled clients from others. Depending on the responses to these questions, any of them could be further explored and addressed according to individual circumstances.

Figure 3

First session questions for establishing the foundations

- a) What do you hope to gain from counselling? Let's explore how we help you with this?
- b) I'd like to tell you how I understand counselling and a little bit about how I practice. Then we can discuss whether or not this matches with your hopes and expectations. We can come back to this at any time as we work together. I normally do this after four weeks from the start as it can take a while to acclimatise to this way of working.
- c) I'd like to give you some ideas about how you might make the best use of counselling and how I can help you with this. We each have tasks and responsibilities so I think it's worth setting some of these out at the start (for example, time-keeping, regularity of sessions).
- d) Counselling involves exploring difficult issues and I guess that's why you have come but it can mean that you'll be in touch with some painful memories and/or emotions. I am committed to supporting you through the process but sometimes it can be helpful for you to have someone to talk to between sessions. Is there anyone that you could do this with? If not, I can give you contact details for services that offer support by telephone. .
- e) Finally, let's take a moment to explore any issues that might affect the work we do together. (I might, for example have a holiday planned, as might the client). Is there anything that I need to know or that you'd like to ask before we begin to discuss what's brought you here? For example, do you have any particular needs that I should be aware of that might affect our work together?

8.5.2. Attending to the working alliance

A crucial way of attending to the client's tendency to hide their experiences which, in this research was the reason for Sandra's suicide attempt and for Shirley's sense of deep depression, is to take great care in establishing and maintaining the working alliance. Watson and Greenberg (2000:177) warn that *"if the bond is weak, or agreement on the tasks and goals of therapy are poorly negotiated between the participants, then ruptures in the alliance can occur"*. An important aspect of building the client/counsellor relationship is that the client must feel comfortable enough with the counsellor to talk about their innermost thoughts and feelings (Henkelman and Paulson, 2006). Pete was very sensitive to the match between himself and his counsellor because he felt that working with a male counsellor would have reinforced his feelings of being abused. Both James and Shirley felt that they were not well matched with their counsellors and while James became more comfortable with his counsellor in time, Shirley did not. Kevin found it helpful that his counsellor had been engaged in equality training and Alastair and Bill stated that they liked to be challenged by their counsellors. Shirley had a pictorial image of what a suitable counsellor would look like but the counsellor she saw was not at all similar to that. But there does not appear to have been any discussion about their relationship. Sarah, Kevin and Shirley said they would have liked their counsellors to have more knowledge about their impairments. While it may or may not have been possible for these preferences to be met, participants' experiences point towards the need for some discussion about the working relationship in the early stages of counselling.

In Figure 4, I have outlined some of the questions that a counsellor might ask a client at any time in the early stages of establishing the counselling relationship to keep track of how the working alliance is progressing.

Figure 4

Some questions to ask when establishing the working alliance

- How does it feel to be working with me?
- Can we take a moment to discuss whether or not you're getting what you hoped for in these sessions?
- Do you feel able to ask me if there's anything you don't understand or like about what I've said?
- Sometimes people feel too shy to talk about things that matter to them. Do you feel that way with me?
- Is there anything that you're especially happy or not happy about?
- Are we still paying attention to what we agreed? Do we need to change anything?

8.5.3. Working collaboratively

Empowerment is one of the main benefits of counselling as reported by Swain, Griffiths and French (2006) in their research. Parry (2004:63) defines empowerment as the process of facilitating clients to take control of their own choices and decisions. By that description, several participants achieved that outcome, as I demonstrated in chapter 6. Others struggled to feel equal in their relationships with their counsellors.

Most participants felt undermined in their everyday relationships to some extent because they are disabled so it was important that their counsellors did not reinforce this feeling. Power dynamics were demonstrably at play with several participants and their counsellors. Janet felt disempowered when her counsellor imposed his own agenda on her, Kevin felt disempowered by some of the interventions that his counsellors made about his dyslexia. Some participants engaged in hidden labour to maintain connection with others and this pattern was at evidently at play for Shirley.

Jackie Scully (2010) points out that it is the counsellor's responsibility to recognise that this is happening and to seek to equalise the relationship. She notes that a starting point would be to draw the client's attention to this pattern. While this could have been helpful for participants such as Pete, who tried to protect his counsellor from hearing about what happened when he was abused as a child, it is more difficult to see how this would have helped some other participants. Monica for example, had to facilitate the counselling process with one of her counsellors who did not have sufficient deaf awareness or sign language. The scarcity of counsellors with adequate skills and understanding meant that she had to do this but though she persisted for a while, she found that the situation was not sustainable.

One way for counsellors to address the inevitable power imbalance between them and their clients is to make the differences explicit (Parry, 2004). This might involve counsellors speaking with their clients about social and embodied positions in relation to each other. Watson and Greenberg (2000) suggest that where a client is particularly vulnerable or feels disempowered, it can be appropriate for the counsellor to self-disclose more than usual so that the client may feel less alone in their distress and more at ease in disclosing their previously hidden experiences. Shirley said that if her counsellor was open to her own vulnerability, she would have felt more able to talk about how 'crap' it was for her to be disabled. I gave an example of collaborative working in 8.2.4 where I discussed Suzanne Keys (2006) work with a disabled client. She became aware of disconnecting from her client as he talked about his experience of the structural forces that disempowered him because she was distracted by her own issues with structural power. Their experiences were different but when she noticed what was happening, she and the client were able to talk about this disconnect. She understood more about his experience of being a disabled person living within the constraints of institutional power in and she was able to disclose how the constraints of the power within the school that they met in impacted on her. This process enabled both the client and the counsellor to appreciate how they were each responding to their sense of disempowerment and thereby to recover their sense of connection.

I have given some examples of interventions that a counsellor might use to encourage collaboration by checking out and facilitating as much equality in the process as possible in Figure 5.

Figure 5

Sample interventions for encouraging collaboration

- **Talking about the power dynamic.**
 - Sometimes people feel that I have all the power in these sessions, for example you may feel that I am directing you in any particular way?
 - I'd like you to feel that you are in charge of what you bring. Do you feel that there's anything you can't bring to these sessions? If so, maybe we can discuss whatever is getting in the way.
- **Disclosing vulnerability**
 - 'I got that wrong'; 'I guess I was distracted there'; 'I don't think I said that very well, I'll try again. my thoughts are not coming easily right now'
- **Noticing the client's hidden labour**
 - I wonder how it was for you to tell me about your condition just now.
 - Do you feel burdened by that?
- **Noticing moments of disconnection**
 - I'm feeling a bit disconnected from you just now. Do you feel that way? I wonder what might be happening between us.

8.5.4. Introducing the Social Model of Disability

Counsellors may learn to use this model as a way of enabling disabled clients to appreciate that the burdens they carry are not simply a result of impairment but that the social and physical environment also disables them. It may also help them to appreciate that social norms can be challenged. It has to be acknowledged that in non-directive counselling, the person-centred approach for example, introducing ideas such as the Social Model of Disability (SMD) could be problematic. I have suggested one way of introducing the SMD, based on the work of Karen Parry (2004) in Figure 6, who (ibid p 67) adds a note of caution when she says that

“It may be some time before a client is ready to think about the structural and institutional barriers that construct their impairment as disability, and to begin to reformulate their identity within this new framework. Other clients may not see themselves as disabled and never integrate this within their own identity”.

