

Changing position: an exploration
of the meaning of sexual well-being for
physically disabled people

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Abstract

The aim of my work was to explore the meaning of sexual well-being for physically disabled people and to use the knowledge gathered to inform social work practice with adults. It uses a practice project and research to achieve this aim. The well-being principle in the Care Act 2014 makes this a topical subject for social work practice with adults in England. The study uses theoretical concepts such as humanisation of care services to develop an understanding of well-being focused practice.

The thesis comprises four elements: (i) a literature review; (ii) a research study; (iii) a practice development project; and (iv) a narrative which is interwoven throughout, highlighting points of reflexive decision making. A phenomenological approach was used to collect data through a series of unstructured interviews with six physically disabled participants. The findings revealed that disabled people experience discrimination regarding sexual expression, and this has a negative impact on their well-being. Insights gained from the research led to a practice project based on regard for sexual well-being, enabling social work practitioners, and other professionals, to confidently and knowledgeably explore sexual well-being with service users who wish to do so. Making the insights from this research useful to practice requires overcoming barriers to practitioner engagement with learning and research, and I develop a learning tool and practitioner research network as potential ways of addressing these barriers.

I end this thesis with a narrative review of my work, identifying both potential contributions to knowledge and potential limitations.

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Chapter 1: The Doctoral Journey

Introduction

This thesis investigates the meaning of sexual well-being for adults with physical impairments.

Sexual well-being is potentially one of the most significant aspects in life (Taylor, 2011), deeply connected to human well-being (Esmail, et al., 2007; Myers and Milner, 2007; Dunk, 2007; Owens, 2015). The concept of well-being is now at the heart of social work practice with adults in England since the implementation of the Care Act 2014 with its underpinning well-being principle (Department of Health, 2014). My research considers how the well-being principle can assist service users to address their sexual well-being.

A professional doctorate is located within my practice discipline (Boud and Tennant, 2006; Fenge, 2009). My research topic, the meaning of sexual well-being, arose from questions posed by a profoundly physically impaired young man with whom I worked. For him, the absence of an intimate relationship and even opportunities to meet people was the source of emotional discontent made manifest in physical symptoms of stress such as spasms, as well as low mood. Becoming alert to his sexual well-being needs, and the revelation that his situation is the case for others too, has continued to motivate me throughout the long doctoral journey. I have been able to put this knowledge to use within my practice and have become a source of information for other practitioners. Changing this situation, with its negative impact on service users, is the motivation for this research which is a:

“journey of personal and professional development which enables individuals to use their experience and knowledge from practice to inform their study”

(Bournemouth University, 2015a, 12.5.1).

I have been a social worker for over 20 years, participating in the many changes to the profession during that time. I have critically analysed the social and political framework within which social work operates in order to contextualise the purpose of my research. This reflects daily social work practice, which must critically examine situational factors, the politico-economic context and the power relations involved in the life circumstances of those with whom we work in order to understand and act (Parker, 2007). This includes how and why the law defines sexual activity (Sexual Offences Act, 2003) and disability (Equality Act 2010 (S6 (1))), and determines services and need (Care Act, 2014).

Undertaking a Doctorate of Professional Practice (hereafter the 'D Prof' or 'Doctorate') at this point in my social work career prompted me to examine my changing identity, reflecting on my growth as a confident and capable practitioner and, latterly, my development into a researching practitioner, and now fledgling academic. I empathise with Forbes's (2008) account of her own research experience in which she grapples with the self, continually remaking herself through new learning and transformative thought which create 'ruptures and shifts' (Forbes, 2008, p450). Throughout this thesis, I return to my own shifting 'situatedness'; at times in harmony with my work and self, while at others in a battle between competing selves or multiple subjectivities (Ruch, 2000) and emerging knowledge. Research is more than learning to be able to do – it is:

“also about self and others, research as a social practice and the engendering in participative learning of a new more ethical self-positioning and identity in relation to others”

(Forbes, 2008, p.451).

To denote my location within the research I use the first person throughout this document. To do so is unusual in doctoral-level study, however, the Professional Doctorate is specifically designed for the practitioner/researcher and recognises the subjectivity this duality brings (Fenge, 2009). It is a means of generating knowledge from practice where the researcher is embedded as a practitioner, but

takes a critically reflective stance examining their actions and assumptions, and the social context in order to develop practice (Smith, 2008). The capacity to critically reflect is equally core to critical social work practice, where reflection on and in action lead to insights which stimulate change (Trevithick, 2005). In addition, reflective social work, like qualitative research, recognises the active participation and influence of practitioners in knowledge construction (Healy, 2014). With this commonality between critical social work and research in mind, undertaking the D Prof has been the ideal means for me to further develop these critical skills and offers the opportunity to contribute to professional knowledge and practice in a way that is especially meaningful to practitioners, emerging directly from the complexity of social work experience.

My journey to becoming a researching practitioner has taken a thoughtful path, and has involved me taking time to clarify the question and gain a deeper understanding of what I am seeking to achieve. I set out with grandiose aims to develop new and revolutionary services, however, what has been revealed during the course of the research is that for social work to focus on sexual well-being, information, knowledge and an attitude which values disability and sexual well-being are required. The dominance of a culture which devalues social care (Lymbery, 2014) and disability (Briant, et al., 2013) needs to be challenged, and this can be effectively achieved through raising awareness and sharing knowledge about the lived experience of disability and sexual well-being. My research seeks to provide and disseminate this knowledge to social work practitioners, as it is from such learning that social change flows.

Literature concerning disability is not usually read by the general population, or even social workers, who instead get their ideas from cultural imagery (Milligan and Neufeldt, 2001). Therefore, challenging attitudes around sexuality and disability requires a different approach other than the production of academic literature. One way of doing this is suggested by Milligan and Neufeldt (2001) who state that professionals can challenge attitudes by helping to foster positive regard in people with disabilities towards their own sexuality. This is dependent on professionals' knowledge and skills of reflexivity through which we understand how we and others

exist *within* our context and also act as an influence *on* our context (Savin-Baden, 2004). Such reflexivity leads to an understanding of our values and openness to addressing sensitive subjects such as sexual well-being, thereby helping to raise awareness of the issue within professional networks. Identifying a means of achieving this awareness raising within social work practice has led me to the development of a learning tool to provide information and stimulate personal reflection. This tool includes voices from my research findings, as I believe people's stories of lived experience have the power to transform attitudes.

This opening chapter develops these introductory comments, providing details of both my motivation and practice context, and how these have interacted to influence the nature of the research and its dissemination.

1. Why study sex and physical disability?

At the outset of this research I worked exclusively with physically disabled people. Part of my professional purpose had been to assist in identifying service users' needs and desired outcomes and plan how these could be achieved. Within my work, sexual well-being has been an outcome sought by a number of physically disabled service users, but one that is difficult to achieve. It is, potentially, one of the most meaningful aspects of human life but is rarely addressed in health and social care practice (Taylor, 2011). It is a sensitive issue that makes many professionals feel uncomfortable, or even fearful (Medlar, 1998; Walters and Williamson, 1998; Guest, 2000; Weerakoon, 2001; McLaughlin and Cregan 2005; Shuttleworth, 2010; de Than, 2015). Discussions with social work colleagues confirmed an apparent reluctance for practitioners to get involved matters of disability and sexual well-being, some even expressing surprise that it should be an issue considered within practice. This reflects societal attitudes to both sex and disability, which are so ingrained in myself and others that overcoming our inhibitions requires conscious effort and even overt permission.

Through my research I have become aware of the frustration many people with disabilities experience regarding their sexual well-being. Frustration not just about the nuts and bolts of 'doing it' but about the effects an unsatisfactory or absent

intimate life has on the sense of self (Kaufman et al., 2007). Many researchers suggest that sexual activity remains a very important part of life, and indicate that sexual satisfaction, intimacy and love are directly related to quality of life (Walters and Williamson, 1998; Tepper, 2000; Browne and Russell, 2005; Wiegerink et al., 2006; Liddiard, 2013a; Owens, 2015). This research and my professional encounters have led me to question what sexual well-being means for people with physical impairments and how social work practice can be enabled to effectively address this aspect of life.

Despite the significant improvements to the quality of life of people with disabilities brought about by years of campaigning by disability organisations and the subsequent equality legislation (such as the Disability Discrimination Act 1995 and Equality Act 2010), sexual well-being has received little attention (Shakespeare, 2000, Liddiard, 2013a). The literature review reveals that people with disabilities still experience discrimination regarding their sexual well-being, with the notion of asexuality or deviance remaining prevalent in their personal accounts (Shakespeare et al., 1996; McCabe, 1999; Mills, 2001; Weerakoon, 2001; McCabe and Taleporos, 2003; McLaughlin and Cregan, 2005; Esmail et al., 2007; Stevens, 2010; Liddiard, 2013a) as well as in cultural representations of disability (Darke, 2004; Tepper, 2000; Milligan and Neufeldt, 2001; Harris, 2002; Gowland, 2002; Dune and Shuttleworth, 2009; Stevens, 2010). This perception of asexuality or deviance, with service providers tending to disregard sexual nature and needs (Shakespeare et al., 1996; Milligan and Neufeldt, 2001; Kaufman, et al., 2007; Bywater and Jones, 2007; Owens, 2015), is a failure to recognise people's full humanity and is therefore contrary to a holistic or person-centred approach to social care service provision.

“Being deemed asexual is the most egregious sexual harm that disabled people contend with because it is a direct assault on our personhood”

(Stevens, 2010, p.62).

In contrast to the narrative of asexuality, my professional work, the literature review and interviews undertaken for this research all reveal that while impairment might

affect a person's expression of their sexuality, it has no connection to asexuality or deviance. I consider this narrative of asexuality to be central to the topic of sexual well-being. It is a form of 'othering', creating a different, unequal 'them' whose very difference enables the dominant, able bodied from identifying with or thinking about disability (Kaufman et al., 2007). This relates to Goffman's (1963) social analysis of stigma: people experience pressure to conform to a socially accepted type (which, it can be argued, is the purpose of rehabilitation) and those that cannot, or will not, change experience stigma. Inequality is experienced as stigmatising: once a person experiences the difference of not being equal to others they become invisibly labelled, outside of the mainstream majority (Burke and Parker, 2007) and therefore at risk of abuse (as identified by Bournemouth, Dorset and Poole Safeguarding Adult Policy (2015)).

The condescension towards disabled people (for example, the notion of the 'brave' disabled) and the labelling of those who use social care services (for example, deserving and undeserving) are stigmatising, and this stigmatisation renders the person asexual (Milligan and Neufeldt, 2001). This experience makes disability more than just physical impairment; it renders it a political issue, created by environmental and societal structures (Oliver, 1996; Oliver and Sapey, 2006). A full discussion of the definition and models of disability, along with analysis of the impact of political and cultural ideology on the discourse of disability features within the literature review.

2. Why a Professional Doctorate?

The Professional Doctorate, unlike the PhD, is designed for professionals wishing to undertake practice-focused research whilst remaining in practice, giving an 'insider' perspective by creating knowledge in action (Fenge, 2009). It is an effective route for bridging the perceived gap between theory and practice (Scourfield, 2010). It shares many of the same features as 'real world' research which "is the cornerstone of applied learning, evidence-based policy and informed decision making" (Robson, 2011, p.10). The D Prof requires the same level of academic rigour as other doctoral programmes and is a challenge to achieve whilst also in social work practice. The emotional labour required in practice – both the

commodified, emotional performance (Hochschild, 1983, cited in Howes, 2008) and the genuine human-to-human exchange of emotion occurring within the often intense situations encountered in social work – can be draining physically and mentally (Howe, 2008; Foster, 2010). I contend that this labour leaves little energy for academic endeavour, so undertaking doctoral study undoubtedly requires stamina and determination. At the outset of my research journey, I was told by a supervisor that ‘a fire in the belly’ is needed to maintain momentum for what would be a long trek. The ‘fire’ for me has been the recognition of the inequality and stigmatising of marginalised groups and the deficit in knowledge about sexual well-being. This has led to the desire to contribute my learning to improve social work practice.

The need for such determination beyond the considerable demands of practice, alongside employers giving research activities a low priority, may account for the low numbers of doctoral students amongst social workers in comparison with other professions (Scourfield, 2010). However, Scourfield (2010) and Boud and Tennant (2006) report that this situation may be changing with the increase in availability of D Prof courses in the UK which offer:

“diversity within education and the candidate population...increasing participation of women, more part-time students, greater age mix.”

(Boud and Tennant, 2006, p.294).

This diversification makes doctoral study more accessible, especially with the potential for part-time study. It enabled me to participate in doctoral education from which I was otherwise excluded due to economic constraints as well as family and employment commitments.

I was the first social worker in Dorset to receive local authority sponsorship for doctoral research. The purposes of a local authority and a university are clearly very different, so straddling the two means juggling diverse requirements. My ‘day job’ involved being focused on people and the bureaucratically prescribed tasks

which are a feature of modern social work. In contrast, my research has been largely autonomous with guidance and support from peers and supervisors. The regular peer group supervision marks a significant difference between the professional doctorate and a traditional PhD. This was an important factor in my decision regarding whether undertaking a research degree was realistic. I was aware that the majority of my studying would take place off campus, away from an academic environment, where distractions would be rife. But such study is also about being separate from the shared learning community and academic atmosphere, and the succour which comes from being present. Without the nourishment (Carr et al., 2010) of monthly group sessions where research progress is shared and critical thinking developed (Fenge, 2009), I was aware that all too easily time could pass without any advances being made.

My sponsorship has been unrestrained by any formal reciprocal obligation. Most social workers undertaking Professional Doctorate qualifications hold senior posts within an organisation (Scourfield, 2010) and may have to undertake research into an organisationally prescribed topic. This makes my sponsorship unusual as I am neither a senior manager, nor was I guided in my choice of research subject. I was fortunate to be managed at that time by an individual committed to practice development and innovation who advocated vigorously for my sponsorship.

Without the influence of this individual, my research journey may not have begun. This reflects the absence of clear academic practitioner development pathways (Carter, 2014), but also the lack of funding for social work research which then impacts on the development of the profession's evidence base (Bywaters, 2008; Orme and Powell, 2007; Howard, 2009; Carter, 2014). These issues are discussed in Chapters 2 and 7 in relation to my practice development work.

First and foremost I see myself as a social worker: in my personal narrative I am cast as the 'good guy'; my social work role imbues me with courage, its radical history suggests something of the anti-hero who, despite the frequently bad press, upholds the faith in principles of social justice (or at least my interpretation of them). Therefore, my work is a crucial part of how I understand myself to be. I

remain committed to social work, yet I am also a curious student seeking the opportunity to learn and be challenged – and I certainly have been challenged. Undertaking this research caused me to fundamentally question what it is that I do in my professional role and why. Engaging in education at any level prompts reflection on the self and on the context of practice, but involvement in qualitative research in particular is likely to profoundly change the researcher (Davison, 2004). This has become manifest in myself in the multiple conflicts both within myself and with management as I attempt to reconcile professional values with everyday social work practice. My reflexivity has resulted in ‘ruptures’ and the stability of my pre-doctoral study self has been ‘re-examined, called into question and subverted’ (Forbes, 2008, p.451) by my becoming research minded. Reflexive inquiry:

“unsettles representation by suggesting that we are constantly constructing meaning and social realities as we interact with others and talk about our experience”

(Cunliffe, 2003, p.985).

This means that as a practitioner and researcher I need to be aware of my self-construction and to disclose my value-base to research participants (Savin-Baden, 2004) in order to be honest about the interpretation through which I filter my learning and my experience of the world (Alvesson and Skoldberg, 2000). This has led me to recognise power imbalances within society established through, and maintained by, ideologically informed social policy leading to the exclusion of marginalised groups from the full benefits of sexual citizenship. My work responds by using my learning and status as a peer to raise awareness of sexual well-being amongst social work practitioners and to contribute towards increasing awareness of this topic within wider society.

3. Overall D Prof aims and objectives

Aims:

- to understand the meaning of sexual well-being for a sample of physically

disabled adults;

- to communicate this new knowledge to inform social work practice with physically disabled people.

Objectives:

- to critically examine existing knowledge of social work, sexual well-being and well-being;
- to explore the social work task with disabled people through a personal narrative;
- to gain a deeper understanding of sexual well-being and the lived experience through a phenomenological approach;
- to develop a practice-based learning tool.

4. Thesis structure

Given the above aims and objectives, the thesis is divided into chapters to provide clarity about activities undertaken, amounting to a comprehensive argument about the relevance, necessity and usefulness of my research. Undertaking a professional doctorate is a journey of personal change; the thesis becomes, in part, a journal recording one's own changing perspective. To reflect this, the narrative element of my thesis is not limited to one chapter but is woven throughout.

This thesis begins with the aims of my Professional Doctorate establishing at the outset the purpose of this study. I provide details of my professional practice context, giving insight into the current operation of social work in England and its historical foundation, which is useful for a deeper appreciation of how change has influenced contemporary social work. This contextualisation leads into a narrative section giving an account of my development as a researching practitioner. I explain how, in the course of my own development, I recognised the barriers to practitioner research engagement. I recount my endeavour to help practitioners become more research minded in light of these barriers to share my own

experience in order to develop practice. This researcher development section concludes with a positive account of the potential for the Principal Social Worker role to mediate between social workers and senior management in advocating the importance of practitioner engagement with research, and the potential for the Pan Dorset Health and Social Care Academy to provide the forum to facilitate this engagement in Dorset.

Having become aware of the apparent gaps in knowledge regarding sexual well-being and disability I then progress to the literature review to fill or confirm these gaps. Within the literature I consider the purpose of social work with physically disabled people and how this has changed in light of the progress made by the disability movement towards inclusion and equality. The literature provides insights into the lived experience of disability, which is crucial for the content of a practitioner learning tool. In addition, I explore how concern for sexual well-being fits within the professional social work task. An examination of the concept of well-being follows, with consideration of how and why this has become significant to social policy, and to social work in particular, following implementation of the Care Act 2014. This part of the literature review demonstrates the interrelationship between sexual well-being and general well-being, but its absence from the well-being literature.

Having identified gaps within the literature, I then account for my search for a methodology which enables me to explore the lived experience of sexual well-being and disability. I explain why I require a methodology which is both compatible with my professional values and prioritises the voices of my research participants whose insights illuminate the meaning of sexual well-being. This flows into a critical exploration and discussion of methods used to fill the gap in the literature and to answer the research question regarding the lived experience of disability and sexual well-being. This section analyses the advantages of using interviews, but also the potential for bias and problematic evidence that interviews bring. As a D Prof, a further purpose of data collection and analysis of findings is to draw out implications for practice and presentation of these in a usable format, in this case the creation of a practitioner learning tool.

I then progress to my research findings where analysis of in-depth interview transcripts reveals the complexity of the lived experience of sex and disability. The participants have given powerful and heartfelt insights and the addition of their voices to a practitioner learning tool strengthens its effectiveness, responding to the call for "research that produces more faithful representations of the lived experiences of service users" (Phillips and Shaw, 2011, p.609). A phenomenological approach to this research seeks the essence of sexual well-being through exploration and description of the lived experience (Finlay, 2009b).

The discussion section is divided into three parts. First, I link my findings with the humanising care theoretical framework (Galvin and Todres, 2013) which provides a rationale for care based on the meaning and experience of human well-being. I demonstrate alignment between the humanising framework and Care Act 2014 well-being domains which offers social workers the opportunity to focus on well-being as well as address sexual well-being. The final part of the discussion chapter turns to my concern for the well-being of practitioners. I argue that the humanising approach to care enables a 'humanising attitude' to develop which can transcend and endure the current context of social work characterised by change and conflict. The discussion chapter provides the underpinning philosophical approach for the practice development project which is reported in the following chapter. This is an account of how the power of my research findings has compelled me to search for a means to communicate my work in a format that is relevant and accessible to practitioners. I discuss the development of a flexible and interactive learning tool and the challenges and opportunities of developing and disseminating tools for practice.

The final chapter draws my thesis to a close, revisiting the key messages and discussing the limitations of my research and practice development. I identify areas which require further research and make a number of recommendations based on insights from this research.

5. My location within the language of disability

Language is a powerful, value-laden tool in the construction of socio-political concepts (Healy, 2014) and can be used to challenge or reinforce oppressive ideas. Therefore those who control the language control the nature of the discourse.

The Disability Discrimination Act 1995 defined disability as:

“A physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities”

(Disability Discrimination Act 1995, Section 1).

Following successful campaigning by the disability movement, disability was defined in Improving the Life Chances of Disabled People (2005) with a social model emphasis as:

“...disadvantage experienced by an individual resulting from barriers to independent living, or educational, employment or other opportunities that impact on people with impairments and/or ill health”

(Cabinet Office – Prime Minister’s Strategy Unit, 2005, p.8).

However it was replaced in the Equality Act 2010 with:

“A person (P) has a disability if –

(a) P has a physical or mental impairment, and

(b) the impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities”

(2010, Section 6 (1)).

This definition maintains the situating of disability within the individual rather than the socio-political environment. My use of the term ‘physically disabled people’ challenges this individual focus. The term signifies my alignment with a social

model definition of disability where disability is created by social organisation, not by having an impairment. It represents disability as:

“the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It arises from the social, economic and physical environment in which people with impairments find themselves”

(Burchardt, 2004, p.736).

However, impairment cannot be equated, or used interchangeably, with disability because many non-disabled people have impairments (for example, short-sightedness) but are not disabled (French and Swain, 2000).

6. Definition of sexual well-being

The World Health Organisation’s (WHO) holistic definition of sexual health encapsulates its multi-faceted nature including mind, body and environment:

“Sexual health is a state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction.”

(World

The term ‘well-being’, rather than ‘health’, is used in this research to distinguish the topic from medical matters such as fertility or sexually transmitted diseases, whilst retaining all the elements of the multi-faceted definition of sexual health in the WHO statement.

Well-being is a contested term, a social and cultural construction defined by the agent employing it (Ereaut and Whiting, 2008). A full discussion of the origin of the

concept of well-being and its current political application in social policy occurs within the literature review. However, the meaning of well-being utilised at the data-gathering stage of the research relates to how people experience their lives – specifically their sexual selves. It is not only the absence of problems or the presence of happiness but concerns the person's experience of self-actualisation, social integration, expectation and equality of potential – mind, body and environment (Local Government Improvement and Development Report, 2010).

The use of the term well-being also purposefully references my research to the work of Galvin and Todres (2013) on the humanisation of care services through the employment of a life-world approach. They developed a conceptual framework of eight dimensions of humanisation and demonstrate the applicability of each to care activities. Galvin and Todres' work responds to the recent debate about the apparent lack of care in UK health services (highlighted in the Mid Staffordshire Hospital case and subsequent Francis Report, 2013). I argue that their work is equally relevant to social work which has become increasingly bureaucratised since the NHS and Community Care Act 1990 at the expense of relationship-based practice (Jones, 2001; Williams, 2001; Ruch 2005; Munro, 2011; The College of Social Work, 2014a). I use Galvin and Todres' conceptual framework of a humanised approach to care to inform the design and development of the practitioner sexual well-being learning tool, as discussed in the later practice development chapter.

7. Practice context

To locate my research within my professional context I have critically analysed the social and political framework within which social work operates. This includes examining the situational factors involved in practice: its politico-economic context and the power relations involved (Parker, 2007).

In-depth examination of social work practice from a critical perspective provides insights into the complexity of social and political organisation and the place of social work within these structures. Beresford (2013) suggests that such examination reveals that outcomes of social work interventions may be very

different from the declared intentions, for example, social workers being social controllers rather than agents of change.

7.1. What is social work?

Social work is a broad profession working with people across the life-course and in multiple sites from large institutions such as schools and hospitals to individual homes. Social work encompasses children and adult services, involving such concerns as mental health, disability, housing issues, poverty and marginalisation in all its forms. Each service operates specific systems and approaches relevant to that context as determined by legislation and statutory guidance. This very diversity leads to contention about the definition of social work and its potential to be a cohesive profession (Moriarty et al., 2015a).

Social workers operate between the state and service users, trying to appease both whilst also protecting some personal interests (for example, their own mental well-being) (Carey, 2008). Traditionally, social work has been focused on individual and family casework – the micro level – which allows for an individualised client-centred approach. There have been long-standing debates about whether social work should be focused on the personal or the social (recounted by Jones, 2014, amongst others). But professional practice focused solely on micro-level work separates care from social justice at an organisational level and this has resulted in the marginalisation of welfare (Bradt and Bouverne-De Bie, 2009). For social justice to be part of social work practice in action, as well as values, social workers need to critically consider the impact of macro-level culture and society in order to provide insight into the construction and solution of social problems (Bradt and Bouverne-De Bie, 2009; Hugman, 2009). Examination of macro-level cultural oppression explains why mainstream, micro-level interventions and traditional approaches to social problems do not work without changes to social structural organisation (Turbett, 2013).

To challenge the traditional focus on the individual, social work needs to be a social political practice that connects individual work with community and social policy. A binary division between micro and macro work is simplistic; social needs have both

individual and social aspects (Hugman, 2009). Social workers need to find a way of working across these levels, which involves critically examining the situational factors connected with practice: combining service delivery with social action analysing the economic context and the power relations involved (Parker, 2007).

Parker (2007) recognises that statutory social work is determined by law; therefore, its prescribed tasks reflect the priorities of the dominant political ideology of the day. However, in contrast, social work often represents itself as apolitical (Ferguson and Lavalette, 2013b). For social workers motivated by the wish to improve lives, this contradiction is a fundamental challenge to their integrity, setting up emotional dissonance (Galliana, 2010).

Some commentators, such as Bell (2012) and Jones and Lavalette (2013), argue that the purpose of social work is to focus on social change to improve lives and achieve the goals of social justice. However, without a clearly articulated means of achieving this, the profession will remain contested, and therefore vulnerable to political ideology (Munro et al., 2005). Social work is contested, both by those within and without the profession, about what the role and theory should be (Ferguson and Lavalette, 2013b; Moriarty et al., 2015a). Some academics challenge the notion that social work concerns changing society, stating that it is in fact a normalising, controlling profession (Herz and Johansson, 2012; Galliana, 2010; McLaughlin, 2010; Bradt and Bouverne-De Bie, 2009; Jones and Lavalette, 2013). McLaughlin (2007) argues that social work does not have a fixed identity, but can be so loose and changes so fundamental that it is no longer social work.

Ferguson and Lavalette (2013b) make a clear distinction between popular social work undertaken with disadvantaged individuals and groups challenging inequalities (agents of social change), and state social work performed by the majority of social workers in the UK as part of local authority employment concerned with “surveillance, rationing of resources and control” (Ferguson and Lavalette, 2013b, part one). Social work in the UK is largely statutory, unlike in other societies where a community focus is highlighted. This can be linked to its early roots in the administration of the Poor Law, with social workers today carrying

out the tasks of the Poor Law Relieving Officers, such as assessing need and arranging residential care (Rashid, 2000). This distinction is illustrated by the mismatch between social work definitions and what practitioners actually do in the UK (Jones and Lavalette, 2013), highlighted by the International Federation of Social Work's (IFSW) definition of social work put forward at the IFSW general meeting in July 2014:

“Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance well-being.”

(IFSW, 2014)

The IFSW definition is aspirational, describing what Jones and Lavalette (2013) and Ferguson and Lavalette (2013b) call popular social work. It makes social change an intentional outcome, yet front-line practice in the UK is focused on micro-level interventions, helping improve lives but making little impact on structural inequalities as it does not ‘speak to power or campaign’ (Beresford, 2013, part one). Social work elsewhere, specifically the Global South has an alternative focus on community work (Hugman, 2009, cited in Moriarty et al., 2015a). However, social work in the UK is wider than front-line work: senior local authority managers, policy makers and academics, many of whom will be registered social workers with the Health and Care Professions Council (HCPC), do speak to government including via the chief social workers, Isabelle Trowler and Lyn Romeo. But the issue is, first, what (statistics or accounts of the lived experience of practitioners and service users) and how evidence is presented, and how much the government is able to listen to complex information which may conflict with other governmental priorities (for example, funding conflicts between departments) and ideology. The impact of ideology on social work is explored in the literature review.

7.2. Historical contextualisation

Statutory social work's position within the UK's socio-political organisation is within the welfare state. Social workers are an arm of social policy whose duties and responsibilities are set out by the law, which also defines social problems and thereby determines who service users are (Harris, 2005). Social policy developed during the nineteenth-century period of industrialisation, building on the Poor Law, to manage the social problems "created by naked capitalism" (Ferguson and Lavalette, 2013b, part one). The post war consensus of the late 1940s, taking note of civil disturbance regarding poor living conditions, health and lack of adequate pension provision, saw cross-party agreement in the value of reforming capitalism from above rather than having revolution from below (Beresford, 2005), with social work as part of the strategy to improve (or control) the lives of the least advantaged. The key architects of post war reconstruction, Beveridge and Keynes, advocated that the state could be both the caretaker and the moderniser of society, the funder and provider of services emphasising the value of creating a secure society within a capitalist framework (Butcher, 2000). This led to a form of welfare capitalism dominating social policy from 1945–1979 where a combination of Keynesian economics and governmental economic instruments financing, providing welfare and managing the economy aimed to reduce instability, minimise unemployment and eliminate poverty (Davies, 2000). Welfare was organised around the 'ideological triangle' of nation, family and work: a normalising, gendered conception which remains resonant today with the emphasis on work as the route out of poverty and into social participation (including: Morris, 2001) while women remain principal care providers both within the home (Stokes, 2013; Carers UK, 2015) and through employment (Franklin, 2014).

Since that time a major change to the administration of welfare has been of particular and ongoing significance to social work:

"The NHS and Community Care Act 1990... introduced management and business approaches such as markets and the purchaser/provider split"

(Ferguson and Lavalette, 2013b, part one).

Competition was introduced as the driver and guarantor of responsive, quality services. The Conservative government of 1979–1997 aimed to ‘roll back the state’ (Harris, 2005) as public welfare spending was considered (then, as now) to be the cause of economic problems (Jones, 2000; Harris, 2005; Ferguson and Lavalette, 2013b). Such a negative view of public spending frames welfare as a burden rather than the expression of responsibility of citizenship and continues into current welfare discourse (Briant et al., 2013; Zipfel et al., 2015).

The NHS and Community Care Act 1990 radically reformed social work through its introduction of the Care Manager role and managerialism to adult social work. Both of these organisational instruments have had a profound and enduring effect on the purpose, practice and experience of the profession. I contend that the barriers to practitioner research engagement which I have encountered during my research journey can be partially accredited to the loss of professional confidence and innovation brought about by managerialism stifling creativity (The College of Social Work, 2014b; Beresford, 2013). Managerialism assumes better management will resolve economic and social problems. It is a feature of the dominance of neo-liberal capitalism with managerialism conceptualising the service user as customer and society as a market (not a community), with relationships based on cash and contract (Jones, 2000; Butcher, 2000; Beresford, 2005; Farnsworth, 2006). Care management is a prescribed role leaving little scope for professional discretion and has been identified as deskilling practitioners, making it a technical exercise characterised by a routine approach and the loss of reflexivity (The College of Social Work, 2014b).

The introduction of these ideas into social care was part of the rise of neo-liberalism based on the economic theory of Hayek (New Economics Foundation, 2015) advocated by Margaret Thatcher, the British Prime Minister from 1979 to 1990. Within neo-liberal economic theory market value becomes the basis of decision making which seeks to rescue services from the inefficient public sector (Farnsworth, 2006). It prioritises management and business knowledge as the key to increasing efficiency, which is the measure of success (Tsui and Cheung, 2004). Taxation is considered a disincentive and to be coercive (Le Grand, 2000) rather than a contribution to the social good, and whilst inequality may result from free

market activities, individuals are seen as being free to improve their situation through exercising their capacity to make rational choices to maximise their advantage.

This managerial approach to social care has been problematic, even controversial, seen as a means to make social work interventions standardised and routine (Tsui and Cheung, 2004; Thompson, 2006; Coulshed and Orme, 2012; Beresford, 2013) – a matter of common sense, which anyone can carry out (Coulshed and Orme, 2012). However, human service organisations are based on different values and principles to those of the market, values which cannot easily be accounted for fiscally. In addition, bureaucratised approaches to social work reduce complex problems to quantifiable variables, requiring workers to inappropriately commodify people (Carey, 2008). This creates conflict within social workers between their professional values and the tasks they are expected to enact. It is as though policy states social work intervention is driven by 'care' while practice experience suggests policy is driven by resources (Ferguson et al., 2002).

The 1990 NHS and Community Care Act enabled the transfer of long-term service users from institutionalised settings into the community. The Act also widened the provision of home care from private care agencies. However, continually restricted financial commitment from successive governments has meant that the policy has not been entirely successful; indeed 'community care' has become an ongoing narrative of failure which is now embedded and normalised (Beresford, 2013). Failure of community care policy is blamed on flawed systems and professional inadequacy rather than governmental economic choice. In addition, the marketisation of social care has created unstable provision (for example, the failure of Southern Cross (Dunning, 2011)) and a care sector characterised by poor pay, zero hours contracts and high staff turnover (Moriarty et al., 2012; Skills for Care, 2014a,c). Failures, such as the closure of Southern Cross, the "biggest provider of residential care for older people in the UK" (Ferguson and Lavalette, 2013, part one) all contribute to the generally negative perception of social care (Beresford, 2013).

New Labour's Third Way approach to welfare continued marketisation and globalisation, forcing social work into a business performance model where best

value, judged against targets and performance indicators, became the basis of practice judgements (Jordan and Jordan, 2000). Globalisation, dominated by neo-liberal emphasis on free markets and the associated economic rights of the individual, has become the context of the welfare state and statutory social work organised in terms of commodity, production and consumption (Ferguson et al., 2005). Globalisation embeds capitalist management structures within public sector organisations (Farnsworth, 2006; Ferguson and Lavallette, 2013b). The reforms New Labour introduced to the welfare state aimed to create an 'enabling state' promoting independence and social and economic inclusion whilst requiring civic responsibility (Department of Health, 2005). Through its Modernising Social Services (1998) agenda and subsequent social care legislation, policy and guidance, the vision of a transformed adult social care sector was provided which focused on prevention, choice, provision of information, use of technology and integration of health and social care. The concept of personalisation was introduced extending direct payments and emphasising independence, choice and control over services. Social workers in this model became brokers and advocates (Department of Health, 1998) and continued to be assessors of eligibility. Harris (2005) argues that because no alternative economic system was advanced, capitalism became self-legitimising and was seen as the only system capable of delivering economic growth. The economic downturn of 2008 has challenged the supremacy of free market capitalism, but it remains the dominant economic instrument in western societies with no alternative system widely promoted (Jones 2014; Peston 2012; Hutton, 2011; Chang, 2010).

The Conservative-led coalition government of 2010–2015 and subsequent Conservative government extended the conceptualisation of service users as consumers with responsibility for their own health and well-being, emphasising choice and control, prevention and active citizenship. The 2010 document *A Vision for Adult Social Care: Capable Communities and Active Citizens* (Department of Health, 2010) outlines the vision which has subsequently set the agenda for the reforming Care Act 2014. I quote extensively from this document here because it summarises the current professional context for my research and illuminates the

political influences on disabled people's lives examined further in the literature review:

“People’s expectations are changing, and neither those who provide the services nor those who receive them expect to trade autonomy for dependency. The answer is to strengthen communities, while changing the role and our relationship with the state. It is a new vision for government which does not simply look to the state for answers to the issues we face, but outwards to communities. This approach underpins our vision for social care – a vision grounded in the Coalition Government’s values.

The first value is Freedom. We want to see a real shift of power from the state to people and communities. We want people to have the freedom to choose the services that are right for them from a vibrant plural market.

The second is Fairness, through a lasting settlement to the question ‘how do we pay for care?’

The third is Responsibility. Social care is not solely the responsibility of the state. Communities and wider civil society must be set free to run innovative local schemes and build local networks of support”

(Department of Health, 2010, foreword).

This outline of government purpose establishes the agenda for change through which my research has been undertaken; an agenda which continues to change the lives of service users and social work practitioners with benefit cuts, cuts to services, organisational restructuring and changes to education provision, all of which have made social work a difficult and stressful profession (Moriarty et al., 2015a) and the lives of service users often more challenging (Joseph Rowntree Foundation, 2016a). Nonetheless, government states that social workers have a crucial role in the reformed care system, as a skilled workforce increases the quality of provision which, in turn, leads to service users having a reduced need for ongoing care and support (Caring for Our Future, Department of Health, 2012). Modern social work is concerned with supporting people to live independently,

promoting choice and control, enabling people to manage their own risks and knowing and applying legislation. These are tasks which are compatible with social work values and, therefore, uncontentious in themselves. However, within the context of austerity these tasks take on a different, ideological, meaning which potentially leads to conflict for social work practitioners attempting to reconcile their values with what they do. This point is explored in the literature review where I examine the influence of ideology on practice and how an appreciation of this influence can assist with the development of the content of the practitioner learning tool.

7.3. Regulation

Social work in England is a regulated profession, currently overseen by the Health and Care Professionals Council (HCPC). A new regulatory body was announced by Nicky Morgan, Secretary for State for education, on 14 January 2016 (Community Care, 2016). The HCPC standards require social workers to practice legally and ethically, including ensuring that relationships with service users are based on respect and honesty, acknowledging the power dynamics within such relationships (HCPC Standard 2). The standards indicate that social workers need to be multi-skilled and must have, amongst many other abilities: high quality interpersonal skills; the ability to engage with the often difficult to reach; the ability to understand human behaviour; an appreciation of the matrix of influences on service users lives; the skills to analyse data; and the ability to manage administrative tasks efficiently. The 2015 report from the service user network *Shaping Our Lives* (Meakin and Matthews, 2015) expresses concern about the ability of social workers to continue to meet the professional standards in light of public spending cut backs since 2010 which resulted in cuts to staff numbers (reported in *Community Care* 3 February 2016). This highlights the very challenging practice context in which this study takes place, something my own professional experience confirms.

7.4. The relevance of this research to safeguarding adults

Social work is becoming increasingly focused on regulatory processes with the concept of risk being central to policy and practice (Pollack, 2010). Some sections

of the population are labelled as particularly at risk, including disabled people (Hollomotz, 2010). During the period of my research, practice in relation to safeguarding adults has altered; a change reflecting the outcomes of multiple serious case reviews and reports from children and adult services. The focus of public services has moved towards safeguarding people deemed to be at risk so social work concentrates on risk avoidance rather than the enablement of rights (de Than, 2015). My research, valuing the ideals of personalisation and a rights approach to social work, is particularly relevant to safeguarding as:

“The vision for adult social care and health services is one where the person has real choice and control over what happens ... aiming to promote well-being and prevent abuse and neglect from happening in the first place.”

(Care Quality Commission et al, 2014, p.2).

My work seeks to develop an understanding of sexual well-being amongst social work practitioners, who can then use this awareness to enable the empowerment of vulnerable adults to protect themselves. Such an approach will also counteract the narrative of vulnerability, by raising awareness, confidence and sexual self-esteem. Social workers have a unique role, with privileged access to often marginalised people, and our preparedness to discuss difficult and sensitive subjects is a professional strength (Bywaters and Ungar, 2010). But this requires confidence and the provision of quality information and training.

Safeguarding adults concerns human rights: all people have sexual citizenship, access to justice, the right to a private life and to participate as full citizens with access to social opportunities, work, education and recreation. For practice to advance human rights it is not enough to avoid oppression; it also has an obligation to promote rights, meaning actively challenging injustice and inequality. Well-informed attitudes, promoting the advancement of inclusive citizenship and understanding lived experience, are essential to effectively challenge embedded discrimination and for change to impact on all aspects of society.

The relationship between risk management and risk enablement is particularly

relevant to my research as social workers build the management of safeguarding risks into care planning, including within relationships. This concerns:

“The need to balance a person’s right to a private life with the right for protection if that private life is harmful. A rights-based approach can, therefore, be conceived as a balancing act between different rights. Disabled people must be empowered themselves to be meaningfully involved to get the balance right. Central to a process of balancing rights is a focus on managing risk.”

(Hoong Sin et al, 2011, p.72).

Social workers have to make challenging judgements while being careful not to over risk manage, thereby effectively limiting the social inclusion and life chances of people. We need to respect the independence of service users whilst also having a protective role, using our authority responsibly. The historical exclusion of disabled people from sex education (Shakespeare et al., 1996) along with limited work opportunities, social isolation and the generally negative view of disability impacts on the opportunities disabled people have to participate in the experiences which develop sexual esteem. Marginalised people can experience ‘othering’ which enables abuse and neglect to occur and be sustained. Services which do not acknowledge people’s full potential neglect opportunities to empower service users in this aspect of their lives, leaving them vulnerable to abuse and disadvantage due to lack of self-esteem, confidence or knowledge. Research indicates that disabled people are at greater risk and experience higher levels of targeted violence and hostility compared to non-disabled people (Cunningham and Drury, 2002; Quarmby, 2011; Joseph Rowntree Foundation, 2016a).

Prevention is becoming the primary goal of health and social care (Department of Health, 2016). Preventing people from losing their independence and ensuring that people are well and active citizens reduces demand for services. Prevention requires a change in personal attitude towards responsibility and empowering people to be clear about their rights as well as having the confidence to be assertive. Enhancing safeguarding awareness amongst the users of social care

services is a vital preventative role that practitioners play. In relation to sexual well-being this means that social workers and other care staff must recognise and promote sexual well-being, as the individual defines it, whilst balancing rights and risks.

7.5. Where is the voice of the social work profession?

In this context of reform and changing practice, social work requires a professional voice to relate the lived experience of practice and advocate on behalf of often silenced groups. The Social Work Reform Board led to the establishment of The College of Social Work, along with the appointment of the Chief Social Workers for Children and Adults and the appointment of Principal Social Workers in local authorities for both children and adult services. These roles create the means to increase the professionalism of social work, raise standards and act as a voice for the profession to government. However, to be effective this requires receptiveness and the literature for this study leads me to conclude that receptiveness of government is determined by factors such as political ideology, political philosophy and economic expediency. There seems to be ongoing hostility from politicians towards the public services, as evidenced by:

“Oliver Letwin, the lead policy minister in the Coalition Government, said that public sector workers needed ‘real discipline and fear’ to improve productivity. All demonstrate a hostility to a public service and professional ethic which is at variance with market forces and untrammelled competition as the dominant political, economic and social discourse”

(Jones, 2014, p.489).

Practitioners’ voices are stifled by the extent to which they feel able to engage in activities of social change, specifically whether the surveillance of social workers through regulation allows them to act according to the principles of radical and relational practice (Lymbery, 2013). Professional regulation and the terms and conditions of employment tie practitioners to certain behaviours restricting activities in and outside of the workplace (HCPC, 2016). This has both positive and negative outcomes: whilst it aims at professionalism, assigning social work the same status

as other registered professions, where known standards can be applied, such monitoring can also engender a sense of fear and mistrust (Moriarty et al., 2015a, 13.1) and adds to the notion that social workers are both a danger from and to others (McLaughlin, 2007 and 2010).

In the UK, social work is moving away from the IFSW definition as it becomes increasingly concerned with policing and uncertain about its role beyond legislative operation (Graham and Shier, 2010), with policy regimes moving to pathologising and brutal approaches to poor and marginalised groups (Lavalette and Ferguson, 2013; Briant et al., 2013). Impoverished client groups and a reduction in resources with which to meet increasing need results in uncertainty about social work's legitimate role (Graham and Shier, 2010). In recognition of this ambiguity, the College of Social Work produced the advice note *The Roles and Functions of Social Workers in England* (The College of Social Work, 2014) stating that the role is to support individuals and families to meet life's challenges through safeguarding people's rights and building relationships to support and empower people to make important choices about the direction of their lives using a distinctive range of legal and social work knowledge and skills.

The College also produced (The College of Social Work, 2012) a *Business Case for Social Work* discussion paper which highlights the compelling financial reasons for retaining the social work role as they identify and for managing risk and vulnerability, especially where personalisation has altered the landscape. It reports on the unique preparation through training that social workers have to be able to foster the social capital which makes active citizenship possible. I contend that the definitions of social work, its codes, values and ideals are incompatible with the realities of social work practice in the current social context characterised by the long-term devaluing of the concept of care, with the sense of empathy, respect and the mutuality of the human experience overridden by commodification, obligation and responsibility (Ferguson and Lavalette, 2013b). However, neo-liberal economic discourse has:

“created unexpected spaces for service users of service provider empowerment. Notions of 'choice', so central to neoclassical theory, may create spaces for increased service user choice in some domains of service provision, such as the introduction of direct payments”

(Healy, 2014, p.56).

This means that a balanced critique of political influence is important as polarised thinking reduces debate to simplified ‘good’ and ‘bad’ (Fook, 2002), which is inappropriate for the development of mature practice.

8. Summary

The challenges in social work make it difficult to reflect, with the limited time for reflection being focused on practice issues relevant to day-to-day work rather than thoughts about the larger contextual questions which shape its purpose. However, my research, along with that of other students, is a demonstration that despite the challenging context social work innovation and practice development continue. I also contend that understanding the apparent mismatch between the IFSW definition of social work and what day-to-day UK statutory practice actually is aids practitioners’ clarity about their actions. This clarity enables professional power, discretion, values and theories to be used to create opportunities where the unique skills of social workers can be put to work effectively with service users whilst also developing practitioners’ own resilience. The cynicism of social work professionals (Lymbery, 2013; Jones 2001; Tsui and Cheung, 2004; Carey, 2014) can also be a motivator for change, a theme I return to in the later discussion chapter. It is only by understanding the wider context of social work practice that social workers can be really effective, questioning the assumptions of the socially dominant (Fook, 2002).

However, the challenging context of social work practice makes it is unsurprising that the average working life of a social worker is just 7.7 years (Holmes et al., 2013), with the recruitment and retention of experienced workers becoming a major concern for employers, threatening their ability to meet their statutory duties (Carter, 2016). Adding to this challenging environment is the considerable criticism

of professional university-based social work training (Gove, 2013; Narey, 2014; Croisdale-Appleby, 2014) including claims that ill-prepared, poor quality students are graduating from courses too focused on theory (Gove, 2013). This criticism of education is leading to a series of reforms in the education and practice of social workers, primarily in children and family services but also affecting adult care (Department for Education, 2016). The growth in the fast-track training programmes – Step Up and Front Line in children’s services and Think Ahead in adult mental health social care – have caused controversy within social work’s academic communities. Concerns have been expressed about the promotion of specialist training, the influence of funding sources on course content (partial private financing (*Guardian*, 18 March 2016)) and the quality of the courses which “are training people to do a job...we are educating for a profession” (Samantha Baron, head of social work at Manchester Metropolitan University reported in Brindle, 2015). Baron’s comment reflects concern that graduates from the fast-track programmes will have less engagement with traditional social work values while Ray Jones (Professor of Social Work at Kingston University) states that the expansion of fast-track schemes would mean “disproportionate amounts of funding to this programme and to the students on it, with the larger body of trainees receiving much less advantage and support” (Silman, 2015).

It is my desire to help myself and colleagues understand, and reflect on, the wider social context in which social work operates and in which service users and social workers live that has led to my personal development as a researching practitioner. I now progress to a narrative account of this development and the action I have taken to develop a practitioners’ research network in response to my own growing research mindedness.

Chapter 2 Practice Development Part 1: The Development of a Researching Practitioner

Introduction

As a researcher I am immersed in my research with personal development occurring simultaneously with the advancement of the study (Darlington and Scott, 2002). The practice development element of the professional doctorate turns the focus onto specific aspects of practice, where the researcher is seeking to address a perceived deficit or need. This makes it personal as practice development is about improving the researcher's own knowledge and skills for practice and that of their professional colleagues. Engaging in practice development disturbs the familiar world of practice; for myself this was as though I became both observer and participant, making it difficult to distinguish between myself as practitioner, researcher and student (I imagine the multiple roles humans undertake each day as akin to participating in a dance where context brings one or other movement to the fore; in my case, my dance has expanded to include researcher and student 'moves'). Study encourages critical reflection which has led me to fundamentally question the purpose of social work and how to help others to critically reflect on their professional activities. Without a clear continuing professional development (CPD) pathway (Croisdale-Appleby, 2014) and absence of learning presented in a way that encourages critical reflection (a personal observation on in-house training), it is difficult for social workers to maintain their critical skills (Hart, 2015).

The integration of my new role of practitioner researcher also impacted on my colleagues. They were initially interested and supportive, however, following reorganisation a new team was formed with new management and whilst colleagues remained supportive – if rather bemused about why I should 'put myself through' doctoral study – it became clear from managers that my researcher role must not impact on the work of the team in any way, most especially in terms of mine and others' time. This effectively resulted in me leading a dual life for the duration of my studies; practitioner for part of the week and research student for

the rest of the time, with all research activities undertaken in my own time away from the workplace. Reflecting on this, I appreciate my privileged situation being able to afford to work part time, which enabled me to dedicate time to study. But my experience of the disconnect between work and study, and the absence of management interest, is a lived example of the barriers to practitioner research engagement. These include structural factors such as the lack of time and attitudinal factors such as study and work being considered unrelated activities. The lack of any work-based incentive for undertaking this research means I have relied on intrinsic motivation such as the achievement of a personal academic goal along with a desire to contribute to practice knowledge. Awareness of these barriers motivated this first part of my practice development and informed the nature of the second part of my practice development work.

My research began with a question raised by a service user about their sexual well-being. My inability to locate information or services to satisfactorily assist him unsettled my identity as a confident practitioner. The subsequent exploration of the topic along with my development as a research practitioner has led to a follow up question: how can the knowledge gained from this study be disseminated and used to positively influence social work practice in order to be of benefit to the people with whom we work? My response to this latter query forms the foundation of my practice development project which is twofold:

1. To help develop a culture of research mindedness through the establishment of a research network within Dorset County Council Adult Social Services.
2. The development of a learning tool to provide practitioners with up-to-date knowledge and skills regarding sexual well-being and physical disability.

I pursued the two elements of practice development separately, but concurrently. Both have been subject to the same external influences of professional reform and organisational restructure plus internal influences brought about by competing demands on my own time and energy. I have divided the practice development chapters into two parts as the content of this first part flows from my early

engagement with research activities while the later chapter and learning tool flows from the findings and discussion.

Engaging in my own research has highlighted the barriers to undertaking research whilst involved in the complexity of social work practice which involves conflict between multiple stakeholders, along with changes in personnel, limited funding and uncertainty within the profession regarding essential skills and knowledge. My research journey has led me to question whether it is in the interests of statutory social work employers, as government agencies subject to an austerity programme underpinned by political ideology (discussed within the literature review), to encourage independent critical thinking amongst its employees. Critical thinking questions the motivation and agenda of policy so has the potential for highlighting conflict between policy and practitioner values. Practitioners have reported that this conflict is a source of stress and potential burnout (Gallina, 2010; Reamer, 2011; Cooper, 2015). However, the contribution of critical thinking social workers to service development is a requirement of the Social Work Professional Capabilities Framework within the Professional Leadership domain. Critical thinkers can therefore be seen as both an advantage to an employer through their contribution to service development, but also a challenge to authority (the awkward squad?). In addition, the framework identifies other skills and capabilities related to critical thinking and includes ethical practice, challenging oppression (within or without the organisation) and critical reflection as key practitioner attributes. Engagement with research and learning encourages critical thinking (Coulshed and Orme, 2012; Webber and Carr, 2015) and I draw on supporting literature to examine the barriers and opportunities for practitioner research engagement and how I have used this information to assist in my own development and to help other practitioners become research minded through the creation of a research network.

1. Gestation of a practitioner research network

Reviewing the literature for this study revealed the widespread lack of research engagement amongst practising social workers (Staudt et al., 2003; Lyons and Manion, 2003; Munro et al., 2005; Orme and Powell, 2007; Bywaters, 2008). This reflects my own experience of encountering barriers to accessing current research,

alongside a lack of dedicated time to follow this up. The awareness of these difficulties led me to question how practitioners can be helped to fulfil this essential aspect of registration (and personal development) within my own employing agency. When challenged by my sponsor (my employer) to identify a means of making my research activities useful to the organisation, and thereby justifying continued sponsorship, enabling practitioner research engagement was immediately apparent as an area of practice to address. The suggestion of developing a research engagement strategy was accepted by my sponsor as an appropriate activity meeting both my need to undertake a practice development project and meeting the organisational goal of creating a research-minded workforce.

I collaborated with members of the learning and development and research departments to establish a steering group of interested employees to devise a social worker research engagement strategy. This involved more than a dialogue about collaboration as each member attended with particular views, managerial approaches and desired outcomes according to their own contextual need. Therefore, an open discussion about expectations was required at the outset. Reflecting on the development of the steering group I appreciate that I am not personally motivated by a need to achieve individual success; instead, I am drawn to collaboration with people who contribute different skills. This amenability is helpful in establishing partnership working, but has to be balanced by strength of purpose to avoid loss of the original aim. My collaborative approach is based on recognition that being human involves interdependence; this leads me to distrust hierarchies of power but rather to respect each member's contribution. The trust and respect this brings forms the "glue that holds people together and thus sustains a partnership" (Dhillon, 2005, p.215). I recognise my belief in the value-added nature of partnership work which can "lead to benefits which would not otherwise be achieved" (Dhillon, 2005, p.215). This led me to establish the steering group with a sense of optimism and even the naïve assumption that members would share this same belief. My inexperience at initiating such a group also meant that I undertook this as a learning experience, open to advice and guidance, and drawing in people within the organisation whose area of interest complimented the

aim of the group. This spirit of openness was matched by the other members, each of whom were keen to collaborate in a project which they saw as useful and necessary to their own workplace role, as well as being beneficial to the organisation. Personal gain, in this case through demonstrating usefulness to the organisation and thereby increasing job security, was a strong motivational force for my own and others' involvement, but additional motivation was found through personal development resulting from engaging in innovation (Leonard et al., 2005). There was a sense of membership in a shared community of practice (Wenger, 1998) developed from such willing partnership (Dhillon, 2005), characterised by mutual ownership of the purpose of and responsibility for the project. A community of practice creates new knowledge by sharing a joint enterprise and devising new resources (Wenger, 1998), which succinctly describes the aim of the steering group. Each member took on responsibility for tasks that were related to their own work, for example, the learning and development leader arranged the training venues and course participant recruitment, while the newly qualified members undertook learning presentations at training events. In addition, all steering group members shared responsibilities by rotating steering group tasks including chairing meetings, minute taking and communicating with senior management. Dorset is a large rural county so to enable attendance both at the steering group meetings and learning events it was agreed that the locations would also rotate around the county. This was a successful arrangement until venues became restricted through social work teams integrating with health teams and moving into health authority accommodation. As a consequence, meetings were later held at central offices in Dorchester, but this increased travel time for many members and affected their manager's willingness to allow time to attend. However, involvement in the steering group seems to have been a welcome and creative project for everyone involved, at least until the impact of organisational restructuring affected attendance and membership (discussed later in this chapter).

An interesting observation is that the majority of members of the group were female and attempts to draw in men occupying senior positions proved difficult. There is insufficient space within this research project to explore the issue of

gender and collaborative work, or the prevalence of men in senior roles within a largely female-dominated organisation, but both points require examination and further research.

The research network established by the steering group links directly to the registration and PCF requirements cited above. The network was named the Research Interest Group (RIG). Previously, an evidence-informed practice steering group had been run, organised and attended primarily by managers. This had faded away as competing commitments and organisational restructuring changed the group members' priorities. Instead, RIG was something different: a 'bottom up', practitioner-led group seeking to meet the needs and interests of social workers in the field; a means to give a voice to practitioners across the county:

“Such research may present the only opportunity to evaluate innovative local projects, so that lessons from them, whether good or bad, are not lost. Furthermore, the practice-closeness of qualitative practitioner research can make it more applicable to local contexts than more distanced studies.”

(SCIE, 2012b)

Recruitment was initially undertaken via an email outlining the purpose and rationale for the group which I sent to locality managers requesting that they cascade to team leaders and social workers. Additional practitioners joined the group as interest gathered. The group met for a minimum of four times each year following its inaugural meeting in 2012. The group modelled and implemented a practitioner research engagement strategy. A core group made up of eight practitioners, including myself, along with two team leaders and representatives from the research and learning and development departments attended over the subsequent years. However, attendance was variable according to other priorities and changes to personnel. Reorganisation had a considerable impact on RIG as key members were redeployed, making forward planning extremely challenging.

2. The purpose of the Research Interest Group and who defined this

The initial steering group had representation from front-line practitioners and

corporate services (the learning and development department). An agenda of shared interest was agreed and then driven by recognition of the needs of employees and their wish to engage with research in order to develop and improve their practice. This had been demonstrated in the Health Check surveys undertaken by Dorset County Council in 2012 and 2015 which identified practitioners' wish to read, use and undertake research. In addition, the steering group agreed that RIG would contribute to the responsibility of DCC to enable social workers to undertake practice development (BASW 2012c; Social Work Reform Board, 2012; PCF, 2012; HCPC, 2012). As such, RIG was advantageous to both staff and employer by enabling staff to meet the demands of professional registration leading to increased engagement in continuous professional development (CPD) activities.

Development of RIG can be understood as a problem-solving cycle which moves through a process of problem definition, information collection and analysis, improvement planning, implementation and review (Gray, 2010, p.4). I use this same problem solving model in the development of the learning tool in Chapter 7. In the sections which follow, the stages of this cycle are identified in parenthesis immediately after the heading.

2.1 Diagnostic analysis (definition, data collection and analysis)

I undertook an analysis of literature concerning social work(er) research along with data from the local authority Health Check survey as a diagnostic exercise to identify the barriers to practitioner engagement (discussed below). I did not recognise myself as a leader or manager in undertaking this exercise but subsequent reflection enabled me to identify that I was acting as an "organisational GP" (Handy, 1985, cited in Gray, 2010, p.3) who diagnose and then develop treatment plans to treat organisational disorders. Gray (2010) suggests this function of managers indicates their primary role as problem solvers. This also relates to my use of problem-solving skills in social work practice which are transferable to other problem-solving situations. I recognise that I have a pragmatic approach (discussed in detail in the methodology chapter) and my work with RIG demonstrates this through the application of a 'what works' problem-solving

strategy. This data revealed aspects which a research engagement strategy such as RIG could address, and formed the framework for RIG activities. The data also highlighted aspects of research engagement beyond the scope of RIG to influence, such as high caseloads. This provided both contextual information useful in the development of RIG, and identified points of contact where bottom up and top down research strategies meet with the potential for routes of communication to form. For example, corporate subscription to Research in Practice for Adults (RiPFA) services, including the ability to access their publications and training, is agreed by senior management according to funding priorities beyond the scope of RIG, however, because RIG used the training, support and resources provided by RiPFA in an innovative and measurably effective way, management agreed to continue the subscription. Latterly, this meeting point has been through the Principal Social Worker whose role spans senior management and practitioners. This role with RIG is discussed further within this chapter.

2.2. RIG terms of reference (improvement planning)

The diagnostic exercise identifying barriers to practitioner engagement provided the rationale for the purpose of RIG. I took responsibility for drawing up RIG's terms of reference (Appendix 1), which were then ratified by the group to ensure that the definition of purpose was mutual.

In terms of my own research, RIG is both a means to address barriers to practitioner engagement with research and a route for the dissemination of my findings. At the outset, the objectives of both my employer and myself for RIG were the same, however, as personnel changes took effect and cutbacks occurred, tensions developed regarding staff attendance at the planning meetings and training events, and regarding the development activities we could undertake. This tension remained unresolved and negotiation was required with managers to enable RIG to continue. Research indicates that successful practice development requires shared ownership, vision and values, and when external influences interfere with these shared factors, for example, by emphasising other priorities (in this case the focus on core regulatory tasks), continuation of practice development requires ongoing negotiation (Dhillon, 2005).

2.3. Barriers to social worker engagement with research and how RIG has addressed the barriers within its scope (implementation)

The barriers to research engagement include factors relating separately and jointly to individuals, organisations and wider cultural attitudes.

2.3.1 Research skills and confidence amongst practitioners

a) Barrier

The Croisdale-Appleby review into social work with adults education (2014) stated that social workers have a threefold role: as “practitioner, professional and social scientist” (2014, p.17). However, this last role requires skills which social work training does not often develop, including research expertise and rigour (Orme and Powell, 2007; Webber, 2015). Furthermore, employers have been unwilling to invest in building the research capacity of social work practitioners (Orme and Powell, 2007; Shardland, 2012). In addition, high social work caseloads inhibit opportunities to develop research skills or undertake research whilst in practice, so university staff recruited from practice do not have the skills to pass on to new students (Orme and Powell, 2007).

For longstanding practitioners who have been out of education for many years there may be a sense of fear due to lack of confidence (Fenge, 2009) as well as a deficit of skills (Webber, 2015).

b) Contribution of RIG towards a solution

In response to this challenging environment, an inclusive approach to the meaning of research engagement was used by RIG to encourage engagement of all types. By naming activities in which social workers already participate, such as reading policy summaries, engagement with research allowed connection with everyday practice to be made. This demystified the issue of where research fits into practice, countering the view that research is separate from practice, or only for academics. This broad understanding of research activity provides a means to share research experience and offer mentoring and encouragement, along with specific training on research skills through the learning events with RiPFA.

2.3.2 Time to engage

a) Barrier

High caseloads inhibit time and energy to think beyond the immediate situation (Munro et al., 2005; Taylor, 2015). Competing priorities add to the time pressures on front-line practice (Webber, 2015). In addition, issues with the recruitment and retention of staff, along with staff turnover means there is a limited number of staff to undertake research (Munro et al., 2005; Skills for Care, 2014a,c).

b) Contribution of RIG

RIG could not influence caseloads, however, a workforce appreciation of the role research plays in effective practice promotes a confidence to assert the necessity of time and opportunity to engage in research and reflection. The appetite for research engagement amongst practitioners is apparent from Dorset County Council's Health Check survey undertaken in 2015 (not in the public domain). I have searched for similar information across the country but have been unable to find any details. Dorset County Council is aware of this appetite for research engagement and is now actively involved in the development of the Pan Dorset Health and Social Care Academy as the site of CPD and practitioner research.

2.3.3 Incentives and support

a) Barrier

The lack of funding for research activities within practice and the lack of reward for such activities do not incentivise staff to undertake research (Staudt et al., 2003; Bywaters, 2008; Sharland, 2012). In addition, the perceived problem of dissemination within and beyond organisations, lack of visibility and value for such activities demotivate staff (Bywaters, 2008). Lyons and Manion (2003) suggest that practice skills have been valued over research within agencies resulting in decreased work-based research activities. Nevertheless, practitioners at every

stage of their career are required to engage with evidence-based practice (PCF, Knowledge and Skills Statements).

b) Contribution of RIG

The intrinsic value of research engagement was emphasised during the RIG meetings and training events. This includes the increased confidence that knowledge and critical thinking skills bring. In addition, by highlighting the necessity of research engagement for registration and then promoting realistic ideas of how this requirement can be met, for example, through support networks such as journal clubs within and across different teams, practitioners were given the means to turn a requirement into action.

2.3.4 Research-enabling organisations

a) Barrier

The Croisdale-Appleby review (2014) compares social work research engagement with that of other professions such as medicine which have a history of generating research for practice. However medicine has both the funding and superior social status which enables research to be prioritised, unlike social work (Howard, 2009; Sharland, 2012; Taylor, 2015).

SCIE states that:

“Experience in the health care field has shown that there is no magic research wand that produces change in practice. There is therefore a need for strategies to encourage:

- *ownership and assimilation of research ideas;*
- *implementation into practice;*
- *impact on delivery of services”* (SCIE, 2012b).

These factors are influenced by the work environment and the organisational culture; organisations need to be flexible, experimental and imaginative if

practitioners are to adopt and implement research into their practice. The working environment is therefore crucial to making evidence-based and evidence-informed practice happen (SCIE, 2012b). However, barriers within the employing agency infrastructure inhibit engagement, not just in respect of lack of funding for research but also in regard to the absence of links with researching organisations (Howard, 2009).

b) Contribution of RIG

RIG highlighted the registration requirements and practitioner appetite for research engagement. Routes of influence were opened by involving management in RIG. However, agency reorganisation and the reform of services in the light of implementation of the Care Act 2014, along with budgetary cutbacks, meant little attention was given to RIG by managers.

2.3.5 The location of research in practice: the practice/theory divide

a) Barrier

There is a perceived gap between the domains of practice and research (Webber and Carr, 2015). This gap generates distrust regarding the relevance of research along with a notion that academics who produce theory are removed from the realities of practice; the theory is perceived as “abstract, inaccessible, and that is reduces spontaneity in helping people” (Coulshed and Orme, 2012, p.1). In addition, social workers can struggle to identify the theories they use (Gordon and Cooper, 2010) and it is not always easy to identify the impact of research on practice (Darlington and Scott, 2002), although research is, in reality, woven through social work policy, legislation and practice guidance (Webber and Carr, 2015). The lack of focus on research engagement in qualifying or post-qualifying professional education and practice serves to accentuate a perception of the gap between research and practice (Sharland, 2012).

b) Contribution of RIG

RIG sought to demonstrate the relevance of research to practice by bridging the divide between theory and practice. By promoting an appreciation that social work research has shared goals as social work practice, specifically the alleviation of human suffering by finding solutions to social problems. This includes:

“What sets social work research apart is its positioning as emancipatory.

This can be described as:

- 1. Being prepared to challenge inequality and oppression in all aspects of the research process.*
- 2. Understanding that the voices of service users and participants from all fields must be included appropriately”*

(SCIE, 2012b).

In addition, the distrust of research may be changing with the increased acceptance of qualitative research (Lyons and Manion, 2003) which has resonance with daily practice. RIG promoted the idea of research champions within teams who source research and encourage practice discussion through a regular journal club or learning meeting over lunch. By encouraging unobtrusive learning events such as these, a learning culture develops (Hart, 2015). These ideas are not new and such events were already taking place in some locations and, on reflection, I understand the significance of the individual team manager to the success of failure of sustaining a learning culture (Hart, 2015). In retrospect, RIG should have targeted the involvement of more team managers.

2.3.6 Accessing research

a) Barrier

SCIE reports that the separation between the worlds of research and practice can make it difficult for those providing services to access the research information they need (2012b). This is because findings can be in books or journals that are hard to access or are aimed at an academic audience. In addition, journals and academic

books are expensive and access to libraries which contain peer-reviewed work is limited (Hart, 2015).

b) Contribution of RIG

Dorset County Council already had multiple sources of research through its dedicated intranet web pages and library. What RIG identified was the complex routes to these resources and the lack of practitioner awareness and use. Hence, the group sought ways of aiding access. This included:

- making research accessible and available to practitioners by updating intranet sources and making access to this simpler ;
- promoting internet access to multiple sources including online journals;
- promoting RiPFA resources to which Dorset County Council subscribes;
- promoting research bulletins;
- encouraging the creation and maintenance of journal clubs and reflective discussion groups;
- encouraging research projects by advertising what research has been, and is being undertaken by staff.

The group, in conjunction with trainers from RiPFA, have delivered a series of training events focused on the intellectual skills of practice such as finding, evaluating and using research in practice, critical thinking and evidence-informed practice. Presentations from local practitioner/researchers have featured as part of these events in order to illustrate the possibilities of research engagement and to promote local research already being undertaken and inspire more. Part of this is to give voice to research engaged practitioners and make connections with fellow social workers.

Undertaking a rolling programme of training events focused on finding, appraising and using evidence and research for practice, research and evidence informed decision making and analysis and critical thinking skills. These have been repeated as the events have been oversubscribed.

3. Evaluation of RIG (review)

3.1 Nurturing peer support

Feedback from members of RIG highlighted the nurturing aspects of the peer support provided by attending the group, specifically the encouragement gained from a shared interest in developing a research engagement strategy. Learning is traditionally presented as an individualised phenomena, however, Wenger (1998) offers an alternative model located in social participation in the world, responsive to the social nature of humans which emphasises shared endeavour. Communities of practice (Wenger, 1998) form around an endeavour, supporting the shared motivation to learn and improve. RIG formed such a community of practice, it created the link between practitioners of all levels of experience and different teams. We learnt from each other and through participation in RIG.

3.2 Regulation compliance

Contributions to RIG provided practitioners with evidence towards their records of professional development required by the HCPC. It was also of benefit to professional graduates undertaking their Assessed and Supported Year in Employment (ASYE), assisting in the fulfilment of their assessment requirements in terms of knowledge and practice development. Line managers enabling staff to attend the group was interpreted by ASYEs as signifying agency commitment to their successful development as newly qualified professionals. However, attendance was variable due to competing demands on staff time when attending RIG could not be prioritised.

3.3 Value of practitioner-led training events

The training events organised by RIG were subject to standard agency attendee evaluations which have been collated and analysed. These indicate universally positive responses about the events, citing, for example, pleasure at having the opportunity to think about the fundamental skills of social work such as critical thinking and research analysis. Participants also appreciated the research presentations provided by practitioners undertaking research (primarily myself and a colleague who I have been mentoring) as a source of inspiration. This reflects the importance of practitioner-led initiatives such as RIG which have an 'insider'

approach, a sense of understanding and which relate to the issues of daily practice; something that top down initiatives often lack (McCormack and Garbett, 2003).

3.4 Personnel

Initially, RIG was modelled on the well-established and attended occupational therapist steering group and study days, the organisation, funding and administration of which are overseen by a member of the learning and development team. Collaboration with this team member provided the experience and link to senior management required to establish something similar for social work staff. Her redeployment was a significant loss to RIG, followed shortly after by the loss of a senior research officer. In addition, structural changes throughout the organisation led to there being a severely limited number of people being available to contribute to the work of RIG, from senior management to ASYEs. The loss of the founding members disturbed the developing relationships across departments as well the deepening relationships within the group itself, which was especially important as “the basis of continued and effective partnership depends upon social relationships amongst the people in a partnership” (Dhillon, 2005, p.218). Furthermore, members felt increasingly unable to commit to forward planning due to uncertainty about their ongoing role. This resulted in tasks being assigned to a very small group of people which became burdensome and unsustainable. The experience of establishing RIG has indicated that, without commitment from leadership, ‘having the ear’ of management, support, promotion and becoming an accepted feature of an organisation are extremely difficult (Dhillon, 2005).

3.5 Impact of change

Establishing RIG has highlighted the appetite for research engagement amongst practitioners and created a momentum for promoting research in practice. But it also highlighted the barriers to maintaining such a strategy in an organisation subject to change. Maintenance and development of RIG require a commitment from leadership to become a learning organisation which values learning opportunities and acts on the employer’s responsibilities to enable practitioner reflection and involvement with research. This could be achieved through enabling

access, protecting time and developing a culture which values research. But commitment to such a plan is subject to the multiple demands on the organisation from government and users, all occurring in a period of austerity which can be the justification for prioritising operational tasks over workforce development. The Principal Social Worker role has the potential to be an advocate for practitioners; a route by which they can communicate their need and desire to engage with research direct to leadership. It is then up to the leadership to act on this information, creating an environment of learning or to expect practitioners to find their own ways of meeting registration requirement.

3.6 The future of RIG

Since RIG's inception, the role of Principal Social Worker has been introduced following the acceptance of Munro's recommendation to that effect in her report on the tragic case of Peter Connelly (Munro, 2011) and the work of the Social Work Reform Board. The precise function of this role has been open to interpretation by employers and consequently actioned differently across the country with Annie Hudson, then chief executive of the College of Social Work stating:

"PSWs are often what was described as a 'go between' – between practitioners and managers, between adult and children's services and between national and local networks, it is the case that the role is not only being developed but it is being developed differently across the country"

(Schraer, 2014)

The role is generally considered to be a driver of professional standards with principal social workers taking a professional lead across an organisation, and having a responsibility for supporting and advising on the quality of practice (BASW, 2014). However, there is concern that the principal social worker is at risk of being absorbed into just another part of the organisational structures that have:

"got us here in the first place. The opportunity is now for practice leadership. And if we don't seize it, others will define it for us"

(Stanley, 2015)

This reflects the negotiated nature of the role within individual authorities. Most relevant to my work and the future development of RIG is the statement that principal social workers have responsibility to:

“Create and sustain an environment that promotes learning and practice development, facilitating research within the organisation and with strategic partners”

(BASW, 2014, p.1)

The principal social worker in my agency had become involved with RIG at my time of leaving the organisation, and is now taking on the development of a research-minded workforce as part of his role. RIG has served as a prompt to management and principal social workers that practitioners have an appetite for research but require a culture of learning along with access in order to be able to engage. These ideas are being taken forward into the development of the Pan Dorset Health and Social Care Academy.

Initiating RIG has contributed to my ongoing development as a researcher. Reflection on the development of the group leads me to appreciate how much its early success was dependent on the fortunate coincidence of gathering a specific group of individuals who were prepared to negotiate and collaborate in an environment where creative innovations were encouraged and a degree of freedom allowed. The individuals were of sufficient authority within the organisation to be able to make decisions with budgetary implications, which meant we could make decisions and take action. But the majority of members were practitioners meaning the focus remained on developing practitioner skills and confidence rather than organisational concerns such as demonstrating the outcome of RIG to justify its continuation. Considering the challenges and opportunities of my practice development experience led me to the work of McCormack and Garbett (2003) who reviewed the functions and activities of practice developers. Their review provides a helpful structure with which to analyse my work with RIG:

a. Promote and facilitate change – RIG was a new practitioner-led venture and consequently established new relationships within the organisation, bringing

together interested parties from across council departments as well as geographical locations. My primary aim as practice developer was “supporting, raising awareness and helping create a culture to support change based on the perceptions and needs of staff themselves” (McCormack and Garbett, 2003, p. 320). However, because practitioner research engagement is necessary for both individual and organisational advantage (as discussed earlier in this chapter) the purpose of RIG was also to support change and raise awareness at management level, hence the importance of the inclusion of management representatives amongst the group membership.

b. Translation and communication – this involved my initiation of RIG, gathering information to explain and then communicate to a number of departmental representatives why such a group was needed at that particular time. On reflection, I perceive that I was advocating for recognition that practitioners need to be enabled to engage with research. It was a 'social worker as advocate' response to my perception that practitioners exercise less power than management within an organisation and therefore require a route to express their needs (perhaps also meeting my need to be a 'hero').

c. Responding to external influences – as already discussed, social workers have a regulatory responsibility to engage with research and to demonstrate critical thinking throughout their professional career (PCF and HCPC). This involves the ability to consider the multiple influences on themselves and service users which impact on well-being. In addition, the hostility to social work from the media, particularly following the death of children known to social services (for example, *The Daily Mail*, 14 December 2015: “Blitz on failing social services”), government criticism of social work education (Gove, 2013) and subsequent reforms (such as the proposed imprisonment of social workers (Stevenson, 2015)) require social workers to have the confidence, skills and resilience to, first, continue in practice and, secondly, develop a robust, defensible professional knowledge base. RIG provided a route to achieve this by creating a shared community of practice characterised by peer support.

d. Education – RIG organised practitioner training events through collaboration with RiPFA. These events were educative in themselves but from a personal development perspective I gained an appreciation of the practice development role as one which “provides access to personal and professional development” (McCormack and Garbett, 2003, p.322).

e. Qualities and skills – as mentioned previously, RIG members brought different qualities and skills, including expertise in organising learning events. The shared ‘can do attitude’ demonstrated by the group reflects the energy, enthusiasm and vision required to undertake practice development activity identified by McCormack and Garbett (2003). However, they also identify a range of skills which are unlikely to be found in any one person and therefore suggest that ‘centres of practice’ might be a way forward. In social work, the introduction of the role of Principal Social Worker includes aspects of the practice developer (Schrear, 2014), it is a role which continues the work of RIG by promoting research engagement and linking management and practitioners. In addition, in Dorset the development of the Pan Dorset Academy, in collaboration with Bournemouth University, offers the potential to be a ‘centre of practice’ where practice development activities can be facilitated and supported.

RIG’s decline reflects the changing workplace environment over recent years where local authority budgets have been cut by 27% (Penny, 2015) resulting in the curtailment of innovations beyond core work. But also the introduction of the PSW role reduced the need for such a group. All the original members of the steering group were reorganised into other posts and attendance declined as staff took on other responsibilities due to cutbacks. The enthusiasm which motivated the group for several years, and influenced senior management due to the increasing visibility of our activities, was replaced by uncertainty over job security and a sense of fatigue. I understand that the decline of RIG coincided with my growing scepticism about governmental commitment to social work and well-being which influenced my ability to ‘drive’ RIG. For such an initiative to survive in a hostile environment it has to be more than a practice development project, it needs to become part of a whole organisational commitment to the development of a research-minded

workforce. In relation to the problem solving process (Gray, 2010) discussed previously, I perceive that successful implementation depends, first, on who defines the problem and their level of influence within the organisation and, secondly, how closely the problem aligns to the purpose of an organisation at that time. With RIG my status as a practitioner gave credibility to the identification of the problem, with academic and analytic rigour assumed due to my additional identity as a D Prof student. In addition, the timing of RIG was beneficial as it alerted the organisation to practitioners' appetite for research engagement and the impact enabling such engagement has on staff well-being, recruitment and retention. In light of this realisation I was pleased to be able to pass the learning from RIG to the PSW to use in the development of the Pan Dorset Academy.

This account has been a narrative of contextual change and the implications this has for 'grass roots' practice development subject to the influences of organisational restructuring and reform of the profession. There is an evident desire amongst practitioners to engage in research yet the organisational infrastructure enabling them to do so is lacking. RIG offered a model for research engagement which was valued for its 'bottom up' approach. However, for such a group to be sustainable through periods of change senior management commitment is necessary, but this potentially introduces a 'top down' effect, prioritising the needs of the organisation over practitioners. The introduction of Principal Social Workers to raise standards and promote research-informed practice offers an opportunity for 'bottom up' initiatives like RIG to meet 'top down' needs as agencies change. With the recruitment and retention of social workers becoming an issue for employers (Skills for Care, 2014a,c; Carter, 2016) and ongoing professional development and learning opportunities being a recognised factor in attracting candidates to employment, agencies need to embrace initiatives such as RIG.

I now progress to my research literature review exploring sexual well-being, social work and disability. I have been reading the literature throughout my research journey and all the activities related to the various elements of a D Prof have nurtured one another, including the literature providing stimulating material for RIG

training sessions and meetings and RIG providing the peer support to aid my motivation.

Chapter 3: Literature Review

Introduction

Through my social work practice I have become aware of the apparent absence of information regarding sex and disability. I now move to the literature review undertaken in order to discover whether my perception of this gap in knowledge is replicated in the literature.

Research on disabled people's sexual lives has typically focused on:

“how well their genitals work, whether disabled people feel as positive about their bodies or sexual lives as non-disabled people, how their sexual lives and relationships compare to non-disabled people's lives and how disabled people adjust sexually when they become impaired”

(Shuttleworth, 2010, p.1).

This list suggests research generally focuses on comparison between disabled and non-disabled people, underlining difference, conceiving the disabled person as the research object rather than co-producer. It indicates that there is little research into the experience of sexuality and disability, or the everyday issues disabled people bring up when talking about sex, including opportunities and barriers. My research seeks an alternative perspective looking at the meaning and lived experience of sexual well-being to physically disabled people from three interlinking perspectives: social work practice, physical disability culture, and well-being knowledge, with the aim of identifying gaps in the literature. Through this exploratory process I aim to determine both how my research fits within the existing body of knowledge and how my research might contribute new and unique knowledge (DePoy and Gitlin, 2016). I have undertaken three separate literature searches and begin this literature review with an account of these three searches.

a) Social work, sex and physical disability

As this D Prof is located within UK social work the research has been appropriately

undertaken in light of literature and information collected from relevant cultural sources. Therefore, the sources for this research have been gathered from Western capitalist societies, reflecting the socio-political context in which I practise. It is beyond the scope of this study to provide in-depth analysis of the complete history of UK social work with physically disabled people, so literature from 1997 to the present has been gathered. The year 1997 represented a shift in policy with the election of the New Labour government and introduction of the Modernising Social Services introducing personalisation, leading to a fundamental change in adult social work.

There is a vast amount of literature on social work so to further focus the search, and to maintain a UK perspective, I have referenced only UK legislation, guidance and policy, social work books, regulatory body documents, social work association resources, blogs and news articles. However, within the journal articles I have included some particularly pertinent studies from elsewhere in Europe and Australia where social care is situated in similar, democratic political systems (Moriarty et al., 2015a).

Table 1 illustrates the search terms used, databases and other sources searched, and the types of literature discovered.

Table 1: Search terms for social work, sex and disability

Search terms used	Databases	Websites searched	Other sources	Types of literature
social work and sex and disability	Academic Search Complete	The British Association of Social Work	Hand search of references / bibliographies	Academic journal articles
social work and sex and physical disability	Bournemouth University Research Online	The College of Social Work	Hand search of <i>The British Journal of Social Work</i> 1997–present	Academic books
social work and sex	CINAHL Complete	Community Care	Hand search of contents pages of library resources	Governmental reports, legislation and policy
social work and sexual well-being	Cochrane Library	Google Scholar		Master's and doctoral theses
social work and need	Ebrary Academic Complete	Health and Care Professions Council		Blogs, interviews and lectures
social work and power	Ebsco e-books	Research In Practice for Adults		Disability Literature
social care and sex	Sage Journals Online	Skills for Care		Podcasts and radio broadcasts
	Social Care Online	SCIE		
	Web of Science	www.gov.uk		

After filtering abstracts I identified 342 sources in addition to books and the other sources itemised above. I read all 342 sources – these have provided contextual background.

b) Physical disability, and sex and physical disability

This research specifically concerns sexual well-being and physical disability rather than any other group (for example, people with a learning disability), as this is my practice context but more importantly because it is an under-researched topic (Schlesinger, 1996; Milligan and Neufeldt. 2001; Grossman et al., 2003; Rockcliffe-Fidler and Kiemle, 2003).