Figure 6

Working with the Social Model: an example

Client: I hired a taxi to take me to take me home from the cinema where I was meeting my friends last week. As the driver transferred me down the ramp to the front of my house, he bumped the kerb – I think it was an accident - and I fell out of my wheelchair. I wasn't hurt but I felt shaken. He didn't apologise but instead he got angry and said how much he hated driving wheelchair users. I didn't say anything because I know the company doesn't have many drivers so I might be driven by him again and I don't want him to refuse to drive me next time.

Counsellor *I feel really shocked to hear about this and I'm glad you weren't hurt physically.*

[they go on to discuss how he felt and still feels about this]

Counsellor *I get that you wanted to say on side with the driver but I feel concerned that you felt silenced. I wonder if you're aware of the term 'disablism'?*

Client: Not really, no

Counsellor *Shall I explain?*

Client Yes please do

Counsellor *Well, it is used by disabled people who adhere to the Social Model of Disability to apply to any attitude or behaviour that undermines disabled people as inferior*

Client What's the Social Model of Disability?

Counsellor *It's a way of regarding disability as a social rather than a medical condition. That means that although it can be difficult to live with some medical conditions, or impairments, the social and physical environment that we all live in is geared towards non-disabled people so that disabled people become marginalised. .*

Figure 6 cont'd

Counsellor *How does all of this sound to you?*

Client It makes a lot of sense. I was aware of that idea but hadn't used the terminology before

Counsellor *Does it help in any way?*

Client It does make me realise that I was almost blaming myself for causing the driver to feel so frustrated. If I hadn't been in a wheelchair, he wouldn't have been so angry.

Counsellor *Mmmm, maybe we could talk some more about that...*

8.5.5. Inviting feedback

In order to keep the channels of communication open and to enable the relationship to function effectively, counsellors are encouraged to monitor the alliance throughout the counselling process and to be prepared to adapt to the client's needs and personal characteristics where necessary (BACP, 2015; Horvath, Del Re, Fluckiger and Symonds, 2011). One of the reasons for doing this is that clients and counsellors experience the counselling process differently but counsellors do not always know how the client is responding to them (Henkelman and Paulson, 2006). This is exemplified in Janet's story. If her counsellor had invited feedback, they may have been able to address her unspoken thoughts and feelings and then re-evaluate the aims and purposes of their work together. As Henkelman and Paulson (2006:146) point out, this means that *"the ability of counsellors to be able to handle negative expression and feedback is critical"*. Disabled clients, as exemplified by participants in this research, often find it difficult to express their concerns directly to their counsellors because they fear that potential conflict may lead to rejection. On looking back at my own experience of being a counselling client, I can recall that I avoided conflict with my counsellor because I felt fragile in terms of my relationships both with myself and with others but as I grew in confidence, I began to tell her when I felt uncomfortable with her interventions. This did not come easily and it led to some rocky encounters but eventually I managed to maintain a sense of myself while disagreeing with her so that the relationship felt more mutual.

In Figure 7, I have outlined some interventions that counsellors might make in order to encourage clients to talk about concerns they may have about how they experience their counsellors. These interventions could be made on a regular basis where appropriate to the client's process. They are very much in keeping with what I have said about establishing the working alliance and working collaboratively. If this does not fit with the client, it may be helpful to invite them to put their concerns in writing if they are able to do so. This could pave the way for counsellors to *"use the information in a respectful way to make changes in the counselling process"* (ibid). It is the responsibility of the counsellor to find suitable, sensitive ways for the client to express their concerns.

Figure 7

Inviting feedback

a) Sample interventions for general feedback

- How do you feel about how our work is going?
- Is there anything that isn't working for you?
- How do you feel generally about the way I am responding to you?
- Has anything that I've said jarred with you?
- Is there anything you'd like from me that you're not getting?
- I know it's not always easy, but please feel free to tell me at any time if anything doesn't feel right

b) Inviting specific feedback: an example

Counsellor Is there anything you'd like from me that you're not getting?

Client *Sometimes I'd like more response from you*

Counsellor Is that how you're feeling just now?

Client *Yes, you seem a bit distracted today*

Counsellor Ah, I'm sorry you feel that way. I'm glad you pointed it out. You might be right but I hadn't noticed. It could be that my daughter is sitting an exam today and it's not quite gone from my mind. I do apologise. Now that you've said it I feel more connected but please let me know if you feel that way again.

8.5.6. Staying present

As I pointed out in 2.4.2, there can be a danger that counsellors may inadvertently distance themselves from disabled clients because of their own unacknowledged fears about disability and vulnerability. If they do not address these issues, they may project their feelings onto their clients and fail to be fully present to the depths of their clients' experiences. Nick pointed out that as a wheelchair user he is often on the receiving end of other peoples' projections so it was important that his counsellor did not respond to him in this way. Reynolds (2004b:116) points out that when working with people who have recently acquired impairments

“It can be painful for therapists to listen in a committed way to their personal stories and to walk beside them in a landscape that is often bleak, chaotic or frightening”.

This may have been what was happening with Shirley and her counsellor. She was in a state of acute trauma following her sudden loss of vision and it may well have been frightening for her counsellor to walk alongside her in her deepest need for connection and understanding. It seems as though Shirley was aware of her counsellor's disconnection through her non-verbal communications as Reynolds (2004b) suggests. This makes the general point that for counsellors to stay present to their clients, they must have the capacity to notice their own disconnections and to reflect on them in supervision and personal therapy. An example of how this might be addressed in supervision is presented in Figure 8.

Figure 8

Working in supervision on staying present: an example

Counsellor *I'm getting quite frustrated at how slow this work is going with my client*

Supervisor You want to move things along a bit?

Counsellor *She seems to be stuck in the downside of what's happening and can't seem to shift – it's been going on for weeks now.*

Supervisor I can see that's frustrating but I wonder what else you might be feeling with this client

Counsellor *Hmm that's a good question. I know I shouldn't say this but sometimes I find it hard to stay with how hard it is for her just now. It all seems so desolate and I just want her to have a wee bit of joy in her life. .*

Supervisor I'm glad you felt able to say that and I'm wondering if there are some parallels with your own life here

Counsellor *I was hoping that you wouldn't ask me about that but now that you have I should tell you that I've just broken up with my boyfriend and I'm heartbroken. I thought it wouldn't interfere with my client work but maybe I'm finding it hard to hear my client when she's struggling so much. My boyfriend's Mum is disabled and this client reminds me of her.*

Supervisor I'm sorry to hear that but glad we've made that connection. Could we take some time to talk more about this?

8.5.7. Working with ruptures

While a disabled client's fear of disclosing negative feelings about counselling could be attributed to feeling silenced in the face of perceived authority figures, a further fear is that this kind of disclosure has the potential for differences and conflicts to arise. Conflict can lead to rejection and estrangement so disabled people, such as participants in this research who have already experienced rejection, may feel it is too risky to speak out. Jordan (2004b:57) argues that "*revealing the blockages that get in our way often opens the way toward reconnection*". She refers to these blockages as the misunderstandings and empathic failures (2004c) that can occur in therapeutic relationships. If these can be brought to awareness and discussed in such a way that the relationship is restored, clients may develop a sense of confidence in talking about ruptures in other relationships without feeling the need to withdraw. Jordan (2004c) adds the vital point that if counsellors are to work with ruptures, they may need to explore how they respond to conflict in their own personal relationships in order to develop their own resilience. Again, counsellors can work on their own issues in personal therapy or therapeutic group work.