I undertook a scoping exercise to identify potential literature for inclusion. Literature from 1990 to the present (with the exception of foundational texts written prior to

1990, which have been included) written in (or translated into) English have been gathered. These parameters reflect the relatively recent recognition of the topic as a focus of academic study and created a realistic limitation for a lone researcher project. Table 2 illustrates the disability and sex literature search process

Table 2: Search terms for physical disability, and sex and physical disability

Search terms	Databases	Websites searched	Other sources	Types of literature
sex and physical disability/disability	Academic Search Complete	BBC Ouch	Hand search of the journals: <i>Sexuality and Disability</i> and <i>Disability and Society</i>	Academic journal articles
sexuality and physical disability/disability	Bournemouth University Research Online	Disability Now	Hand search through references and bibliographies	Academic books
sexual well-being and physical disability/disability	CINAHL Complete	Community Care		Master's and PhD theses
Physical disability/disability and relationships	Cochrane Library	Google Scholar		Conference reports
	Ebrary Academic Complete			News articles
	Ebsco e-books			Blogs, interviews and lectures
	Sage Journals Online			Literature from disability organisations
	Web of Science			Cinema films, television programmes

This process provided 191 relevant sources (articles and reports) in addition to the books, blogs and the other sources identified above. I have read all of these sources.

c) Well-being

The literature review also explores the concept of well-being, examining the philosophical foundations and why and how well-being has become so significant in social policy, specifically its underpinning the Care Act 2014. Literature from 2005 was gathered as it was in this year, with the publication of New Labour's Green Paper Independence, Well-being and Choice (Department of Health, 2005), that well-being became part of the government's agenda (New Economics Foundation, 2012a and 2012b; Webber and Rickard, 2013).

Table 3: Search terms for well-being

Search terms	Databases	Websites searched	Types of literature
well-being	Academic Search Complete	Office of National Statistics	Governmental reports and policy statements
well-being and social policy	CINAHL Complete	www.gov.uk	Academic journal articles
social work and well-being	Cochrane Library	New Economics Foundation	Conference presentations
disability/physical disability and well-being	Ebrary Academic Complete	The College of Social Work	Podcasts and radio broadcasts
sexual well-being	Sage Journals Online	Skills for Care	News articles
sex and well-being	Social Care Online	Social Care Institute for Excellence	Blogs, interviews and lectures
		The Young Foundation	
		The Legatum Institute	
		Department of Health	

This search provided 55 relevant sources, all of which I read.

All the literature was approached with the question of whose beliefs and interests are being represented as a means of critically questioning the 'taken for granted truths' (Fook, 2002).

The results from this search have created a diverse collection of literature; a mixture of academically presented, evidence-informed research alongside more impassioned personal accounts of real life experience, as well as campaign literature aimed at challenging the status quo. The inclusion of such a diverse range of sources recognises that knowledge useful to social work practice comes from various sources and in various forms (Bell, 2012; Healy, 2014). I read the literature critically using the Critical Appraisal Skills Programme (CASP, 2012) qualitative research appraisal checklist as a guide in order to assess the quality of the information and understand the assumptions underpinning it. By questioning the purpose, method of production and authority I endeavoured to ensure a balanced weight was given to each type of evidence. The CASP checklist was applied as a guide only as I did not want to exclude the personal accounts offered through such sources as blogs, which provide unique insights into lived experience. Both social work and disability issues have generated enormous amounts of literature which might have been included as part of the wider context of this research topic. By focusing on social work, sex and disability and well-being I have been able to include a breadth of literature resulting in an examination of the topic from a range of perspectives, but without becoming so broad that the topic is lost in a general discussion of either social work or disability issues.

I read the literature chronologically, according to publication date, in order to gain a perspective of the topic's development. Cross reference was made with social events such as changes in government and economic and social policy to provide the social context.

The literature was annotated whilst being read, and the subsequent notes reread and coded to identify points recurring in two or more sources, or where the author

places particular significance, indicating the need for further exploration. I have divided these codes into emerging, sense-making themes which I have subsequently used to structure this chapter.

These themes represent the genesis of this literature review where I first gathered literature about social work and physical disability – theme one – exploring information about tasks undertaken including assessment of need and risk and how this has to be balanced with empowerment and rights. This led me to an exploration of the influence of political ideology on social work and how this determines the nature of the work, which naturally led me to theme two, an examination of the ideological constructs of disability, including looking at how the body is constructed and its meaning, and how the notion of independence is used within society.

I then progress to theme three which changes the focus to sexual well-being, exploring how it fits into social work practice. This section includes an examination of sex in terms of activity and meaning, how the law defines and restricts sex, why professionals are reluctant to include the consideration of sexual well-being in their work and how impairment impacts on sexual well-being. This flows into theme four in which I explore the literature on the concept of well-being, looking at its significance to social policy and social work, specifically in relation to physically disabled people.

To assist the reader navigate the breadth of literature included within this review, Table 4 details the themes and their constituent parts. This table demonstrates the complexity of the topic, which requires exploration of diverse subjects in order to identify gaps and examine whether there is a thread running through the background and ongoing context of the topic creating an absence of information on this issue.

Table 4: Literature review table of contents

	Theme	Details			
Theme 1	Social work and physical disability	1.1 Need	1.2 Assessment	1.3 Risk assessment	1.4 Safeguarding adults
		1.5 Empowerment and rights	1.6 The Care Act 2014	1.7 Personalisation	1.8 Political ideology
Theme 2	Ideological constructs emerging from the literature	2.1 Disability: 2.1a Economic factors in the creation of disability 2.1.b Models of disability	2.2 The Body: Effects of physical disability on body image	2.3 Independence	2.4 Work: the source of inclusion and value
Theme 3	Sexual well-being and social work	3.1 What is sex	3.2 Sex and the law	3.3 Notion of asexuality	3.4 Professionals' discomfort discussing sex
		3.5 Education for professionals	3.6 Impact of physical disability on sexual relationships	3.7 Impact of physical disability on sexual activity	3.8 Increased sexual activity and pleasure
		3.9 Gendered disability			
Theme 4	Finding a definition of well-being for sexual well-being	4.1 What is well-being	4.2 Why are governments interested in well-being	4.3 How well-being is defined in social policy	4.4 Is well-being happiness
		4.5 The economics of well-being	4.6 Barriers to well-being		

Theme 1: Social work and physical disability

Disabled people have the right to full participation in every aspect of life with equal access to all the opportunities offered (Disability Discrimination Act 1995; Equality Act 2010). Yet this is not the experience reported in either the literature or personal accounts gathered for this research. In addition to the estimated 10% of the world's population being disabled (WHO, 2009, 2.1) many people will become elderly and experience illness or disability during their life-course (Medlar, 1998). This idea, known as Temporarily Able-Bodied (TAB), reminds us that disability is relevant to all, however, its subtext is contentious: equality of access, opportunity and

inclusion should be addressed as it is relevant to all on the grounds of self-interest (Crippledscholar, 2015). An alternative view is that a genuine commitment to social justice and equality will result in improved lives for marginalised populations. Social work, with its historic commitment to social justice, could be contributing to the social change required to enable disabled people's full participation. This literature review explores whether social work fulfils this potential, looking specifically through the lens of sexual well-being as it has long been argued that disabled people have the same sexual and social needs as everyone else, yet still face many barriers (Shakespeare, 1996 and 2000; Kaufman, et al., 2007; Liddiard, 2013a,b,c; Owens, 2015).

Social work with disabled people has been influenced by the Independent Living Movement (ILM), which has helped move practice on from controlling service users to working in partnership. The literature repeatedly states that more of the voices of physically disabled people need to be heard within social policy (for example, Schlesinger, 1996; Milligan and Neufeldt, 2001; Grossman et al., 2003; Rockliffe-Fidler and Kiemle, 2003) which will aid the continuation of the influence of the ILM. Giving people a say is empowering, reducing the 'othering' by influencing and educating audiences. This empowerment, through the articulation of often silenced voices is a motivator for my research, spurred on by Milligan and Neufeldt (2001) who state that exploratory qualitative investigations eliciting the experiences of people with disabilities should be a priority to enhance our understanding of personal and social barriers. I seek this understanding, to identify where there are gaps in understanding and will then use the information to effect change in practice.

Statutory social work with physically disabled people has been organised within local authorities as either a specialist or a generic service, the latter usually justified as a means of increasing equity between client groups. However, I contend that whilst physically disabled people may face similar barriers to inclusion as other social work client groups (for example, access to public transport may be difficult for physically disabled people, older people and carers of young children), absorbing physical disability social work into generic teams fails to recognise the

particular issues concerned with individual client groups, reducing the opportunity to build relevant knowledge and resources. An additional complexity to understanding social work with physically disabled people is the need to be alert to accusations of the 'parasitic' nature of their work where the professionals effectively feed off the needs of disabled people (Barnes et al., 1999; Swain et al., 2003). Disability academics point to the creation of an industry around disability where professional jobs are created based on existing power structures rather than any expert knowledge or skills (Swain et al., 2003). McKnight (1995), cited in Swain et al. (2003), relates this to the increase of the service economy in the UK during the 1980s when manufacturing declined. This has led to the creation of new categories of people being deemed in need of assistance, with jobs then created to meet these needs. This serves the interests of the workers by keeping them in employment whilst also reinforcing notions of dependency. It is "like a market seeking new growth potential" (Swain et al, 2003, p.142).

Oliver and Sapey (2006) criticise social work with disabled people for failing to develop a theoretical and practice base, accusing many social workers of being unaware of the impact of disabling conditions and are, therefore, unable to appreciate the needs physically disabled people might have. They cite evidence that social workers are not interested in working with disabled people and suggest this might be because disability:

"has a low profile in local authorities. Inappropriate teaching in qualifying social work courses leads to a misunderstanding about what work with disability is like"

(Oliver and Sapey, 2006, p.20).

Criticism is also made of social work organisations for using, and individual social workers for internalising, an inappropriate model of disability: specifically one of biomedical, individual tragedy which creates a false foundation for subsequent social work activity and theory (Oliver and Sapey, 2006). But I contend that practitioners are often committed to the social model of disability, along with developments such as the citizenship and affirmative models. However, whilst they

endeavour to practice in ways that promote these models, the social structures within which social work operates limit what can be achieved by micro-level work. Individual, micro-level work improves lives but it 'does not speak to power' (Beresford, 2013). Campaigns such as Stand up for Social Work (Community Care, relaunched in 2015) and Social Workers Against Austerity (BASW), and the request made to the Chief Social Workers for England to act as the voice of the profession (Leigh, 2015) in light of the College of Social Work closing in September 2015 endeavour to promote the value of social work, to strengthen its professional voice and increase the profession's potential social influence.

Social workers undertake diverse tasks. The following section of this literature discusses key activities, examining their purpose and how this relates to sexual well-being.

1.1 Need

The concept of need is contested: positivists see 'need' as an objective, measurable phenomenon (Ife, 2001) which can be identified through an assessment instrument. In contrast, a postmodern view conceives need as having aspects of value-laden social construction. The creation of new categories of need for economic purpose cited above supports a constructionist view: need is determined by the context, including economic expediency. The Care Act 2014 recognises the absence of a fixed definition of need by requiring the inclusion of the service user's own definition in terms of what factors are significant to their well-being (Department of Health, 2016:1.13, b and e).

Drawing on the two polarised conceptions of need it is possible to understand that there are universal elements of human need as well as those relating to one's particular context. Maslow's (1954) concept of the hierarchy of needs, with the goal of self-actualisation (level 6) only being possible once the lower-level needs have been met, offers insight into the human need for affection, acceptance and connection (level 3). For social work, this means that to help people achieve their potential and achieve self-actualisation, and thereby increase their well-being, focus is needed on how to meet the lower needs, including level 3, cited above

(Trevithick, 2005). Eric Berne, the founder of Transactional Analysis (Davies, 2000), added to Maslow's conceptualisation when he identified six fundamental human hungers or needs, including physical contact, sex and respect. The literature review reveals that the lived experience of physical disability, as it is currently constructed within Western society, threatens the potential to meet these fundamental needs (Wendell, 1996; Shakespeare, 2000; Quarmby, 2011; Owens, 2015). Therefore, a constructivist understanding of need, created by one's context and circumstances, is introduced to notions of fundamental, universal human need. Whilst physical impairment may alter sexual function it does not eliminate the basic human need, drive or desire for love, affection and intimacy (Milligan and Neufeldt, 2001). In addition Freudian theory suggests the libido is the energy for all life, so frustration negatively impacts on the vitality and motivation of the individual, affecting their self-esteem and quality of life (Cheausuwantavee, 2002). Later research (Markey et al., 2007; Handley et al., 2015) details this negative impact on health providing evidence that the absence of a partner (who satisfies the libido, physical contact and social companionship needs) may be as detrimental as smoking, high blood pressure and obesity. In addition, there is growing evidence of the psychological benefits of romantic partners; this concerns individuals in relationships experiencing the protective effects offered, for example, greater social networks and social integration (however, the quality of the relationship is crucial) (Markey et al., 2007). For social work practice this means accepting and acknowledging service users as sexual beings (rather than as 'disabled' or 'old', for example), appreciating the significance of intimate relationships to physical and emotional well-being and finding ways to empower service users to find and sustain positive relationships.

1.2 Assessment

Assessment and review remains core to all forms of social work; at its best it is an exploratory study that forms the basis of decision making and action and can be a positive intervention in itself (Trevithick, 2005; Coulshed and Orme, 2012). It can be the opportunity for service users to articulate their needs, including those around sexual well-being. But assessment can also be an instrument of oppression

depending on how it is approached by the assessor and organised by the agency (see Coulshed and Orme, 2012 for details of assessment models). Assessors act as gatekeepers who require evidence of need to demonstrate eligibility. For assessment to be holistic, taking into account the social and individual aspects of disability:

“They need to be undertaken by competent and knowledgeable professionals in collaboration with disabled people”

(Oliver and Sapey, 2006, p.86).

Local authorities have a statutory duty to assess the social care needs of residents when requested (Care Act 2014, S9), and the definition of need is crucial to the outcome of any assessment. For physically disabled, people this is especially pertinent as a definition focused on physical need (such as for personal care) rather than the need for social integration profoundly alters the approach to support planning (Oliver and Sapey, 2006; Foster et al., 2006).

Coulshed and Orme (2012) suggest that there are two major approaches to assessment:

“1) Positivist where the assessor organises, systematises and rationalises knowledge.

2) Constructionist where assessors are interpreting evidence and the question is whose version of events is being prioritised”

(Coulshed and Orme, 2012, p.26-28).

Constructive assessment recognises the uncertainty within social work (Parton and O’Byrne, 2000; Trevithick, 2005). In contrast, the imposition of pre-decided theoretical causes within positivist models of assessment excludes the individual’s response which depends on their unique set of circumstances and experiences (Oliver and Sapey, 2006). Such assessment can be experienced as oppressive (Parton and O’Byrne, 2000), making reflective engagement in the assessment

process an essential guard against potential for oppression. Examination of different perspectives in light of theory, research and evidence add rigour, with the reflexive practitioner examining the assumptions they bring to the assessment (Fook, 2002) (further evidence for the Research Interest Network discussed in Chapter 2).

The Care Act 2014 offers a means to address the oppression which can occur through the assessment process through extending access to advocacy (Department of Health Care Act Guidance, 2016). Advocacy is associated with a rights-based approach and more radical forms of social work (Parton and O'Byrne, 2000) so its extension is progressive. However, I suggest caution on two counts: first, because of the limited availability of advocacy due to resource constraint (McNicoll, 2016b); and, secondly, in relation to whether the purpose of advocacy within the Care Act is intended to ensure correct application of a process (thereby focusing on the individual worker) rather than ensure equity and fulfilment of rights. Whilst both of these purposes are valid, and the former ensures good practice, only the latter results in social change.

The Care Act 2014 combines the capacity for both positivist and constructivist approaches, extending self-assessment and prioritising service user voices, but still requiring professional assessors to interpret and organise what is accepted as knowledge and evidence according to the organisational requirement. This offers the opportunity for service users and practitioners to use the assessment as an exploratory investigation or a scientific diagnostic tool. With pressure on social work teams to meet targets, high staff turnover and frequent reorganisation, the danger is that assessment becomes limited to diagnosis. This relates to increasing emphasis on evidence-based or evidence-informed practice (EBP/EIP) within the profession, employers and government (Oliver, 2013). EBP can be considered a social Darwinistic scientific ideological device resulting in a 'how to do' social work approach based on specific theoretical assumptions about individuals and society (Carey, 2009; Bell, 2009) with scientific knowledge being promoted at the expense

of qualitative, experiential knowledge. This emphasis on a scientific approach to evidence is at odds with the subjective aspects of well-being assessment and the gathering of service user perceptions as required by Care Act assessments. This contradiction creates tensions within practice as to the priority that can be assigned to evidence, the answer being subject to agency priorities created in part by resources (Beresford, 2013).

The Government has sought ways of reducing the need for assessment through the prioritising of prevention and delay of need, with the integration of health and social care being a primary government goal (Care Act 2014, S2 and 3). This is driven by the perceived need to reduce public spending and the pursuit of independence conceived of as self-sufficiency (the ideological construction of independence is discussed later in the literature review). A number of strategies have been introduced to promote prevention including: the introduction of multi-agency Health and Well-being Boards which oversee all local authority activities; health and social care integration; reablement teams (who provide short-term intensive rehabilitation); early intervention through information giving and signposting; and the extension of self-assessment and personal budgets where professional involvement is limited. These strategies have resulted in adult social service reorganisation moving social workers away from casework (Pollack, 2010). This reduces the opportunities for relationship-based social work, despite the Munro review (2011) identifying the enhanced quality of service relationship based social work offers. Social workers are often the human face of welfare (Oliver and Sapey, 2006), mediating between service users and the state; their removal from casework reduces the human aspects of welfare.

1.3 Risk

Risk is one of the primary barriers to social work addressing sexual well-being because it concerns both the risk experienced by service users and how this is managed, but also risk to social workers themselves (Schraer, 2014). There is fear amongst front-line staff of something happening 'on their watch' for which they will

be personally accountable (Faulkner, 2012). Risk includes fear of litigation, complaint and conflict, which is now central to social work and which negatively changes the relationship between social worker and service user, making partnership extremely challenging (Parton and O'Byrne, 2000). However, clear pathways of complaint (when justified) are empowering, offering an essential method of maintaining service standards and enable service user voices to be heard. What creates risk for the social worker, leaving them open to criticism and complaint, can be poor practice due to lack of clarity about purpose (Moriarty et al., 2015a) and poor supervision (McKitterick, 2012) (as well as deliberate malpractice).

The relationship between risk management and risk enablement is particularly relevant to my research because managing risk, which can be an aspect of enabling people to live full lives, is a core element of care planning (The College of Social Work, 2013). Managing means balancing rights and risks; in relation to sexual well-being this can be the right to a private life, but also the right to protection if a private life is harmful. Social workers have to make challenging judgements, being careful not to over risk manage, thereby effectively limiting the social inclusion and life chances of the people with whom they work. But they also need to empower service users to take the risks which enhance their lives, including activities which enable sexual well-being (de Than, 2015).

The concept of risk is used in different ways; this includes a contradiction occurring between agencies making formal affirmations of risk enablement yet demonstrating organisational risk avoidance (Furedi, 2011). Neither is risk policy a response to service users whose views have received little research attention (Furedi, 2011). Physically disabled people are often defined as 'at risk' because of their impairment and are not endowed with the capacity for agency; thereby, they are denied their rights (deThan, 2015; Quarmby, 2011). Hoong Sin et al. (2011) identify two forms of risk commonly associated with disabled people, both of which lead to oppression:

“First, there are risks to disabled people as a result of their disability. This is

intimately related to the portrayal of disabled people as vulnerable due to their disability, and hence in need of protection. Second, disabled people are portrayed as risks to themselves and to others. This depicts a disability as a 'defect' that has the potential to cause disabled people to bring harm upon themselves, or to have an impaired ability to avoid harm"

(Hoong Sin et al, 2011, p.64).

It is not the disability that increases risk but, rather, society's response: the culture of risk avoidance sends the message that disabled people cannot and should not expect to lead full lives (Hoong Sin et al., 2011). Furedi's (2011) report for The Joseph Rowntree Foundation indicates that it is agencies which think in terms of risk not the people subject to risk management policies who instead want greater control over their routine, access to rights, order and sensitive care. Truly person-centred practice will embrace risk enablement, including encouraging service users to achieve sexual well-being (Bywaters and Jones, 2007). But this creates anxiety within a culture of risk aversion.

1.4 Safeguarding adults

A further level of the complexity of risk is how it is managed in social care when harm has or is likely to occur. As discussed in the introduction to this thesis, safeguarding adults is relevant to my research due to its dominance within the day-to-day operation of social work. The discourse of safeguarding highlights the construction of social work as a method of social risk management (even risk aversion) rather than one of rights enablement, leading to the potential "bubble wrapping" (de Than, 2015, p.95) of service users. The concepts of risk and protection are integral to contemporary social work (Pollack, 2010; ADASS, 2014; Care Act 2014), yet how risk is conceptualised is determined by ideology, leading to social workers becoming the administrators of neo-liberal agendas (Ferguson and Lavalette, 2013b). In order to contextualise these comments a discussion of safeguarding adults within social work follows.

The meaning of safeguarding adults

Safeguarding adults refers to a specific, time restricted, investigative and action-planning process triggered by an incident of harm, or potential harm, occurring to a person deemed to be at risk. The Coalition Government of 2010–2015 stated that safeguarding and personalisation in adult social care are intrinsically linked (Department of Health, 2010). This raises the question about how safeguarding can be maintained in the light of freedom from bureaucratic oversight and employment of unregulated personal assistants which personalisation is intended to give to users of social care services (Schwehr, 2014). This is a “concern for all client groups whose direct payments may attract ‘false friends’, exploitative social contacts, and electronic crimes (scams)” (Manthorpe, 2015, p.209). The consumer model of personalisation, with service users as engaged, rational and active participants in a care market, presumes that service users are able to protect themselves from exploitation and that competition between providers will ensure quality. However, the reality is a market where demand outstrips supply leaving service users purchasing what care they can rather than what meets their needs (Skills for Care, 2014a,c).

The formal process of safeguarding adults is situated in law (now placed on a statutory basis in the Care Act 2014) with criminal justice often being part of the process. However, procedural intervention is only available to a specific population defined as at risk of abuse and neglect.

The safeguarding (section 42) duties apply to an adult who:

- *“has needs for care and support (whether or not the local authority is meeting any of those needs)*
- *is experiencing, or at risk of, abuse or neglect*
- *as a result of those care and support needs is unable to protect themselves from either the risk of, or the experience of abuse or neglect”*

(Department of Health, Care Act 2014 Guidance, 2016, 14.2)

Abuse and neglect is about the misuse of power and control that one person has over another and includes sexual abuse, which makes social workers cautious about considering sexual well-being in case of any allegation of sexual abuse. Sections 42–47 of the Care Act 2014 give local authorities specific new safeguarding duties, most relevant to this research being the prevention of, and protection from, abuse and neglect. The Care Act Statutory Guidance (14.8) (updated 2016) changes the focus of safeguarding adults policy from a protectionist stance to an outcomes-focused approach where best practice means the person concerned, or their representative if the individual lacks capacity to participate, is fully involved in defining the outcomes they wish to achieve. The safeguarding outcomes referred to in the Care Act concern the promotion of well-being and prevention of abuse and neglect to ensure safety and well-being. This may cause tension between service user and social worker if the outcomes people may wish involve risk, for example, participating in online dating.

To meet these new responsibilities social workers require knowledge about how, why and to whom abuse occurs and the factors which aid prevention. Such knowledge can be used to promote personal skills and the social structures which prevent harm. Safeguarding policy (Bournemouth, Poole and Dorset, 2015) identifies the factors which are thought to increase and decrease risk of harm. These have particular significance to this research as many relate to social inclusion and access, as well as the importance of social connectedness, all of which are aspects in the achievement of sexual well-being.

Factors increasing potential vulnerability include:

- *Dependency on others including physical and financial dependency*
- *Difficulties in making choices due to influence from others*
- *Lack of information or access to it, not being aware of options available*
- *Issues related to language and culture*
- *Unwillingness to pay for support*
- *Lack of social support network, isolation or social exclusion*
- *Unrealistic expectation of others (family, neighbours etc)*

- *Negative experiences of engagement in the past*
- *A lack of understanding of the implication of not receiving appropriate health-related treatments.*

Factors that minimise risk may include:

- *Positive family relationships*
- *Active social life and circle of friends*
- *Able to participate in the wider community*
- *Good knowledge and access to community activities*
- *Remaining independent and active*
- *A protection plan in place that remains relevant*
- *Information that is received in a timely manner and fully explains the implication of care, support or health treatments.*

(Bournemouth, Poole and Dorset, 2015, appendix 8, p71)

Whilst usefully identifying risk factors the safeguarding policy does not address the causes of harm, so this list needs to be used as evidence to underpin social inclusion policies focusing on the factors which minimise risk, for example, social inclusion.

1.5 Empowerment and Rights

An essential part of the social work role is the empowerment of service users (Ife, 2001). This should include sexual rights, as commented upon by Lord Justice Munby in the case of MM, a woman who had been stopped from having a sexual relationship by her local authority:

“Physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare. What good is making someone safer if it merely makes them miserable? None at all!”

(Munby, re MM, 2007, cited in de Than, 2015, p.87).

Fundamental human rights are stated in law: article 8 of the Human Rights Act

1998 states that everyone has the right to respect for their private life and family life; the European Court of Human Rights holds that this protects sexual autonomy, confidentiality, dignity, forming and maintaining personal relationships and allowing them to develop (de Than, 2015).

This is made more specific for disabled people by the International Convention on the Rights of Persons with Disabilities (2008) which:

“includes a range of civil and political, as well as economic, social and cultural, rights, covering areas in which disabled people have been discriminated against such as access to justice; participation in political and public life; education and employment”

(Parker and Clements, 2008, p.509).

Article 19, entitled “Living independently and being included in the community” requires governments to take action to facilitate disabled people’s “full enjoyment” of this right and their “full inclusion and participation in the community” (Parker and Clements, 2008, p.509). In addition, the Equality Act 2010 requires the making of reasonable adjustments for disabilities which could be used to argue for education, information or the provision of equipment to aid sexual well-being (de Than, 2015).

Legal entitlement is clear: people have the right to a private life including their sexual expression and to have relationships of their choice. However, the application of rights in the social world is made complex by competing human interests and values. Fear can result in avoidance of risk by individuals and organisations leading to people:

“undergoing the equivalent of being bubble-wrapped and placed into storage. This is a human rights violation and could lead to legal liability for those whose decisions restrict the rights of people with disabilities”

(de Than, 2015, p.87)

Marginalised groups are devalued, assigned low-value roles or struggle to find a socially valid role which brings with it integration and social acceptance. This

relates to Social Role Valorisation (SRV) theory (Wolfensberger, 1983 cited in Barnes, 1996), which holds that the good things within a society will be accessed by those assigned roles. The negative discourse of disability, along with the narrative of illness, age and disability being a burden, reinforces role devaluation (Briant et al., 2013; Quarmby, 2011). An example of this negative discourse can be found in *Well-being, Why it Matters to Health Policy*:

“A policy focus on well-being can lead to improved well-being and improved health outcomes and may ultimately reduce the healthcare burden”

(Department of Health 2014, p.2).

The reality of a negative discourse has led former UN Secretary-General, Kofi Annan, to state:

“On paper, [people with disabilities] have enjoyed the same rights as others; in real life, they have often been relegated to the margins and denied the opportunities that others take for granted”

(United Nations, 2006).

Bauman’s notion of conceptual nets (2008), the philosophical and ideological frameworks informing the social context in which we live, demonstrates the complexity of the realisation of the goal of equality and access to rights. Social organisation is a necessity for living together. Certain frameworks (conceptual nets) are imposed which establish boundaries without which:

“There would be no guidelines for understanding either who we are, where we have come from, what we should do, or where we are going”

(Swain et al., 2003, p.20).

The powerful within society determine the framework which promotes their interests, so:

“While we may experience our own individuality as unique, the range of identities open to us are limited and structured around currently prevailing culturally accepted ideas”

(Swain et al., 2003, p.21).

The conceptual nets define and create vulnerability by means of societal attitudes and values (such as consumerism) and can even add to the potential for harm through protectionist procedures meant to address vulnerability but which can actually result in marginalisation and ‘othering’ (Swain et al., 2003; Hoong Sin et al., 2011).

Neo-liberal economics which has dominated social welfare discourse in the UK since 1979 (Fitzpatrick, 2001; Beresford, 2005; Farnsworth, 2006; Pollack, 2010; Beresford, 2013; Ferguson and Lavalette, 2013b) is said to reject the concept of a right to welfare: welfare has to be earned and deserved (Fitzpatrick, 2001; Ferguson et al., 2005; Beresford, 2005). Alternatively, welfare can be conceived as part of collective citizenship, through which social inequality is addressed and service users supported to exercise their rights as citizens (Lymbery, 2014). Social justice is achieved through fair and equal access to rights and opportunities as well as resources (Bradt and Bouverne-De Bie, 2009) and it is through the exercise of rights that social inequalities are challenged and societal change is achieved (Baylies, 2002). These points are developed in the well-being section of this literature review where the relationship between equality and well-being is explored.

In relation to this research, a significant factor in the achievement of sexual well-being is changing attitudes as it is these which will challenge the ‘conceptual nets’. This is why human rights informed practice, policy, research and campaigns are so important as each effort takes a cumulative step along the path for equal citizenship to be meaningful in more than words, and to challenge the protectionist approach where ‘risk’ is used to discriminate (Disability Rights Commission, 2006). For social work practice to advance human rights it is not enough to avoid

oppression, but instead creates an obligation to promote rights, meaning actively challenging the conceptual nets which create injustice and inequality. A rights-based approach to social work alters the narrative from one of negative conception of dependency to a positive one of empowerment and entitlement to full participation (Healy, 2008; Kanguade, 2010; Ferguson and Lavalette, 2013a; de Than, 2015). In terms of sexual well-being this means:

“to apply concepts of sexual citizenship and sexual rights to physically disabled people, emphasising the right to be free from abuse and the right to information”

(Grossman et al., 2003, p.95).

The concept of sexual citizenship (Weeks, 1998) promotes rights specifically connected to sexual well-being. The sexual citizenship of physically disabled people challenges exclusion on the basis of disability and is grounded in principles of human sexual rights (Kanguade, 2010). This involves three dimensions:

- *“demand for control over bodies, feelings and relationships;*
- *demand for access, representations, relationships and public spaces;*
- *demand for choice about identities, lifestyles and experience”*

(Kanguade, 2010, pp210–211).

All three of these dimensions feature as crucial and recurrent elements within the literature, confirming their significance to physically disabled people.

1.6 The Care Act 2014

The context for social work in England altered significantly in 2015 with the implementation of the Care Act 2014. This Act is a major piece of reforming legislation consolidating many of the multiple laws concerning social care. It introduces the well-being principle obliging local authorities to ensure that everything they do aims to increase well-being. Eligibility for social care

interventions are redefined as based on 'risk to well-being' as opposed to the 'risk to independence' previously set out in Fair Access to Care (Department of Health 2003, updated in 2010).

The Care Act prioritises the prevention of ill health with early intervention aimed at maintaining health and well-being. It also seeks to extend service user choice and control through access to personal budgets and the provision of information about council and other services (Department of Health, 2014).

The Act potentially offers practitioners and social work organisations scope for creative engagement with service users and carers focused on their well-being, a concept compatible with social work values (International Federation of Social Work definition, 2014). (An exploration of the meaning of well-being used in the Care Act features within the well-being section of this literature review.) In addition, the Act gives statutory authority to safeguarding adults policy for the first time, thereby adding clarity to a complex process. Other requirements set out in the Act include its emphasis on a person-centred perspective, ensuring participation is central to all processes, whilst seeing people within their contexts so that assessment must take into account the needs of the whole family and carers and balancing the well-being of all parties. There is an assumption within the Act that the individual is best placed to judge their own well-being with emphasis on the least restrictive action, and assessment and planning being proportionate to the need (Department of Health, 2016, 6.3). However, caution is advocated by Slasberg et al., (2012) who state that the 1990 reforms started with the same vision of personalised and person-centred care but did not achieve the transformation promised. It is too early to assess the full impact of the Care Act 2014 on social care but:

“The practical challenges are significant, both in the interpretation of well-being goals and in determining how the care system might be configured to achieve them”

(Forder and Fernandez, 2015, p.2).

Implementation of such radical, reforming law during a period of austerity leads practitioners to be fearful of what can really be achieved (Netten et al., 2012; Beresford, 2013; Community Care, 2016). Cuts of 27% to local authority budgets to 2014/2015 (HM Treasury, 2010, cited in Lymbery, 2012; Penny, 2015) have impacted on services, often used by the most vulnerable citizens (Lymbery, 2012). This means:

“The potential of social work to offer a proactive and positive supporting role within the framework of personalisation is therefore being severely constrained”

(Lymbery, 2012, p.789).

The well-being principle presents social workers with the opportunity to directly apply their interpersonal skills in the exploration of the meaning of well-being in all its complexities with the people with whom they work. The concept of sexual well-being takes the topical notion of well-being and applies it to a specific aspect of life which has been problematic in social work practice with physically disabled people (Bywater and Jones, 2007; Myers and Milner, 2007). However, the well-being principle underpinning the Care Act 2014 presents an opportunity for practitioners to promote the positive concept of sexual well-being for physically disabled people.

1.7 Personalisation

The Care Act 2014 extends the scope of personalisation within social care, and promotes it as a means to enable well-being (Department of Health, 2014). Personalisation at its inception referred to a sum of money (called either an individual or personal budget, delivered as a direct payment) being provided to the service user as an alternative to services purchased and arranged by social care workers (Beresford, 2013). This option was conceived as the mechanism for achieving equality through increased choice and control, and was a model grounded in the Independent Living Movement advanced by disability campaigns for equal inclusion, access and participation in mainstream life (Beresford, 2013). But the term has been broadened:

“Personalisation means thinking about public services and social care in a different way – starting with the person and their individual circumstances rather than the service. It affects everyone in adult care and support”

(SCIE, 2012a, p.1).

Personalisation is often used interchangeably with person centred planning which:

“Discovers and acts on what is important to a person. It is a process for continual listening and learning, focusing on what are important to someone now and in the future, and acting on this in alliance with their family and their friends”

(Thompson et al., 2008, p.27).

These are encouraging statements to practitioners as they appear compatible with both professional values and the wish to keep service users central to all activities. However, critics such as (Beresford, 2013) question whether in reality personalisation is a means of extending a market approach to care and reducing costs. Neither has personalisation been fully embraced by the profession which continues to express concern:

“One of the problems is that personalisation as a policy has been presented to social workers with all its structural constraints and little opportunity for any dialogue about how and why it is being applied which raises suspicion about its motivation”

(Gardner, 2014).

Whereas direct payments were originally introduced to disabled people as a form of liberation, Beresford (2013) argues that the more recent interest has an ideological rationale, extending the marketisation and bureaucratisation of care. Such a critique is extremely challenging to social work as it indicates a change in the social care relationship from one of empathetic care based on human rights to one built on consumerism (Lymbery, 2013). This point is of critical relevance to this research as a relationship based on the purchase of support services does not easily enable exploration of such a sensitive subject as sexual well-being (other than purchasing sexual services/equipment).

Seeing personalisation in the form of direct payments or individual budgets as liberation challenges the power associated with social work, which has been the source of oppression and control (Oliver and Sapey, 2006). This is helpful to reflective practice as a prompt to re-evaluate what is of positive value in social work. However, conceiving social care relationships in terms of commercial interactions does justice to neither the complexity of the lives of people who use social services, nor the reality of an unstable, high turnover care market characterised by low wages and poor status (Beresford, 2013; Skills for Care and Ekosgen, 2013, Skills For Care, 2014a,c; BBC Radio 4's *Today* programme, 13 May 2015). The consumer model simplifies social work with adults and fails to acknowledge the multiple roles undertaken by practitioners. Services can only become personalised if the multiple roles undertaken by social workers are researched and understood such as:

“How front-line workers navigate the often contradictory demands of policy and practice change and the needs of service users”

(Innes et al, 2006).

There is a contradiction in trying to introduce personalisation in a climate of fiscal cuts which risks the implementation of personalisation by local authorities being undertaken in ways which respond to budgets rather than the principles of choice and control (Lymbery, 2013). Lymbery (2013) reports on the ideological nature of personalisation rhetoric underpinned by the assumption that service users are willing and able to maximise control over their lives, with policymakers seeing personalisation as a matter of personal freedom (Furedi, 2011). Yet the Vision for Adult Social Care (Department of Health, 2010) says ‘we want people to have the freedom to choose’ suggesting that it is the policymakers, not social demand, that is responsible for personalisation (Furedi, 2011).

SCIE (2012a) identifies a further barrier to meaningful implementation of personalisation in the persistence of the medical model amongst social care providers which, respondents to SCIE’S research stated, is often accompanied by what they called the “professional gift model” (SCIE, 2012a, p.8) where gratitude

was expected rather than an acknowledgement of services resulting from citizen rights. Without a foundation based on rights, personalisation is subject to political change and policy priority.

Other barriers to personalisation identified by SCIE'S research have worrying implications for how realistic its extension in the Care Act 2014 can be. These barriers include:

- *lack of market to purchase services with personal budgets;*
 - *funding cuts are leading to the closure of some services and organisations and this is reducing the choice people have over the services they can use;*
 - *funding cuts to support services – this includes those that relate directly to the personalisation of social care services and cuts to broader services such as Citizens' Advice Bureaux and Legal Aid;*
 - *local authorities not listening to what people want;*
 - *inflexibility around use of personal budgets and direct payments;*
 - *risk assessment panels blocking some people's choices;*
-
- *dividing people/fragmentation – personalisation strategies only supporting people to do things on their own, not with other service users, which works against collective approaches like pooling budgets;*
 - *lack of support for people who are isolated and do not have independent support.*

(SCIE, 2012a, p.9).

I recognise each one of these barriers in my own recent social work practice.

1.8 Political ideology

Ideology permeates every aspect of social organisation; it determines the fundamental rationale of political policy:

“A body of ideas that reflects the beliefs and interests of a nation, political system, etc and underlies political action; the set of beliefs by which a group or society orders reality so as to render it intelligible”

(Collins Online Dictionary).

This definition poses the following question: What and whose beliefs and interests determine the body of ideas? It is precisely this question that social workers need to be asking as we critically examine the factors involved in practice (Parker, 2007). This question is crucial to my research because ideology determines the profession’s legislative framework for its work with disabled people, the wider social structures in which disabled people live (made known through social policy) and social discourse around social work and the issues concerning its client groups.

This includes such notions as:

- *'deserving and undeserving' service users;*
- *benefits: a disincentive, a safety net or an enabler;*
- *poverty: economic and opportunity;*
- *work seen as the source of redemption/reintegration;*
- *taxation: a disincentive or an expression of social responsibility*

(adapted from sources including: Ferguson et al, 2002; Oliver and Sapey, 2006; Fitzpatrick, 2001; Beresford, 2005; Farnsworth, 2006).

The connection between welfare and social justice which was so strong at the inception of the welfare state has become blurred, resulting in the marginalisation of welfare within social work and wider society allowing for a negative discourse to dominate (for example, welfare portrayed as a burden – Bradt and Bouverne-De Bie, 2009). Ideology legitimises the status quo which ensures that the ideas and assumptions that underpin established power relations remain unchallenged (Thompson, 2001). Thompson states that ideology provides the framework that enables people to make sense of their world by forming the link between the objective external world of social circumstances and the internal subjective world of meaning. However, this framework becomes so ingrained that we do not see it so, for example, inequality seems natural and inevitable as expressed by politician

Boris Johnson (2013) citing inequality as both inevitable and a positive motivational experience.

The influence on both attitudes and services within social care of the economic crash and consequent recession, change in government and subsequent cutbacks cannot be overestimated. The literature review suggests that statutory social care has moved towards what Oliver and Sapey (2006) term the compliance model, where focus is on the provision of essential statutory duties with social workers increasingly undertaking administrative functions in order to meet targets (Moriarty et al., 2015a).