Shirley's experience offers an example of how empathic failure could be worked with. She held onto a sense of 'pseudo-relatedness' (Safran and Muran, 2000) with her counsellor, where she acted as an appreciative client even though she felt estranged for most of the time. Jordan (2004b:50) suggests that a way to work with this is "*to first name the disconnection and explore the interaction pattern, [that] led up to it*". If Shirley's counsellor noticed the disconnection, she may have been able to name it so that she could facilitate a discussion about what Shirley was feeling. If Shirley voiced her concerns, and there was some disagreement or misunderstanding, "*staying with difficult feelings such as anger [...], not going away physically or psychologically, is what can move that situation along*" (Miller, 1986:12). It seems as though this was difficult for both Shirley and her counsellor and the situation was vividly apparent in the story that she told about feeling harnessed like her guide dog. This was a potential moment for connection that was sadly missed. Counselling practitioner and researcher Kim Etherington (2002:227) offers some understanding of this issue, saying that

“Some stories [...] do not develop over time and therefore do not move on. [...] The challenge we face is to hear these stories without pushing the tellers to connect with their feelings before they are ready, whilst at the same time not colluding with their avoidance of painful acceptance of present reality. If the story reaches unrecognised painful parts of our own experience we may be tempted to move too quickly away from the client’s experience; our own wounds may be threatened by exposure”.

This may or may not have been the case with Shirley’s counsellor but it highlights the need for counsellors to develop sensitivity, non-defensiveness and an empathic relationship with their own woundedness in order to work with clients who have been traumatised or violated. In Figure 9, I present an example of how a rupture might occur between client and counsellor and how it might be addressed.

Etherington (2002) advocates the use of creative non-verbal techniques such as writing, painting, working with clay and paying attention to body language when working with clients who have difficulty expressing their emotions through speech and where past trauma is still being lived in the present. While this may or may not be possible for disabled clients, Leijssen (2006) adds that any form of non-verbal expression can enable communication and this was an important element for me in communicating with Nancy. As a deaf person, she was accustomed to using non-verbal expression to enhance her capacity to communicate with hearing people. For other participants, speaking directly with their counsellor was facilitative.

Figure 9

Working with ruptures: an example

Counsellor I think we just skipped over something important there

Client [silently looks out of the window]

Counsellor What just happened there? I feel as though I lost you just now?

Client *I'm not sure*

Counsellor Did something just come to mind when we were talking?

Client *Maybe [begins to cry]*

Counsellor I see tears

[Pause]

Counsellor I think we touched on something very painful. Is it a memory?

Client *Yes, It was that word 'skip'*

Counsellor Ah

Client *I couldn't skip in the playground with other kids and the others just laughed at me*

Counsellor I can picture that wee girl feeling frightened and lonely when that happened

Client [sobs]

They both sit in silence while the client continues sobbing

They are back in connection with one another

8.5.8. Speaking directly

Some research indicates that counsellors may feel too inhibited to talk about disability or impairment with their clients (Swain, Griffiths and Heyman, 2003). They may feel that this is a sensitive issue that may be frightening for clients to explore (Segal, 2002). This view does not take into account the counsellors fears that are highlighted by Etherington (2002) and Jordan (2004c) above. Shirley's experience indicates that there can be fears on both sides of the counselling relationship but it is possible for counsellors to develop skills in addressing this sensitive subject and participants in this research revealed some useful pertinent questions.

James' counsellor asked him how his impairment affected him and Bill's counsellor asked him how his impairment would affect their work together. At one point in my interview with Nick, I noticed that he was talking rather obliquely so I asked him if he was talking about his sexual feelings. In naming the issue directly, he experienced slight discomfort along with some relief but he followed my question by talking more explicitly about feelings that had been deeply shameful for him. Jordan (2004b:51) validates this intervention, saying that *"often simply naming the different feelings as clearly as possible is helpful. Increased clarity of experience is an important part of moving back into connection"*. This is an important skill for any counsellor to develop but it is a valuable intervention for clients such as the participants in this research who tend to keep their knowledge of disability and impairment hidden and who, like Shirley, are reluctant to expose their vulnerable selves. Some further examples of interventions that involve direct speaking are presented in Figure 10.

Figure 10

Sample interventions to encourage direct communication

- I see you are using a white stick. Is there anything you'd like me to know about so that we can make sure you're comfortable with the way we work together?
- I notice that you are shifting around in your chair just now. Are you in pain? Is there anything we can do to help with that? Another cushion maybe?
- Did I upset you just now with what I said?
- I noticed that you laughed just now. I wonder if you were shrugging off that very painful experience as though it didn't matter.

8.6. Developing person-centred counselling theory

Having addressed issues that arise from this research that inform affirmative practice for disabled people in terms of counselling training and practice, I now turn to exploring how this research informs person-centred counselling theory and how this in turn might affect an affirmation model of counselling disabled clients. Donna Reeve (2006:96) states that

“There is a need to take account of the personal effects of living with disability in a manner which differs from the traditional psychological models of loss and adjustment”.

She suggests (2000:18) that a theory of ‘disability counselling’ is needed for working with disabled clients and that this would involve having the SMD as its ‘cornerstone’. Contrary to her suggestion, I suggest that the person-centred approach can incorporate an understanding of social and cultural conditions of worth (see 2.3.2). In this section, I consider this issue further by drawing on person-centred theory; feminist thinking and ideas from DS.

8.6.1. Disability and identity

Reeve (2000:18) suggests that a goal of counselling should be for the client to develop a *“positive sense of identity”*. While it is important for disabled people to be seen by others in more positive ways than just being tragic souls, it is equally important that they gain acceptance by being confident enough to feel accepted whether or not disability is viewed positively in society. This does not mean accepting societal and cultural conditions of worth or avoiding challenging them in different contexts. It is more in keeping with the plea made by Morris (1991) and Cameron (2010) for disabled people to be accepted as they are and not as other people expect them to be. That involves disabled people accepting all aspects of their self-concepts, not just those characteristics that are perceived by others to be positive. This is crucial because, as some participants have indicated, it can be stressful to live according to the expectations of others by presenting a socially acceptable public image that does not include being disabled.

Disability and impairment as configurations of the self

Watermeyer and Swartz (2008:609) emphasise the “*bi-directional and dynamic*’ nature of relations of oppression where both the oppressive acts and the ways in which oppressed people respond to these acts are worthy of exploration. Instead of focusing wholly on the oppressor, they state (ibid p 601) that

“Part of hearing the experience of disabled people is hearing the internal conflict, the ambivalence, the collusion, the confusion. Exploration of these aspects is essential in the process of giving disabled people back their alienated, colonised experience”.

They qualify this by saying (ibid p 609) that this does not diminish “*the atrocity and horror of deprivations under which disabled people survive each day*”.

Some disabled writers tackle the issue of how non-disabled people view them by thinking of disability as separate from personhood. Tanya Titchkosky (2007) and Joy Oliver (1995) for example, suggest that disabled people would like to be seen as people first and disabled second. It seems to me that this perpetuates the notion that disability is undesirable and shameful. From a person-centred perspective, it is important to value *all* aspects of the self (Mearns and Thorne, 2000). One of the key contributions that this approach can make to the debate is to consider disability and impairment in terms of configurations of the self. Cameron and Tossell (2012:244) seem to concur with this view, without being aware of this, when they point out that “*impairment forms an important, though by no means necessarily the most important, part of people’s identities*”. This is exemplified by participants in this research as they have all displayed other aspects of themselves than being disabled. Regarding disability and impairment as configurations of the self is in keeping with contemporary understanding of the self as multidimensional and the self-concept as a fluid rather than a stable construct.

In my analysis of the research interviews, I was struck by how difficult it seemed to be for some participants to find a place for their disabled selves internally in a way that they could accept. Using the notion of configurations of the self and myself as an example, I could consider ‘disabled me’ as a configuration that has thoughts and

feelings about the limitations of the social and physical environment and that develops strategies for dealing with these issues. Similarly, my 'impaired body' configuration has its own thoughts, feelings and strategies. Each disabled person has other configurations to draw on. Taking Bill as an example, I understand that he has his intellectual configuration as well as his impaired body; his disabled self and a range of other self 'narratives' (Mearns and Thorne, 2000). In his grief for the narratives that he could not have (musician, skier) and his uncomfortable relationship with disability and impairment, he has tended to focus on only one configuration (his 'head'). He seems to have lost sight of other configurations so that these narratives could not emerge. Bill identified his own 'head' configuration, which in practice is important (Mearns and Thorne, 2000) because the counsellor takes the lead from the client and does not impose their own ideas. Using this approach and by way of illustration, if I were Bill's counsellor I would have noticed him talking about his 'head' and not his 'body' and I could then enable him to expand on these configurations by exploring the thoughts, feelings and strategies that he associated with each. Equally, I might have noticed other configurations that he liked so that he could have a more balanced view of himself – one that might enable him to become more self-aware, self-understanding and hopefully more self-confident.

A further advantage of considering disability and the impaired body as different configurations is that the dissonance between them and other configurations can be explored (Mearns and Thorne, 2000). Kevin, for example, was able to do this with his last counsellor. As Mearns and Thorne (2000) point out, each configuration has a developmental component and this is clear from Amanda's story where she tried to deny her impaired body until it became impossible to ignore it. She managed to develop a more nurturing attitude to her visually impaired self over time, partly as a result of counselling.

Self-actualisation as an embodied experience

Person-centred theorist Art Bohart (2013:86) explains that the actualizing tendency is a largely unconscious developmental process that indicates people's motivation to survive, maintain and enhance themselves. He explains that this is a "*biological*

force”, a movement towards wholeness and integration and “*a proactive tendency to organize the organism for optimal functioning given the circumstances*”. Watson (2011) argues that this movement involves an increasing awareness of bodily sensations and emotions. As a person develops from childhood into adulthood, they develop a more conscious sense of ‘self’ and begin to “*process their experience in relation to external values*” (McMillan, 2004). They develop a self-concept that is based on conditions of worth. Self-actualisation is a subset of the actualising tendency that involves maintaining and enhancing the self-concept. This means that the person will strive towards functioning in the best way that they can in relation to their environment and their social world. The person becomes self-directing and their self-concept becomes fluid and changing by adapting to new experiences. Part of the process is to develop the “*capacity to listen to and respect others’ realities, as well as to productively dialogue with them*” (Bohart, 2013:92).

As I have said, the person-centred counselling literature does not give a huge amount of attention to clients’ attitudes towards their bodies despite this being a matter of deep concern and shame for many (Orbach, 2010). This research illustrates how shame and embodied experience are important aspects of the self that are subject to conditions of worth. Embodiment is central to the process of self-actualisation and could be given greater emphasis in person-centred theory as well as in counselling practice. In my view, self-actualisation involves a tendency for the body to maintain and enhance itself. This process involves acceptance and integration of the body and emotions as they are experienced at any moment in time, whether the experience is of anger, pain, frustration, or of an appreciation of the ‘good days’ (Cameron, 2010). Body psychotherapist Nick Totton (2015:26) asserts that

“If the mind is inherently embodied, and if its extension into the world happens through and in embodiment; then therapy must pay serious and deliberate attention to each client’s embodied experience, and to the embodied experience of the practitioner”.

Disabled writer Margrit Shildrick (2009:173) sheds some light on this process from a disabled person’s perspective though she is not involved in counselling. She

considers the body to be an unstable entity and 'disabled embodiment' to be "*just another variable in the infinite modes of becoming*". With the enhancements that technology can offer, including new developments as well as simple aids such as wheelchair, walking sticks and hearing aids, the body can be seen as changing and developing across the lifespan; subject to conditions of worth and capable of fulfilment and enhancement. Thinking of the body as an aspect of the process of becoming fully functioning may point the way towards a "*positive reframing of disability as 'embodied difference'*" (Fawcett, 2000:26).

I have highlighted embodiment as an aspect of a disabled client's process of becoming more authentic in their relationships with self and others because this is a neglected aspect of counselling.

8.6.2. The affirmation model of disability

According to Cameron (2010), the affirmation model of disability (Swain and French, 2000), which he and others refer to as the 'affirmative' model, offers a different way of conceptualising disability from the medical model. This framework incorporates the SMD and goes further into the realms of interpersonal relationships. It supports the view that it is possible for disabled people to live successful and fulfilling lives despite the limitations that they encounter. Cameron (ibid p 256) states that the model

"provides the basis for a self-respectful stance to be taken in the face of cultural assumptions of personal tragedy. It contextualises the experience of impairment within current discourse on diversity and establishes the rights of people with impairments to be recognised and valued as who they are. [...] to feel okay about themselves and to take pride in who they are even when they are having crap days, and to be able to have crap days as well as great days or ordinary days without having to pretend otherwise".

This model offers a way of framing the psycho-emotional effects of disability and impairment as natural responses to difficult circumstances. Using this model, Cameron recognises that identity formation is a fluid process where there is scope for movement and change. He conceptualises impairment as a part of the self, not

an all embracing identifying marker. He states (in Cameron and Tossell, 2012:244) that

“In defining impairment as difference, the affirmative model avoids making negative evaluative judgements in terms of ‘loss’, ‘abnormality’, or ‘limitation’. This is not to say that impairment doesn’t sometimes, often even, involve pain or discomfort, but it is to make the point that this isn’t all that impairment signifies”.

From this statement, I understand Cameron to mean that it is possible to recognise that some people experience positive aspects of being disabled. Janet, for example, found that she made deeper friendships after becoming disabled because she dropped her previous facade of cool-headed professional woman. As Cameron (2010) points out, the disabled affirmation model can be used as a framework for understanding disability and in my view, it concurs with the attitudes expressed through the person-centred approach.