In Western democracies the government is tasked with fostering an environment where citizens can lead safe and fulfilling lives actioned through social policy and legislation (Aked et al., 2010; Thomas and Evans, 2010), with statutory social work traditionally being one of the instruments with which this responsibility is carried out. The Care Act 2014 radically changes the role of social work with adults, leading the College of Social Work to publish both the *Business Case for Social Work* (2012) and *The Roles and Functions of Social Workers* (2014) to highlight the contribution social work continues to make to society and to justify its continuation. The picture is complicated by the wide-ranging impact of public spending cuts on resources which also affects the type and degree of social care needs. In addition, the effect of health and social care integration, whilst improving routes of communication between services, threatens the loss of the unique perspective offered by social care (Community Care, 2015).

Theme 2: Constructs emerging from the literature review subject to ideological influence

2.1 Disability

Most western societies use a definition of disability stated by the World Health Organization (WHO) (Barnes, 1992) and now updated by the Convention on the Rights of Persons with Disabilities as:

“those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others”

(WHO 2009, 2.1).

The definition of disability depends on the specific environment which determines what is possible, what activities are essential to survival and what aspects of personhood are valued (Wendell, 1996). Disability is, therefore, not just a health problem but rather a complex phenomenon, reflecting the interaction between a person’s body and the social environment. Yet this literature review indicates that disabled people still experience significant barriers to inclusion:

“The ignorance and attitudes of society and individuals, including health-care providers, raise most of these barriers – not the disabilities themselves”

(WHO, 2009, p.1).

These barriers are created by a disabling society whose structures are ideological in nature. Social workers and social care organisations need to be aware of both the barriers and their causes in order to improve lives and social circumstances.

2.1.1 Economic factors in the construction of disability

The continuing oppression of disabled people relates to the development and dominance of Western capitalism with its narrow objectives and failure to accommodate difference (Oliver, 1990b; Barnes, 1996). Capitalist economics and globalised markets led to disabled people became increasingly segregated,

excluded from participating in the developing industrialised and capitalist society with their exclusion justified by difference. Oliver (1990b; 1996) reports on the emergence of a notion of disability brought about by the industrialisation of the 19th century which was:

“founded on individual responsibility, competition and paid employment. Those perceived to be unable to meet these ideals were regarded as deviant”

(Oliver, 1996, p.24).

The industrialisation of the 19th century coincided with the Age of Reason, which heralded scientific rationality and the philosophy of liberal utilitarianism promoting individual and rational self-interest (Barnes, 1996). It was during this time that the individualisation and medicalisation of disability emerged, leading to the personal tragedy theory of disability and the eugenics movement, which used Darwin's theories to promote the notion that impairment is a threat to Western society. The growth in institutionalisation of those unable to fit the industrial worker model was in response to the perceived need for social provision and control. These old institutions have now largely disappeared, however, the ideology on which they were built persists (Oliver, 1990b; White, 2009).

The modern globalised market, built on capitalist principles, requires a frenetic pace of work in a constant state of competition, an environment which only suits a select workforce (Finkelstein, 2001). British welfare is founded on a form of Darwinian theory of fitness combined with a capitalist marketplace where bodies are considered commodities to be used and worked on (Tilley, 1998), resulting in welfare being likened to dehumanising 'freak shows' where people get money for displaying their bodies, giving them up to scrutiny and measurement (Solvang, 2007). Dominant neo-liberal economic policy requires that disability is financially disadvantageous; otherwise, it is claimed, it becomes attractive as a means to avoid work and responsibility (Wendell, 1996) and leads to dependency.

Evans (2002) describes the desires which capitalism generates as 'monstrous' as they direct, deform and manage the body in ways which serve the capitalist system

rather than human needs. The enduring nature of the concept of the 'body beautiful' is sustained by consumer capitalist culture; huge profits are generated by the beauty industry and to maintain this people have to be reminded of their faults (Wendell, 1996). A cultural shift is needed to transform an unrealistic and limiting view of beauty into an appreciation of the diversity of beauty (White, 2009). A transformation which identifies the relationship between the myth of the perfect body and the material and cultural forces which sustain it (Barnes, 1996). However, the world is organised with the unacknowledged assumption that to be 'normal' everyone has to be healthy, young and often male, and this creates disability through neglecting what is needed in order for others to participate (Wendell, 1996; White, 2009). The standards of normality are important to our identity; they are the preconditions of participation which become internalised through unnoticed social disciplinary processes and only come to light when our ability to meet the standards is threatened, for example, through disability (Wendell, 1996). Performance is needed to meet these standards in order to participate. Liddiard (2013c), developing the work of Hochschild (1983), discusses the emotional labour and work required of disabled people, in the workplace and within private, intimate relationships, in response to the social expectations of non-disabled culture.

2.1.2 Models of disability

The construction of disability by health and social care agencies and their employees determines how physically disabled people are approached and the nature of the subsequent relationship. This has a profound effect on the individual's experience of a service and the conception of the self-reflected through the values demonstrated by the service (Morris, 2001). There have been a number of models of disability and I provide an overview of these in order to understand how disability is socially constructed.

Medical model

The medical model defines disability "in terms of a person's impairment that medical science can treat or "cure" (Williams et al., 2006, p.11). It is an individualising model where focus is on the individual and their impairment rather than on how society is organised or structured. Disability is considered a threat

challenging the:

“established notions of discipline and normality because it serves to draw attention to uncontrollable nature – to limitations placed upon the ability of humans to shape and organise the world around them as they wish”

(Swain et al, 2003, p.23).

Impairment is seen as an unwelcome reminder of human mortality and the frailty of life, and therefore must be assigned to the individual to reduce its relevance to all humans. This model emphasises individual loss and focuses on inabilities which contribute to the notion of disability equating to dependence (Barton, 1996). There is an assumption that physical disability is negative, that it is a tragedy to be avoided and automatically leads to a poor quality of life (Swain et al., 2003). Historically, particularly since industrialisation, this model has resulted in disabled people being removed from society and institutionalised, viewed as inferior and dangerous because “our ideas about disability and about ourselves are generally formed by those who are not disabled” (Morris, 1991, p.37).

The medical model ignores the political, social and economic factors of disability and undermines the individual’s perception of their impairment (Oliver, 2004). Medical expertise retains a dominant hold over disability with developments in the science of genetics being both curative and preventative. The role of professional ‘experts’ underpins the medicalisation of disability, leading to the dominance of professional voices over those of disabled people, resulting in oppression (Lymbery, 2013). In particular, the notion of social workers having expert knowledge of disability issues has devalued service user knowledge and ideas (Wilson and Beresford, 2000). Medicine, based on theories of being, selects the characteristics we value (Swain et al., 2003) and devalues atypical bodies. Post-modernist thinkers such as Wendell (1996) and Shakespeare (1996; 2000) consider disability to be ideologically constructed by those who have power through the exercise of knowledge, such as medical professionals and legislators (Thomas, 2004). The idea that the body can be controlled is “part of the western scientific myth that nature can be controlled” (Wendell 1996, p.94). The positive experiences of physically disabled people valuing the social dimensions of

relationships challenge such a negative assumption (Morris, 1991).

Rehabilitation model

The role of rehabilitation within the medical model has a specific normalising purpose set by 'experts'. Disability is equated with "sickness and deficit and it is the responsibility of individuals to engage with professionals to return them to normality" (Oliver 1996, p.20). Rehabilitation can be seen as a form of state-provided compensation in response to a conceptualisation of disability as tragedy; health and welfare services provide action for change for individual loss (Finkelstein, 2001). This model lacks an appreciation of diversity or the potential of impairment to offer any positive outcomes. Neither does the rehabilitation model address the impact of societal organisation.

Alternative models

The disability movement is a strand of the politics of difference (Barton, 1996) which involves challenging ideological conceptions and:

"definitions which isolate and marginalise and replacing them with those which engender solidarity and dignity"

(Barton, 1996, p.11).

The movement has successfully countered powerful social discourses through vigorous campaigns, academic work, arts projects and evidenced-based argument. This has led to the implementation of legislation such as the Disability Discrimination Act 1995 and the Equality Act 2010 providing legal entitlement to services and protection from discrimination. Alternative models of disability have arisen from disabled people's struggle for realisation of their civil rights (Burchardt, 2004).

The social model

The social model emerged from the disability movement campaigning for social inclusion and recognition during the 1970s. The movement resonated with other rights-focused efforts for social change including campaigns for gender and race equality (Baylies, 2002). It:

“stemmed from the Fundamental Principles of Disability document first published in the mid-1970s (UPIAS, 1976), which argued that we were not disabled by our impairments but by the disabling barriers we faced in society”

(Oliver, 2013, p.1024).

The model emphasises the social, economic and environmental barriers to participation in society (Oliver, 1990b; Baylies, 2002; Burchardt, 2004) and thereby shifts the location and cause of disability away from sole focus on the individual to the social disadvantages faced by disabled people (such as access to employment and housing). It has been very influential in the UK, aiding the development of “independent living, direct payments, mainstreaming and the requirement to make ‘reasonable adjustments’ under the Disability Discrimination Act” (Williams et al, 2006, p.1). The model became the unifying idea for “collective disability consciousness” (Oliver, 2013, p.1024). Societal organisation can be arranged in ways which directly aid or hinder inclusion and equality; it is the structural choices made which impact on the experience of impairment, rather than individual behaviour alone. Social circumstances cause impairments: poverty causes impairment due to, for example, inadequate access to medical treatment, poor nutrition and substandard living conditions, and is a result of impairment due to, for example, limited access to paid employment and inadequate benefits (Baylies, 2002). Disability is, therefore, a political issue as it is via social and economic policy, informed by political theory, founded on concepts of human purpose and value, that society is organised.

But the social model is not static – it is subject to debate and development (Swain et al., 2003) – nor is it an all-encompassing framework which can explain everything which happens to disabled people. Rather, it is a tool for understanding (Oliver, 2013). Appreciation of the phenomenology of embodiment has particularly prompted development of the social model. Increasing awareness that one’s sense of self, the materiality of the body and the external world of others is in a constant process of mutual construction is particularly important to understanding the experience of disability (Shildrick, 2007). This adds an appreciation of the embodiment of disability, that individual physical form is significant. Disability is not

simply concerned with how the organisation of society impacts on people but also how the individual experiences their environment and social world. The body, with its particularities, is vital to self-conception because it is in and through this physical vessel that the experience from which the self is made is located (Shildrick, 2007).

Citizenship model

Oliver (2004) advocates an alternative citizenship model where disabled people are conceived as valuable members of society, as workers and customers, recognised as empowered individuals and active citizens (Oliver, 2004).

Government would argue that such a citizenship approach is present in The Care Act 2014, with its promotion of service user as consumer, their own expert and involvement at every stage (Department of Health, 2014). The citizenship model extends the earlier social model introduced by Oliver and other disability academics and activists who:

“Wrest(ed) this term (disability) from the powerful grip of doctors and social workers and set about entirely reconstructing its meaning in the light of the social exclusions encountered in their own lived experience”

(Thomas, 2002, p.21).

Affirmative model

As subjective quality of life is dependent on personal perceptions, the assumption that disability is a wholly negative experience, with disabled people not wanting to be different, is one of the greatest forms of oppression (Morris, 2001). The affirmative model, arising from the disability and disability arts movements, provides an alternative view (French and Swain, 2004). It is a model which encompasses the positive social identities of disability and is grounded in the benefits to life experience disability brings: how it offers a different perspective on life and can be a relief from some social expectations, leading to a sense of freedom not enjoyed by the able bodied (Swain and French, 2000). Such affirmation, celebrating diversity, is expressed and recorded through the disability arts movement exhibiting different experiences of disability and impairment and the consequent different ways of knowing and being in the world (Barnes, 2003). The disability arts movement has reclaimed language such as ‘cripple’ (Mairs, 1986)

through its development of 'crip culture' (Kuppers, 2006), which is becoming more mainstream with comedians such as Francesca Martinez (whose cerebral palsy leads her to describe herself as 'wobbly') appearing on national radio and television programmes (for example, BBC Radio 4's *The News Quiz* and BBC2's *The Russell Howard Show*).

The affirmative model challenges the notion of disability as tragedy questioning the assumption that disabled people want to be 'normal', 'independent' or to 'adjust': it is the expectation that the only possible response to impairment is a negative one, which results in unhappiness rather than the impairment itself (Swain and French, 2000). However, Swain and French (2000) do not deny that some people do experience their disability as tragic – not to do so in the UK social context where negative messages about disability prevail (Quarmby, 2011; Briant et al., 2013) is very difficult. This is a brief overview of the primary models of disability which demonstrates that disability is a complex social construct.

2.2 The body

The body has become the focus of debate as the notion of the Cartesian duality of mind and body has given way to recognition of embodiment (Shaw, 1998; Wincup 1998), where the self is experienced and expressed through the physical. Shaw (1998) suggests the increased interest in the body has been initiated by the rise of consumer culture, which makes the body an object to be worked on, a site of labour and a focus for anxiety. Personal identity has been loosened from the fixed external points of, for example, religion, and is now open to be created through consumption of goods and services (for example, gym membership, diet and clothing). In a capitalist society the conceptualisation of the body as a site of consumption or of a personal project to work on and perfect makes it a particularly important source of potential profit.

The body has been theorised in ways which have a profound impact on lives; the naturalistic perspective conceives the body as a purely biological entity with fixed qualities where differences – or inequalities – between bodies are natural and inevitable. Alternatively, the body can be conceived as a social construct, its meaning relative to the cultural values of the time. Both theories hold truth, as there

is both a created body of particular societies and, at the same time, in the same physical space an individual human being – a ‘real’ body (Evans, 2002, p.9).

Bodies are subject to legal, religious and medical surveillance and control, and are of particular interest because of the politicisation of the body (for example, due to feminism), demographic changes and deliberate cultural shaping (the body and identity are commodities) (Swain et al., 2003). This encompassing of bodies within the grasp of government through social policy and the law has occurred because:

“It is as though the existence of non-normative bodies creates an unspoken anxiety that leads to denying sex has any place in physically disabled lives, or fetishizing it”

(Shildrick, 2007, p.1).

She argues that only through enabling the full embodiment of disability will the issue of sexuality be opened up. Humans are physical beings and the details of our physical selves are important to how we interact with the world and how we construct our identities; people have different relationships to their impairments (for example, relief at relinquishing certain expectations or grief over loss of certain abilities) and this influences how we live (Shakespeare, 2000). The connecting of individual experience of the physical body to collective experience of social structures has the potential to reconcile private and public spheres of life (Shakespeare, 2000) which ultimately aids all as disability and illness is likely to be experienced by the majority of people during their lives.

The enduring negative view of embodied pleasure can be traced to ancient Greek dualistic thought which juxtaposed body and soul, with the pleasures of the flesh ranked as the lowest of goods (Tepper, 2000). The Greeks idealised bodily perfection (Barnes, 1996), a notion absorbed and spread by the Romans, still persistent, to the detriment of physically disabled people (and everyone) today (Quarmby, 2011). Barnes points out the link the Greeks and Romans made to impairment as punishment for sin, with St Augustine later claiming people with impairments are the living proof of Satan’s power:

“The notion of ‘the sins of the flesh’ suggest that it is only through punishment of the body that the soul can be purified – an imperfect body implies gluttony, laziness a lack of self-control.”

(Seidler, 2006, p.7).

Protestant cultures have continued such ideas developing a tradition of self-denial, such as Puritanism in which sex is a weakness necessary for procreation, not a source of pleasure or an expression of love. Catholicism also strengthened the negative attitudes conceiving sexual pleasure as sinful. These beliefs were reflected in the art and culture of the time (for example, Shakespeare’s portrayal, of Richard III, Bedlam and ‘freak shows’ being a source of entertainment). However, a more contemporary Christian view contends that disabled people, like everyone, are created in the image of God and, therefore, are sexual with the capacity to love and be loved (Chance, 2002).

The ideas of physical self-control have become culturally embedded (the virtue of health and fitness) and almost unconscious, expressed in part through law but also the more subtle social roles which exert control over bodies (Tilley, 1998; Solvang, 2007; Shildrick, 2007). Disability is perceived as interfering with these roles, even provoking existential fear as the disabled body is seen as a threat to the wholeness of self and the natural order of things (Solvang, 2007). Social workers need to have an understanding of the meaning of the body within society and to the people with whom they work in order to be able to challenge negative conceptions experienced by service users. By encouraging positive attitudes to physical difference social workers can contribute to building self-esteem and resilience within service users.

Effect of physical disability on body image

The dearth of realistic and positive cultural representations of disability contributes to the ‘otherness’ of disabled people and increases fear and ignorance (Wendell 1996; Kaufman et al., 2007; Stevens, 2010; Briant, 2013). This adds to the negative effect of impairment impacting on the person’s sense of their sexual allure (Walters and Williamson, 1998) and sexual health (Stevens, 2010). Social workers, again, need to be aware of the impact impairment can have on body image and the effect of the media on reinforcing negative impact. Social workers have a

responsibility to encourage disabled people to develop an attitude towards their body which is realistic, without “launching into 'let's learn to love our bodies' or ignoring the issue altogether” (Myers and Milner, 2007, p.94).

People living with degenerative conditions also have a constantly changing relationship with body image as their condition alters (Shildrick, 2007). Research has given a voice to people expressing anguish over changes in their appearance and body image which have led to them withdrawing from social contact (Karlen, 2002). Sexual and body esteem, and sexual satisfaction, are strong predictors of general self-esteem and less depression amongst disabled people (Taleporos and McCabe, 2002). The pain and fatigue associated with impairment can affect intimacy, sexual activity and self-identity which impacts on self and body image (Schlesinger, 1996) with the impact increasing when fatigue and depressive symptoms are high (Seawell and Danoff-Burg, 2005).

The ideology of female beauty has been constructed in terms of male desire which makes disabled women especially disadvantaged as they cannot easily participate in the western social system based on the Darwinian theory of fitness and a capitalist market economy: they are at risk of being considered ‘damaged goods’ and therefore less sexually ‘marketable’ (Tilley, 1998, p.94). Rintala et al., (1997) support this with a survey of 430 single women, 250 with disabilities and 180 without, which revealed that women with disabilities are perceived as ‘damaged goods’ or asexual which then impacts on their opportunities to date. The notion of being ‘damaged goods’ had a more profound impact than the impairment itself (Tilley, 1998; Walters and Williamson, 1998). Howland and Rintala (2001) add that this leads to women feeling they should be grateful for the attention of any man, even if this attention is abusive. Only the definition as ‘invalid’ or pathological have been open to disabled women (Milligan and Neufeldt, 2001).

In recognition of this, the Sex and Relationship Facilitation Project’s (Davies, 2000) aim was to promote disabled people’s self-esteem and positive feelings about their bodies and develop their relationship skills. They state that for many disabled people their only experience of touch is intrusive and functional. Disabled people

may have experienced multiple medical interventions which effectively turn the body into an object to be worked on, something which becomes the property of 'the (medical) system' (Kaufman et al., 2007). The Sexual Health and Disability Alliance (SHADA) and associated Outsiders organisation aim to raise awareness of the sexual needs of disabled people. Shuttleworth (2000) describes the social and cultural issues and impediments in his study: *The Search for Sexual Intimacy for Men with Cerebral Palsy*. He states that the cultural ideals of attractiveness and body image, like that of female beauty are inappropriate for disabled people. He describes the embodied response to the:

“evaluative gaze of non-disabled people, for example the exacerbation of spasticity”

(Shuttleworth, 2000, p.266).

But impairment does not necessarily have a negative impact, and to assume that it does is oppressive, as demonstrated by the research undertaken by Swain and French developing the affirmative model (2000) of disability. Social workers therefore need to approach the topic of body image with openness, being informed about what it means to the service user without imposing preconceived assumptions.

2.3 Independence

My research concerns the lived experience of physical disability with participants who require care and support services due to impairment. In social policy terms this need for support is conceived of as dependence, something to prevent, delay and avoid

“Care must again be about reinforcing personal and community resilience, reciprocity and responsibility, to prevent and postpone dependency and promote greater independence and choice”

(Department of Health 2010, p.5).

The dominance of capitalist and neo-liberal economic theory in contemporary Britain has resulted in independence becoming the primary goal of social welfare policy (Secker et al., 2003; Lymbery and Postle, 2010). Independence is conceptualised in terms of self-sufficiency (Secker et al., 2003; Swain et al., 2003; Leece and Leece, 2011; Roulstone, 2012) which medical services such as physiotherapy and occupational therapy have been designed to help disabled people attain. The emphasis in policy on independence is rooted in ideological concepts promoting the idea of autonomous, self-actualising individuals (Shildrick, 2007). Such a conceptualisation of independence denies the reality of human existence which is characterised by both interdependence (for example, social networks giving personal validation) and dependence (for example, the physical support needed due to the illness, impairment or age which the majority of us will experience during our lives). The promotion of such a limited, ideological conception of independence isolates people (Secker et al., 2003) and by promoting this social workers are not only in danger of perpetuating the status quo (where loneliness and isolation have been identified as equally damaging to health as smoking 15 cigarettes a day (Markey et al., 2007; Handley et al., 2015)) but also of avoiding the need to develop mutually supportive social structures which create well-being, build resilience and reduce the potential for hate crime (Quarmby, 2011; Ferguson and Lavalette, 2013b). The narrow conceptualisation of independence as self-reliance directly relates to the personal and social factors in the risk of harm itemised in the safeguarding section of this literature review; isolation creates greater opportunity for harm to occur. There is an apparent contradiction in the ideology of independence as the very social structures created to support it, such as neo-liberal economics with its prioritising of profit, also create dependency. For example, an experience from my own recent practice occurred where a wheelchair user was dependent on a carer to access a new residential property which had been built without disability access requirements in order to reduce expenditure. This reflects Oliver's point made in 1990, and still relevant now, that:

“Dependency is created amongst disabled people, not because of the effects of functional limitations on their capacities for self-care, but because their lives are shaped by a variety of economic, political and social forces

which produce it”

(Oliver, 1990b, p. 94).

An alternative understanding of independence is advocated by some disabled people, the Independent Living Movement and academic study (Secker et al., 2003) which takes into account the lived experience of dependence/independence. The Independent Living Movement in the United States was part of the wider civil rights movements and has influenced disability social policy across the Western world. The independent living centres, which emerged from the movement, were created to be run by and for people with disabilities, focused on peer support, advocacy and empowerment, a challenge to the notion of services for rather than with disabled people (National Council on Independent Living, 2016).

Independent Living is “not about disabled people living in ‘splendid isolation’ but supporting people to live their lives as equal citizens” (Parker and Clements, 2008, p.510). Having self-determination and control over life is identified as a significant factor in the lived experience of independence (Swain et al., 2003). This sense of control is possible even in the presence of total care needs if the provision of support is organised in a person-centred, self-directed way which balances the promotion of self-direction with avoidance of undue risk (Secker et al., 2003). Support that enables people to remain in their homes and community is central to a sense of independence, so long as “comfort, affection and reciprocity” (Secker, 2003, p.386) – that is, the meeting of needs both physical and emotional – are addressed.

Social care policy uses both of these conceptualisations, the former in modelling outcomes of independence where individuals care for themselves (or purchase support) without recourse to the state, and the latter where eligibility for care and support services is determined and personal budgets are allocated to the individual who controls this as a consumer of services in a market. However, the market also requires people to be dependent on care services in order to secure employment in the disability and care business, which has become commodified and commercialised (Barnes, 1996).

The notion of the welfare system creating a negatively conceptualised form of dependency (as opposed to a recognition and support of human interdependence) continues to be a widely held narrative within political and media debates (Briant et al., 2013). This has been part of the justification of substantial cuts to welfare provision since the election of Conservative-dominated coalition government in the UK in 2010. Reducing state intervention will lead to disabled people living lives characterised by isolation and poverty, financially penalised for not conforming (Oliver and Sapey, 2006; Beresford, 2013). The reality of this prediction is now evidenced by research:

“The official figures show 3.1 million disabled people are in poverty (26%), but JRF research shows the true figure is at least one million higher”

(Joseph Rowntree Foundation, 2016).

There is a contradiction in social policy concerning the perception of services such as education and public transport. Non-disabled people are assisted to participate in the public world by the provision of such services, which are perceived as a right of citizenship and not a marker of dependence. Whereas disabled people are seen as needing ‘help’ or specialist provision to participate (for example, adapted transport), rather than having an entitlement (Wendell, 1996). Society has created the disability through poor social conditions, unrealistic social expectation and the methods of social organisation.

However, it is possible to conceive a model of being which accommodates both high levels of dependence and high levels of felt independence (Shildrick, 2007). To accomplish this requires the creation of reciprocal communities of support with equitable access based on an assessment process that takes into account the person’s context and meanings. Both of these are theoretically met by the Care Act 2014 (section 5, promoting diversity and quality in provision of services) which tasks local authorities to commission community based support resources. In addition, the Care Act assessment (section 9) seeks the individual’s perceptions, however, the power to judge whether the individual’s perceptions meet strict eligibility criteria still remains with the social care professional, subject to the law.

2.4 Inclusion and value through work

Work is a significant factor in subjective well-being as it provides social connection and purpose (depending on the nature of the work) (Graham and Shier, 2010). How work is conceptualised and the social status assigned through employment impacts on self-esteem and identity, which feeds into mood and sexual esteem. Physically disabled people are less likely to be employed (Joseph Rowntree Foundation, 2013; MacInnes et al., 2014) so are excluded from the psychological and fiscal benefits of employment, as well as opportunities to meet potential partners. Oliver (2013) observes that the approach taken to support disabled people in employment, such as making reasonable adjustments, is done on an individual basis rather than considering wider disabling social structures. This approach further underlines individual difference.

Within social policy, work is promoted as the primary means of economic inclusion, autonomy, self-esteem, purpose and the route out of poverty (Morris, 2001; Department of Health, 2014). This aspect of social policy neither addresses inequality nor the exclusion of disabled people who cannot work due to either their disablement or lack of suitable employment (Morris, 2001; Joseph Rowntree Foundation, 2016). Quarmby (2011) in her work on disability and hate crime reports that the emphasis on work within social policy has led to an increase in hate crimes against disabled people. She states that not only has the notion of disabled people being benefit scroungers become prevalent but also the idea of disability being a social burden. Such negative messages psychologically impact on well-being (Briant, 2012). In addition, the emphasis on work as the solution to social problems such as poverty leads to alienation (according to Marxist theory) experienced by those without capital, who are excluded from the labour market and are very often the people dependent on the welfare state (Joseph Rowntree Foundation, 2016).

A wider recognition of the concept of work could be offered which incorporates unpaid or voluntary activities such as informal caring and domestic tasks. Care as work needs to be recognised and invested with status and disabled people need to be recognised as work creators (Morris, 2001).

Theme 3: Social work and sexual well-being

The literature search found little information specifically relating to social work and sexual well-being (with the exception of Myers and Milner, 2007; Dunk, 2007; Bywater and Jones, 2007); there was also little research on this topic undertaken by social workers or social work academics. One explanation for this might be Myers and Milner's (2007) suggestion that social work is concerned with anti-discriminatory practice related to sexual identity or with negative sexual experiences such as abuse, whilst the responsibility for enabling sexual well-being is considered a health or individual matter, not relevant to social work. The apparent prioritising of abusive sexual experiences relates to the management of risk-taking primacy within social work (Ferguson 2007; Carr 2010). Shildrick (2007) reports that the state is focused on risk with matters relating to sex (other than reproduction) having little or no purchase on state funds. Yet I agree with Myers and Milner (2007) that sex:

"is a key area of social work because there is a clear relationship between sexual ill health, poverty and social exclusion"

(Myers and Milner, 2007, p.60).

My exploratory, participatory research takes this association between poor sexual health/well-being with social problems as the rationale to explore the lived experience of sexual well-being, creating new knowledge to inform social work practice which enables social workers to address social problems through encouraging sexual health and well-being within the people with whom they work. I acknowledge the argument that the responsibility for raising the issue of sexual well-being lies with the individual service user, and that personalisation and the focus on service user perspective in The Care Act is the vehicle enabling service users to do so. However, without services acknowledging sexual well-being as a legitimate concern (and thus giving people permission to raise the matter) it can remain hidden or an 'add on'.

The Care Act 2014 tasks social care workers to assist with the issues which impact

upon well-being (Section 1, Care Act Guidance, 2016). The literature review demonstrates the significance sexual well-being has on overall well-being – therefore, social workers need to be knowledgeable about the topic and confident in their skills to tackle the related issues.

3.1 What is sex?

The meaning of sex is contested (Milner and Myers, 2007) with debate about whether sex is socially constructed or a fundamental biological description (Merriam Webster, 2016). Additional complexity and contradiction concern what constitutes a sexual act which is “limited only by the imagination and physical body” (Myers and Milner, 2007, p.8). Yet, contrarily, sex is subject to legislative boundaries, state intervention and control regulating its permissible forms and location (Myers and Milner, 2007; de Than, 2015). Philosophy is drawn on to create a moral overtone to traditional definitions of sex and correct sexual behaviour, using notions of “normal and abnormal” (Teichman and Evans, 1991). The dominance of medical discourse also influences human understanding of sexuality and sexual activity, contending that there are biological reasons for sexual preferences (Myers and Milner, 2007). Sex can be defined with an essentialist emphasis as an “overpowering yet functionalist force in the individual that shapes personal and social life” (Stephen, 2002, p.35), whilst Foucault’s (1990) work on the discourse of sexuality (cited in Stephen, 2002) offers an alternative view, contending that sexuality is not a natural quality of the body but is the effect of historically specific power relations, which result in the dominance of certain forms of acceptable sexual expression.

My research concerns the lived experience of sexual well-being and this literature review highlights that both biological and constructionist conceptions of sex are relevant to lived experience: whatever the source (biological or socially constructed), people experience their sexual drive as a physical and emotional urge, yet the meaning attached to sex is moderated through socialisation, constructed by the individual within a specific context and is therefore variable between different people (Myers and Milner, 2007).

Sex and good sexual health are components of well-being. They are:

- *“a link with the future through procreation;*
- *a means of pleasure and procreation;*
- *a sense of connection with others;*
- *a form of gentle, subtle or intense communication;*
- *enhanced feelings of self-worth;*
- *a contribution to self-identity”*

(Nusbaum and Rosenfield, 2004 adapted by Myers and Milner, 2007, p.59).

3.2 Sex and the law

Sex is caught up in the mechanisms which maintain and construct the social order (Shildrick, 2007). De Than (2015) points out that the:

“criminal law is lagging behind human rights law in the way that it perceives disability: it sees people with disabilities as vulnerable potential crime victims and, sometimes, potential wrongdoers, rather than as autonomous individuals with the right to sexual expression”

(de Than, 2015, p.93).

In the UK, the Sexual Offences Act 2003 defines criminal offences stating that sexual activity with consent is generally lawful (de Than, 2015). To give consent one must have capacity as defined in the Mental Capacity Act 2005, but this can be difficult to assess with certain disabilities. There is particular concern about those disabled people who have communication-related disabilities because if a person's ability to communicate consent is impaired, the Sexual Offences Act 2003 presumes they do not have the capacity to consent. Therefore, anyone having a sexual relationship with them cannot have a reasonable belief that there was consent (de Than, 2015, p.99). This is a particular challenge for social workers who have to comply with the duty of care to assess and report risk, but must carry out this duty in a way which balances all rights. This means excessive safeguarding can breach the duty of care if it prevents the person exercising choice and control.

For those who have communication difficulties but wish to engage in sexual activity, the law makes this balancing of the duties of care problematic. The Sexual Offences Act 2003 potentially criminalises even long-standing relationships where one partner has lost the capacity to consent and best interest decisions in the Mental Capacity Act 2005 cannot apply to sex as no one can consent to sex on behalf of someone else (de Than, 2015, p100).

According to de Than, a person has the capacity to consent to sex if they understand on a simple level:

- “(a) the mechanics of the act;*
- (b) that there are health risks involved, particularly the acquisition of sexually transmitted infections;*
- (c) (if relevant to them) that sex between a man and a woman may result in the woman becoming pregnant.”*

(de Than, 2015, p.101).

In respect of carers or people in a position of trust, paid or unpaid, sections 38–41 of the Sexual Offences Act 2003 make it unlawful for care workers to influence those who have capacity to participate in sex acts (de Than, 2015). The Act also states that a sexual act may be illegal if it takes place in a place deemed not to be private; having a third person present (for example, a facilitator or carer) may constitute the place as public.

Sexual surrogacy is not illegal but is expensive, and so is beyond the means of many physically disabled people. The cost of accessing social opportunities or purchasing services through which sexual expression can be achieved is prohibitive for many physically disabled people (Fraley et al., 2007). Research indicates that fear of criminal liability for supporting disabled people with their sexual expression (for example, assisting them in making appointments with sex workers) is very common in the health and social care professions (de Than, 2015). Moreover, there is misunderstanding regarding the law around the purchasing of sex which makes carers thinking of arranging sexual services extremely cautious. Shuttleworth (2010) states that:

“these impediments (to disabled people accessing sexual services) are programmatic, attitudinal and architectural and not related to the legality of the service”

(Shuttleworth, 2010, p.5).

De Than (2015) states that the primary offences related to sex work are soliciting, inciting or controlling prostitution for gain, brothel-keeping and paying for sex with someone who has been coerced or trafficked. Social workers have to be conscious of the risk to both service user and sex worker if they are aware of service users making use of sexual services. There are internet resources where such services can be sourced which guarantee workers are not trafficked (see Appendix 2). It is not generally illegal to purchase sex or to “arrange for an adult with capacity to enjoy the services of a sex worker” (de Than, 2015, p.94), however, social work involvement in such arrangements could be construed as condoning sexual exploitation. Without clarity in codes of practice or through social policy this is potentially a problematic issue for practitioners who may work with service users who require assistance to access sexual services and, therefore, need to negotiate ways of assisting which do not breach professional standards.

3.3 The notion of asexuality

The literature review reveals that disabled people still experience discrimination regarding sexual well-being. Notions of asexuality and deviance being associated with disability remain prevalent in disabled people’s personal accounts, and in cultural representations of disability (Addlakha, 2007; Kaufman et al., 2007; Stevens, 2010; Kangaude, 2010).

To uphold the social work value of respect for the person, social workers cannot condone the damage done to physically disabled people by assuming asexuality because sexuality is the prime site where identity is inscribed, and to:

“strip sexuality of its significance or to silence it is to damage the very notion of being human”

(Foulcault (1988) cited in Bywater and Jones, 2007, p.59).

The literature repeatedly refers to disabled people being considered asexual (including Guldin, 2000; Howland, 2001; Milligan and Neufeldt, 2001; Stevens, 2010; Kangaude, 2010), or even being incomplete (Chance, 2002), citing personal narratives, cultural images and the absence of attention to sexuality paid in rehab settings as examples of this evidence, along with empirical investigations. The concept of asexuality leads to sexual disenfranchisement (Milligan and Neufeldt, 2001). It is a form of stigmatisation which renders the person asexual as they are excluded, deliberately or as a matter of omission, from the opportunities where romantic and sexual relationships often occur (Milligan and Neufeldt, 2001). When people believe the myth of asexuality themselves it limits their possibilities as sexual beings and damages self-esteem (Kaufman et al., 2007).

Shakespeare (2000) argues that a social model of disability is required which is sensitive to difference and the impact of impairment, whilst challenging the notion of normality. This can be used to show that the problem of disabled sexuality is not about how to do it but, rather, who to do it with due to societal disablement. Kaufman et al. (2007) explore the myth of the idea of asexuality of physically disabled people. They consider the notion that people living with disabilities are undesirable, but point out that many disabled people have good quality sexual relationships and the myth persists due to unrealistic portrayal of sex within the media as only for the young and beautiful. Non-normative bodies create anxiety in others that leads to the denial of sex having any place in the lives of physically disabled people (Shildrick, 2007; Kangaude, 2010). Social policy is silent on physically disabled people's sexuality (Shildrick, 2007), unlike issues such as employment, access and education, which benefit from dedicated legislation and policy. This silence is due to physically disabled people being perceived as asexual: the silence is harder to contest as it amounts to control via non-recognition (Shildrick, 2007).

3.4 Professionals' discomfort discussing sex

The notion that professionals feel uncomfortable discussing sexual matters is a recurring point (including Walters and Williamson, 1998; Guest, 2000; Weerakoon,

2001; McLaughlin and Cregan, 2005; Shuttleworth, 2010; Dyer and das Nair, 2013; Blackburn et al., 2015). So, too, is the need for professionals to feel confident and comfortable with their own sexuality if they are to be helpful to others. This includes recognising their own and other's values (Medlar, 1998; Weerakoon, 2001; Myers and Milner, 2007). The barriers reported include fear of embarrassment, lack of time, training and policy and fear of not knowing what to do (Dyer and das Nair, 2013), while de Than (2015) also discusses fear of illegality or safeguarding concerns.

Professionals still have difficulties recognising patients and service users as sexual beings with the same sexual needs as others (D'ardenne, 2004). Medlar (1998) highlights this reluctance but does not condemn the professionals for this, instead arguing that this can be addressed by training so that professionals recognise and understand their own sexual values, attitudes and how these influence them in their work (Guest, 2000). Studies indicate the responsibility professionals have in terms of enabling the sexual health of the people with whom they work (Milligan and Neufeldt, 2001; Chance, 2002; McLaughlin and Cregan, 2005). These studies concern medical professionals; however, my research suggests that this is of equal relevance to social work practice.

However, the difficulties practitioners may experience in discussing sexual matters is not a reason for the topic to be avoided. Social workers have privileged access to individuals and their support networks, and because social work's "primary professional territory is at the point of psycho-social transition which may often be times of stress and distress" (Jones, 2014, p.495), encounters are often intimate in subject matter and emotional in content. As social work does not avoid other sensitive topics, avoidance of sexual well-being cannot be justified. Furthermore, research reveals the:

"emergence of the sexual self as of central concern to the individual immersed in contemporary social life. Each citizen must now negotiate the sexed aspect of their self"

(Dunk, 2007, introduction).

To remain relevant to contemporary life, knowledge of sexual issues is vital to the practice and education of social workers working with people dealing with the increasing complexities of modern society; this is of relevance to all client groups. Social workers' codes of practice task them to advocate for the rights of the people with whom they work (BASW, 2012a) which includes sexual rights (de Than, 2015) and, in light of the Care Act, improving well-being.

Social workers bring themselves, as well as their professional skills and identity, to the social work relationship and, therefore, have both influence on, and exercise discretion over, the development of the relationship, no matter how brief that may be. Whilst the encounter is prescribed by procedural processes (specifically assessment and review), social workers have discretion regarding the skills they employ which can be used to open or close down communication. Part of the social work task is to empower service users to address the issues which matter to them, which impact upon their lived experience. This requires an openness to the other and the emotional intelligence to recognise and respond appropriately to the encounter. Emotional intelligence has become a significant concept within human services since Goleman published *Emotional Intelligence* in 1995. He argued that emotional intelligence is as important as cognitive intelligence to success (Goleman, 1995). Emotional intelligence is a key skill in social work because humans are "awash with emotions" (Howe, 2007, p.14) and the emotionally intelligent social worker can use their ability to:

"provide feedback on other people's emotions, understand and analyse affective states, regulate and manage emotions and arousal and co-operate and collaborate with others in mutually rewarding relationships"

(Howe, 2007, p.14).

These skills are crucial when exploring sexual well-being with service users to ensure that the topic is approached sensitively. Being emotionally attuned to oneself and others enables the confidence to enter the world of the other whilst retaining personal and professional boundaries (Howe, 2007). Because professionals may feel discomfort about potential boundary violations, guidance is

needed to be able to distinguish between boundary crossing for the benefit of service users and boundary violation which concerns the benefit of professionals (and is therefore subject to disciplinary proceedings) (Nusbaum and Rosenfeld, 2004). This is crucial because it is not just services that impact on lives; the primary need in improving the experience of sexual well-being for physically disabled people is addressing negative attitudes. The Care Act 2014 presents the opportunity for social work with adults to use the well-being principle to revise professional attitudes, to focus on the rights and well-being of service users across the life-course, in all forms, physical, psychological and sexual. Evidence is found (McLaughlin and Cregan, 2005) of staff discomfort and an assumption that physically disabled people do not want to discuss the subject. However, Walters and Williamson (1998), exploring the relationship between sexual satisfaction and quality of life, found that individuals expressed relief and appreciation when professionals affirm their sexuality through discussion and rarely thought such discussions inappropriate. This finding was confirmed by Aizenberg et al. (2002) where participants reported their willingness to engage in discussions around their sexuality and wanting their sexual needs recognised.