8.6.3. Autonomy and interdependence

Several participants struggled with the need to feel independent and indeed Western cultures tend to emphasise this quality (Tudor, 2010). Person-centred counselling theory, like other approaches to counselling, incorporates an individual model of personal development. This reinforces the view that predominates in DS, that counselling individualises disabled people’s issues instead of seeing them as social problems. Käll and Zeiler (2014) point out that autonomy is usually ascribed to a person from the outside as an expectation that people can function without environmental or relational constraints. Tudor (2010) contests this view, arguing that Rogers’ theory of personal development can be understood in terms of interdependence if the social environment is taken into account. Feminist writer Linda Barclay (2000) broadens out this notion, asserting that everyone is a product of their environment and that people make choices and decisions in relationship with their surrounding environments as well as the people they associate with. Tudor (ibid p 64) makes a plea for a *“therapy which counters the reification and hegemony of the individual”* and that emphasises the value of community living. This concurs with disabled writer Tobin Siebers’ (2008) view that the idea of complete

independence is a grandiose notion whether or not clients are disabled. Shakespeare (2000b:79) takes a similar view, arguing that people in the helping professions

“need to challenge the philosophy of independence as it is narrowly understood and replace it with a demand for negotiated autonomy, based on the inevitable interdependence of modern societies”.

If underground knowledge is to be uncovered in counselling, it is important to recognise that choices and decision-making are shared tasks so people can be *“quite compatibly both autonomous agents and deeply social selves”* (Barclay, 2000:68). This view can be enabling for disabled people who may depend on others for their care as it encourages them to guide their own actions but at the same time to co-operate with others without feeling disempowered. Miller (1986:5) argues that connection is formed through encouraging a sense of community because each person contributes to what happens in a relationship. This is an important point for disabled people, some of whom, like Shirley, can feel that they have nothing to contribute to society.

8.7. Summary

In this chapter, I have discussed my findings in relation to the work of writings in DS and counselling and I have highlighted the contributions that this research has made to knowledge in both academic fields of study and research. In response to arguments presented in DS about counselling, I found that counselling can enable disabled clients to feel more connected with themselves and others and therefore reduce their sense of estrangement. Counselling may not be an oppressive pursuit per se, but some participants have felt undermined by their experiences of being counselling clients at times. Counselling enabled some participants to reveal their hidden knowledge to others in their social worlds, thereby fostering deeper connections with others and social change at a micro level. The contributions that the work of DS writers make to counselling are to highlight the impact of social and cultural conditions of worth on disabled people; to differentiate between impairment

and disability and to provide an understanding of why disabled people often feel the need to keep substantial aspects of their experience hidden from themselves and others.

In terms of counselling, I have highlighted and discussed the sense of tension that many participants have experienced between the need to withdraw from social situations and the desire to have meaningful connection with others. This pattern is a result of conditions of worth, impairment effects and other difficult life experiences. Participants experience this pattern in the counselling relationship through hidden knowledge and the reluctance to offer feedback to their counsellors about the ruptures they experienced. I have suggested that person-centred theory offers an appropriate framework for working with disabled people and that is compatible with the understanding, attitudes and values of some writers in DS. Implications for counselling practice are based on my understanding of participants' experiences and from knowledge in DS and counselling. Counsellors may be able to assimilate the recommendations in the contexts of training, continuing professional development, supervision and personal counselling.

Chapter 9: Conclusion

As I said in chapter 1, I began this research because I was aware that it can be difficult for people to speak with others in their social circles about their experiences of being disabled. My own experience suggested that disabled people often feel estranged and disconnected from others but I was not fully aware of the reasons for this. I wanted to find out if counselling could help disabled people to feel more connected with others. I found out that the sense of estrangement that participants experienced was connected with social and cultural conditions of worth; with impairment effects and with a combination of these and other life circumstances. Perhaps a more contentious finding is that enhancing relationships in both counselling and in interpersonal relationships is a two-way process. This may be a difficult notion for some who feel that they are unable to challenge oppressive forces. Where disabled participants have been subject to conditions of worth that have weighed them down emotionally, psychologically and in terms of their sense of agency, change in counselling involves them being able to bring their hidden knowledge to the surface and this may mean that they encounter shame and difficult emotions and memories. I have found that counsellors can facilitate this process if they are willing to acquire appropriate knowledge, self-awareness and skill by engaging with their own personal and professional development in ways that I have discussed. Changes that take place for the client and at times for the counsellor at this micro level can effect change at other social levels through a ripple effect. This can happen if client and counsellor are able to work together to bring hidden knowledge about living with disability out from the underground so that it can be understood and known in other social spheres. There is no suggestion that this is an easy process.

It was never my intention to imply that all disabled people need counselling or that every disabled person feels estranged. I have been investigating the experiences of people that have been clients in order to bring insight into the counselling relationship and process. This research is intended to make these insights available to counsellors and to the Disabled Studies (DS) community. I presented participants'

experiences in story form because narratives can offer alternatives to culturally dominant views about disabled people (Couser, 2010). It has been argued that *“opening out the frame of reference of another person or group can be an informative, useful and powerful end in itself”* (Mearns and McLeod, 1984:388). I brought disabled clients’ views to centre stage because their particular voices are not always heard or understood. I hope that readers will find resonance in the stories that I have presented and that it will deepen their understanding of how disabled people can experience themselves and others in their everyday lives.

DS literature offers insight into the experience of being disabled and challenges counsellors to think more carefully about the social and cultural context of their client work. My findings, including my own experience and much of the counselling literature, suggest that ethically practising professional counsellors are unlikely to be intentionally subordinating disabled people. The profession as a whole aims to be anti-discriminatory and inclusive. Instead, my findings indicate that client/counsellor relationships and processes are affected by a lack of awareness of the forces that militate against emotional, psychological and relational wellbeing. Characteristics such as unconscious othering, projection, thoughtlessness and defensiveness can arise in the client/counsellor relationship and can undermine the client and reinforce social and cultural conditions of worth.

My reading of Disability Studies literature has given me new perspectives on the theory and practice of counselling. This has illuminated the depth of my understanding of how disability can affect people in terms of their self-concepts and their everyday relationships, I have been drawn to reflect on the notion that counselling as a profession is rooted firmly within an ableist culture, without sufficient awareness of issues such as ableism, disablism, internalised oppression or social and cultural conditions of worth that have detrimental effects on disabled people. While some counsellors may make their own attempts at challenging the established norms that adversely affect their clients, others do not always have sufficient knowledge or awareness to contextualise their work with disabled clients. The situation is encapsulated by Campbell (2008:6) when she says

“The conundrum of disability is not a mere fear of the unknown, nor an apprehensiveness towards that which is foreign or strange. Rather, disability and disabled bodies are effectively positioned in the nether regions of ‘unthought’.”

The counselling profession upholds inclusive values but people who are associated with minority groups are still considered as ‘different’, so some of the literature considers how counsellors might work with ‘differences’ such as people from other cultures; genders and ways of expressing themselves sexually; social backgrounds; specific pathologies. Debates about issues such as ‘able’ and ‘normal’; where we are coming from when we discuss groups as ‘different’; how we position ourselves in relation to these differences and in our own communities; how we might notice and challenge binary thinking deserve greater attention in counselling training and in the counselling literature.