3.5 Education for professionals

The need for professionals to be educated in the sexual implications of a physical disability was stated by Eisenberg as early as 1978. This returns as a repeated point stated in much of the literature, for example, Caruso (1997) and Weerakoon (2001) who states that:

“Health professionals must take full responsibility to ensure that they have the knowledge, expertise and skills to meet the sexual health care needs of their patients”

(Weerakoon, 2001, p.129).

A number of studies report on the necessity of rehabilitation staff, psychotherapists and other clinicians to have training in sexual matters (Milligan and Neufeldt, 2001; Chance, 2002 and McLaughlin and Cregan, 2005). Browne and Russell (2005), authors of an Australian study, refer to research participants stating that they would

ask their caregivers to assist with sexual activities (such as positioning or hoisting) but believe they would need training to do this sensitively and without embarrassment, a point repeated by Sakellariou (2006).

McLaughlin and Cregan (2005) noted professionals' uncertainty about whose job it is to address sexuality, with some staff stating it is everyone's job to at least feel comfortable with the subject to enable the patient to discuss it with whomever they feel most comfortable.

“Social workers need to be comfortable with their own sexuality, check their sexual knowledge and develop a sexual language before talking to service users about such matters”

(Myers and Miler, 2007, p.67).

Greater understanding of disability and sex also informs social work intervention, for example, Myers and Milner (2007) state that early onset of impairment tends to affect social and sexual confidence, but not sexual risk taking, whereas “later impairment is likely to be an issue of loss” (Myers and Milner, 2007, p.94).

3.6 Impact of disability on sexual relationships

The literature reveals the complexity of change to relationships when one partner experiences disability which social workers need to be alert to in order to consider well-being. It is apparent that partners can be a source of strength, but also stress, to each other, as in any relationship. However, disability introduces particular positive and negative effects which, if acknowledged, can be used to assist the relationship and mitigate the negative. But effects cannot be assumed; each individual experiences disability differently and at different life stages which means that no single approach to enabling sexual well-being is appropriate (Myers and Milner, 2007). This is an acknowledgement that impairment can cause significant difficulties in life, both because of the social structures, but also the individual experience of the impairment itself (in reference to the social model of disability and later challenges). Acceptance of this point is of relevance to everyone, social workers, policymakers and service users alike, as disability or illness will be

experienced by most people during their lives (Medlar, 1998; Solvang, 2007). Yet disability creates anxiety in the able bodied due to the recognition that they, too, are vulnerable to body alteration (Solvang, 2007). This anxiety gives rise to stigmatising attitudes towards disabled people.

The extent of the impact of disability on relationships is affected by the nature of the impairment and even more significant is the pre-existing quality of the relationship and individual personalities: stable intimate relationships appear to mitigate the effects of physical disability and illness (Hwang and Johnston, 2007; Markey et al., 2007; Handley et al., 2015). In Esmail et al. (2007) the participants with multiple sclerosis (MS) reported that their partner's love and support were vital to their adjustment. Survival of the relationship is related to the extent partners can negotiate adjustment to their changed lives with external support potentially assisting. Results from Westgren and Levi (1999) suggest the influence of pre-injury sexual experience is important to post-injury adjustment.

Banks and Pearson (2004) and Ruhlman et al. (2008) report that the majority of participants in their research experienced negative impact on their relationships following impairment. The literature review for Esmail et al. (2007) suggests that MS impacts negatively on romantically attached couples, but can also strengthen the relationship through increased communication, while conceptualising adjustment to impairment as a shared 'project' is good for relationships as a focus of possibility. Relationship status is related significantly to mood and emotional well-being (McCabe and Taleporos, 2003) and romantic partners are the primary positive influence of healthy behaviours, such as diet and physical activity (Hwang and Johnston, 2007). The theoretical basis of this idea is the theory of social control: relationships influence health through, first, the indirect process of the internalisation of relationships in ways which motivate individuals to maintain healthy habits and, secondly, via direct processes such as providing specific instructions. The majority of adults' social experiences revolve around the lives they share with their partner so for health and social work interventions to be successful the consideration of partners and the social context is vital (Hwang and Johnston, 2007) (conversely, the impact of the absence of a supportive partner needs to be taken into account).

Disability, impairment and illness affect both partners:

“Chronic illness changes not only how the couple see each other, but also how they see their world and how they are perceived socially”

(D’ardenne, 2004, p.293).

As illness dominates the landscape, social networks can drop off. D’ardenne states that anger from the care giver relates to how much they perceive the care as a burden, with the most resentful being overprotective and controlling, which then interferes with the person’s development of independence skills leading to alienation of other sources of support and further isolation. This is relevant to social work in its activity with carers and alertness to safeguarding concerns. In addition, greater attachment anxiety resulting from disability may alter relationships; hence, individuals who fear separation may be more prone to abusive relationships. This is important to disabled people who may feel a sense of dependency (Quarmby, 2011).

3.7 Impact of physical disability on sexual activity

Different impairments have different effects on sexual function. Social work with physically disabled people needs to be aware of this in order to appreciate the impact on well-being. Multiple sclerosis, for example, can result in decreased libido, lubrication problems and men can experience erectile problems (McCabe et al., 1996). Richards et al. (1997) report that the participants were aware of a conscious ‘shutting down’ of their sexuality in the immediate post-injury period, with half of the respondents assuming sexual pleasure was now impossible. The study indicates the occurrence of cognitive-genital dissociation where parts of the body are seen as separate and worthless, resulting in feelings of depression. Other impairments such as brain injury (Oddy, 2001) can damage the areas of the brain associated with sexual functioning leading to the loss of confidence and an increase in anxiety and depression, which then affects sexual functioning. Research into the impact of chronic pain indicates that it negatively affects intimacy and self-identity (Schlesinger, 2003). This is supported by D’ardenne (2004) who states that long-term health conditions affect sexual relationships both through the

specific physical effects of the condition and treatment, and the negative psychological effects on self-image and the impact on the partner.

Research into sexual esteem amongst physically disabled people (McCabe and Taleporos, 2003) indicates that people with more severe disabilities had significantly lower levels of sexual esteem and significantly higher rates of sexual depression. A phallogentric view of sex that focuses on the function of the penis (Sakellariou, 2006) is oppressive and can lead to feelings of emasculation amongst physically disabled men whose condition results in erectile issues. Knowledge of this enables social workers to empower service users to seek alternative methods of sexual activity.

3.8 Increased sexual activity and pleasure after the onset of a physical disability

Some disabilities can result in increased sexual activity, for example, a qualitative study into the positive sexual effects of lupus amongst women unexpectedly found that, for some women, lupus brought improved sexual functioning and relationships (Karlen, 2002). The study refers to other research which found similar reports related to other conditions. Other studies report that sexual relationships had improved through increased communication (Esmail et al., 2007). The ability to talk and even joke about sexual difficulties is important (Parker, 1993; Westgren and Levi, 1999; Karlen, 2002; Esmail et al., 2007), while some of the participants in the study by Richards et al. (1997) found they could not talk to their partners about sex, which caused them significant relationship difficulties; Banks and Pearson, 2004 support this view and add that none of the participants had received any information about the likely impact of their stroke on relationships. Impairments affecting communication can be especially problematic, effectively excluding people from the usual methods of relationship building and maintaining (Richards et al., 1997).

However, studies such as Karlen (2002) and Esmail et al. (2007) indicate that sex lives can improve after the onset of disability through the improvement in communication and a willingness to explore and experiment. Healthy intimacy is

characterised by open communication which is non-defensive and spontaneous (Mills and Turnbull, 2004).

3.9 Gendered disability

Feminism has led to the consideration of gender as a category of difference in all scholarly analysis, including disability studies (Tilley, 1998). However, it was not until the 1980s when disabled women started to write about their lives that feminism and disability connected; prior to that time many disabled women felt alienated by the feminist agenda and forgotten by the disability movement (Tilley, 1998). Feminism has identified the ways women's bodies have been controlled by men through commodification, medicalisation and the law (Wincup, 1998). Women are perceived as being more connected and subject to their bodies and are controlled by biomedical processes (for example, hormones) denying autonomous action; a consequence of this is that women are more aware of their bodies (Sheldon, 2002). Feminists have highlighted the contribution the media has played in the objectification of women's bodies (Shaw, 1998), including the unrealistic cultural ideals of beauty. By accepting these standards, society creates disadvantages for all women (Wendell, 1996), but women with disabilities face discrimination in patriarchal societies both on grounds of gender and disability (Schlesinger, 2003).

Research on couples' experience of disability after marriage (Parker, 1993) comments on the different expectations the men and women participants had in terms of personal care giving: the women did not expect their male partners to provide such care to them – and felt guilty if they did – whereas the men did have an expectation of such care giving. Parker (1993) reports that relationships are based on notions of exchange and reciprocity, and while this may not be immediately apparent when the balance of what is considered equitable alters, for example, through illness or impairment, conflict can occur. When the exchange balance changes, both parties examine their relationship which entails threats to each other's identities, for example, the carer not wanting to take on their partner's previous roles as this may be considered a threat. Devaluing may take place, of the carer to reduce the 'debit' and the disabled person devaluing themselves.

Shakespeare (2000) states that the disability movement, which in his view is macho and confrontational, tapped into the tradition of the labour movement rather than feminism as male issues were considered more urgent than relational (traditionally female). However, he argues that sexuality and sexual relationships are often the source of disabled people's deepest oppression and, therefore, should be the focus of disability action. Disabled women experience disproportionate disadvantage in relation to men who are more likely to be in, and remain in, satisfying relationships than disabled women. In addition, married disabled women with a non-disabled partner are often subjects of curiosity and comment (Myers and Milner, 2007).

To be effective, social workers need to be aware of and sensitive to these potential threats to well-being amongst the people with whom they work.

Male identities

Bancroft (1998) in his research into men's lifestyle magazines argues that in western societies young men are the object of regulative discourse and coercion, where personal relationships with women are largely overlooked. Disability challenges the social norms of male sexuality, and Shuttleworth (2000) talks about the search for sexual intimacy amongst men with cerebral palsy who cannot initiate, or respond to, intimacy. The study found that those who compared themselves with the social norms of masculinity were more likely to remain socially isolated as they did not live up to the ideals whereas those who could draw on other ideals, such as interdependence or prioritising emotional intimacy, were more open.

For men, too, disability is seen to compromise traditional notions of masculinity which are often defined in negative terms, for example, not being emotional or dependent (Seidler, 2006). However, the male role has changed enormously in Britain, largely in response to feminist critique leading to cultural and legislative changes such as the introduction of paternity leave and workplace change brought about by equality legislation enabling women to succeed in the workplace

(however, this is not complete with equal pay still a problem and the 'glass ceiling' remaining an ongoing concern). Traditional male identity as the breadwinner and protector has had to adapt, but this is not a painless process of relinquishing power and involves challenging the:

“Hegemonic (theories of) masculinity that offers a universalised top-down vision that orders the relationships between diverse masculinities only in terms of power and subordination”

(Seidler,2006, pxix).

Tepper (1999) discusses how he freed himself from socially imposed concepts of masculinity following a spinal injury, but it was not immediate or painless. How gender expectations are ingrained through the processes of socialisation are not easy to relinquish. Tepler (1999) states that the socialisation of men provides little that is helpful to the formation and maintenance of intimate relationships, nor are the sexual messages conveyed in our culture helpful as they are unrealistic, leading to a disabled person assuming their sexual life is over if they cannot meet those expectations. The emphasis on male strength, physical and emotional, leads men to deny they need help which can then be masked in substance abuse or violence towards self and others (Tepler, 1999).

Rapala and Manderson (2005) discuss human performance and the disturbance to gendered narratives disability creates. Arrington (2003) gathers narratives from survivors of prostate cancer and found that the onset of illness is the turning point in their definitions of sex, their identity as sexual beings and their sexual relationships. Some consider erectile dysfunction as the end of their sex lives, while others report that it was a new beginning to a different kind of sex and intimacy. This suggests that an alternative male narrative is required for well-being to which social workers are well placed to contribute, although with the changing roles of social workers already discussed, this may be more difficult.

Theme 4: Finding a definition of well-being for sexual well-being

In the early design stages of my research I became aware of the increasing political use of the concept of well-being and its influence on social policy. I became

intrigued and sought to understand the potential contradiction between making the conceptual notion of well-being, with its potential for multiple definitions, an explicit policy and practice goal, whilst also implementing austerity measures. The following section of the literature review seeks to explore the complexity of well-being, its meaning for social care practice and why it is an essential element of my research. How the concept of well-being fits into the UK political agenda is significant to the aims of my D Prof study as the participants recount their lived experience of well-being and, specifically, sexual well-being. These experiences are profoundly influenced by remote political decisions and policies, societal attitudes informed by the dominant social discourses and their own particular views shaped by their personal circumstances. All citizens of a society are subject to the impact of political decision making and the participants, like other citizens, are able to make representation, however, the participant's potential marginalisation by dint of disability muffles and distorts their voices. This study provides a means of expressing these voices by relating real life evidence of the impact of political choices.

4.1 What is well-being?

Well-being is a complex and contested concept (La Placa et al., 2013) involving subjective and objective dimensions, with the question of whose responsibility it is to create, enable or encourage well-being contested. There is debate as to whether well-being is a neutral (nothing wrong) or a positive (feeling good) state, or even whether it is a state at all but, rather, a continuous process (Ereaut and Whiting, 2008; La Placa, et al., 2013; Galvin and Todres, 2013). Whether humans even have the capacity for happiness or well-being is debatable. Schopenhauer (cited in Teichman and Evans, 1991) suggested that human wants and desires are a perpetual source of misery because they can never be satisfied. Capitalism perpetuates this drive by creating more wants and desires to feed the market which leads to economic growth. In contrast, Bertrand Russell (1930) (cited in Teichman and Evans, 1991) defends an optimistic attitude, stating that there is no intrinsic reason why happiness is not possible, but that unhappiness dominates due to economic inequality and greed. This complexity indicates that the meaning of the term well-being cannot be assumed, analysis of how and for what it is being used

is necessary for understanding (Ereaut and Whiting, 2008).

Well-being tends to be defined in two related ways: *hedonia* involving pleasure, and *eudaimonia* involving notions of living a meaningful life or flourishing as first described by Aristotle (Dunn and Brody, 2008). Every definition has implicit values which might bring *hedonian* or *eudamonian* ideas to the fore, each definition resting on what the definer thinks it means to be human, specifically a 'whole and well human' (Sarvimaki, 2006). To understand well-being, therefore, requires a philosophical understanding of being, invoking existentialism, the philosophy of human existence (Sarvimaki, 2006).

Existentialism considers the way humans exist in the world, our freedom and responsibilities exercised through the:

“dialectical interactions of individual factors (my choices, values, actions) and wide sociopolitical factors (oppression). Existence is a constant interplay of the two, simultaneously personal and social”

(Thompson, 2000, p.70).

This quote illustrates the movement of life, the 'constant interplay' or existential mobility which “calls us into our future possibilities” (Galvin and Todres, 2013, p.65). This theory of well-being incorporates Heidegger’s notion of home coming which concerns the unity of dwelling and mobility which he termed “abiding expanse” (Galvin and Todres, 2013, p.65); homelessness and homecoming combine into the expression of valuable human potential. It is consciousness of the experience of homelessness which occurs when moving away from the taken-for-granted securities which opens a path of energising potential felt as well-being.

“But homecoming does not eradicate suffering, it is a kind of peace despite everything – it is Gegnet – the coming together of mobility and dwelling as a unified experience. Well-being is both a way of being in the world and how this way is felt as experience... the feeling of rootedness and flow, peace and possibility.”

(Galvin and Todres, 2013, p.75).

The essence of mobility is in all the ways we are called into existential possibilities of moving forward, and the essence of dwelling is all the existential ways we come home to what we have been given in time, space, others, mood and our bodies. Well-being is found in the union of dwelling and mobility, where the potential to move into possibilities of engagement co-exists with the experience of peace, restfully accepting what is present; letting be. Heidegger (1927) described ‘letting be-ness’ as the human potential to reconcile ourselves with whatever is possible in spite of our limitations. It is about being “at home... coming to rest with how things are and forgiving life its changes” (Galvin and Todres, 2013, p.41). Well-being and suffering are on a continuum in relation to one another, with one being emphasised over the other at different times; therefore, it is always in process and humans need to accept the possibility of both well-being and suffering (Galvin and Todres, 2013, p.98).

Applying this concept to my own experience I recognise the ‘homelessness’ I have felt from the destabilising forces of deeper critical learning about social work theory and practice stimulated by D Prof study. My homecoming results through the reconciliation between what is, with the potential for what can be; an ‘abiding expanse’ of opportunity where sexual well-being can become an issue integrated into social work practice. The learning tool resulting from this study is my contribution to this process of “constant interplay” (Thompson, 2000, p.70).

4.2 Why are governments interested in well-being?

The concept of well-being has a potent contemporary political currency (Ereaut and Whiting, 2008; Thompson and Marks, 2008; Penny, 2015) and is now embedded

into social care policy in England through the well-being principle within the Care Act 2014. Beyond social care a well-being industry has grown with personal self-help guides and programmes for the development of well-being within schools such as the piloting of Heads of Well-being (Bevan, 2015). Well-being is understood not only to increase the quality of life for the individual but also to improve national outcomes and demonstrate social progress (Penny, 2015), therefore making it a political concern.

Social progress has traditionally been measured by increases in Gross Domestic Product (GDP), however, the work of Easterlin (1974) demonstrated that GDP alone is no longer an adequate measure. The Easterlin paradox (1974) revealed that, despite significant increases in GDP and consequent improvements in the standards of living in Western societies, the reported levels of life satisfaction have not increased in parallel. Once a living (rather than survival) level of income is achieved people tend to rate the non-monetary aspects of life as more significant to their well-being (Bacon et al., 2010): well-being does not increase with increasing income. In response, international governments have set the measurement of social well-being as a complementary method of measuring social progress. The Stiglitz, Sen and Fitoussi Commission (2009) set the agenda for measuring social well-being beyond GDP (Thomas and Evans, 2010) which added to the growing international interest in well-being as an explicit policy goal (Bacon et al., 2010).

The ongoing financial crisis, which started in 2008, has resulted in a sharper focus on understanding how state spending influences well-being (Bacon et al., 2010) and now this has become an explicit policy goal (Department of Health, 2016). However, there is debate amongst academics about the potential for improving national well-being through the application of well-being-informed social policy. Ormerod (2012) argues that there is an absence of evidence which demonstrates the effectiveness of such policy, instead stating that increasing income is a positive well-being factor, along with marriage and religious faith, whereas Dorling (2016) argues that government can create the environmental and social circumstances which increase well-being. This debate adds to the complexity of understanding

and applying well-being theory to social policy. There has been significant erosion of the social conditions which are identified as increasing well-being such as strong and inclusive communities due to multiple economic and social changes resulting in increasing health and economic inequalities (Wikinson and Picket, 2009). Zipfel et al. (2015) provide powerful narrative accounts from people across the UK living in poverty, highlighting the negative impact on their health and well-being of the changes to welfare and social attitudes (such as their portrayal as ‘scroungers’ although most are ‘working poor’) since 2008. In addition, Penny reports on the effects of austerity measures on public services:

“as people’s lives are becoming more insecure and their need for support grows, swingeing public sector cuts are making public services more conditional, more targeted and increasingly focused on acute need. Local authorities will, on average, see their budgets reduced by 27 per cent by 2015; local authorities in the most deprived areas, where need is greatest, are experiencing the biggest cuts. Research is showing that these cuts are affecting important human services – such as adult and social-care services, childcare services, youth services, mental-health services, housing services and debt advice to name a few”

(Penny, 2015, p.4).

The relationship between well-being and equality is discussed later in this chapter.

4.3 How well-being is defined in UK social policy

The UK Government is committed to measuring well-being but lacks a cross-departmental consensus on its definition (La Placa et al., 2013; Webber and Rickard, 2013). However, a broad definition has been devised by the Department for Environment, Food and Rural Affairs (DEFRA) following collaboration with stakeholders:

“Well-being is: A positive physical, social and mental state; it is not just the absence of pain, discomfort and incapacity. It requires that basic needs are met, that individuals have a sense of purpose, that they feel able to achieve

important personal goals and participate in society. It is enhanced by conditions that include supportive personal relationships, strong and inclusive communities, good health, financial and personal security, rewarding employment, and a healthy and attractive environment”

(DEFRA, cited in Allin, 2007,p.46)

This definition draws on sources from multiple disciplines including economic theory, positive psychology, neurological sciences and social research (Allin, 2007). It represents information gathered from government-commissioned research and academic investigations which have identified individual and social factors believed to enable or inhibit well-being. This includes the New Economics Foundation (NEF) (report authored by Aked et al., 2008) who were commissioned by the UK Government in 2008 to review interdisciplinary international work to identify a set of evidence-based actions to improve well-being. The resulting model describes how an individual’s external conditions act together with their personal resources to enable them, or not, to function well. The NEF identified five markers that aid well-being, which government can encourage through social policy creating the necessary structures and environments:

*“**Connection with others:** family policy, carer’s rights, work life balance, encouraging local involvement, transport.*

- ***Being active:** exercise, public spaces, and urban design.*
- ***Taking notice:** awareness of others and of one’s environment.*
- ***Keep learning:** personal goal achievement.*
- ***Giving of one’s time, energy and resources:** reciprocity builds networks, creates resilience and positive communities”.*

(Aked et al., 2008, title page).

The UK Government Strategy Unit later identified five aspects of an individual indicating their potential for well-being (Bacon et al., 2010):

1. ***Genetics:** there is debate about how much of an individual’s potential for well-being is genetically predetermined, with between 40–50% being*

suggested.

2. Personality: *particular personality traits are associated with well-being such as self-esteem, optimism, planning skills and low levels of neuroticism.*

3. Physical attributes: *for example, those which conform to the definitions of male and female attractiveness perpetuated by the dominant discourse (of relevance to the participant's experiences).*

4. Gender: *women report higher levels of subjective well-being than men.*

5. Age: *older people report higher well-being.*

(Adapted from Bacon et al., 2010).

In addition, the Department of Health defines well-being as feeling good and functioning well (DH, 2014). It comprises:

1. Subjective well-being, including life satisfaction (evaluation), positive emotions (hedonic) and meaning (eudemonic).

2. Objective well-being based on assumptions about human needs and rights.

(Department of Health, 2014).

Ill health, poor employment and unsatisfactory relationships are associated with reported low well-being, however, good physical health in itself does not lead to contentment, nor does illness or disability necessarily lead to discontent; but the situation in which these states are experienced do affect well-being (Department of Health, 2014). Here, well-being is a positive possibility which is independent of health and illness but is a resource for both. It reflects the notion that well-being is dynamic and never complete (Galvin and Todres, 2013).

In 2010, the Office for National Statistics (ONS) was commissioned by Prime Minister David Cameron to develop measures of well-being and undertake a national debate to identify 'what matters to you?' (ONS, 2011). The results indicate that well-being involves:

- *health;*

- *good relationships;*
- *job satisfaction and economic security;*
- *how we spend our time;*
- *the environment;*
- *cultural activities;*
- *transport;*
- *functioning democracy;*
- *the quality and availability of government provided services.*

(ONS, 2011, p.5)

The ONS points out that running through all of these factors is the view from respondents that a sense of equality and fairness is a prerequisite to well-being, a point of particular relevance to social work practice. Equality is discussed later in this section.

The development of positive psychology has helpfully contributed to the focus on well-being. It is concerned with improving lives, well-being and potential future development (Dunn and Brody, 2008), and so aligns with social work goals.

Positive psychology identifies three significant factors in well-being:

1. *Positive connections to others;*
2. *Positive personal qualities such as resilience; and*
3. *Life regulation qualities (such as retaining autonomy self-control).*

(Dunn and Brody, p.414).

Technological developments in neuroscience have also led to an increased understanding of well-being. Physiological evidence of the mechanisms connecting psychological well-being and physical health are now available (Helliwell et al., 2015) which adds to human understanding of well-being, specifically the brain function involved in the experience of well-being. The brain circuits implicated in well-being all exhibit plasticity, and therefore can grow and change (Helliwell et al., 2015). Contextual influences, such as life circumstances and experiences upon which social work intervention can positively impact, are shown to induce plastic

changes in brain structure which then impact on well-being. These changes can be purposefully manipulated, indicating that the capacity for well-being can be altered, for example, through collective action resulting in social changes such as increasing equality, or individual action such as mindfulness exercises.

These various definitions illustrate the complexity of the notion of well-being which can consequently be conceived of as a:

“dynamic process, in which a person’s external circumstances interact with their psychological resources to satisfy – to a greater or lesser extent – their psychological needs and to give rise to positive feelings of happiness and satisfaction”

(Thompson and Marks, 2008, p.2)

Aked et al. (2010) examined the multitude of meanings as applied in social policy and identified four key commonalities:

- 1. well-being is about how people experience their lives, for example, a sense of purpose;*
- 2. well-being is more than the absence of illness or problems, it is a positive condition;*
- 3. well-being is about the personal and the social: it involves connections;*
- 4. well-being is more than happiness; it is about flourishing.*

(Aked et al., 2010, 1.2).

This research concerns whether, and how, these commonalities and the individual and structural domains of well-being fit with the lived experience of physical disability, and how social workers can help enable well-being. At a strategic level a number of policy initiatives are underway to promote well-being; these include the integration of health and social care, prevention strategies (such as reablement) and personalisation all of which are part of the Care Act 2014 (Webber and Rickard, 2013). To ensure ethical practice, as has been previously stated, social workers need an understanding of how well-being is defined (and the assumptions underpinning the definition) in the policies they are enacting, including the strategic

changes. Without such awareness, social workers may unconsciously participate in changes which negatively impact on the well-being of service users.

4.4 Is well-being happiness?

Subjective well-being can be used to mean happiness. Action For Happiness (an international movement founded in 2010 by Professor Richard Layard, Professor of Economics at LSE and part of the Young Foundation, identifies ten key elements to happier living:

- *giving;*
- *relating to others;*
- *exercise;*
- *appreciating;*
- *learning and trying;*
- *goals;*
- *resilience;*
- *positive emotions;*
- *self-acceptance and meaning;*
- *being part of something bigger than the self.*

(Action for Happiness, 2016, p.3)

These factors overlap with those cited for well-being, indicating the close relationship between the two and, therefore, the potential for confusion. Research identifies five positive predictive factors for happiness:

1. *Being employed.*
2. *Frequency of sex/social connection.*
3. *Frequency of experiencing positive mood.*
4. *Being optimistic.*
5. *Self-esteem.*

(Dunn and Brody, 2008, p.416)

The literature review exploring the contemporary experience of disability demonstrates that disabled people's access to opportunities which create these happiness indicators have been restricted by disabling social structures and environments. For example, opportunities for physically disabled people to participate in employment (Joseph Rowntree Foundation, 2016) and romantic relationships (Shuttleworth, 2010; Liddiard, 2013a; Owens, 2015) are limited. However, reflecting the evidence cited above regarding the plasticity of the brain, Action for Happiness (2016) state that happiness is not 'set in stone'; although genes influence approximately 50% of our capacity for happiness and 10% is affected by our circumstances, the remaining 40% is due to the activities we undertake and our choices. This suggests that happiness can be altered both through addressing social barriers but also psycho-emotional support. The Care Act 2014 with its well-being principle presents social workers with the opportunity to use the legislation as an instrument to increase the well-being of the people with whom they work, both through challenging oppressive social structures and offering therapeutic support.

4.5 Definition of well-being used in the Care Act

The government's vision of well-being for social care was set out in the White Paper 'Caring for Our Future: Reforming Care and Support' (2012) and the subsequent Care Act 2014 which uses a definition of well-being relating to the following domains:

- *personal dignity;*
- *physical mental and emotional health;*
- *protection from abuse and neglect;*
- *control over day-to-day life;*
- *participation in work, training and recreation;*
- *social and economic well-being;*
- *relationships;*
- *sustainable accommodation; and*
- *contribution to society.*

(The College of Social Work et al., 2014, Webber and Rickard, 2013, Department of Health, 2014).

These domains of well-being partially coincide with definitions used across other departments (Webber and Rickard, 2013). However, the domains include additional aspects of particular significance to the operation, and even history of adult social care, such as protection from harm and control over day-to-day life. Social care assessment explores an individual's perception of their well-being in reference to the above domains. Assessing subjective well-being enables service users' views on their experiences to be central to care planning, design and delivery. However, assessors determine eligibility for services by judging whether disability or ill-health results in a significant negative impact on the individual's well-being.

The Act tasks local authorities to promote well-being across all its operations:

“Promoting well-being involves actively seeking improvements in the aspects of well-being... when carrying out a care and support function in relation to an individual at any stage of the process from the provision of information and advice to reviewing a care and support plan”

(Department of Health, 2016, 1.7).

It does not specify how well-being is promoted but states that this moves adult care from providing services to 'meeting needs' (Department of Health, 2016, 1.9) and builds on preceding changes to social care such as the extension of personalisation in the form of personal budgets allocated to all eligible users. This model is an extension of the notion of service user as consumer, self-directing the services to meet their needs; there is an assumption of rationality in choice and access to a mixed economy of care. The Care Act concerns the promotion of independence conceived as self-reliance. It is legislation reflecting a neo-liberal agenda with its focus on individual and community responsibility for the prevention of illness and the foundation for ongoing health. Reduction of apparent dependence on the state for care and support, prevention of need and increasing reliance on the self, family, personal networks and community is the goal

(Department of Health, 2016). This conception includes the notion of strong communities built around resilient sets of relationships producing a healthier population enabling both reduction in the responsibilities of the state and costing the state less (White, 2009). Increased well-being is an important part of achieving this goal as individual citizens with high well-being contribute more and cost the state less because well-being “adds years to life, improves recovery, is associated with positive health behaviours and broader positive outcomes” (Department of Health, 2014). However, this vision of strong communities denies the reality for significant numbers of individuals and communities within the UK population, many of whom are users of social care services whose lives are characterised by deprivation, instability and economic inequality; conditions incompatible with strong communities (White, 2009; Furedi, 2011).

Application of the well-being principle potentially addresses this concern as it reframes social work with adults with the concern for human well-being as the driver of practice, allowing compassion to flourish. However, there are barriers to implementing the well-being agenda:

“the context of austerity measures and budget cuts will impact on the ways in which initiatives to promote well-being are designed and implemented. Difficulties in defining and measuring well-being will affect the enactment of this concept in practice and local authorities will have to find ways for it to fit with other areas, such as need and addressing inequality.

(Webber and Rickard, 2013, p.16).

This comment reflects the previous discussion concerning the barriers to the implementation of personalisation resulting from governmental austerity measures and the miscasting of personalisation as a commercial interaction rather than one of a person-centred nature (SCIE, 2012a). It is this contradiction between policy and reality which contributes to professional cynicism so prevalent in current social work (Carey, 2014). Social work practitioners need to be alert to how rights and well-being are defined within their agencies because a lack of explicit definitions adds to the ambivalent place social work already occupies between theory, policy

and practice. This can make workers feel like failures because:

“We administer welfare policies that cement poverty. We’re asked to help but not make people dependent. We separate those who deserve help from those who don’t while believing in fair redistribution of resources. We decry racism and declare our allegiance to anti-oppressive practice while working in primarily white agencies. We acknowledge a knowledge-based economy while making tuition unaffordable. And into this breach enter social workers with our desire to make a difference, and our theories on how to do that”

(Rossiter, 2005).

Further complexity is added to the challenging role of social work by the austerity measures undertaken in the UK over the last six years. This harsh economic environment requires practitioners to advocate vigorously for opportunities to improve lives through demonstrating eligibility for care and support or identifying alternative sources of support. I contend that if the Care Act 2014 is to be effectively used by practitioners to improve the well-being of service users they require a methodology able to promote the more abstract concepts of human well-being, rights and social justice whilst also focusing on immediate lived experience: it means finding a way to align conceptual thinking with action. My successful search for such a rationale for practice features in the later discussion chapter of this thesis.

4.6 The economics of well-being

Economics underpin all political activity – without resources government cannot operate. The fundamental economic questions concern how these resources are generated and from what activities and from whom and for what purpose they are used. For a society to be successful within a neo-liberal capitalist economic model, such as the UK, a thriving market is required (the degree of market regulation set by the dominant political policy ideology); citizens are expected to create wealth, provide for themselves and their families and contribute towards universal services through taxation (again, the amount being recovered according to the dominant ideological notion about taxation and what constitutes essential social

infrastructure). In a global market, a country has to compete offering cheaper, better and more innovative goods and services (New Economics Foundation, 2015). Consumers are required to keep the market active so innovation is essential, including well-being as the 'project of the self' where individuals have increasing responsibility for their health which can be purchased via the market (Ereaut and Whiting, 2008). Until the downturn of 2008 the general economic consensus was that individual well-being increases through consumption, based on the assumption that individual needs can be satisfied by transactions in the free market (Gleibs et al., 2013). Money is the means by which these transactions are undertaken, therefore, the more money an individual has the more transactions they can complete and thereby increase their well-being.

Many adult social care service users are excluded from this economic model through age, disability or ill health (Oliver, 1990b): facilitating the achievement of their well-being will not necessarily lead to any additional economic contribution nor cost the state less in terms of service provision and, therefore, focusing on their well-being is not an economic priority. Whilst the Care Act 2014 promotes the principle of well-being, the crisis in adult social care funding (Penny, 2015) and cuts to disability related benefits have negatively impacted on disabled people's quality of life (McVeigh, 2016), which suggests an alternative governmental priority.

An alternative to traditional economics has been developed called the discipline of happiness economics (Bacon et al., 2010). This is based on notions of utility and welfare where measures of subjective well-being, validated by positive psychology theoreticians and academics, are used to measure economic utility with results indicating that people who experience well-being are healthier and more economically productive (Bacon et al., 2010). This evidence is persuasive to governments seeking to reduce state spending and to justify policy focus. A review of the role of local government in promoting well-being (Aked et al., 2010) indicates that social rather than medical factors are crucial to well-being with the austerity measures introduced since the financial crash of 2008 creating urgency to the development of resilient individuals and communities. An All Party Parliamentary Group has subsequently been established to promote well-being as a cross-

departmental government goal and to encourage the use of well-being measures as indicators complementary to GDP (Berry, 2014). The group aims to integrate well-being economics into social policy and seeks to identify how policy could enhance well-being without increasing public spending (Berry, 2014). Focus has been given to four specific policy areas:

- *The labour market: promoting labour market policies which acknowledge the psychological value of good quality work which offers stability and security, personal development, tackles poverty and work life balance.*
- *Planning and transport: affordable homes, social cohesion and opportunities for leisure activities.*
- *Health and education: mindfulness in health and education professionals to enable the integration of mental and physical care to make ‘whole person care’.*
- *Arts and culture: the impact art and culture has on key well-being drivers such as health.*

(Berry, 2014, p. 4-7).

The group’s report (Berry, 2014) provides evidence contending that building a high well-being economy benefits all citizens, addressing the inequality which leads to poor well-being. However, without attention to the needs of those unable to participate in the above policy domains, for example, disabled people who cannot work, use public transport or access arts and culture due to the cost, such policy initiatives are at best irrelevant and at worst reinforce difference.

4.7 Barriers to well-being and its measurement

a) The ‘nanny state’

Political objection to the state being involved in either the creation or measurement of well-being has led to accusations of paternalism or “nanny statism” (Thompson and Marks, 2008, p.2). Alternatively well-being is considered “as at best a luxury for good economic times, and at worst a sideshow with little or no relevance to

economic policy” (Berry, 2014, p.18). This relates to the enduring debate about what the legitimate role of the state should be, specifically whether the state should provide more than protecting citizen’s rights to private property and ensure that they do not harm others by their actions (Thompson and Marks, 2008). However, in the UK citizens have consistently expected government to:

“promote their interests; for instance, there is consistent support for the welfare state, the NHS and for government interventions to protect the environment and to relieve poverty. Hence, it is argued that using well-being indicators in policy is consistent with these expectations.”

(Thompson and Marks, 2008, p.2).

This suggests that public opinion may not match political rhetoric, with the population wanting a more active state. Evidence suggests that if improvement of well-being is to be a genuine goal of policy, understanding and action to reduce the negative impact of poor living conditions and life events on well-being is essential (New Economics Foundation, 2011). This means that causal links between inequality and poor health and well-being must be considered in the design and application of social policy. These links are demonstrated by the increase in reported well-being within societies where income is more equally distributed and there is less social stratification (Wilkinson and Pickett, 2009). The economic inequality and poverty experienced by many disabled people has been underestimated (MacInnes et al., 2014), whilst the impact on health of chronic stress caused by financial instability or poverty has only been recognised recently (Wilkinson and Pickett, 2009). Research indicates that societal well-being is dependent on the distribution of economic, social and environmental resources in a population, but this can be impeded by discrimination (Aked et al., 2010).

b) The impact of economic and social inequality on health and well-being

There is growing evidence (Aked et al., 2010) that relative deprivation and social injustice erode mental well-being and increase stress, thereby adding physical symptoms to mental distress. Since 1979 there have been significant increases in

wealth and health inequality across the UK (Ferguson et al., 2002; Wilkinson and Pickett, 2010; Bacon et al., 2010; Simms and Boyle, 2011; Penny, 2013; Jones, O, 2014). The Young Foundation's 2010 review (Bacon et al., 2010) concludes that there is strong international evidence that well-being correlates with particular forms of democratic government and policy. This is because governments cannot make people happy but they do shape the economy, culture and society which create the conditions in which people are more likely to have higher well-being (Bacon et al., 2010). The literature reports that inequality is an indicator of poor national well-being and governments which target inequality raise well-being (Wilkinson and Pickett, 2010; Berry, 2014).

Governments cannot make citizens equal in terms of physical abilities or characteristics but they can make them equal in other ways such as equal access to goods and services or by redistribution of wealth (Teichman and Evans, 1991). Beveridge's social settlement in postwar Britain promoted equality through public services with a fair distribution of entitlements and universal access to a core set of good-quality public services including health care, housing and education (Penny, 2015). Social and economic policy since Beveridge's reforms has continued to redistribute wealth through taxes and benefits, to changing degrees, in order to address inequality, however "the UK is now one of the most unequal countries in the OECD (Organisation for Economic Cooperation and Development) in terms of income and wealth...and life expedencies vary by over 11 years depending on where you live" (Penny, 2015, p.3). The changing degrees of redistribution relate to the debate within welfare theory between the respective value of universal or selective, targeted redistribution. The former is associated with an ethic of citizenship and rights, however, it perpetuates inequalities as everyone benefits to the same degree, whereas selective redistribution is divisive, identifying the deserving and undeserving (Fitzpatrick, 2001).

Within a neo-liberal capitalist economy, such as the UK (New Economics Foundation, 2015), where money brings status, participation and access, it has become a factor in how people orientate themselves to others and evaluate their happiness (Gleibs et al., 2013). Evidence demonstrates a link between well-being

and economic and social capital as the 'atomisation' of society has led to increased occurrence of depression (Bacon et al., 2010), which indicates that social systems which embed the value of social capital and encourage its growth rather than focus on economic status need to be developed (Fitzpatrick, 2001). It is the contexts in which people consider their well-being which influences what is valued, so a society where status is given to income will value economic capital more than social. Hence, social values are relevant to well-being. However, research reveals that the relationship between money and well-being is more variable and complex: if people are focused on money, perhaps through experiences as diverse as poverty or hyper-consumption, income affects their well-being (Gleibs et al., 2013). The Care Act does not address inequalities as it is focused on the individual.

Conclusions

Within the literature review I have comprehensively explored sexual well-being from the three interlinking perspectives of social work practice, physical disability culture and knowledge about human well-being, with the aim of identifying any gaps in the literature. I have found that there is little research about sex and disability relating to social work practice, and neither does the well-being literature overtly consider sexual well-being or disability. In addition, there is a deficit of research into the lived experience of sexuality and disability, which my research seeks to address and thereby contribute new knowledge.

Through demonstrating the connection between the three elements of the literature (social work practice, disability and well-being), linked by the Care Act well-being principle, my work offers a new means to include concern for sexual well-being in practice. I develop this within the practice development element of the D Prof and use Bywater and Jones's (2007) helpful guidelines for best practice in the promotion of sexual well-being as guiding principles:

- *Awareness of the significance of the Declaration of Sexual Rights to social work values and commitment to social justice.*
- *Awareness of how one's own practice contributes to the construction of sexuality.*

- *Awareness of the nature of discrimination around sexuality and being prepared to challenge oneself and organisations.*
- *The necessity of being comfortable about one's own sexuality so as to be comfortable, open and sensitive with others.*
- *Do not make assumptions about others' sexuality.*
- *Ascertain how open service users are about their sexuality and establish boundaries when discussing sexual issues.*
- *Develop good communication skills, be able to talk comfortably.*
- *Check your knowledge and keep up to date.*

(Bywater and Jones, 2007, p131).

I now progress to my exploration of methodology and how I sought to effectively gather accounts of lived experience and explicate the meaning of sexual well-being to physically disabled people.

Chapter 4: Methodology

1. Journey to a successful methodology

This section narrates the path I have taken to arrive at a methodology which aligns with the aim of the research: to understand the meaning of sexual well-being for physically disabled adults, focusing on personal accounts of lived experience. The research methodology offers the philosophical underpinning of the study, to reveal the ontological (understanding of being) and epistemological (knowing) stance of the research(er). Research methodologies reflect different assumptions about “human behaviour, experience, meaning and knowledge and about how we learn about these phenomena” (De Poy and Gitlin, 2016 p.17). The methodology is arrived at after a process of “radical looking at, listening to, reading about and questioning” (Clough and Nutbrown, 2012, p.26) the research topic, to make the familiar strange. It forms the justification for the methods used within the study.

Reflection on this process has revealed my philosophical stance, which has naturally led me to a specific methodological tradition. I have become aware of my pragmatic approach: having identified a gap in knowledge I have sought an efficient means of uncovering new knowledge. It is a ‘real world’ (Benjamin, 2003) approach where knowledge acquisition is not a matter for the intellect alone but is related to action. I identify this pragmatism with my professional, systematic approach to problem solving where concerns are broken down into their constituent parts and addressed methodically, with a clear focus on what needs to be done and why (Thompson, 2000). I am aware that such a ‘what works’ approach can overlook the unique personal perspective resulting in a procedural rather than responsive approach. I therefore balance pragmatism with a distrust of positivist accounts of apparent objective reality and truth. My distrust is built on lived experience where ‘truth’ has been demonstrably filtered through human perspectives, subject to individual psychological bias. I view current truth, meaning and knowledge as tentative and as changing over time (Robson, 20011). This leads me to a ‘what works for this person at this specific moment’ approach

(Creswell, 2013), which appreciates the shifting, complex and often contradictory nature of reality for humans whilst recognising that action is nonetheless required. Robson (20011) and Creswell (2013) provide further complementary accounts of the features of the pragmatic researcher, many of which I identify within my own approach, including my recognition of the existence and importance of the physical world as well as the social and psychological world, how knowledge is both constructed and based on the reality of the experienced world and my rejection of the reduction of culture or beliefs to neurobiological processes.

My research aim, an exploration of the meaning of sexual well-being to physically disabled people, leads to the research question: What is the meaning of sexual well-being to physically disabled people? From the linked aim and question I have identified two key ideas in determining the methodology.

1.1 Exploring meaning

Personal meaning is assigned by the perspective of the individual encountering the phenomenon (Langdrige, 2007). Meaning in this personal realm is subjective, informed by, and interpreted through, the individual's unique experience of the world and their conceptualisation of the micro and macro social context in which this experience occurs. Exploration to uncover meaning can be collaborative, requiring cognitive engagement and communication between the participant and researcher. Mere physical proximity involves communication through body language and the unconscious signals given by our physical beings. Collaboration suggests the involvement of the researcher in the process to uncover data. The researcher is not, and cannot be, wholly objective from the research activity as their values and beliefs influence both the choice of research topic and methodology (Alston and Bowles, 2003). The researcher makes judgements about what are considered critical elements of the study, both in its design and engagement with the phenomenon at its heart (Robertson and Dearling, 2004).

I take a reflexive stance to this study, appreciating my own influence on the meaning uncovered by this research. The potential for bias this involvement introduces must be balanced by academic rigour and openness about my

presence (Robertson and Dearling, 2004). Nevertheless, the focus of the research is on the participant, with their voice being dominant. As researcher I bring to this exploratory project my own unique strengths which have been formed by my life experience. This includes my professional role as a social worker, which has had a profound influence on my personal skills, identity, values and world view. The researcher aids exploration through active, respectful listening, along with responding and prompting when appropriate, in order to understand life from the “inside of other people's perspectives” (Alston and Bowles, p.10). Such communication skills are essential in genuinely human-to-human encounters. Communication is as essential to research as it is to the social work task, which is often exploratory in nature; looking to understand life events and human behaviour.

Therefore, a research methodology acknowledging the presence of the researcher and one which utilises the power of human-to-human communication is necessary to successfully achieve the research aims and answer the research question.

1.2 Embodied physical disability

Physical disability is an embodied experience. Human consciousness exists within the embodied form, there being a dynamic relationship between the physical world, our physical selves and our consciousness. The world is experienced through our senses which are enabled by our physical bodies. Therefore, physical difference leads to different encounters with the external world. This can have diverse effects and meanings, for example, a stiff door is merely an inconvenience to me but a barrier to a wheelchair user, potentially impacting on their access to the social world and suggesting a judgement of the worth assigned by others to their inclusion in the world (Quarmby, 2011; Simcock and Castle, 2016).

Physically disabled people are not a homogeneous group with one voice. A research project cannot capture all of these voices. However, a research project can aim for depth of knowledge by focusing on a small number of participants and explore with them their perception of a particular phenomenon (in this case sexual well-being), and the meaning they assign to this. This provides unique information about contemporary life for physically disabled people, whilst also being a feasible

project for a lone researcher to undertake.

1.3 Influence of practice

There is a further factor to be taken into account in my journey to a successful methodology: this is a study for the qualification of Doctorate of Professional Practice, focused on both creating knowledge for, and development of, practice. Hence, my professional context makes demands on a methodology, it must be aligned with the aims, values and theories of that profession, in this case social work, and it must be able to create knowledge which positively contributes to professional development.

In summary, my search has been for a methodology which meets my needs imposed by the nature of the qualification, my professional context and my own world view which wants to hear often silenced voices. The methodology for this study has the following requirements:

- 1) focus on the unique perception of the participant resulting from their lived experience;
- 2) recognise the subjective role of the researcher, who becomes a co-producer of knowledge through a genuinely human to human encounter;
- 3) value the embodied nature of human consciousness; and
- 4) be compatible with social work with its fundamental respect for persons and its obligation to explore the personal, cultural and structural influences on both participant and researcher.

With these four specific requirements in mind, I set off on my journey to identify an appropriate methodology.

2. A phenomenological approach

My research is person focused, valuing individual perception, and using communication as the method of investigation. As such, a qualitative methodology, focused on words rather than statistics was appropriate (Taylor et al., 2015). I was seeking the articulation and recording of the lived experience of physically disabled

service users, a way of exploring the experiences of social problems and the receiving of services. As such, a quantitative or statistical methodology such as surveys would not gather the depth or data rich information focused on perception that the topic requires (Taylor et al., 2015). Neither do some qualitative methodologies. Ethnography does not fit this requirement with its focus on the study through observation of cultures or groups (Denscombe, 2003). As has been said physical disability is too varied and widespread to create an identifiable, observable group. Nor does grounded theory (DePoy and Gitlin, 2016) fit the research aims which do not involve the generation of theories but seeks to collaboratively explore meaning. Similarly action research with its focus on practical problems and promotion of change (Robson, 2011) does not fit. Narrative inquiry (DePoy and Gitlin, 2016) offers elements to satisfy the research aims with its focus on personal narratives, an important part of this study. People make sense of their lives through telling stories (Fox et al., 2008). But narrative inquiry attempts to capture the whole story, whereas my research aims to communicate an understanding of a specific phenomenon (Webster and Mertova, 2007).

Exploring qualitative methodology led me to phenomenology with its focus on lived experience where the:

“phenomenological stance seeks to approach events and activities with an investigative mind deliberately open, consciously trying to 'bracket' out assumptions and remain attentive to what is present.”

(Willis 2001, p.1).

This bracketing is not about objectivity; rather it is about being open and engaged: “Researcher subjectivity is prized and inter-subjectivity is embraced” (Finlay 2011, p.23).

Phenomenology is philosophical in nature emanating from the work of Husserl in Europe, who sought to discover the universal features at the heart of human experience (Denscombe, 2003) and to “return to the things themselves” (Husserl, 1931, cited in Langdridge 2007, p.4). Willis (2001) describes phenomenology as a

reaction to positivism which “posits that the world exists “out there” independently of human consciousness” (Willis, 2001, p.2), which “makes people imagine themselves to be separated from the world” (Willis, 2001, p.3). It was developed by Sartre and Heidegger who share “a concern with investigating the essence of human experience and the meaning of everyday life” (Denscombe, 2003, p.100), and whose focus was on understanding existence (Langdrige, 2007).

The life-world is a fundamental phenomenological concept (Finlay, 2008; Galvin and Todres, 2013). It is where we live and experience the world and its social interactions with all their complex meanings. Husserl’s (1931) (cited in Galvin and Todres, 2013) concept of the life-world is described as having multiple dimensions including embodiment, sociality, spatiality, temporality and mood-as-atmosphere (Galvin and Todres, 2013). Experience is interpreted through the dimensions of the life-world where intentionality occurs; consciousness in relation to subject are “joined in mutual co-constitution” (Finlay 2008, p.2) and the phenomenological researcher’s aim is to describe and explicate the meaning (Ashworth, 2003). The experience of the life-world which the participants of my research describe has particular resonance and is explored in detail in the discussion chapter.

Willis (2001) states that phenomenology is not a particular methodology but is rather an approach, an alternative path to human knowledge which asks what the subject makes of the experience. It has contributed to social science research by:

“bringing into view the subjective states and interpretations of people who have engaged in a common experience and which may have been overlooked or repressed by powerful groups in society.”

(Willis 2001, p.7).

The common experience in my research is that of living with a physical impairment.

Phenomenology concentrates on getting a clear picture of things in themselves – the things as directly experienced by people (Denscombe, 2013), in this case sexual well-being.

Phenomenology is also interested in the embodied lived experience (Finlay, 2009b), which is the perspective that has provided the richness and vitality of this research. My work is concerned with individuals who are defined by their bodies: physically disabled people, whose eligibility for social care services is determined by their physical bodies. How individuals experience the world through their body engaging with the surrounding world is of concern to both the social worker in determining what services will be of assistance and the phenomenological researcher (Engelsrud, 2005). As Merleau-Ponty (1962 cited in Finlay, 2009b) states, the world is experienced through the body, but it is the world which makes us conscious of our bodies, suggesting the importance of the individual's social and cultural context in their and others' responses to their body. This is as relevant for the researcher as the participant, as both experience the research encounter in and through their bodies and may respond in embodied ways which open up (for example, open posture, smiling or nodding) or close down the interaction (for example, anxiety impacting on thought processes) (Engelsrud, 2005).

Regarding the fourth requirement; social work encounters individuals in their social contexts. It is focused on people and the lives they live. Phenomenology as a research methodology sits comfortably with traditional social work values with the shared emphasis on reflexivity, non-judgemental attitude and bracketing of assumptions. The social worker, like the phenomenological researcher, is engaged in an 'inter-subjective' encounter describing what it is to be human with the process being potentially transformative (Holroyd, 2001; Ashworth, 2003; Dahlberg, 2006a; Finlay, 2009a).

I have therefore selected phenomenology as the approach for this research; it is the approach which satisfies my goal to create genuinely human-to-human interactions. However, the phenomenological approach has critical limitations which must be acknowledged to ensure academic rigour.

3. Critique of the phenomenological approach

3.1 Credibility

Phenomenological research seeks depth rather than quantity, and focusing on small participant groups requires careful interpretation to avoid generalisation (Darlington and Scott, 2002; Dahlberg, 2006a). A phenomenological approach, like other forms of qualitative research, aims to “create an understanding of the world from the perspective of some participants within that environment” (Taylor et al., 2015, p.94). This means that clarity about the limitations of the study findings and the context of the research is necessary to aid rigour. Through such clarity applicability to other situations can be assessed.

In addition, a phenomenological approach seeks the essence or structure of meanings of the phenomenon of study, so through examination of the essential, concrete parts of the whole phenomenon insights can be made. In my research this relates to sexual well-being involving the concrete experience of sensual pleasure – the exact nature of the sensual pleasure (for example, physical sensation, visual stimulation or sound) might be individual but all describe it as sensual pleasure. From this, an insight can be drawn that sexual well-being involves sensual pleasure.

3.2 ‘Doing’ empathy

The exercise of empathy is crucial to the success of the research encounter and later analysis which rest on the researcher’s attitude of openness, their willingness to enter into the life of another and preparedness to undertake intense reflective concentration (Langdrige, 2007). But empathy can be inauthentic, becoming ‘doing empathy’ much like ‘doing rapport’ when interviewing. The constant attention to whose words are in the foreground can slip, with the researcher becoming the subject rather than collaborator, thereby projecting their own views onto the data. However, the goal of phenomenological research is to gain insight and understanding of the phenomenon of interest not necessarily ensuring empathy at all times (Finlay, 2006).

I engaged in reflexive review at every stage of the research process, examining my

motivations, insights and assumptions, sharing my tentative stance with participants, whilst being open to challenge and new perspectives. This involved situating myself within the participant's context, imaginatively stepping into their world of perception (Savin-Baden, 2004). A reflexive approach is equally essential to both social work practice and qualitative research and I brought highly developed skills in reflexive questioning of myself and others through many years of professional work to the research. Reflexivity enabled me to retain a commitment to relationship-based practice, and helped guard against inauthentic empathy despite the increasingly bureaucratic approaches to complex situations (Ruch, 2005).

3.3 The elusiveness of essences

The phenomenological approach is an exploration of the meaning of essences (Dahlberg, 2006a). The essence is the structure of essential meaning which describes the phenomenon of interest – what makes it a particular phenomenon and not something else. The essence is already there and research assists in uncovering the meaning already existing in the life-world. Discovering the essence of some phenomena may appear easier than others, for example, the essence of what makes a horse a horse rather than a donkey seems obvious until the meaning of a horse is introduced; for example, it might be an object of labour to one person or a source of companionship to another.

The research descriptions have to be 'rich' for essences to be found. This includes variations, even contradictions, in descriptions which illuminate the phenomenon from different perspectives. Because meaning is found within the perceptions of individuals in relation to events in the life-world it is contextual and infinite, therefore, essences are "open, infinite, expandable and never completely explored or described" (Dahlberg, 2006a, p.16). As such, my research offers insights into the phenomenon of sexual well-being to add new perspectives to the literature, but I do not claim final and complete uncovering of the essence of sexual well-being.

3.4 Transcriber, describer, interpreter or author?

Transcription and analysis becomes a “solo waltz” (Finlay, 2006, p.3), open to researcher influence by creating distance between the research interview, data and results. Transcripts cannot contain all the nuances of person to person communication “when spoken word becomes text” (Langdridge, 2007, p.47). The joy of collaborative discovery is ‘flattened’ by data appearing as text, removing it from the event both in time and place, dehumanising the data and making it something I can move around, potentially changing its meaning by emphasising one word over another.

The integrity of the researcher is vital to making the analytic process ethical and the findings genuine (Potter, 2006). To mitigate the potential of imposing my own meaning I transcribed the interviews verbatim including the non-verbal communication. This was a painstaking process, but I viewed it as an essential stage in the process of analysis and one which was necessary for both authenticity and academic rigour. Investing time in transcription followed by paying close attention to the data, re-reading the transcripts several times, dwelling with the text – allowing meaning to emerge before writing any form of analysis – protected me against imposing meaning. Dahlberg (2006a, p.16) summarises what I sought to avoid: “to understand too quickly, carelessly or slovenly and make definite what is indefinite”. Transcription and analysis again required reflexivity and the ability to question myself and my place in the research, therefore bringing awareness of my social self to the encounter and analysis (Robertson and Dearling, 2004). Bringing myself to the data in this way, dancing between description and interpretation, aids understanding, which is revealed after the interview and once the data is transcribed. Turning speech into text changes the data and I was therefore not only the describer and interpreter of the data, but also the co-author.

3.5 The hidden nature of felt/lived experience

Research focused on lived or felt experience cannot be verified in standard tests to replicate the findings (Krycka, 2006). Instead, the phenomenological approach seeks to find a way to name and portray human experience where its meaning is subjective, but has resonance beyond the individual (Willis, 2001). Its power is in

drawing the reader into the life of another to allow a deeper understanding of human experience (Finlay, 2008) and shed light on experiences and perceptions which, although not universal, have meaning across a population. My investigation into the meaning of sexual well-being illuminates aspects of the human experience of well-being, offering insights into opportunities and barriers which have implications beyond the participant group (for example, access to social venues).

4. Methods

Human interactions, valuing embodied communication, are at the heart of my research; therefore, I considered face-to-face contact to be essential in meeting the research aims. I chose unstructured interviews as the method of data collection as such personal encounters allowed individuals to speak privately in a location of their choice, to describe in their own words their unique perspective, and enabled the flow of rich information needed to interpret the lived experience. Using a phenomenological approach I did not want to overly influence the interviews, but having already read some literature I was aware of particular recurrent issues and wished to gain the participants' views on those issues. In unstructured interviewing, prompts used have to be flexible and responsive to each "conversation with a purpose" (Burgess, 1984, p.42). I therefore prepared keyword prompts, rather than full sentence questions, for use as the interviews progressed. By engaging reflexively, by being meaningfully alert and present and by allowing participants to start where they wished in their account in order to self-prioritise their experiences and to choose their own terms, I was able to approach the interviews open to possibility, with a sense of discovery and an assumption that the social world "is not a place where we can assume that we all share the same understanding of different things" (Sheppard, 2004, p.144). The keywords written in my interview notebook enabled me to ensure relevant content whilst retaining the flexibility to phrase each prompt according to the words used in each individual interview. The keyword prompts were:

- physical experience;
- felt experience;
- emotional effects;

- barriers, personal, environmental, social;
- opportunities;
- professionals, help, hinder.

These brief prompts emerged from extensive preparation and thinking about my reading and practice experience. The last prompt was of particular significance because this is a D Prof study; therefore, I sought views about what could be done differently in social work practice. I was already confident with the topic, willing and capable of exploring related “lines of questioning, while always keeping the core research question in view” (Robertson and Dearling, 2004, p.121). For example, the firm certainty expressed by one participant that his sexual life is temporarily on hold until a cure for his progressive condition is found could have closed down the flow of conversation. I therefore used prompts in the form of exploratory questions, using his own words, about how this impacts on his physical and emotional well-being in the present, for example: ‘is having some fun with a girl important to you now?’ (in the interview this relates to emotional effect). He concludes that it is as though he occupies a separate time zone from those around him whose lives proceed while his is in abeyance.

Another participant had limited sexual experience and required prompting to consider her views relevant. For her, I phrased the prompts as ‘can/how/what do you think?’ questions. However, with another participant no prompts were required as her personal experience of addressing sexual well-being for herself and with patients at a spinal injury unit provided a wealth of free flowing information.

Alston and Bowles (2003) encapsulate my use of in-depth unstructured interviews in their description of the interview as a conversation guided by the respondent with the researcher providing input as part of the discussion, where an equal relationship is aimed at rather than one between expert researcher and participant; it is a partnership of knowledge creation. Interviewing as a method is founded on the modernist construction of participants as rational and self-reflexive beings (Alldred and Gilles, 2002) which has the potential to be progressive by often including marginalised groups not normally included in participant populations – my

research represents an example of this progression as disabled people continue to experience marginalisation.

4.1 Strengths of use of interviews

a) Transferable interview skills

I recognise both a personal strength and weakness in my use of interviews: in-depth interviews commonly form part of social work interactions, and my extensive experience of interviewing gained through practice makes this method a personal strength. I prepared for the interviews anticipating potential problems (discussed below) but later analysis of the transcripts revealed that my largely unconscious interview techniques effectively avoided the anticipated problems. My interview technique is founded on open communication and an ability to build rapport through alertness to the participant's perspective. Within the interviews I demonstrate genuine curiosity, seeking clarity and a responsiveness to verbal and non-verbal signals which draws participants out, and use humour to share observations on the comedic aspects of human life. For example, one participant struggled to articulate his thoughts and required permission to discuss and acknowledge his sexual needs, which he has suppressed since the breakdown of his relationship several years previously. My interest in his opinions and regard for him as a sexual human being, with the potential to participate in sexual activities, led him to reconsider his sexual identity. We were able to sensitively discuss the practicalities of sexual function with a catheter whilst also sharing laughter over the absurd realities of human bodies. Another participant was apologetic in his demeanour, with head held low and a hunched posture, and needed confirmation that his sexual language was acceptable and reassurance that I really did want to know about his understanding of sexual well-being. His voice became louder and clearer as he became more comfortable as the interview progressed.

b) Confidence to explore sensitive subjects

A strength of social work research and practice is its focus on sensitive subjects (Bywaters and Ungar, 2010) and its preparedness to address the delicate issues

that matter to people. Long-term practice experience makes the skills enabling the discussion of intimately personal subjects natural, even taken for granted. I was not consciously aware of my own interview skills until I listened to the transcripts again. This revealed the interplay of communication characterised by the participant's free expression of their thoughts and experience whilst prompt questions and comments sought clarity, further detail or brought the participant back to the topic when the conversation became too tangential. For example, one participant provided a detailed account of their ex-partner's later relationship; this account provided valuable data about his own perception, but in order to clarify his thoughts and refocus his mind on himself I probed with questions including: 'Can you explain how you felt about yourself at that time?', 'How did you respond?' and 'Can you explain why you responded in that way?'

c) Trust

Relistening to the interviews led me to recall that several participants stated they would not have spoken to another researcher about their sexual well-being (the importance of trust is discussed in the findings chapter), but trusted me because of our previous work together (as service user and social worker) where a relationship founded on positive regard had already been established. These relationships were built over several years of usually co-operative work but included occasional conflict, reflecting the changes to social care policy. This reminder caused me to reflect on the power dynamics within the participant interviews and my consequent ethical responsibility not to exploit the pre-existing relationship for my personal gain as well as the need to respect the privileged access I had to the unique data being disclosed. I recognised that no one else had – or could have – accessed this information because I, as a unique individual with a particular set of skills, was integral to the process of collaborative knowledge creation.

4.2 Weakness of interviews

a) False rapport

Qualitative research and the use of interviews in particular create an ethical dilemma which Duncombe and Jessop (2002, p.107) call 'doing rapport' or 'faking friendship'. This describes the potential for insincere empathy and relationship building undertaken during interviews, a manipulation of emotions in order to elicit data. It is the commodification of rapport seen in market research (Duncombe and Jessop, 2002) where false familiarity is established. This can be both off putting to participants, closing down communication due to insincerity, and a form of emotional manipulation. My experience as an ethical practitioner has raised my awareness of the potential for such manipulation and that countering this requires honesty, respect and justice based on care for the other and awareness of the distribution of power within the research relationship (Edwards and Mauthner, 2002). I was able to use a reflexive approach within the interviews to check my motivation, making sure that the participants were comfortable with the content and nature of the conversation in order to avoid manipulation and exploitation. Reflexivity forms the links between methodology, epistemology and ethics, keeping honesty and accountability in mind (Doucet and Mauthner, 2002).

b) 'Too much' rapport

Research interviews between participant and researcher who have an existing relationship can risk impediment to data collection processes, as each thinks they 'get each other' (Darlington and Scott, 2002). To avoid this I used a questioning approach to clarify what participants meant, for example: 'What did you mean when you said you isolated yourself?'

c) A conversation with(out) purpose

Unstructured interviews provide flexibility allowing the conversation to guide the interview, building on ideas expressed by the participant (Robertson and Dearling, 2004), but this risks the interview becoming too conversational, failing to generate the information needed, or even taking on the appearance of a therapy session. To

mitigate against the interviews going 'wrong' in this way I had my prepared prompt words as discussed previously.

d) Distress

I prepared for potential emotional distress and participants' withdrawal from the interviews by being open to verbal and non-verbal signals; however, this preparation was not required as all the participants offered an invitation to further interviews.

e) Reverting to familiar roles

As already stated, responsive questioning is part of social work discourse and I was aware of the potential weakness of using interviews as a research method where I might revert to the familiar social worker role, or the participant slip into social care client role with the associated expectations (service delivery on the one hand and service provision on the other). To avoid this, a clear definition of purpose was provided in the pre-participation information (see Appendix 3) and repeated verbally during the initial contact and later interview.

f) Too much information

Interviews create a large body of data which is time consuming to transcribe and difficult to analyse (Robertson and Dearling, 2004). However, a phenomenological approach reframes the time transcription and analysis takes as an opportunity to relive, dwell with and re-encounter the interview experience. It is through this imaginative revisiting that the data 'speaks', revealing its meaning. The interviews for this research did provide a large amount of data so I focused on the meaning of sexual well-being and how the participants described what sexual well-being is *not* (for example, sex without emotional connection).

g) Researcher and participant bias

All interviews are potentially subject to bias as they are a social encounter based on the rapport between people who speak from a unique subjective perspective (Robertson and Dearling, 2004). The rapport might lead to the desire to please, while the researcher may acknowledge only the data which supports their views. I

mitigated these risks by building into the interviews and data analysis a reflexive approach, reflecting on my effect on the participants and the assumptions I brought to the research (Taylor et al., 2015). I achieved this by questioning myself, examining the data from both my own perspective – what it meant to me – and that of the participant. For example, asking why these particular individuals agreed to participate led to awareness that in two cases this was because they wanted to help me rather than any desire to contribute to knowledge creation. In a third case their participation was predicated on their wish to retain contact with me as our professional relationship had ceased. This insight enabled me to discuss motivation with each participant and restate my research aims to ensure their consent to participate was based on a shared understanding of purpose and expectation. The participants did wish to proceed and their accounts offer profound insights. Whilst it is not possible to eliminate all bias, reflexivity leads to alertness and a preparedness to recognise and acknowledge bias (Robertson and Dearling, 2004).

h) Trustworthiness and rigour

People tend to present themselves in ways which conform to dominant forms of social and research discourse where participants are the research subject (Allred and Gillies, 2002). A phenomenological approach to research aims to create a collaborative rather than traditional researcher/subject relationship which appreciates the constructive nature of 'truth' (Cunliffe, 2003; Finlay, 2009a), an approach which can be criticised for potential untrustworthiness as participant and researcher construct themselves in different ways at different times (Robertson and Dearling, 2004). But phenomenological research acknowledges this through its exploration of the variable meaning and perception of the lived experience. It does not seek an external, observable reality and this makes the concept of trustworthiness contentious (Finlay, 2009a). This means that rigour is dependent on the accuracy of collection, transcription, description and interpretation of the data (Fox et al., 2008). The participants in this study were asked to check the completed transcripts and findings. This was completed in whatever way each person preferred, for example, by email or in person. All but one of the participants chose to check their transcript. This process does not negate the worth of the

original data, which was not deleted – but, rather, builds on it – demonstrating the changes made to the perception of phenomena which reflection on initial data brings.

5. Participant recruitment

Phenomenological research seeks depth, it is about ‘rich description of people’s experiences so we can understand them in new, subtle and different ways and then “use this new knowledge to make a difference in the lived world of ourselves and others” (Langdrige, 2007, p.9). The number of participants is therefore limited. My ‘insider’ perspective enabled the identification of those who are usually silent, either unable or unwilling to engage in the established forums. I began recruitment with purposive sampling. Ten potential participants were identified to contact initially; these were service users who represent a range of ages, both genders, different relationship statuses, with both acquired and congenital physical disabilities. They were individuals who, during previous conversations, expressed an interest in the topic and in fact prompted this research by asking challenging questions around sexual well-being. An introductory letter inviting people to contact myself on a confidential number was sent along with the research information sheet and letter of consent (see Appendix 3). Six of the initial ten either contacted me to say they did not want to participate or did not reply, whilst the remaining four recruited a further two participants from their own networks making a total of six research participants. Robertson and Dearling (2004) identify the benefit of using such a snowballing technique as personal recommendation is more likely to result in participation. However, it introduces potential bias through participants’ choice of contact, perhaps only suggesting people who support their own views. But as has already been stated, phenomenological research concerns depth and seeks insights rather than generalisability.

The population from which the sample group for this research was drawn is limited as entitlement to publicly funded social care services requires meeting strict eligibility criteria as determined at the time of recruitment by the Fair Access to Care Services Criteria (2003, updated 2010). In addition, the nature of the participants’ disabilities meant that several visits were required so geographical

location was of significance as they needed to be practically accessible to me as a lone researcher, further limiting the relevant population. These criteria effectively made me a “gatekeeper” (Miller and Bell, 2002, p.53) determining who the population of participants would be. However, recruitment for qualitative research is often non-random sampling or purposive (Robertson and Dearling, 2004), drawing in people who have expressed an interest in a topic or who have particular experience. I mitigated against my potential ‘gate-keeping’ by inviting more people to participate than I required in order to allow a degree of self-selection. By initially inviting ten people, expecting some of those to decline and anticipating having to recruit others, I introduced an element of self-selection.

There is a lack of ethnic diversity amongst the participant population, however, this is representative of the general population of Dorset (95.5% white: 2011 census, Dorset For You) (excluding Poole and Bournemouth). In addition, I recruited participants of working age as this was the specific client group I was working with at the time. The essential feature of the participants is physical disability and the perspective this provides.

6. Data analysis

Unstructured interviews can be difficult to analyse due to the amount of data generated and potential for wide variation in content (Robertson and Dearling, 2004). The purpose of data analysis is answer the research question by breaking down the information into its component parts (or units of meaning (Langdridge, 2007)) and trace these back to their underlying sources, thereby exposing the general principles which can be used to explain the phenomenon being researched (Denscombe, 2003).

Phenomenological analysis of data aims to:

“describe and elucidate the lived world in a way which expands our understanding of human being and human experience”

(Finlay 2011,p.126).

The researcher dwells with the data and listens to the recorded interview several times, remembering the embodied lived experience of the interview, drawing out its meaning by asking what it suggests about the experience of the world (Galvin and Todres, 2013). In my work, this concerns the sexual world experienced by individuals with physical disabilities.

Dancing with the data

The data was analysed using the descriptive phenomenological method described by Giorgi which encompasses three interlocking steps:

- “1. the phenomenological reduction;*
- 2. description; and*
- 3. search for essences”*

(Giorgi, 1997, p.238).

I joined the phenomenological ‘dance’ (Finlay, 2008), moving between the whole and the parts. The analysis reveals the essence of sexual well-being and its constituent parts and the variations.

First, I transcribed the interviews verbatim, relistening to the recordings to ensure accuracy and to imaginatively return to the physical and emotional site of each encounter. This enabled an understanding of a sense of the whole interview, its content and feeling, as I stepped into the world of the other. Transcribing the interviews facilitated a close consideration of each interview, listening in detail to the non-verbal signals of participants’ emotions, such as sighs and laughter, as well as the words offered. Self-transcription enabled me to reflect on my own contribution to the content of each interview, how I influenced the participants and how we cooperated to explore and create an understanding of the topic. I am not an objective observer of the research encounter and its formation. I am influential simply in my being present.

Data analysis is an ethical endeavour with the researcher holding the power over

the “invisible nature of the interpretive process” (Doucet and Mauthner, 2002, p.129) which demands transparency about the assumptions researchers bring to data analysis and an openness to alternative world views. I am aware that I bring to the research a world view formed through many years of working with marginalised people. This view propels my study but also puts me at risk of interpreting complex situations as narratives of victim and exploiter, which is potentially oppressive through the removal of accountability or agency from the ‘victim’. Dwelling with the data displaces my familiar world view discomforting me, but allowing other voices to enter, hearing and feeling their strength, fear and frustration, sharing humour about the universal human predicament of life within frail bodies.

My aim was to provide rich descriptions of the constituent parts of sexual well-being to reveal essential general meaning structures of the phenomenon (Finlay, 2011) so I approached the data asking what the participants felt, thought and experienced as sexual well-being. Letting the data speak through repeated rereading/relistening, allowed meaning to surface. It was an inductive process allowing the data to provide the structure. Each transcript was broken down into meaning units as shifts in meaning occurred within the data. The meaning units emerged “like knots in the web of experience around which meaning is spun” (Van Manen, 1984, p.59). These were examined to reveal insight into the participants’ lived experience. Whilst rereading the transcripts I kept notes on content and other responses (such as laughter) which recurred in more than one interview, surprising points, points of particular emphasis and content reflecting or contradicting the other interviews to add depth to the meaning units.

Further reading of the transcripts and contemplation of the data led me to identify shared elements amongst the meaning units which enabled me to group them into six overarching themes. The themes relate to, but are not the same as, the prompt words I had prepared for the interviews in light of my increasing familiarity with the literature. However, I undertook the analysis with curiosity and a willingness to encounter unique perspectives. Therefore, the themes are my ‘sense making’ of the data which I use to structure the findings while the quotes are verbatim

statements. I checked the themes with the participants to ensure I did not impose my interpretation on their meaning. The first theme relates to the main research question with which I opened the interviews; the other themes have emerged from the participant's descriptions of sexual well-being, including what it is and is not to them.

1. The meaning of sexual well-being.
2. The experience of sexual discontent.
3. Who am I, what does this body mean to me?
4. Isolation – internal and external.
5. Asexuality – not us but 'them'.
6. What we want from professionals.

Because I did not want to impose a false sense of categorisation on the data, or lose the common features across the units at the beginning of each section, in the findings chapter I identify a small cloud of words of particular significance which the participants use and repeat. These words create a link between the participants, who do not know each other, demonstrating commonality within the human experience of sexual well-being. From these words the larger word cloud at the beginning of this chapter was formed to provide a visual image of interrelationship.

Limitations of analysis

Analysis of the interview data has been challenging principally due to the quantity and emotional content of the material. I chose not to use computer software, considering the process of transcription and 'dwelling' to be a crucial part of the human-to-human interaction through which the data was gathered. This meant allowing sufficient time to undertake this exercise and a willingness to imaginatively engage.

The quality of analysis is contingent on the ability of the analyst (Robson, 2011), who might be subject to the tendency, for example, to see recurrence of data as evidence of truth, or to look for data which corroborates a finding. To avoid such tendencies I used an inductive approach to identify units of meaning, or themes,

and reviewed these throughout the analysis to ensure I did not limit the data of interest to only that which fitted the themes. The quantity of the data created multiple points of interest. I was aware that novice researchers, such as myself, tend to develop elaborate lists of coded points, which then become too numerous to group into manageable themes (Creswell, 2013). However, having already undertaken some reading (which aided in preparing keyword prompts for use in the interviews), I was able to use insights from the literature to inform manageable themes into which the data was then organised. Meaning within the data emerged through dwelling with it, and being familiar with the content and circumstances of its creation. I heard repetitions, similarities, differences and metaphors which communicated significance (Robson, 2011). For example, one participant's repeated reference to the impact his birth father has had on his own sexual identity led me to consider familial contexts in the experience of sexual well-being. But analysis is a delicate, intuitive process, balancing the organisation necessary for management and presentation with the imposition of a false structure. The skills of reflexivity again offered the check on my actions asking, for example, whether the number and nature of the themes were for my convenience or a genuine representation of the data. Bringing to this research professional integrity enables an ethical stance commensurate with social work practice. In addition, participant verification of the resulting transcripts and analysis safeguarded the contents as theirs not mine. My analysis was discussed with participants to ensure that their voices held primacy rather than my own interpretation and the validity of the analysis. There is debate about whether this method of validating findings is effective as what was "true for participants at the time of interview may no longer be true" (Finlay, 2011, p.223). I chose to share my findings in this way because the participants expressed interest in the outcome and I felt it was the moral thing to do (Ashworth, 1993).

7. Ethical considerations

Ethical approval for this research was gained from the School of Health and Social Care Research Governance Review Group at Bournemouth University. This included submitting a summary of the research aims, objectives and background information, consideration of ethical concerns and an appropriate risk assessment

for participants and myself, along with information for participants including letters and consent forms. My submission was reviewed and subsequently agreed on 11 January 2013. In addition, I made an application to Dorset County Council for research approval which involved submitting the above information to the Research Department. Approval was agreed in December 2012.

Research is an “ethical activity with political consequences” (Alston and Bowles 2003, p.19) which requires consideration of who the research is for and what is its purpose.

Along with the fundamental prescript of ‘do no harm’ laid down in the Declaration of Helsinki is the requirement that research participants give informed consent (Bournemouth University, 2009, p5; Department of Health 2005, paras 2.2.1 and 2.2.3). All participants in this research have mental capacity as described in the Mental Capacity Act 2005. Informed consent relies on the provision of good quality information and the opportunity to ask questions. In addition, acknowledgement is needed that truly informed consent is not possible at the outset of the unstructured interviews as the lack of structure keeps the content open. This means that consent needs to be ongoing (Miller and Bell, 2002).

To address these ethical considerations I first sent a letter of introduction, along with the research information sheet, to the participants in advance of the proceeding. The letter invited them to contact me, by telephone or email, to ask questions or to arrange a meeting to discuss the research, if they were interested in participating. Alternatively, potential participants could return the consent letter (supplied along with a stamped addressed envelope), after which I contacted them by telephone to arrange an interview.

During each interview I reiterated that participants were free to withdraw at any stage and could state or signal any discomfort or wish to change the subject or withdraw any statement. Participants have the right not to reveal their innermost thoughts which might emerge through an interview (Duncombe and Jessop, 2002) so ethical research necessitates a clear exit strategy.

8. Inclusive practice

One participant was able to understand English but was unable to read, write or communicate without skilled assistance due to his physical disability. His input into this research has been extremely valuable, adding the perspective of the literally 'voiceless'. This was essential as:

“Given the ongoing shifts in how disabilities are conceptualized, the stigma attached to disability, and our current lack of knowledge about the lives of people with disabilities, involvement of those we aim to study in all levels of the research process is an imperative.”

(Eckhardt and Anastas, 2007, p.247).

The Social Research Association Ethical Guidance (SRA, 2003) states that social researchers have a responsibility to ensure the inclusion of individuals who might otherwise be excluded for reasons of “communication, disability, comprehension or expense” (Social Research Association, 2003, 4.5). Facilitating this service user’s involvement meant accommodating their specific needs, in this case by use of a third party to read to them the initial letter of introduction and to contact me to arrange an appointment when the research information was read aloud, whilst being audio recorded, to ensure that the participant heard all the information, clarified any questions and gave their informed consent. This participant was unable to independently operate any electronic device such as a CD player so being given an audio version of the research information was inadequate for their needs. I included an audio description of the means the person used to indicate their agreement to participate within the interview audio recordings and subsequent transcript. This follows advice from the Equality and Human Rights Commission (EHRC) provided to medical professionals when gaining consent from patients with disabilities: “If leaflets are used to describe issues, then these need to be either available in different formats or communicated to the patient in an alternative manner, eg by being read out” (EHRC, 2010). Principles of inclusion and enabling self-determination in these circumstances justify this approach, which could otherwise be considered coercive. It is ethical to enable their involvement and unethical to exclude people with such disabilities, for without such support they will

be absent from the research and:

“we are not continuing to tell stories about people with disabilities, but facilitating the process by which individuals with disabilities can tell their own stories”

(Ashby, 2011, p.133).

All the participants live in their own homes and I am aware of disabled people living in residential care whose voices also need to be heard on the topic of sexual well-being. As a lone researcher it was necessary for me to focus on an accessible participant group, hence my decision to only include people living in the community. Sexual well-being in residential care is an area recommended for further research in Chapter 8.

9. Autonomy

The research information stated clearly that consent to participate could be withdrawn at any time in the research process. This could be done either verbally face-to-face or by telephone, or in written format via email or letter. Those with speech could verbally terminate. A termination symbol/signal was agreed with the participant without speech.

10. Non-maleficence

The subject is of a sensitive nature which requires preparedness to respond to strong emotions in both the participants and researcher (Mitchell and Irvine, 2008). This is equally relevant to most social work encounters as:

“the social work profession...has always understood that emotions lie at the heart of its concerns” with “emotionally intelligent practitioners not only likely to be more sensitive; but also likely to be more resilient”

(Howe 2008, p.9).

Reflexivity encourages the growth of emotional intelligence along with intelligent practice. Through my professional role I have gained extensive experience of

managing emotionally charged situations and ongoing work on developing a reflexive attitude and emotional robustness continues. I had prepared for participants becoming distressed and was ready to acknowledge these feelings with sensitivity and empathy. The interview could then either finish or continue as the participant wished. Contact details of the support and advice organisations around sexual well-being and disability – the Sexual Health and Disability Alliance (SHADA) and Outsiders – were provided. The interviews ended after a discussion of a neutral topic giving the participant an opportunity to regain their equilibrium. There were established professional support networks available to me, including supervision and peer support, throughout the period of data collection. This support network is an advantage of being a practitioner researcher.

11. Beneficence

Contemporary social care practice is intended to be person centred:

“Asking what a person’s goals are, what their gifts and talents are. What they can achieve and want to achieve themselves.”

(Burstow, former Minister of State for Care Services, 2012)

and:

“where growing numbers of people and their families are leading and defining their own support services, rather than simply consuming them.”

(SCIE, 2012a, p.5).

The achievement of these aims demand opportunities for service users’ voices to be heard and their views to inform and influence practice about the issues which matter to them; participation in this research provided the participants with such an opportunity.