To some extent, this research is situated within an ableist perspective because I have been researching ‘disability’ and ‘disabled clients’ who by definition are being discussed as an identifiable group deserving of particular recognition. However I have acknowledged and reflected on this perspective throughout this thesis. As a researcher in the counselling field, an aspect of my contribution to knowledge is to address debates and issues that are largely uncontested. As someone who has been immersed in the counselling profession and who has not been involved in disability politics or Disability Studies before embarking on this research, I am undoubtedly immersed in an ableist society and part of an ableist profession. In my role as a counselling researcher, I have exposed myself to being challenged by much of what I have previously assumed. This is evident in my research analysis. My research contributes further to debates in DS by offering and exemplifying an in-depth insight into the lived experience of being a disabled client in counselling within such contexts. In this way, I have provided *“a critical perspective on how things could and should be”* (Marks, 1999b:613). In addition, this research challenges writers in DS to understand that counselling, and the person-centred approach in particular, has much to offer disabled people who struggle with their relationships with other people, particularly with those who are not disabled. Understanding the disabled self and the impaired body as configurations of the self is a unique way of considering

how these experiences could be integrated into the self-concept in a way that offers scope for further exploration and for recognising that other aspects of the self have equal significance.

I conclude this thesis by outlining the main limitations of this research (9.1) and I bring my findings together by offering a theoretical framework for understanding disabled clients in counselling (9.2). Finally, I bring together some key principles that could be adopted in the practice of counselling disabled clients (9.3).

9.1. Limitations of the research

I focused on the experiences of disabled people in general, rather than on a particular group within this broad category, in order to bring attention to a broad client group that is not adequately represented in the counselling literature. Although the range of participants was diverse in some respects (see Table 1) I did not find anyone from a black or minority ethnic background. The constraints of time and space meant that I emphasised the commonalities at the expense of the differences that subgroups within the disabled category would present. This means that although issues such as sexual orientation, age, social class and gender were present within the group of participants, constraints of time and space meant that I could not explore the impact of any of these on the experience of being disabled in any depth. It is worth noting, however, that some male participants discussed their anxieties about sexual attractiveness but none of the female participants mentioned their feelings about this. This is an issue that can be very distressing for disabled women (Payne, Hickey, Nelson, Rees, Bollinger and Hartley, 2016; Wendell, 1996) but I could not add insight to this from my research findings.

It would be remiss to neglect the impact of financial constraints and the limited availability of counselling that meet the needs of disabled clients. While I recognise this as a major issue, I have chosen to focus this research on developing counselling practice.

The whole research is set in time and place as Mearns and McLeod (1984:379) note

“The process-orientation of person-centred research not only recognises that the participant is in process, but that the relationship between researcher and participant is in process. Also, the research study as a whole is an evolving process”.

I have listened to, analysed, discussed and presented stories that were told at particular moments and participants may well tell them differently to different people at different times. However, their resonance with the literature indicates that they add substance to existing knowledge.

9.2. An affirmation approach to counselling disabled people

I summarise what I have found by formulating what I call an affirmation approach to counselling disabled people by bringing together ideas from Disability Studies, the person-centred approach and the gay affirmative approach.

I could have used race as a model because there are many parallels with disability but I do not find that it is formulated in the counselling literature to the same degree of sophistication as the gay affirmative approach.

The struggles that disabled people encounter have some parallels with those faced by the gay community. Gay affirmative counselling was developed as a framework for people who had not yet ‘come out’ as gay to understand the prevailing attitudes towards homosexuality and to support the client to feel comfortable with their sexual orientation. It involves the integrating of the experience of homosexuality into the person’s sense of self instead of denying or distorting that aspect of their self-concept in order to feel accepted (Perlmani, 2003). It is worth noting that the struggles that disabled people make to be accepted in society are different from the gay community in the sense that disabled people often need support from governments and charitable organisations to help with their everyday needs. In this way, they have a low status in society. I suggest that it is timely to learn from the work of the gay community and to build on the work of Cameron (2010), Swain and French (2000) and Swain, Griffiths and Heyman (2003) to consider the idea of an

affirmation approach to counselling disabled people. As McLeod and Sherwin (2000) note, oppression is a huge barrier but not necessarily one that is insurmountable.

I suggest that an affirmation approach encapsulates what I have learned about working with disabled clients in this research. This approach would highlight social and cultural conditions and recognise that these forces engender shame and disempowerment. Although the counselling process is by no means the sole way of enabling disabled people to live as equals in their relationships with others, I suggest that an affirmation approach may be enabling. I provided examples of how this approach could be incorporated into counselling training and practice. I now formulate a set of principles, based on a person-centred framework that can summarise the personal qualities, knowledge and understanding and skill that would be necessary for counsellors to adopt an affirmation approach to counselling disabled people.

9.3. Key principles for an affirmation approach to counselling disabled clients

There are three main aspects to an affirmation approach, namely the personal qualities that the counsellor brings to the relationship; the knowledge that they need to understand what it is like to be a disabled person and client in counselling and the use of these qualities and skills in offering environments that are conducive for working with disabled clients.

Self-awareness and personal development

I have mentioned the need for counsellors to engage in ongoing personal development as an essential aspect of working with disabled clients. My findings indicate that this would involve the counsellor reflecting on their own experience of vulnerability; their own emotionally painful experiences; their own experiences of feeling different from others and on how they experience their embodied selves. The

capacity to reflect on and process these issues may enable counsellors to avoid the dangers of projection, 'othering' and disconnecting from painful client material.

Knowledge and understanding

I have presented knowledge about disability and counselling disabled people throughout this thesis. The key areas of knowledge that would equip counsellors to empathise with and accept their disabled clients include understanding that some issues can be attributed to impairment effects; some to the disabling environment and others to a mixture of both. Such knowledge will enable counsellors to differentiate and respond to these different experiences as they listen to their clients. Understanding the nature of internalised oppression may help counsellors to notice and respond to their client's tendency to hide aspects of their experience of disability and impairment. Understanding disability and the impaired body as configurations of the self can pave the way for the counsellor to affirm the positive and negative aspects of living with disability and impairment and to recognise and value other configurations as the client presents them. Understanding that self-actualisation is an embodied process can help the counsellor to appreciate disability and impairment as fluid concepts that can change over time and that can impact clients in different ways at different points in life. Similarly, identity formation can be viewed as an embodied, multi-faceted, fluid and continuously developing process. The concept of the fully functioning person as an embodied, relational, interdependent state can allow room for considering disability and impairment as integral aspects of the self-concept.

Creating a conducive environment

It has been noted that Rogers' therapeutic conditions (Appendix A) are easily understood but demanding to apply (Natiello, 2001). Offering genuine respect and empathy to disabled clients in ways that they can internalise involves understanding the client/counsellor relationship and process in its social and cultural context. Empathy involves understanding disabled clients' issues in terms of the conditions of worth that derive from their interpersonal relationships as well as from the social,

cultural, political and historical attitudes that influence their self-concepts and capacity to engage in satisfying relationships with others. The counsellor's attention to power involves understanding disabled clients in terms of embodied difference. It may also involve developing the capacity to address their social and embodied positioning in relation to their clients.

Other elements that I have highlighted in terms of creating a conducive environment for working with disabled clients include being alert to and attending to relevant issues and requirements as part of the process of establishing the therapeutic frame and alliance, particularly at the beginning stages of counselling. For example, this may involve accommodating some particular physical needs of the client and/or developing appropriate communication mechanisms and styles. Once the groundwork has been prepared, it is important to invite regular feedback from the client to remain alert to any relevant experiences that the client is reluctant to disclose.

As in gay affirmative counselling, the attitudes, skills, values and principles that I have grouped together in the form of an affirmation approach to counselling disabled clients are not exclusive to person centred counselling but can and should be part of any counselling approach.

9.4. Indications for further research

The research offers some pointers towards further exploration. Most significantly, my deliberate focus on disabled clients' perspectives means that the counsellors' points of view are not represented. Research into what it is like for counsellors to work with disabled clients would offer a different and valuable perspective. Aveline (2005) points out that people use other resources than counselling for personal development and it would be interesting to find out about other ways of enabling disabled people to enhance their relationships – for example the use of body-work (see Totton, 2015), or journaling. There is a developmental aspect to the issues that participants brought to counselling in the sense that the issues that arise at

various points across the lifespan can be different. I have made reference to some of these in the thesis but further research on working with disabled young people, elderly disabled people, and disabled people who experience race, class or gender issues that isolate them socially would add to the findings from this research. A valuable contribution to counselling and DS would be to discover more about how disabled people respond effectively to overt hostility and oppression. Rosemary Garland Thompson's work (2009; 2010a; 2010b) goes some way towards this but it is an area that deserves further research. Swain, Griffiths and French (2006) suggest that disabled people may be encouraged to become more assertive through group activities. Group work has a high profile in person-centred counselling so it could be helpful to conduct further research on how disabled people might use this approach to personal development to enhance their relationships with others, perhaps especially with non-disabled people.

In conclusion, this research has offered considerable insight into the relational experiences of a range of people that define themselves as disabled. Findings point towards the importance of attending to hidden knowledge in the client/counselling relationship. Counselling has been highly effective for some participants but there is much to learn from participants' experiences that enhances existing knowledge in both DS and counselling. Similarly, there has been significant learning for counselling training and practice from both the successful and the difficult experiences that participants have offered. This research has offered a critical contextual perspective on the counselling relationship and process and offers recommendations for developing counselling training and practice for working with disabled clients. It has provided a unique invitation for DS and counselling writers to enter into dialogue with each other and to further the debates and points that have been presented here.

Siebers argues (2008:93) that disabled people could be seen as a *“resource for thinking about fundamental democratic principles such as inclusiveness and participation”*. In this research, disabled people have been a resource for providing knowledge, experience and principles for counsellors whatever their orientation, to become more inclusive and understanding of a range of clients who have felt

oppressed and disempowered, especially those who are associated with minority groups.

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Appendix A: The necessary and sufficient conditions of therapeutic personality change

From Rogers (1957)

1. Two persons are in psychological contact.
2. The first, whom we shall term the client, is in a state of incongruence, being vulnerable or anxious
3. The second person, whom we shall term the therapist, is congruent or integrated in the relationship
4. The therapist experiences unconditional positive regard for the client
5. The therapist experiences an empathic understanding of the client's internal frame of reference and endeavours to communicate this experience to the client
6. The communication to the client of the therapist's empathic understanding and unconditional positive regard is to a minimal degree achieved

The six conditions have been examined, researched and seen to be more complex than Rogers' statement suggests, but I offer a brief, somewhat simplified version of their meaning, based on Sanders (2006).

Condition 1 is complex in the sense that Rogers intended this to mean that the client is in relationship with the counsellor. Contemporary theorists suggest that there are different levels of contact and that contact can be encouraged through the use of pre-therapy techniques (see Prouty, Van Werde and Pörtner, 2002).

Condition 2 means that the client is aware that something is wrong but they may or may not know what is wrong.

Condition 3 has become more nuanced since Rogers first coined the term. Essentially it means that the counsellor is not in a distressed state while in relationship with the client and that he/she is appropriately internally prepared to be in a helping role. This involves having a high degree of in-the-moment self-awareness and being able to listen and respond without defensiveness or putting on a facade.

Condition 4 is often known simply as 'acceptance'. It means that the counsellor is non-judgemental and expresses warmth towards the client. This operates to counteract conditions of worth, which are usually experienced as judgements.

Condition 5 means that the counsellor is able to understand the client's 'frame of reference' as far as possible. That is, to understand their inner processes (perceptions, meanings, emotions) while holding on to the awareness that the counsellor's experience is separate from the clients.

Condition 6 is usually considered along with condition 1, where the emphasis is on the client's perception of the other conditions. Both 1 and 6 are considered to refer to the quality of connection between client/counsellor in the counselling relationship.

Appendix B: Documents used in the advisory group and one-to-one interviews

B.1. Information sheet for the advisory group

INFORMATION SHEET

I am a person-centred counsellor and I teach counselling at the University of Edinburgh, where I am studying for a PhD. I am exploring some of the issues that are involved in counselling disabled people. As a disabled person myself, I am interested to open out discussion among counsellors and disabled people with a view to developing fuller understanding between both groups.

I have invited you to take part in an initial discussion because of your connection with counselling as well as your understanding of disability issues and I hope that the benefits of our meeting will be mutual. My main interest is in hearing about your experience of being a counselling client. Though the focus of your counselling work may not have been about disability or impairment, I would like to find out whether or not you felt that these aspects of your life were understood. In addition, I would like to hear your ideas about what successful outcomes from counselling might be. I will give you further information before we begin the discussion.

I appreciate that this is a very personal and perhaps emotional topic and I would like to emphasise that you are in control of what you offer for discussion.

With your permission, I plan to record the discussion using a digital voice recorder and I will transcribe the discussion afterwards. I will store the recording on my home desktop computer, which is password controlled and the recording will be deleted from there after I have completed my PhD. The recording will not be stored on the voice recorder but will be deleted from there after it has been downloaded to my computer. I will be the only person who listens to the recording but I will summarise the themes of the discussion without including personal names. I will circulate the summary to you and to the other members of the group so that you can ensure its accuracy. My intention is to anonymise any analysis of the discussion but you will be given the opportunity to withdraw anything that you say at the end of the group session. Thereafter, the content of the discussion will be used for my research.

The session will last for an hour and a half, but you are free to take time out at any point. The discussion group will take place in the School of Health in Social Science at the University of Edinburgh (address provided) and it is fully accessible. Lunch will be provided and I will pay travel expenses. Please let me know if you have any particular requirements.

Sometime after the group has met, I plan to conduct one-to-one interviews and, if you are in agreement, I may ask your permission to participate at that point though you are under no obligation to do so.

Thank you for reading this and I do hope that you will agree to take part in the discussion. Please do not hesitate to contact me if you have any questions.

Connie Johnson
Tel: 0131 446 0377
connie.johnson@ed.ac.uk

B.2. Consent form for advisory group

**Group discussion: Disabled people's experiences of counselling
Monday 14 November 2011**

CONSENT FORM

Name:

I agree to being a participant in the group discussion under the terms indicated on the information sheet supplied

.....
(Please sign)

I agree to the audio recording of the group discussion

.....
(Please sign)

I agree to my input to the discussion being used for research purposes

.....
(Please sign)

You have the right to withdraw from the study at any time

Connie Johnson

B.3. Questions for group discussion

1. What do you think the benefits of counselling might be for disabled people in terms of their everyday experience of a) disability, impairment, impairment effects and b) relationships with other people?