12. The role of the researcher

All research requires consideration of ethical practice and being a researching practitioner raises additional concerns, principally around intentionality and power

differentials. Within social work, anti-oppressive practice is both promoted and demanded by the professional values and the Codes of Practice (Health and Care Professions Council, 2012). However, oppression can occur even when the oppressor is motivated by the best of intentions (Strier, 2007). Without constant attention to, and reflection on, our assumptions (the 'taken for granted' (Fook, 2007, p.366)) and sources of power it is easy to oppress, for example, in research through the selection of interview questions which serve to open up or shut down the dialogue according to the interviewer's agenda. Finlay (2011) suggests there is no clear cut solution to this dilemma but the researcher needs to remain mindful of their ethical responsibilities throughout the research process.

This research was conducted with attention paid to several roles (citizen, social worker and researcher), each one subject to personal values, ethical principles or professional codes. The Bournemouth University Research Ethics Code of Practice (2009) provides a clear explanation of the requirements of researchers, stating that it is the researcher's responsibility to consider the ethical implications of their research and the "physiological, social, political and economic consequences for the participant" (Bournemouth University, 2009, 9.1). This standard is reflected in the professional requirements of the HCPC, the Professional Capabilities Framework (The College of Social Work, 2012) and the British Association of Social Work Code of Ethics as well as the Dorset County Council research approval application.

However, inquiry into such a sensitive, personal topic as sexual well-being requires more than external codes of practice. There are ethical considerations which cannot be solved "solely by the application of abstract rules or guidelines" (Mauthner et al, 2002, p.1). It is more about having "ethical ways of thinking" (Mauthner et al, 2002, p.1) which go beyond traditional moral philosophy to embrace reflexivity where the researcher's emotions and feelings are part of the research process. This links to the suitability of phenomenology, where the "phenomenological attitude" (Finlay, 2011, p.73) starts with the participant/client's perception with close attention paid through "curiosity, empathy and compassion" whilst sufficient distance remains to "challenge and be critically analytical where

appropriate” (Finlay, 2011, p.78).

The involvement of participants already known to the researcher raised issues of power and the possibility of people participating ‘as a favour’ and saying what they thought was required. These tensions were balanced by participants’ previous knowledge of my professional and trustworthy conduct enabling them to discuss things that they would not do with an unknown researcher.

The issue arose of whether or not to inform the participant’s allocated social worker of their involvement in the study. Social care can be seen as paternal and risk averse, making decisions *for* rather than *with* service users (SCIE 2010, ppiv–vii). The participants in this study all have the capacity (as determined by the Mental Capacity Act 2005) to choose whether or not to be involved, however, it is a sensitive subject and an aspect of undertaking ethical research is to prepare appropriate support in case of distress, with the allocated worker being a potential source of this support. In addition, 2.4 para (a) of the BU research procedures states that where third parties such as spouses or health care professionals are directly involved in the care of potential participants, informal consent should also be obtained from them. Hence, before any interviews took place information sharing was discussed, either face-to-face or by telephone, to enable the participants to identify their chosen sources of support, over and above their allocated worker, and determine who would be provided with research information. The research information states that the social care worker would be informed once the individual consented to participate. Had a third party objected to the participant’s involvement, this would have been discussed with both parties together to see if a resolution could be reached. This was not required. All participants had the capacity to decide whether or not to be involved so it was their final decision.

13. Confidentiality and anonymity

Dorset is a small place and the disabled community is even smaller. To protect participants’ identities each chose a pseudonym to be used in all written work, acknowledgements and presentations. However, in small communities, even with

the data anonymised, the content of life stories lead to connections being made. I was aware of each individual's identity and adhered to professional standards of confidentiality. The participants were free to share as much or as little as they wished with their support network, with the awareness, through initial discussions and research information, that the more people who knew they were participating, the greater the chance of loss of anonymity. A collaborative approach meant being open to alternative ideas, for example, participants might have chosen to meet together as a group after individual interviews, which could have been arranged once everyone agreed to a clear 'ground rule' of confidentiality. However, such planning was not required as participants did not wish to extend their involvement with the project beyond the interviews and, possibly, dissemination of the findings through their networks. Identifying information such as name, address and exact age, has been omitted to protect the identity of the participants.

14. Cases where confidentiality may be breached

I prepared for the possibility of the disclosure of illegal activity from any of the participants or their carers during the interviews. Professional and moral standards require such disclosure to be passed on to the relevant authorities (social services and/or police). Equally, had significant harm to themselves or others been disclosed this, too, would have been reported in order to conform to the 'duty of care' placed upon the local authority and the safeguarding adults policy. Written information about this was included in the introductory letter. This process was not required but it was available had it been so.

15. Data access and storage

Contact information only was accessed from the local authority records. I am aware of the importance of data protection and conform to the standards required both by the employing agency and professional codes of practice. The collection and storage of data conformed to the Data Protection Act 1998 as detailed in the Bournemouth University procedures section 4.

All interviews (along with recordings of verbal consent) were recorded on a digital recorder purchased specifically, and used only, for this research. The recording

device, paper notes and transcripts were stored in a locked box at my home. After the process of transcription (involving repeated relistening) and once the participants and I were satisfied that the transcript was a full account of the interview, the recordings were deleted from the device and notes were destroyed. Pseudonyms were used for all written material. Information captured primarily concerned individual perceptions and life experience; however, a limited demographic profile was taken for contextual and analytical purposes and included age, gender and nature of disability. I transcribed all recordings on a password protected laptop computer which I alone use.

Research involving people at risk of abuse or neglect requires particular care (Eckhardt and Anastas, 2007, p.248) and planning to facilitate their participation. I was aware of the potential compromise to confidentiality created by the involvement of third parties necessitated by the severity of some participants' disabilities; however, this was outweighed by their unique voices being heard, possibly for the first time outside of their family and care networks.

This chapter has explored the methodological focus I chose to explore the meaning of sexual well-being. The phenomenological approach examined in this chapter will be examined further in the discussion chapter. I now progress to my research findings, which illuminate the lived experience of sexual well-being and disability.

information being sought. It is their assistance which is needed, thus transferring power to the participants. This is a potentially empowering experience provided that I, as the researcher, maintain reflexively alert to the potential for oppression in what I record and how I interpret and present the data.

Introduction to the participants

All names used are pseudonyms.

Kevin is a single man who was diagnosed with a degenerative disease 20 years ago. He is unable to work because of the fluctuating nature of the disease. Kevin experiences significant pain which impacts on his mood, emotional outlook and daily activities. He is keen to talk, and appears open and very thoughtful. He has had several sexual relationships in the past, which have left him emotionally bruised. He would love to find a life partner. The interview involves knowledge exchange as we share information about local and national disability-related organisations. We met at Kevin's home which provides a quiet, safe and private atmosphere where Kevin is physically and emotionally comfortable.

Sense of the whole interview: Kevin and I had not met prior to the interview so establishing rapport was necessary. I achieved this by thanking him for agreeing to participate, reviewing the purpose of the research, inviting him to ask any questions and answering these in an open and honest manner.

Betsy is in her fifties. She has a complex medical history spanning many years. She was chatty and presented with a positive frame of mind, but expressed her occasional feelings of overwhelming despair brought on by her present circumstances and the absence of any sense of hope for future change. She is a care provider to her disabled husband. Betsy is not seeking a sexual relationship but, were her life circumstances to change, such a relationship would be a potential source of pleasure.

The interview took place at a cafe of Betsy's choosing as she did not want her family to know of her participation in my research. It was a busy, noisy environment

which enabled anonymity and uninhibited disclosure of personal information in the quiet corner we found, and remained undisturbed.

Sense of the whole interview: Betsy was engaged, open and responsive to questions.

Zack is in his forties and has been living with a degenerative disease for over ten years. During this time his mobility, speech and cognitive function have deteriorated. He lives alone in his home, which is adapted to meet his physical needs. Zack feels that the sexual part of his life has now ended.

Zack chose to participate in this research following previous conversations when he stated how important the subject is to him and other disabled people. He appeared comfortable and willing to contribute during the interviews, but several times expressed uncertainty about the value of his contribution. The interviews took place over three visits: (i) to gain consent; (ii) for data gathering; and (iii) for data reflection and checking. Our meetings took place at his home.

Sense of the whole interview: Zack struggled to find expression for new thoughts prompted by questions no one had asked him before. There was a sadness and sense of loss of the person he 'used to be'. He repeatedly expressed his desire to return to that person, almost as though if his condition were cured, he would return to his old self unchanged.

He repeatedly stated that he was worried that he had said something inappropriate, but also mentioned that he felt reassured by his sense that he can trust me. We shared lots of laughter during the interviews.

Amy is a young woman. She has a congenital condition which has affected her mobility. Amy is seeking romantic and sexual experiences and is frustrated by her slow progress. We met at her parent's home.

Sense of the whole interview: Amy was open and thoughtful throughout the interview; she was challenged by ideas she had not previously contemplated but willingly considered new perspectives.

Penny is in her fifties. She is in a long-term relationship and has adult children. Penny suffered a spinal injury a few months after getting married. Penny is committed to peer education and support. She feels strongly that spinal patients need hope and that peers as educators and role models are best placed to engender a positive outlook. We met at Penny's home.

Sense of the whole interview: Penny was passionate about the subject of sexual education for people with spinal injuries. This passion made her an enthusiastic participant with deeply held views about sexual well-being as it relates to herself and others.

Jack is in his twenties. He has no speech and little voluntary movement but he is able to communicate passionately through facial expression and with the aid of a symbols, word and number book. Communicating with Jack requires significant concentration and checking. He uses his facial features and head movements to indicate approval, excitement and interest as well as disapproval. Jack has mixed feelings about relationships; he would love to become a father but is ambivalent about having a partner.

Four separate interviews were undertaken: (i) to read the participant information and gain consent; (ii) to gather data (two interviews); (iii) to share the data and collate Jack's comments. He was very keen to participate in the research and wanted to share his experience and opinions. We met at Jack's home.

Sense of the whole interview: Jack was enthusiastic about the subject and keen to share his experience but was less able to consider the experience of others.

As identified in these participant profiles, some interviews occurred over the course of several meetings due to the nature of participant's disabilities, where fatigue is a common experience. Each interview encounter was unstructured and started with the same question – on the subject of the meaning of sexual well-being to the individual – so the participants could explore what is of unique importance to them. Broad themes within the interviews have been adhered to, but participants'

language is reflected, altering the questions and prompts accordingly. Langdrige (2007, p.67) justifies an unstructured approach and states that: “It is not necessary to keep a steely grip on the proceedings; this will only lead to tension” Such a ‘steely grip’ could damage the rapport required for co-operative exploration of the topic. Individuals have been enabled to speak privately about their situation in order to produce the rich information needed to interpret the lived body experience. The participants disclosed their perception and experience in unique ways, which led to a wide range of information. I have attempted to relay both the diversity and commonality of their experiences within these findings.

Each cluster of meaning unit is presented in turn with illustrations from the transcripts breathing life into the text, giving this research emotional resonance as well as academic rigour. I present a series of sub-themes under each one in order to describe specific elements of the theme.

1. The meaning of sexual well-being
2. The experience of sexual discontent
3. Who am I and what does this body mean to me?
4. Isolation; internal and external
5. Asexuality; not us but ‘them’
6. How professionals can assist

Theme 1: The meaning of sexual well-being

Each interview opened by offering participants the opportunity to define sexual well-being in their own terms. Sexual well-being is an ambiguous term, open to personal interpretation, which leads to revelation from different perspectives. Some participants struggled to define the term and instead offered ideas about what it is *not* (described in the impact of sexual discontent section). The meaning of sexual well-being for the participants draws together the physical, the emotional, the social and the psychological. The participants reveal that sexual well-being is the experience of – and possibility for – sensual pleasure, where the self is fully present as human body and human emotion. It is the capacity to communicate, give and receive intense sensual pleasure alerting the self to possibility. The

physical structure of the body is irrelevant. Sexual well-being is humanly validating and allows us to acknowledge that all humans have a fundamental need for love and affection.

The data reveals that sexual well-being is complex and the following statement from each participant is a summary of their description offered to illustrate the diversity of their views:

Kevin: Being close to another, knowing I am alive through sensual pleasure.

Betsy: Sexual self-esteem.

Zack: Having sexual fun.

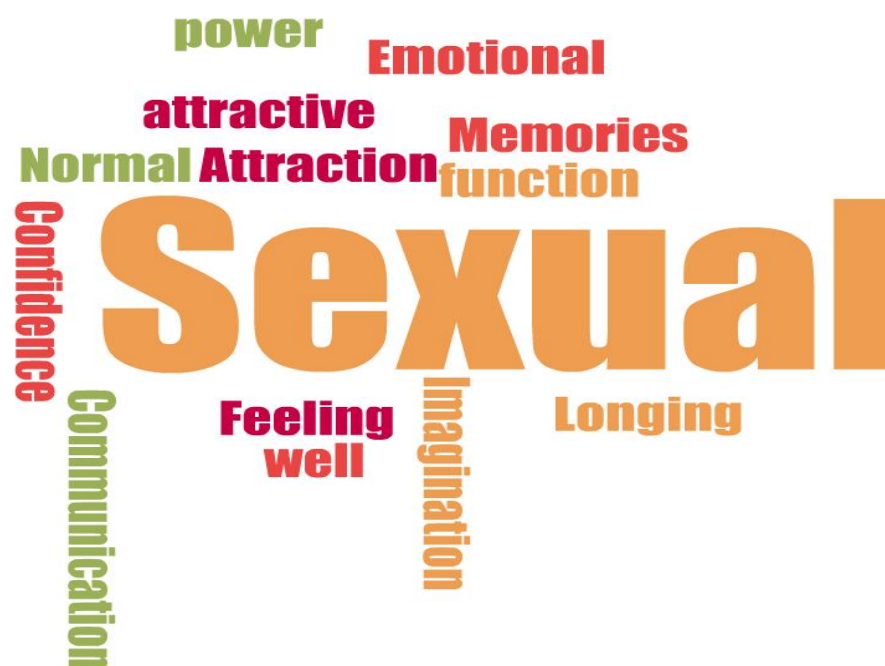
Amy: Being healthy, being desirable.

Penny: Physical and emotional connection to another and having a normal life.

Jack: Being the powerful centre of sexual attention.

The themes are drawn from analysis of the participants' elucidations of the above statements.

Meaning of sexual well-being keywords



Memory

Positive use of memory to construct sensual pleasure is revealed within the data as a significant factor in sexual well-being, something not mentioned in the literature. Memory is a part of our individual identity; how we remember and interpret our experiences influences how we experience the present and anticipate the future world of possibility. In his work in neurology David Eagleman explains that neural networks are developing continuously: "Who you are depends on where you've been...Because they continue to change your whole life, your identity is a moving target; it never reaches an end point" (Eagleman, 2015, chapter 1). For Jack, time spent dwelling in the past is a source of pleasure. His memories create an inner resource on which to draw and inhabit, contributing to his emotional well-being. Jack uses his previous sexual experience as a stimulus, remembering how he:

Did not do it in bed, just the wheelchair.

This memory aids his sense of sexual well-being, providing him with recall of pleasurable physical sensations and reminds him of his potential for more. He is able to use stimulating visual images to imaginatively create mental scenarios of

pleasurable experience drawing on memories of physical sensation. From these fantasies he derives well-being.

Jack has a medically stable congenital impairment so he is able to project into the future without anticipating physical change beyond ageing; this allows his imagination to be founded on past experience with the knowledge that what was possible will be possible again. For Zack this is different. His deteriorating condition undermines his ability to imagine the future positively. For him, memory is a source of torment. Dwelling on his previous positive experiences reinforces his present poor self-esteem; his positive memories are re-experienced negatively in the present. Asking Zack for his personal meaning of sexual well-being prompted memories of positive sexual experiences with a sense of longing, punctuated by heavy sighs:

It means a hell of a lot to me. When I'm thinking years ago what I used to be like... the worst thing is one, I'm in a wheelchair and, second, what I've just done (emptied catheter bag)... I've got a hole in me belly where I am unable to go to the toilet naturally... I want to go back to what I was like. Yes. I think about it an awful lot... it makes me feel like a right sad git.

These words convey the loss he feels about his sexual identity but also the undermining of his 'naturalness' when he identifies his use of a catheter as unnatural. He is indicating his sense of difference as he thinks about his past activities, underlined by his use of the pejorative word 'git'.

Zack's relationship had broken down, he believes, due to the increasing presence of the disease within the relationship. The loss of his relationship adds to his negative self-concept and yearning for the past. Zack states that his life as a sexual being is now over because of his disability.

Sexual health and personal safety

The concept of well-being is relatively new to social discourse so it is unsurprising that participants should interpret sexual well-being to mean the more familiar

concept of sexual health. In contrast, social care professionals are more likely to be concerned with sexual health and the impact of negative experiences of sex (Myers and Milner, 2007), so sexual health is a familiar discourse within social work interventions. Amy initially interpreted sexual well-being only in terms of sexual health:

Being safe from anything which is threatening, um, such as rape and abuse... And being well informed as well, before you go into any of that.

Her comments articulate the aspects of personal safety and sexual health within sexual well-being which the other participants did not consider in the same way. She reflects her personal circumstances which indicate the situated nature of knowledge influenced by personal experience. Amy is a student and has absorbed the information about sexual health and safety provided at her place of study. It is assumed that sexual activity will occur among students, so the aim is to give them suitable information in order that they can keep safe. This inevitably focuses on the potential danger of sexual activity. The need for personal safety and sexual education features within the disability literature, but primarily in terms of identifying the lack of available information and the high statistics of incidents of abuse of disabled people (including: Shakespeare, 1996; Bywater and Jones, 2007; Quarmby, 2011). Amy's comments reflect the knowledge available – especially to technologically able young people used to accessing online information – to guide their understanding of the world. The other participants are either from different generations or are not computer literate so do not necessarily take advantage of such sources of knowledge.

Amy articulates the intellectual exercise required to balance information along with the emotional dimension of informed decision making:

If you are completely clear of the, clear of what the risks are... what the bonuses are... also what the impacts are, the health impacts, then I think it definitely helps to have the emotional well-being in your head.

Amy's lack of personal experience makes her hesitate to express definite opinions,

although she goes on to discuss her experiences of attraction and how some physical intimacy left her thinking ‘that was nice’ and how she ‘liked more the idea that he liked me’, which gave her a sense of her own physical attraction and sexual power. Her comments suggest the pleasure experienced through sexual attraction and a sense of desirability which nurtures her self-esteem and gives her a sense of sexual well-being. Betsy’s comments agree with the significance of a sense of desirability to sexual well-being, observing that flirtation provides the opportunity to improve her self-esteem which she feels has been eroded by the lack of intimacy within her long-term relationship:

We did have a nice few evenings together (a man she met whilst away during a week of respite care), not sexually, just flirtation wise. And it's done me a load of good. Well, it bucked up my self-esteem for one thing. It makes me think: 'Oh you're not that bad after all' kind of thing, you're not someone to throw into the back of the corner sort of thing.

Amy also values flirtation and the positive impact this has on her sense of self, but she feels unable to seek out opportunities for relationships such as by using dating sites because: ‘...then you have to say “I am disabled” and they will be, like, “Oh, bye”.’ For her, the risk to her self-esteem outweighs the possibility of a positive outcome. This makes her responsive to opportunities rather than proactively seeking them out. This data indicates the positive power of sexual attention to reinforce one’s sense of well-being, a point discussed in detail in the identity section of this chapter. The absence of a discourse of pleasure regarding the alternative sexual practices potentially required when physical impairment interferes with the ability to perform traditionally (penetrative, orgasm-focused, genital stimulation) (Tepper, 2000; Darke, 2004; Stevens, 2010) means there is no challenge to conventional thinking.

Personal denial of need

Betsy has a strong sense of personal morality overriding her desire for sexual activity. She repeatedly comments on the seriousness with which she holds her marriage vows:

To me there is a boundary. I think I could (engage in sexual activity in a way which would not exacerbate her chronic pain), but it comes back to the fact that I am married and therefore wouldn't.

For Betsy being seen as a sexual person is:

Important to everybody; maybe not being seen so much as a sexual person but as someone... who has... needs. You know, for affection. Probably more the affection side of things.

This comment relates to the broader definition of sexual well-being beyond sexual function, that affection is part of human need and quality romantic relationships aid well-being (Markey et al., 2007).

Sex as a connection to normality

The participants discussed sex as a connection to normality. The perception that everyone else is having fantastic, spontaneous sex is a myth perpetuated by the media (Dune and Shuttleworth, 2009) which can undermine self-esteem and corrode relationships (Connelly, 2014). Physically disabled people are subject to the same socialisation and expectations as the general population, also internalising notions of frequent, exciting, acceptable, 'normal' sex (Harris, 2002; Dune and Shuttleworth, 2009). Jack has a different view to other participants stating that only penetrative sex can be deemed as sex, and penetration is required for sexual well-being to be experienced. He thinks being able to 'perform traditionally' underlines a difference he is proud not to have. We discussed spontaneous sex, as portrayed in films and TV, and whether he thinks the preparation some people require for sexual activity, such as hoisting, stops it being sex:

Yes. Wheelchair.

He described how a previous girlfriend had climbed on top of him in the wheelchair

for sex, allowing for spontaneity. He identifies his sexual function as important to his being human. He enthusiastically describes, with energetic head jerking, how:

I make sperm easily, I make lots of it. It is not painful that is why it is easy. The sperm comes when I watch TV when girls fight. I do not have to touch, it comes when I am excited, it just happens, when I have my clothes on. It happens in the night sometimes. It makes me feel nice.

He has a sense of pride in a bodily function for which he needs no help and which identifies him as a man (Jack's male identity is of particular significance to him as discussed below). Jack values his ability to have spontaneous orgasms:

I can think about it and it happens. I think about two girls and me, fighting over me. They both want to give me attention.

Jack is able to clarify his meaning of sexual well-being:

Girl, fucking. Sperm comes easy, that my body parts are healthy. Big man-involves being a big man, being macho. In control of a girl, getting her to do things.

Jack states that he likes to make the rules and be in control, something he says he rarely experiences. The notion of control has particular resonance for physically disabled people who have been denied control over decision making due to, for example, paternalistic services and over protective carers (Shakespeare, 1996; McCabe, 1999; Shuttleworth, 2000; Everett, 2007; de Than, 2015). Jack relies on others for all primary functions, and although he has control over when he gets up, what he eats, what he wears and what he does in the day, he nonetheless has to wait for a carer to do these things for him, and each carer will do the tasks in a different way according to their own ability. Jack is used to frequent and intimate physical contact with others because of his need for total assistance. However, this contact is on a professional care giving basis, rather than pleasure focused. He is unfamiliar with intimate, exploratory physical contact and any contribution this may

make to sexual well-being. His control over his sexual fantasies and the ability to reach orgasm without the intervention of others gives him a powerful sense of freedom.

Penny, like Jack, associates sexual well-being with normative sexual activity, but unlike Jack she has a broader definition of what constitutes sex, including pleasure-focused physical contact. She describes how sensitive to touch the areas of skin are around her upper torso, above the injury site, and the sensual pleasure this offers. This pleasure is part of her definition of sexual well-being as it signifies the intimacy she experiences with her partner. For Penny, this intimacy feeds into her sense of self. Sexual activity also connects Penny to everyday life because it is:

Normal. It's part of life. And it's a release too.

Underpinning this statement, Penny explains, is intimate knowledge of her body. She can anticipate the effects of activity in regions of her body without sensation (for example, how long her skin can tolerate pressure before damage occurs as she does not experience pain as a warning). Extensive communication with her husband, which she describes as a source of pleasure, along with openness to her altered body, has enabled her to adapt to her impairment over many years. She has used this information to design personal sexual activity rather than try to emulate the spontaneous, often athletic sex portrayed in the media:

There's no point in hyping yourself up because if it doesn't work it doesn't work. You know, if your legs are in that bad a spasm they are going to kick all over the place you can't do anything about it. So you have to either not have full sex or, you know... hand job or whatever. Or... you just go with the flow and think 'oh well' not tonight.

Penny states this flexible approach is enabled by good communication which echoes the sex and disability literature's reports on the importance of communication both to the quality of a relationship and the potential for adaptation

following impairment (including: Karlen, 2002; Markey et al., 2007; Esmail et al., 2007). Kevin corroborates this point when discussing how adjustment has to be made to accommodate physical change:

But my condition hasn't affected the physical side of things at all apart from having to adjust, as it were.

This leads to the importance of communication between mind and body as well as with a partner as the key to adjusting is:

Just listening to my body. And pain, pain and pleasure are very close together. So, and in some respects it can actually help. And Christ, yeah, having a partner you can talk to and who listens.

Penny provides an example from her voluntary work of the devastating impact that poor communication can have on a relationship:

He (the patient's husband) came in and said 'I don't want to have sex with you. How can I have sex with a crippled person? I don't want you anywhere near my (their) children, how can you look after children as a mother?

This patient's husband is described as having rigid thinking regarding impairment which he was not prepared to reconsider, and which resulted in the breakdown of the relationship. He was not open to communication or to the more creative approach to sexual activity possible when communication facilitates exploration, which makes disabled people potentially better lovers, focused on pleasure rather than performance (Shakespeare, 2000).

Pain relief through sexual activity

Poor health or physical disability does not, in itself, lead to poor well-being, but pain does impact on well-being (Schlesinger, 2003; Galvin and Todres, 2013). Sexual activity can offer a relief to pain and can therefore contribute to improved well-being. The participants corroborate the physical benefits of sex. Jack suffers with

very painful spasms but he finds that orgasms:

...make my limbs relax.

For Kevin, too, sex provides relief from physical pain:

It helps, it helps a lot, but um... it... yeah it really does help. It can be difficult in some respects, 'cos my body in certain positions it, after a short time it does hurt. So you have to be inventive, you have to have a partner who understands.

Kevin echoes Penny's assertion that personal knowledge of one's body is essential for sexual well-being, as well as communication with an open, receptive partner. For some disabled people such as Jack, such personal knowledge is very limited due to their impairment. Jack is able to express pain and he knows what positions he can and cannot tolerate, but he cannot touch himself or explore his physical self to identify areas of pain or pleasure. Neither does he have the ability to easily communicate nuances of sensation. For Jack, this is a barrier to inclusion in a world he sees portrayed in the media which rarely represents people in his situation.

I am different.

Summary

The meaning of sexual well-being for the participants draws together both physical and psychological elements. For sexual well-being to be achieved there is physical, sexual activity involved (adapted according to the specific impairment, either with or without a partner/s) plus psychological engagement, demonstrated by the participants' inclusion in their descriptions of the value of non-sexual physical contact and emotional elements of attraction, flirtation, closeness and acceptance. Memory can be used positively as a source of contentment to draw upon, but can also be a source of discontented longing and frustration. Media portrayals of sex similarly provide a pool of ideas on which to draw from, however, the emphasis on

the beautiful and spontaneous belies the reality for the majority and denies the nuanced nature of sexual well-being and sexuality of some physically impaired people.

Theme 2: The impact of sexual discontent

Key words

Sexual
Yearning
social
Memory
Exclusion
disenfranchisement
confidence
norms
Loss

Loss

Some of the participants explored the idea that people who enjoyed sexual activity prior to impairment experience a greater negative impact from their lack of sexual activity now. Zack and Betsy feel the loss of sexual well-being is more acute for them because they once had an active sex life; they have a sense of loss both about physical function and sex. Zack said that:

At the moment it is as such 'cos I can't do anything. I mean, if I think back years ago when I was first married we'd have sex here, there and everywhere. But I don't know, but, and you never ever forget what you've done sort of thing... no. Um, it's something I very much miss... sex and whatever, the normal intimate things so... I can do nothing about it so it goes no further. And if I had my health then I could do something about it. Which at the moment... I've got what I've got and I am stuck in here (the adapted extension to his home).

Betsy reflects on the loss of aspects of her relationship due to the changing roles brought about by physical change:

It is very hard if you're asking someone to help you with the shower to actually have a sexual life with them. Where are the boundaries? I honestly think that it is an impossible situation, which is why I decided to reply (to consent to participate). To have a male who is a carer, who is also a husband... I think it puts them in an invidious situation, both the person, the cared for and the carer.

Betsy states that her physical change interferes with opportunities for affection:

And then again how do you hold hands when you've got two hands on crutches? I can't practically; it's not going to work.

This loss impacts on the external signals of belonging which people in relationships might share such as holding hands, and the physical closeness this contact brings.

The experience of impairment is unique to each individual so it is inappropriate to rigidly categorise some characteristic or experience as being particular to only people with congenital impairments or those whose impairments are acquired. However, Zack and Betsy both highlight their personal perception that there is a definite difference of experience between the two groups of people, and this reflects the debate within the literature (McCabe and Taleporos, 2003; Hwang and Johnston, 2007).

Missing out

Exploring the idea that she 'deserves' a relationship Amy explains that:

It's been difficult because I do feel it is time, it's been a long time coming. Other people my age have had sex, they've had boyfriends... and I've just, I haven't ever.

This makes Amy feel:

Really depressed sometimes. Just the fact that I have no potential, if that makes sense.

It is as though Amy's life is deviating from the expected social script and this caused internal distress (Wiegerink et al., 2006). She wants to be like her peers; her desires are the same as the majority, and her frustration is evident from her comments. Penny expresses similar feelings of despair experienced by the patients with whom she volunteers. She, too, has faced despair, but says she was supported by her partner:

When Jim (Penny's husband) came in to see me I would say to him: 'Just forget me, go and find somebody else... you don't want somebody who can't move their legs, or, you know, we don't know what sex is going to be like.' He would say 'I just love you, it doesn't matter about your legs, I love you, it doesn't matter about any of this, and we will get through it.' And we did get through it.

These comments are lived experiential illustrations of the effect of relationships, and their absence, on well-being (Markey et al., 2007; Esmail, 2007). The participants recognise the value of such positive relationships but perceive internal and external barriers to finding such relationships.

Fear of rejection

The fear of rejection is significant to the participants without romantic relationships. As already referred to, Amy concludes that for her it is better to avoid rejection than risk her self-esteem, while for Kevin, fear of rejection:

...is what has stopped me so far, but there will come a point...

His comment exposes a dilemma between powerful forces of fear and desire. Kevin states that what he considers a biological compulsion to reproduce will

overcome his fear as:

We're hard wired to produce little ones, we are just animals that, unfortunately, can reason. Which makes life even more... It's really crap because you can see where you are going wrong. And you end up kicking yourself for ages afterwards. But... I hate being lonely. But part of me is thinking so nobody's... or I'm not going to find someone that I love. And I don't, my past experience; I don't just want to settle...

His comment relates to other accounts in the literature, which explore the compromises that physically disabled people may make in relationships. Such compromises can expose individuals to poor quality relationships due to the perception that physically disabled people have limited choice in their relationships (Owens, 2015). Kevin expresses the value he places on having a multidimensional and mutual relationship, rather than just sex. He has felt used by people, or put in a position where there is unequal commitment:

I was doing all the supporting and I wasn't getting anything. This seems to be a pattern, which I... people who are very needy, with problems. But you're not going to find anyone with no problems.

The internet has introduced new opportunities for establishing relationships. Social media offers links to like-minded groups and there are dating websites dedicated to disabled people (for example, Dating4Disabled, Disability Dating and Special Bridge). However, Kevin indicated that even these opportunities posed difficulties for him:

I mean, on the internet it's, some slight flaw, there are so many sweeties in the sweetie shop, right there's a slight scratch so put that one on one side. I'm not very good at selling myself. You need, ultimately that's down to confidence. But at some stage, you see, it comes down to what do you do for a living, and then it's, well, why don't you work anymore?

These comments indicate that even with opportunities being made available not everyone can make use of them because of their own lack of self-confidence, which compromises their capacity for well-being.

Eroded confidence

Kevin identified a lack of confidence as his primary obstacle to making relationships:

My confidence... my confidence is... I don't want to go through this again... the last time I had sex I felt used and it was horrible. Part of me is thinking sex is the problem.

He says he could go to places to meet people but:

There's always that thing, I don't know... I've no problem meeting new people. But when it comes to the romance side of things, that's when it, yeah that's the thing.

Amy, too, identifies her lack of confidence:

If I let my inner self-esteem issues rule my life I wouldn't go outside.

Jack, too, raised body confidence and how his physical and mental frustrations are interwoven:

I want to fuck. I feel stress. I feel different. Hard head, inner turmoil. I feel stress and frustration not having a sexual relationship.

These comments illustrate the crucial role that emotional well-being has in the ability to take up life opportunities leading to life satisfaction. The lack of self-confidence turns manageable challenges, where meeting the challenge leads to the positive reward of personal development, into barriers perceived as negative and wholly insurmountable.

Summary

The impact of sexual discontent mirrors that of sexual well-being: the physical and psychological dimensions are again drawn together in physical and emotional frustration and dissatisfaction.

Theme 3: Who am I and what does this body mean to me?

Keywords



All participants are highly aware of their bodies, being variably attuned between their physical and psychological selves.

The body beautiful and ‘super humans’

All the participants expressed the significance that sex and intimacy have in their lives, commenting on the relationship between their sense of desirability (or lack thereof) and their self-esteem or self-worth. We are all exposed to a powerful battle between discourses of the body beautiful and beauty being from within (Connelly, 2014). Consumer industries have grown around notions of beauty, with extensive advertising of beauty products and services, along with fashion as well as enormous amounts of literature, courses and self-help guides to ‘discover our inner beauty’ (for example, an online search ‘discover your inner beauty’ provided

6,740,000 results). The participants, as much as the general population, are subject to this marketisation of the self. Amy illustrates this point by her grappling with the clash between her view, very much encouraged by her parents, that interpersonal assessments should not be based on physical appearances, alongside the reality of peer and social judgement. She expresses her need for help to develop the skills to deal with the reality of social expectations when she passionately exclaims:

But they are (judgemental), so help me deal with that... It's difficult to hide the bone deformations when you are bare legged.

Amy acknowledges her contradictory inclination to want to conform to Western ideals of beauty while thinking she should rise above what she views as superficial values.

The idealisation of narrowly defined physical appearance underlines the difference of impaired bodies. Amy talks about the importance of diverse role models to counteract the prevalence of conformity to a narrowly defined type of beauty:

I think you have to have the right role models and you have to have the right, good, parents, who instil that in you.

She feels that the media presentation of the 2012 Paralympians was a missed opportunity for positive role models and set up false expectations, a view repeated by Penny:

I think that people who are in the Olympics obviously have talent. If you are a paralysed person or have any disability I think... they are obviously talented to be able to do the things they did and I think anyone who is disabled, oh well, they can do a marathon or they can do swimming. In fact, only a couple of weeks ago we went out, I could see this chap looking at me... he said something like: 'What bloody stupid thing were you doing for you to end up in a chair? How many marathons have you done... I thought

everybody in a chair did a marathon.'

This comment illustrates the power of the media to establish expectations. Penny reports that expectation is also demonstrated in the physical health assessments required when claiming disability benefits:

They are calling anyone on benefits, disability benefits; they're calling anyone in and saying you can go back to full time work, what's wrong with you? Now there's no way I could go back to work... I would love to but I just couldn't do it because of my routine... it takes me twice as long to have a shower.

This point has enormous significance to social policy regarding disability and the importance of accommodation for diverse needs. Penny's reference to the performance disabled people have to go through in order to demonstrate eligibility for benefits reflects the literature both regarding the 'freak show' notion of display for pay (Solvang, 2007) and the labour of disability within relationships (Liddiard, 2013c).

I listen to my body, we work together, we are one

Physical disability highlights the unconscious, taken for granted nature of being through its reminder that humans are physical entities, experiencing life through their bodies (the embodiment of experience). Penny describes how accepting her altered body and recognising its physical signals enables her to manage her bodily functions, absorbing these into her daily routine so they become part of her identity. By achieving this she retains her dignity and maintains her physical confidence. Usual sensation often ceases post-spinal injury, so for everyone the transitory stage between change and understanding the altered body, as Penny suggests:

Takes time to work it out and that's a worrying period for you that you don't want to become, almost a baby again.

Managing urinary continence, for example, is not as simple as measuring how

much you drink; it is also a matter of understanding the diuretic effects of different foods and drink.

But when you get home (from hospital) obviously you are drinking different things, so you may have the odd accident... and usually within a short time they will learn when they need to go to the toilet they will know because they might start to perspire, they might spasm or get various feelings that in turn will direct that they need to go to the toilet.

Penny points out the significance of managing urinary and bowel function to sexual activity:

I always say to ladies when you first go home if you are thinking about having sex make sure your bowels are empty, and your bladder before it happens. Because if you don't and you do have intercourse it can cause you to have an accident.

Penny is very matter of fact about bodily functions and views them as being a necessary factor of being human. She approaches the topic of sexual well-being as a natural and obvious concern to anyone, whereas other participants required encouragement to think that they could have claim to sexual well-being for themselves. Zack, in particular, expresses a contradictory sense of resigned acceptance of his body as it is now, which he describes as unsexual, but also a strong desire to return to the physical ability he had prior to the onset of his disability.

The one thing I'd love to do is to become active down below, if that makes sense. But that is what I used to be like, yes I've got what I've got and I don't like it but that's one of those things. I'd love to go back to what I was... I dream about it yes, but that's as far as it goes 'cos I know at the moment I can do nothing about it. There's nothing more that I'd love to do than grab hold of a girl and have some fun.

Disability can interrupt a life course and adjustment can be very difficult, for Zack it seems rather than adapt he has effectively put any sexual activity 'on hold' until he becomes well. He has a sense of determined optimism and states that he has to be optimistic about a cure to keep himself going:

I mean, eventually they will come up with a cure. I've actually got a bit of paper by the doctors, not by Joe Bloggs, so they must be trustful, and they say in 10 years' time they will come up with a cure. I mean I believe they come up with so many different cures it's a case of join the queue and wait your turn.

Zack is clear about his intention to embrace a cure if it is offered:

Too bloody right. I want to go back to how I was. I've even thought about the job I will do.

On examining this optimism, Zack finds it difficult to consider how his view might be personal rather than a universal truth:

'Cos if you don't and you just remember the bad times then what's the point of being here?

He acknowledges the struggle he has at times to stay positive, however, with medical advances in the treatment of his disability (Panorama, 2016) Zack has grounds for his optimism. But in the meantime he feels he has accepted the disability as part of who he is:

To be honest, I've got what I've got and I don't cover up. I don't shout about it as such. When I had my health I was very much a get up and go person, not a sit back and let it happen person, and I want to return to that, just normal, how I used to be. That's what I want.

Zack was a skilled craftsman where his hands earned him a good living. The

disability has affected his hands; they are no longer the source of money, pride or identity. However, reflecting on how he feels about his body now:

Fine, yeah I do.

He feels that inside he is the same person:

The only way I think I am (different) is because I am in this (indicates wheelchair).

My body and I are separate

Kevin's experience offers a contrast to Zack's. Kevin highlights how a fluctuating health condition erodes the ability to know oneself. He is unpredictable to himself, so plans are made and often cancelled with little notice, risking social approbation. This unpredictability clouds Kevin's self-knowledge and puts relationships at risk:

It's a thing I have a problem with making commitments with people, so I have to make a proviso that I am ok on the day... because you were feeling bad you feel like you are letting them down.

Kevin feels that uncertainty signifies his difference, and reinforces the other uncertainties in his life such as his accommodation and family. He lacks the security of a predictable body within which to encounter the world.

Even after all this time, I was diagnosed in '98, I still can't see patterns. I can be inactive for a while and get pain and I can be active for a while and not be as badly affected as I thought.

When asked if he is aware of any predictors he identifies mood as a significant factor and relationship status as a mood enhancer.

Um unhappiness affects it. Big style, happiness affects it... When I'm in a relationship, I've been in a relationship and things have been going all right, life is a heck of a lot easier... whether it is, you know, knowing there is

someone who cares, just that support I suppose, I don't know.

This underlines how well-being is enhanced by positive relationships (Markey et al., 2007; Handley et al., 2015).

Gendered experience

For the participants the focus of the interview is on their lived experience as a unique individual with freedom to include gender or not. For Jack, his male identity is of great significance to him and this became a feature of the interview. He likens himself to his birth father despite the difficulties this causes with his adoptive family. Jack says he thinks a lot about his father because:

I am like him. Dad needs girls. He has lots of girlfriends. I feel thankful to my father for having me, thankful to be alive and experience pleasure.

Jack also states that:

People protect me too much. It is frustrating. Because of the wheelchair. People look at the wheelchair.

He would like to do more things for himself but he is caught in a dilemma of enjoying the individual attention care offers but also desiring privacy. For Jack, this is a daily negotiation and part of his labour (Liddiard, 2013c).