2. What might inhibit the counselling process for disabled people? - thinking especially in terms of both the client and the counsellor in their working relationship. It would be useful to have some examples from your own experience, especially of being a client, if you have any.

3. What, in your experience, are the most facilitative aspects of the counselling relationship - thinking specifically in terms of working with disabled people? Again, some examples from your own experience would be useful if you have any.

B.4. Information sheet for one-to-one interviews

INFORMATION SHEET

I am a person-centred counsellor, studying for a PhD and I teach counselling at the University of Edinburgh.

What is my research about?

I would like to find out about some of your experiences of being a client in counselling and whether or not counselling was useful to you.

Why have I asked you to participate?

I have invited you to because X has suggested you as a possible participant because of your experience of counselling and disability.

What am I asking you to do?

I am inviting you to take part in a one-to-one confidential interview where I will ask you to talk about your experiences of counselling and whether or not it was helpful. I appreciate that this is very personal but you will be in control of what you choose to talk about.

How long will the interview last?

The interview will last for about an hour.

Where will the interview take place?

If you agree to being interviewed, I will discuss the most suitable location for us to meet and I will reimburse any travel expenses.

How will the interview be recorded?

I will ask you to sign a consent form to permit me to make an audio recording of the interview. With your agreement, I will store the recording on my home desktop computer, which is password controlled and the recording will be deleted from there two years after I have completed my PhD. I will be the only person who will listen to the recording.

What happens after the interview?

After the interview has taken place, I will summarise what we have discussed and I will send you a copy. When you have read the report, I will ask you to sign a second consent form to ask your permission to use some short extracts of your own words in my thesis and in any related publications and at that point I will give you the opportunity to withdraw anything that you say if you wish.

Who will benefit from the research?

My intention is to make my findings available to counsellors and disabled people, through the writing of my PhD thesis and through publication in counselling and disability literature. The ultimate aim is to educate counsellors about aspects of living with disability and to raise awareness of the potential benefits of counselling among disabled people. Anything that I use from the interview will be anonymised and used with your approval through the consent forms that I will ask you to sign.

Thanks

I hope that you will agree to take part in this research and that there will be some mutual benefits from our meeting. Please do not hesitate to contact me if you have any questions.

Connie Johnson

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B.5. Consent forms for one-to-one interview



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Edinburgh
EH8 9AG

Email: connie.johnson@ed.ac.uk

Phone: 07740237282

***“Disabling relational barriers and their effects on the
client/counsellor relationship”***

CONSENT FORM 1

Name:

I agree to the audio-recording of the interview under the terms indicated on the information sheet.

.....
(Please sign)

You are free to contact me at any time about your involvement in this research. Complaints should be directed to:

Seamus Prior (seamus.prior@ed.ac.uk), Chair of the Counselling and Psychotherapy Research Ethics Committee

or

Marion Smith (marion.smith@ed.ac.uk), Postgraduate research coordinator, School of Health in Social Science.

Both can be contacted at the above address.



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Phone: 07740237282

***“Disabling relational barriers and their effects on the
client/counsellor relationship”***

CONSENT FORM 2

Name:

I agree to the anonymised use of material from the interview to be used in the presentation of this research. Results of this research will appear in my PhD thesis with the possibility of some of my findings appearing in published form.

.....
(Please sign)

You are free to contact me at any time about your involvement in this research. Complaints should be directed to:

Seamus Prior (seamus.prior@ed.ac.uk), Chair of the Counselling and Psychotherapy Research Ethics Committee

or

Marion Smith (marion.smith@ed.ac.uk), Postgraduate research coordinator, School of Health in Social Science.

Both can be contacted at the above address.

B.6. Questions for one-to-one interviews

Interview questions

1. When did you first experience your impairment?
2. Do you find relationships with other people to be difficult in any way because of your disability?
3. Did you talk about this with your counsellor?
4. Did you experience any difficulties in your relationship with your counsellor because of your disability? – these could be overt or more subtle? If so, did you talk about this?
5. What did counselling do for you?
6. Did counselling help you in your relationships with other people? Can you give examples?

B.7. Interview questions for Sarah

1. When did you first realise that you had Asperger's?
2. Why did you decide to go and see L?
3. Lots of people struggle to get on with one another, what problems do you have getting with other people?
4. How do other people treat you?

Can you give examples?

5. How do you get on with L?
How did L treat you?
What do you like about her?
Was there anything you didn't like about her?
Can you give examples?
6. Do you get on better with other people now since you saw L?
If so, can you give examples?
If not, can you say why this might be?

Appendix C: Template for the Listening Guide

Adapted from Gilligan, Spencer, Weinberg and Bertsch (2005) and Mauthner and Doucet. (1998; 2003)

Step 1: Listening for the plot and my response to the interview

Part A

- Read through the text and listen for the plot, attending to what is happening, to what stories are being told.
- Attend to the landscape or multiple contexts in which these stories are embedded
- Identify the stories that are being told, what is happening, when, where, with whom, and why
- Note repeated images, metaphors, dominant themes, contradictions, absences (ie what is not expressed)

Identify the larger social context within which these stories are experienced and the social and cultural context within which the researcher and participant come together

Part B

This part is like identifying counter-transference so as not to confuse my experience with that of the participant and so that my feelings don't interfere with my interpretation.

- Identify, explore and make explicit my own thoughts and feelings about, and associations with, the narrative being analysed.
- Note my own social location in relation to the participant; the nature of my relationship with this person; my emotional responses and lack of them; where these responses occur; how this person touches me and doesn't touch me; what thoughts and feelings emerge as I begin to listen; why I am responding in this way and how my responses might affect my understanding of this person

Step 2: I poems

The purpose here is to listen to the participant's first person voice; to pick up its distinctive cadencies and rhythms and to listen to what the person knows of her or himself; to do this before talking about the participant in order to work against distancing myself from that person in an objectifying way.

On the transcript:

- Underline or select every first-person 'I' within the selected passage along with the verb and any seemingly important accompanying words
- Maintaining the sequence in which these appear in the text, place each phrase in a separate line. This is designed to follow free association

Step 3: Listening for contrapuntal voices

This brings the analysis back into the research question to hear and understand the different layers of the person's expressed experience. I start to identify and sort out the different strands in the interview that may speak to my research question.

- Read through the transcript two or more times, each time tuning into one aspect of the story being told, or one voice within the person's expression of his or her experience. My research questions shape this listening
- Specify the voices to be listened for and determine how to mark each voice – maybe by underlining in a different colour. This allows for one statement to have multiple meanings and to see the relationship between the different voices.

Step 4: Composing an analysis

Having gone through the text a minimum of four times, leaving a trail of notes, underlinings and summaries, pull together what has been learned in relation to the research question. An essay or analysis is composed. Look at what evidence forms the basis for the interpretations.

Introduction

Date of interview

My knowledge of the person's impairment

Anything else that is relevant to setting the scene

Communicating with the participant

Any particular issues involved

The wider context of the interview

Shared contexts

Particular social/cultural/political contexts

Geographical contexts

Counselling context

The interview

The dominant themes

Sequencing of themes

My relationship with the participant

How I felt

What particularly struck me

Responses to each of the research questions

Transcribing the interview

How I felt

What came to mind when I was doing this