Penny also reflects on her observations of gender differences in response to impairment and its impact on sexual activity:

I think a woman is happy, or happier to just want to cuddle and kiss at first and work things out slowly. I think if it is a young man his total focus on sex is totally different. Totally different, and they get very frustrated, quite cross, quite angry. And also they think women, if they have not got a partner, they think women are not going to want to be with them but actually it's been proven that it's the total opposite.

Summary

Disability can interrupt the anticipated life course challenging fixed points of identity resulting in a review of the expected personal journey (Galvin and Todres, 2013). The mind and body can cohere with the one appreciating the signals from the other, and a sense of homecoming (I am at home within my body) can be achieved through this unity. Alternatively, changes to the body can be resisted, leading to a sense of conflict between mind and body. However, this disharmony, or 'homelessness', can be a creative motivational force leading to the embracing of new potentials (Galvin and Todres, 2013). Disability goes beyond individual experience of impairment, it is experienced multi-dimensionally, in the social world within interactions and as a physical body in a physical environment which the individual has limited power to influence. This wider concept and context of disability influences the individual experience of impairment.

Theme 4: Isolation, internal and external

Key words

transport
support
isolation
internal
limitations
access
opportunities
loneliness

A sense of social isolation resulting from their impairment was identified by participants who also expressed concern about the isolation experienced by other disabled people. During the interviews the participants explored the nuances of isolation, whether purposefully sought out or externally imposed. Participants reported that they have limited opportunity to attend the usual social events where they might initiate romantic relationships, such as pubs or clubs. This is due in part to the built environment not accommodating their needs, but also their care plans not recognising support for such activities as a legitimate outcome. This experience indicates the impact of isolation on socio-sexual experience (Shuttleworth, 2000; Oddy, 2001).

I don't want to go out

Kevin reveals the negative impact his impairment has on his motivation to have any social contact, reinforcing his sense of isolation. He likens his depression, which he identifies as a reaction to his disability, to a demotivating force, which erodes the confidence he previously had in his ability to socially integrate. It is a destructive, self-confirming cycle where he identifies the constituent parts but feels powerless to break into the continuous cycle:

Yeah thank Christ I'm still mobile, but when I am really bad, you know, when I am having a really bad day with the pain I don't go out, I just stay in. Weekends are the worst, it's weird 'cos every day is the same but weekends, that's when society, when people do tend to put their glad rags on, kick up their heels, whatever. My whole family, they've got partners you see, so when we have family get togethers I'm Billy no mates. Makes you feel a failure.

Kevin explains that he has a tendency to completely isolate himself at times:

I had isolated myself, I still do it occasionally now, 'cos over Christmas I went through a stage of not talking to anybody for four days. The longest I've done it is seven days.

Kevin recognises the impact this has on his mental well-being so has sought help from his GP and psychiatric services. The circumstances in which people experience impairment can contribute to risk to self as identified in the safeguarding section of the literature review (for example, social isolation), as well as being detrimental to well-being as evidenced in the well-being literature (for example, the impact of loneliness on health).

Imposed isolation

Betsy sees the lack of integration as an issue for other disabled people:

I would say, certainly for singles, disabled people, the biggest thing is

integrating them into society where they are going to meet a cross section, not necessarily another disabled person at another disabled day group or day centre or whatever, you know, or disability groups or things like that. You desperately need to get out there and see a whole cross section of society. A group of 19-year-old men need to see a young lady in a wheelchair as much as the young lady in a wheelchair needs to see a group of 19-year-old men. So society has to open its doors and say it's ok.

Betsy described her own social activities but says these aren't universally accessible for disabled people due to the absence of personal assistance. For many disabled people, if they need help they have to provide their own, or not attend social activities, unlike non-disabled people:

It's got to be that disabled people don't feel like they have a hundred bridges to cross before they get somewhere. And that's what it's like.

I asked whether Betsy thought this might make people more creative in finding solutions to obstacles:

I think it can but it can also make them.. .think 'that's not for me, I can't do that'.

Zack identifies his social isolation which he feels can only be solved by returning to full health:

Well, I'm very much restricted in what I can do. If people didn't come here I wouldn't see anyone, so all I know is if I can return back to my health I can get a car, drive and then the choice is up to me.

The wheelchair makes access difficult despite legal requirements for public buildings to be made accessible (Disability Discrimination Act 1995):

Well, it's things like that, it's everything. What I would love to be able to do is

return to how I used to be. And eventually it will happen. A cure will come out.

When I asked Zack if there would be value in his trying to meet people now, the question prompts a thoughtful silence, eventually ended when Zack states:

Well I'm in two minds if that makes sense. Not sure... I don't know. You've caught me out there.

Zack identifies his disability as creating a difference from his 'before' identity. His present identity is one where he cannot go out to socialise. Zack cannot use a computer independently due to physical co-ordination problems. He was not aware of computer equipment such as speech programmes as potential solutions:

Um it could be worth... thinking about as such. For me to say 'yes' I'd definitely be interested, I don't know but...

For Jack, the nature of his impairment requires the constant presence of a carer which he perceives as adding further barriers to integration. He would like a relationship but thinks his disability gets in the way of meeting people:

Jack: Carer. A girls sees me with a carer, it gets in the way.

Sally: What do you think the girl thinks?

Jack: Difficult. But I am worth getting to know.

The constant presence of others makes it difficult for him to make personal relationships. He experiences people talking to his carer rather than himself. In addition, the lack of privacy means he has few opportunities to relax his public persona. If he had privacy he would:

Fuck. I would get a sex worker.

Social capital

The notion of social capital and its positive influence on well-being is evidenced by the participants. Penny has considerable social capital as she is part of a busy family, has an active work life and enjoys social activities. Being part of a long-term relationship, family and links to social networks through work and leisure activities connects her to both the factors reducing risk and enabling well-being as detailed in the literature. Jack and other participants depend on limited public transport to access events, but they cannot use public transport unaided.

Sally: Are there things going on and places you would like to go to?

Jack: Yes. Clubs.

Sally: Is getting there a problem?

Jack: Yes. Money. Time.

These comments reflect the multiple barriers to inclusion including the financial resources to access transport and events. Disabled people are more likely to experience poverty (Joseph Rowntree Foundation, 2013) which leads to reduced social capital as well as isolation.

Summary

The participants experience a sense of difference which creates isolation from the 'norm'. The lived experience of disabled people demonstrates the still-limited reach of equality legislation as access and opportunities to participate in the community remain restricted by services such as expensive transport and the perception of negative societal attitudes.

Theme 5: Asexuality, not us but ‘them’

Keywords

interest
love
asexual
Potential
sexual

All the participants perceive themselves to be sexual beings, but are aware of the notion within society of physical impairment leading to asexuality. Kevin differentiated between the perception and the reality:

I suppose not so much as asexual as not seen as a sexual being. You see someone in a wheelchair or someone with crutches maybe and I suppose some people don't see them as a possible partner.

Kevin reflects on where this notion comes from:

Whether it's the media, I suppose it's society in general. There used to be some nasty jokes around (gives an example). I suppose that's what's out there. They start thinking disabled people are a bit simple, so, and I don't know, some people think they are taking advantage as well. I suppose some people think if they are seen with someone with a disability they, that they are not good enough to get an able-bodied person.

Kevin's comments touch upon the perceived vulnerability to abuse associated with impairment as well as the notion that impairment leads to needs in all aspects of life (de Than, 2015).

Betsy speculated about disabled sexuality:

Is there such a thing as a sexual side to a disabled person? And socially I think there is the assumption that once you start walking with a stick you don't want to (have a sexual relationship).

There is a personal link between impairment and ending sexual activity for Betsy as this ceased when she started using a stick.

Reflecting on the impact of her disability on relationships, Amy states that:

I think the instant someone sees that I am in a wheelchair they must go 'Oh, She's not a potential love interest'.

Her views have been influenced by her experience with a man to whom she was attracted. She felt herself unable to see him when she was unwell (which she associates with being unattractive):

I never saw him at that point. I would wait until I was healthy to see him again. Um, it just made me feel better.

But the relationship was complicated and caused Amy significant emotional distress and guilt. However, she justified this, saying:

I kind of tricked myself into thinking I was ok with that, I deserved something in return because of all my medical things, or the lack of guys interested in me. I have known guys that I have liked but it turns out they don't like me. Or the wheelchair puts them off, which is what I think happened with this one guy I went on a date with.

Her mother suggested it may be to do with the perception that being in a relationship with a disabled person means taking on a big responsibility and also the potential difficulty in ending a relationship with a disabled person. It is as

though the impairment becomes the key factor in a relationship which is, in fact, contrary to the reality of Amy's life in which she manages her disability needs independently. Amy reflects on the impact of the presence of her wheelchair on friendships:

Girls don't want to seem, oh I don't know, they don't want to seem weak hanging out with a disabled person. Or they just seem to think: 'Oh she's not attractive'. It's definitely something that affects relationships. Um, emotional relationships. Physical relationships.

She feels that her wheelchair is noticed first before she is.

Penny describes the societal disapproval she experienced both when pregnant and, subsequently, with her children. She feels this is because they were an obvious sign of her sexual activity:

I had one lady accuse Jim of abusing me by making me pregnant, making me have sex. And then there was another lady... I um, I had all four children with me, the last was a tiny baby... this lady looked at me and said, 'Are they your four children?' And she said 'It shouldn't be allowed, disgusting. How can you look after children, how can you cook their dinner, how can you feed them?'

Penny hopes society has changed since that time; however, she recounts a recent incident which makes her question this hope. After attending a comedy event the comedian singled her out to apologise for the sexually explicit content of the show, giving her the impression that he felt she was sexually inexperienced and particularly sensitive. The notion that disabled people are more sensitive or fragile is a source of oppression as it infantilises people. The disability arts movement has challenged these notions, ridiculing such attitudes by demonstrating the beauty of disabled bodies (for example, Marc Quinn's statue of Alison Lapper on the fourth plinth of Trafalgar Square, 2000 to 2002). Alternatively, disabled comedians such as Mat Fraser comment on the comedic side of impairment.

Penny reflects on media representation of impairment even in programmes or events purportedly supporting disabled people, such as Channel 4's *Sex Education* series:

Because it was showing aids and that for disabled people to have sex, and you don't need aids... so in a way, say able-bodied ladies watching that and she saw a disabled man she would immediately think 'oh he has to have these injections in his penis' or something, and it's not the case always. And there was another one where they had some sort of seat that swung backwards and forwards... she was lifted into it and her legs were put in some sort of stirrup. And again somebody said to me at the spinal centre 'Crikey, do I have to go all through that?'

Whilst it is helpful to have such information on mainstream television, because programmes like this are unusual they are not balanced by a more general representation of, and exposure, to the diverse range of impairment.

Penny observes that in her experience:

For some reason younger ladies want to mother or feel they need to help somebody in a chair, and I know quite a few men who have got married after injury and gone on to have children. We've got a couple of ladies that have got married since being injured. But it's more men. I think men have a different approach when they see somebody in a chair... they don't want to commit because they see what comes with it.

Summary

The participants experience themselves as sexual beings, and while some are passionate about empowering others to achieve sexual well-being, not all recognised other physically disabled people as sexual. However, the participants are socialised into the same British culture and are subject to the same dominant discourses resulting in negative, individualised views of disability.

Theme 6: What is wanted from professionals

Keywords



Non-judgemental attitude

The participants share a requirement of non-judgemental attitudes in professionals, but feel they have rarely found this to be the case. For social workers, a non-judgemental attitude and respect for difference is a core element of the professional code of practice and value statements to which they are subject (BASW, 2012a; HCPC, 2016). At its heart social work concerns human-to-human encounters taking place within the social world, and this requires more than prescribed or fixed codes of ethics, it requires empathy founded on concern for human well-being (Galvin and Todres, 2013). The participants identify this as crucial, but often absent in their encounters with professionals, including social workers. Betsy highlights her experience when working in a social care setting:

I think they (professional colleagues) need to leave their personal opinions at the door. Because the opinions that came out during my experience at work were so strong. Really strong, and nothing would have proceeded if they'd been allowed to voice those attitudes.

Betsy's comment echoes the criticism of social care interventions being

paternalistic with unequal power relations enabling the professional to dominate within social work interventions (Oliver, 2004).

Knowledge

Betsy identifies the importance of professionals having knowledge of sexual well-being:

I don't think it is something for a general worker to actually tackle. Or it might just be talking about personal relationships and if it opens another door. So if they start with an open conversation and if that opens a door, and you know, that answer rang a few bells and maybe I need to go back and chat, and you might even make an excuse, it doesn't matter providing that door is opened.

Betsy recalls her professional experience when she worked in adult residential care 28 years ago. A young couple had wanted to live together and we were able to draw parallels with contemporary accounts from disabled people who similarly experience the infantilising and judgemental approach Betsy talks about:

One person left the employ because they wouldn't stand for it, because they believed this lady was, or should not be considered anything but as a child... "she still wears lacy ankle socks for goodness sake, she can't be active sexually".

Betsy recalls that even a specialist worker bypassed the individual and:

talked to her family, which I thought was wrong. I just thought you would talk to them... (the couple themselves).

Betsy reported that she:

Found it very sad that, why shouldn't we get in the way?

Her comments indicate that professional helpers can actually be part of the barrier to disabled people achieving sexual well-being.

Three participants stated that they would not talk about this subject with a professional they did not feel they knew or trusted. This relates to the significance in humanised care work to establish open, empathetic relationships required in order for issues of personal importance to be safely discussed. Three participants stated that part of their preparedness to raise the issue would depend on their having confidence that the professional has some knowledge about the subject (reflecting Oliver and Sapey's (2006) point about people with disabilities distrusting social workers who do not have knowledge of the issues important to them).

Trust

Zack emphasised that for him to articulate such sensitive thoughts, trust in the listener is required. He struggled throughout the interviews to articulate his thoughts and required repeated reassurance that I had come with a non-judgemental attitude and wanted to hear his views, whatever they may be:

You're one of the few people I am able to talk to and... to be honest I spoke to nobody, you're the first, about sexual things. But a lot of it comes down to, I think, trusting somebody and being able to talk to them.

Amy also repeated similar points in her views about what she requires from professionals regarding her own sexual well-being:

Attitude is the best thing (rather than services). But it's difficult with the cuts and benefits happening now. The cuts to the social area, it's difficult for social workers to look into that when there are other things that are more important. When you are dealing with someone who has a complicated number of issues, that's going to be the last sort of thing on your mind... there needs to be something said as well, you are here to discuss benefits and care but also if there is something they need to talk about going on in their lives I think that is an important thing.

Amy said that trust and rapport is needed with a social worker before she would be prepared to discuss such a sensitive topic:

It's because I know you and feel comfortable with you, so...

The giving and receiving of information and support from others with physical disabilities was identified by all participants as significant. This was expressed with particular strength by the participant with a spinal cord injury claiming that this disability has unique qualities which only another person with a spinal cord injury can appreciate. This denotes identification of membership (and potential pride in that membership) of a particular community with its own knowledge and wisdom. Penny spoke passionately about peer support with professionals there to enable rather than provide support. Penny's injury occurred many years ago when there was only one spinal unit in the UK so she was treated on a neurological unit where:

I was never ever told or explained anything about sex or pressure sores or anything about that because it was a neurological hospital.

Penny explains that the situation has improved with the increase in specialist spinal units but:

They won't be able to tell you the experiences that you have if you have an accident or if somebody has to help you at home or if you have something that goes wrong, and that's when patient teachers come in... people who are in that situation.

However, Penny reports that service cutbacks have impacted on peer support roles, with these, too, being cut back due to travel expenses no longer being covered. This means that patients do not have contact with those living with spinal injury in the community. She explains that, in her experience, staff on the unit see her as providing unique and invaluable support, describing her as 'liquid gold' due to the positive change they see in patients following contact with Penny. However,

she states that the management or budget holders are removed from the ward and, therefore, lack insight into the unmeasured value of peer support:

A lot of the hierarchy professions don't see it because they're not on the wards. It's the nursing staff who realise how important it is.

We discussed whether professionals would benefit from training in sexual well-being and Penny, again, emphasised the importance of peer support:

An able bodied professional will come in and sit and talk to someone who is paralysed and they don't know what they are saying, they don't know what they are talking about because they have not lived it, they don't know the emotional side of it. They don't know what can really happen at home.

Penny has been able to use her personal experience of pregnancy and child care to help other women understand the physical implications of pregnancy, such as the change in her centre of balance:

So, I would be used to going up a small, maybe a two-inch step at the local shop and I remember I bumped up the step and found myself upside down on the floor all of a sudden. So it's things like that that I didn't realise.

Penny states that this is the sort of information that has more resonance for patients coming from a peer rather than professionals, who do not have the lived experience of impairment.

Jack does not think professionals have the knowledge he needs so he talks with his carers but is:

Embarrassed to ask for help.

He has approached professionals before for advice but found the information poor and out of date, and he was advised to contact Sexual and Personal Relationships

of Disabled People (SPOD) which had closed with no alternative information offered.

I sensed that Zack needed to be given permission and the opportunity to discuss sexual well-being. I suggested to Zack that the transcript indicated to me that he had not been given the opportunity to discuss his emotions before and my questions had confused him:

Yeah, 'cos I've never been asked that before, so I was being asked there and that took me...by surprise'

Zack had never had a conversation about sexual well-being with any of the health and care professionals he has contact with.

As for talking to somebody, no not often. I keep quiet. No I'm not used to it... to be honest some of the questions that I was asked (in first interview), I've never ever been asked that before.

Betsy comments on her view that inquiries about sexual well-being from professionals would receive positive responses:

In my experience it is something... I don't think is appreciated... you know, by professionals or anyone else. If you do get asked it's very perfunctory... it might be sort of briefly thrown in... sort of, 'Do we need to do some sort of check on you?' or something.

Betsy states that the only occasion she had been asked about her sexual well-being or sexual health by a professional concerned her fertility and felt it had been to complete a tick box exercise. However, had she been asked more sensitively she felt that:

It might have been quite nice actually if someone asked, but I don't think anyone has.

The literature also raises the potential for positive influence which professionals have in encouraging self-esteem within the people with whom they work. This can be achieved in part through recognising and acknowledging people as sexual beings (Milligan and Neufeldt, 2001).

Summary

The value of a non-judgemental attitude from professionals was commented upon by all the participants. This point emerges from the felt experience of being judged despite codes of practice highlighting the importance of a non-judgemental approach. However, professionals are subject to the same socialised learning, so maintaining a non-judgemental attitude requires a constant cycle of reflection to ensure discrimination does not occur.

Trust also emerged as a significant issue – again, a core part of the social work role is to establish relationships based on trust. In addition, empowerment is a core social work task and establishing peer support networks is a route to empowerment, reinforcing the appropriateness of social worker awareness of sexual well-being. This suggests that social workers are professionally suited to discussing sexual well-being, however, the changing role of social workers discussed within the literature indicates this may not continue.

Chapter 6: Discussion

Introduction

This research provides valuable new knowledge about the little-researched topic of sexual well-being from the perspective of physically disabled people. My work might lead to a new understanding of the meaning and importance of sexual well-being to physically disabled people and how this points to the need for service users to assert their sexual rights, by social workers recognising service users as sexual beings and by the population at large acknowledging the relevance of sexual well-being to all people. The participants have disclosed exclusive data related to the phenomenon of sexual well-being and my status as both social work practitioner and researcher enables a unique, insider perspective unavailable to other researchers.

The phenomenological approach to the data gathering and analysis has revealed a depth and richness to the findings which aims to do justice to the participants' contributions. This approach has ensured that time has been taken to reveal meaning, to dwell with the participant data and allow the voices of the often silenced (by society's approach to disability) to be heard. The revelation of meaning was enabled through the phenomenological research approach underpinned by the existential concern of what it means to be human (as discussed in the methodology section) and how "living from the inside" (Galvin and Todres, 2013, p.12) is a feature of being human. Phenomenological research seeks the essence of the phenomenon of study by examining what is essential, without which the phenomenon becomes something else. This can be achieved through a process of free imaginative variation (Finlay, 2009a, p.14) where all the variables are considered. The participants assisted with the initial stages of this process within the interviews as we discussed what contributes to their experience of sexual well-being and what detracts from it. But:

"phenomenology is not concerned primarily with the nomological or invariant aspects of some state of affairs; rather, it always asks, what is the nature of

the phenomenon as meaningfully experienced?”

(Van Manen, 1984, p.42).

Having become conversant with the concept of the life-world (Husserl, 1931; 1970) whilst exploring phenomenological methodology, I became aware during analysis of the findings that the participants were describing their unique understanding of the meaning of human experience within the dimensions of the life-world. These descriptions reveal the individual in their psychosocial context and demonstrate that understanding the life-world offers social work a meaningful way of understanding the contexts of service users. However, the descriptions themselves only provide insight for practice; this new knowledge about sex and disability has to become useful and applicable to social work practice (crucial to this work not only because this is a D Prof study but also as a pragmatist I seek ways of making knowledge useful). Exploration of ways of achieving usefulness, whilst remaining faithful to my phenomenological research methodology and the revelations of the life-world from the findings, led me to the phenomenologically informed humanising approach to care devised by Galvin and Todres (2013). The first section of this discussion chapter entitled ‘A humanising approach to sexual well-being’, is an exploration of how Galvin and Todres’ humanisation agenda provides a useful conceptual framework to discuss and critically explore my findings and the literature. In the second section of the discussion, ‘Sexual well-being, humanisation and the Care Act 2014’ I develop the usefulness of humanisation and my research to sexual well-being-focused social work. My findings provide a new and critical stance to the application of particular well-being domains within the Care Act assessment process (detailed in Appendix 4).

Whilst my research has been focused on the sexual well-being of physically disabled people I have also identified the stress and well-being concerns for social work practitioners. This is becoming a pressing concern as local authorities face recruitment and retention crises (Skills for Care, 2014a,c) and social workers face increasing stress (Cooper, 2015). Practitioner distress relates to the relentless criticism by the media (McNicoll, 2016), government imposed change (Moriarty et al., 2015a) and the dehumanising influence of technical, procedural and

managerial social work methods such as Care Management (The College of Social Work, 2014b) which obscure the human nature of care work (Bell, 2012). The well-being principle which underpins the Care Act 2014 offers social workers the chance to refocus on a humanising form of practice. However, the literature indicates that well-being in the Act is being promoted through an extension of personalisation focused on a narrow and prescribed notion of independence and neo-liberal economic systems (Beresford, 2013). This seems contrary to the commitment within social work values to work with “the whole person, within the family, community, societal and natural environments, and should seek to recognise all aspects of a person’s life” (BASW, 2012a, p.9). The third section of the discussion, ‘Search for a well-being focused rationale for social work practice’, therefore turns to my contention that social work requires an alternative approach in its promotion of well-being in the Care Act 2014, as well as for wider social work practice. Having sought a philosophical aid to making my research useful, and finding this in Galvin and Todres’ (2013) phenomenologically informed humanisation agenda, I argue that humanisation also meets the requirement of an alternative philosophical approach to well-being.

However, before embarking on the full discussion I revisit the meaning of sexual well-being as revealed by the findings. Restating the meaning of sexual well-being at the outset of the discussion chapter asserts its centrality to the discussion and subsequent practice development.

The meaning of sexual well-being revisited

The participants provide multiple factors to consider in understanding the meaning of sexual well-being:

Kevin: Being close to another, knowing I am alive through sensual pleasure.

Betsy: Sexual self-esteem.

Zack: Having sexual fun.

Amy: Being healthy, being desirable.

Penny: Physical and emotional connection to another and with having a

normal life.

Jack: Being the powerful centre of sexual attention.

The findings reveal the complexity of the lived experience of sexual well-being. It is a holistic experience involving the whole person: body, mind, emotions and self in connection with others. But it is also something which requires the meeting of constituent parts which flow together but may flow apart, as revealed by Kevin, Betsy and Zack in their descriptions of previous relationships in which they experienced sexual well-being, but as circumstances changed (the increasing impact of impairment for Zack and Betsy and loss of closeness for Kevin), constituent parts flowed apart and the sense of sexual well-being was lost. The participants, in their descriptions of sexual well-being, link it to the conditions of general well-being including emotional, physical, environmental and economic well-being such as having a home with privacy (Jack), being physically able to have spontaneous, participatory sexual fun (Zack) and having the economic means to participate in social events (Betsy). But as highlighted in the literature review, well-being is a contested term, interpreted differently according to the user, so for social work practitioners exploring sexual well-being in the context of the Care Act 2014 assessment, this means recognising the individualised and nuanced meanings given by individuals to their experiences of well-being. It is not surprising, therefore, that the findings contain ambiguities and contradictions with the meaning of sexual well-being depending on the unique perspective of each participant.

My research illuminates that sex is a sensual experience made known via the physically embodied senses, primarily touch, hearing and sight. Jack's bodily response (excited movements, the widest of smiles, flushed cheeks and vigorous head nodding, all of which form his vocabulary of pleasure) when retelling his sexual experiences created a direct link to the physical pleasure and excitement he felt at the time of the sexual encounters. Other participants explored the sensual signals of pleasure such as Penny's super-sensitivity after injury and the erotic stimulation found in listening to, for example, quickened breathing during sex. Kevin and Penny also revealed the sensual signals of discomfort such as hyper-alertness to pain on exertion, which might not be too uncomfortable at the time but

could result in significant pain later. Sensory stimulation is as potent for disabled bodies (acknowledging the variable sensory sites which impairment might affect and enhance) as much as non-disabled people, but structural and social barriers interfere with opportunities to experience such stimulation. These barriers include the negative perception of disability within society which undermines the attractiveness and desirability of disabled people as described by Amy and Kevin in their accounts of why they do not make use of internet dating expecting to be rejected and found undesirable. Also, by Betsy in her description of her feeling of 'being thrown into the back of a cupboard' and no longer attractive, and Penny in her accounts of spinal patients with whom she works being rejected by partners after injury. A further barrier is the association of disability with dependence and vulnerability leading to overprotection, which reduces disabled people's opportunities. Jack describes his own experience of this overprotection when he craves, but is denied, privacy because of fears of the risk this would expose him to. Betsy also describes the overprotection of care home residents who were denied a relationship by staff who did not consider the individuals to be independent agents.

The findings reveal that sex as a purely pleasurable physical activity can contribute to well-being through the experience of pleasure and increasing self-esteem derived from a sense of desirability. But without the emotional connection it is sexual activity rather than sexual well-being as described by Kevin who felt immediate pleasure from sex but this was overridden by a later sense of being 'used' because the emotional connection was lacking. This suggests that well-being is an enduring quality rather than the more transitory notion of happiness which orgasm might bring. This relates to the discussion within the literature regarding the connection between well-being and happiness (Aked et al., 2010) and the evidence that well-being involves both endurance and resilience to recover from setbacks (Aked, et al., 2010) which the flow of life inevitably creates. The constituent parts of sexual well-being revealed by the findings form part of the complex flow of life which the well-being literature demonstrates is affected by internal and external influences (such as our genetic inheritance, social circumstances and life choices (Bacon et al., 2010)). The literature and findings together reveal that sexual well-being involves authentic connection with oneself,

others and the world whilst being open to the potential for new and pleasurable sensation and emotional connection. The findings support the literature regarding the enduring influence of the negative narrative of disability and the pervasive assumption of asexuality despite disabled people's evident sexuality. Each participant was acutely aware of their sexual identity, needs and desires, but did not necessarily see this in other physically disabled people. The findings reveal that sexual well-being is a holistic experience which combines embodied sensual pleasure with a sense of one's own power, felt as confidence and desirability, along with emotional connection to others. The literature confirms the importance of all these factors including Tepper's (2000) work on sexual pleasure, research on the importance of sexual confidence and esteem (McCabe and Taleporos, 2003), and evidence reporting on the impact of relationships on health and well-being (Markey et al., 2007). Removal any of these component elements changes the experience, so it is no longer sexual well-being, but rather sexual activity, sexual power or emotional closeness.

The findings reveal the interconnection between the conditions for sexual well-being and general well-being, as presented in the literature (including social connection and self-esteem) (Aked et al., 2008). Well-being is dependent on specific social conditions including inclusion and equality (Wilkinson and Pickett, 2010), therefore, it appears that for social workers to focus on sexual well-being attention is needed on the conditions which give rise to well-being.

1. A Humanising approach to sexual well-being

1.1 The intertwined constituents of the life-world

Dwelling with the findings and subsequent definition of sexual well-being, informed by the phenomenological approach to my research, led me to recognise that the participants were describing experiences of their life-world (Husserl, 1931). Making this link between the findings and the concept of the life-world has provided an interpretive structure for the following discussion and subsequent application of the learning from this research.

The life-world

The life-world is not an objective 'outside there' world but a relational world full of meanings (Willis, 2001; Dahlberg, 2006b; Finlay, 2008; Galvin and Todres, 2013). Meaning is situated in the relationship between a person's consciousness and the world (when we are conscious it is consciousness, or awareness, of something in the world which Husserl names 'intentionality'). This is the focus of both phenomenological study and the foundation for human knowledge which is found, observed, created and communicated by humans who occupy the life-world (Langridge, 2007). I explored the life-world for each of the individuals in this study, revealing the multidimensional meaning of sexual well-being.

Temporality: humans live with time differently at different moments – for example, the past may come to the fore or thoughts about the future might predominate – and these thoughts affect how we live forward (Galvin and Todres, 2013). Well-being can be enhanced by the emphasis of future possibilities, for example, progress of personal projects which leads to a sense of purpose, flow and continuity (Galvin and Todres, p.83). Alternatively, well-being can be derived from the future orientation resulting from anticipation of some pleasurable event. Without future orientation one can feel stuck in time, such as Zack who waits for a cure but part of him is frozen in time until then, or Amy, whose future identity as romantic partner and mother is part of someone else's story. In contrast, Penny's life is focused in the present; she is fully engaged in the demands of her work and family but she also thinks of pleasures to come as some responsibilities are shed and new ones acquired (such as grandchildren).

The participant's perception of time is highlighted within the findings where memory is shown to be an aspect of both sexual well-being, such as Jack's capacity to re-inhabit past experiences, and sexual discontent where Zack's reminder of past abilities taunt his present capacity for well-being. This influences the possibility of forward momentum in anticipation of future pleasurable experiences.

Well-being as temporal mobility is the invitation into a welcoming future (Galvin and Todres, 2013); without hope for a positive future well-being is impossible. The negative narrative of disability (Quarmby, 2011; Briant et al., 2013) reduces hope

for the future such as Betsy's concern that reducing disability benefits will negatively impact on her opportunities for inclusion (a concern supported by the literature (Joseph Rowntree Foundation, 2016)). Amy's sense of her anticipated life-course having been diverted by her disability is a barrier to her moving forward, while other participants also expressed negative thoughts of the future such as Kevin's sense of his deteriorating health impacting on his life opportunities.

Temporal well-being also occurs when a person is completely present and absorbed in the moment, such as during mindfulness activities (Galvin and Todres, 2013). Combining present, mindful well-being with well-being as temporal mobility leads to the unifying of present centredness and future orientation, of dwelling and mobility, or "rooted flow" (Galvin and Todres, 2013, p.84). Penny expresses such a sense of well-being with her multi-generational family, always changing with births and deaths but there being a constant sense of present rootedness. In terms of sexual well-being, this 'rooted flow' involves being completely present in the moment but with a sense of future potential. This suggests that whilst sexual activity might be pleasurable and constructive in terms of self-confidence, unless there is future potential it is sex and not sexual well-being (so the use of sex workers, where the exchange is focused on the act without future orientation, does not constitute sexual well-being, but might contribute by aiding sexual esteem and a sense of desirability).

The participants seemed to value sexual well-being more than sex as each person discussed the importance of emotional connection, except for Jack who initially only talked in terms of sex. However, sexual activity, including sexual flirtation without emotional commitment was also valued, such as Amy and Betsy's pleasurable experiences of flirtation. For Betsy, this reminded her of her sexual self-suppressed by her circumstances, while for Amy it underlined her potential, making her want more. In addition, Zack's desire to 'have some fun with a girl' implies a lightness emphasising pleasure over connection. In contrast, Kevin only desires sexual well-being, not sexual activity because of his experiences of sex without positive emotional connection. For him, this led to negative outcomes and emotional harm.

Spatiality: we live in particular spaces but these can feel close or distant in terms of their significance and meaning – “this personal topography changes moment to moment” (Galvin and Todres, 2013, p. 27). The meaning of our space changes according to our circumstances so we can feel trapped even in expansive spaces, or free and at home, even in confined spaces. For example, Zack feels trapped within his ‘shoe box’ despite it being a large, fully adapted home. But for him it is a reduced space and only part of the home he once occupied. It is an expression of his reduced horizons. Looking out of the window to the garden he used to tend reminds him of past activities and a sense of closing down. Jack, too, feels trapped within his body and home, he is unable to act spontaneously or alone and this makes him feel agitated and restless. However, he is able to experience the well-being derived from ‘adventurous horizons’ through his imaginative engagement with past experiences as well as using stories and films to make up his own adventures.

Physical disability adds a further layer of meaning to spatiality where the environment not only creates ability or disability, but also signifies cultural meaning assigned by others (for example, making social spaces accessible). Environments which are hostile in any form can result in a sense of exile from home and the familiar (Galvin and Todres, 2013): the world as known has become inaccessible. The literature highlights the exclusion of disabled people due to the construction of the physical environment which effectively separates people, underlining difference (Oliver, 1990b; Oliver and Sapey 2006). This was echoed by the participants including Jack, who spoke about inaccessible venues such as clubs, and lack of suitable transport. He stated that he feels different and cannot participate in the social world. Kevin also highlighted how living with a fluctuating condition makes the world unknown and inhospitable from day to day, making him feel different and unwelcome. This ‘othering’ is a form of oppression which is dehumanising and can even lead to hate crime (Quarmby, 2011).

Changing physical and cognitive abilities can also make the familiar world seem hostile and unwelcoming (Galvin and Todres, 2013). Zack felt unable to participate in activities he used to enjoy, such as going to the pub with friends, as he said he

would find emptying his catheter in a pub toilet difficult. For Kevin, his home expressed his own feelings of existential homelessness as he stated he had not invested any effort to create a peaceful space in which to be; he felt uncomfortable and trapped, with no hope of finding 'home' as his condition deteriorates. This sense is both physical and emotional, coloured by and colouring his mood. Penny expressed different views from other participants. She controls her environment through being part of a large and supportive family. She sees her disability as something which requires management rather than something which limits her adventurous horizons. The difference between Penny and the other participants is an illustration of the advantage social and economic capital provides, positively influencing experience of the life-world.

Well-being in the spatial domain is expressed as an "abiding expanse that stretches between home and adventure" (Galvin and Todres, 2013, p.83), the place where adventurous horizons and dwelling at home are held together. In terms of sexual well-being, this requires knowledge about how impairment impacts on sexual activity combined with a willingness to explore and have adventures in order to find different methods of intimacy, such as changed erogenous zones after a spinal cord injury. Penny describes how she and her husband discovered through exploratory touching that her neck and breasts had become super-sensitive following the spinal abscess, an experience reflected within the literature (Richards et al., 1997).

Inter-subjectivity: we are social beings and "how we are in this interpersonal world is often uppermost in our minds" (Galvin and Todres, 2013, p.28). For example, we spend time having internal, imaginative discussions with ourselves and others, practising, exploring and 'trying out' who we are. Inter-subjectivity can be positive or negative, a help or a hindrance to well-being. The participants' illustrate this duality, such as Penny's supportive relationship, or Zack's negative relationship ending in him feeling abandoned and full of conflict. Amy talks about the aversion she perceives from others directed towards her, resulting in her feeling shame at her physical form and wanting to cover herself up. Kevin expresses a profound aversion to being with others at times, having no interest in

others or in himself. His sense of belonging is lost and he states that he experiences great loneliness. He desires a relationship where he has a sense of felt interpersonal kinship and mutual belonging described as intersubjective well-being by Galvin and Todres (2013).

Inter-subjectivity is a crucial aspect of the essence of sexual well-being revealed by the findings. Participants highlighted the importance of sexual relationships involving emotional connectedness, especially Kevin whose experience of sexual activity without emotional connection made him feel 'used'. Marginalised individuals are at risk of alienated isolation where threat from others is perceived at a societal level due to the hostility of the socially dominant towards the least powerful (Quarmby, 2011): "One may feel oneself an outsider whose very existence is not wanted" (Galvin and Todres, 2013, p.105) and this contains the possibility of despair and terror. Of the participants in my research, Kevin expressed the strongest feelings of despair, choosing to isolate himself at times because of his low mood. But others also expressed the devaluing of disabled people, where the sense of being a 'burden' is felt, including Penny's account of public reaction to her having children which she 'can't possibly look after', and Betsy's suggestion of her 'being thrown to the back of a cupboard'".

Embodiment: we live in physical bodies which feel and respond to meanings of the life-world (Finlay, 2009b; Langdrige, 2007; Galvin and Todres, 2013). Disability can cause a sense of lack of movement, a forced withdrawal, both physical and emotional (Galvin and Todres, 2013). The taken for granted bodily functions are interrupted, such as Zack and his catheter which for him is a sign of difference and physical failure. Betsy can no longer spontaneously walk and Kevin's uncertainty about his changing condition and the unpredictable pain and fatigue make him unable to take any function for granted any longer. In addition, pain interferes with the ability to be at home in one's body (Galvin and Todres, 2013).

Physical disability is an embodied experience, with its meaning to the individual shaped by the cultural forces within the life-world, but the focus on the negative impact of physical impairment is inappropriate as there are positive embodied

outcomes as highlighted by the affirmation model of disability (French and Swain, 2004).

In terms of sexual well-being, personal knowledge of the body is crucial as Penny makes clear in her comments about knowing when spasms will interfere with sexual activity.

Mood or emotional attunement: lived experience is “coloured by mood” (Galvin and Todres, 2013, p.29). Kevin clearly articulates this point when he states that his horizons of possibility open up when he is feeling good and close down when his depression comes to the fore. Zack has a determined optimism which, he states, keeps him from giving up the motivation to continue his life. Mood informs our capacity for well-being as it “saturates our being-in-the-world” (Galvin and Todres, 2013, p.29). As such, the factors which nurture and enhance positive mood, such as self-esteem, enjoyable social contact and shared positive experiences, are crucial to well-being. Suffering in terms of mood involves depression which creates a sense of not being able to move forward, a feeling of weight and inertia (Galvin and Todres, 2013). The literature highlights the complex relationship between disability and mood affected by, for example, the individual’s social and economic situation, social expectation, negative narratives of disability, social separation and cuts to benefits (Briant et al., 2013; Simcock and Castle, 2015). In addition, suffering creates agitation which features feelings of disturbance: “There is an unpleasant 'lack of fit' between oneself and the world” (Galvin and Todres, 2013, p 107). Jack expresses this agitation through his account of the turmoil he experiences summarised by his statement that he is ‘different’.

Galvin and Todres (2013), following Heidegger (1927), add an additional life-world dimension of identity where suffering is experienced as “I am unable, useless, or failed” (Galvin and Todres, 2013, p.108). This form of life-world suffering is particularly resonant with this research as participants and the literature reflect on the negative narrative of disability, which focuses on the deficits rather than strengths (French and Swain, 2004). Suffering in terms of identity is reinforced by welfare and health services focused on the individual as an object for scrutiny. This

might occur in social work through the assessments process where needs lead to eligibility, therefore, the focus is on the individual's need rather than strength in order to justify eligibility. Kevin voiced his concern that this leads disabled people to have to emphasise their needs in order to prove entitlement, as though 'asking for charity', rather than services being a right of citizenship. It is an experience which depersonalises people and makes being "at home in one's own skin impossible" (Galvin and Todres, 2013, p 110). The resulting fragmentation of identity can create a sense of brokenness, "a loss of coherence and ability" (Galvin and Todres, 2013, p.111). Alternatively, well-being is experienced as the continuous flow of the self (Galvin and Todres, 2013).

1.2 The humanisation conceptual framework

Analysis of the findings has disclosed "plausible insights which bring us into more direct contact with the world" (Van Manen, 1984, p.3). Such plausible insights (in this case, insights into the meaning of sexual well-being) tell us about our human experience of the social and physical world and act as a guide to influence our actions within the world. Key insights in the current work, for example, include the significance to sexual well-being not only of sexual activity but the emotional and relational context in which such activity takes place. However, to become guides insights have to be made useful, otherwise they remain abstract and easily ignored which is contrary to the aims of this research.

Galvin and Todres' humanisation work is helpful in making the insights from my research useful as it has particular resonance with my own research purpose (to use the learning to influence practice). They are focused on improving care, both the experience of giving and receiving it. This has become vital in light of the recent scandals in nursing care (Mid Staffordshire Hospital (Campbell, 2013) and Winterbourne View (Panorama, 2011)). These scandals are of equal relevance to social care (for example, the death of Baby P). Prompted by these issues, Galvin and Todres (2013) developed a humanising theoretical framework for care which applies the concept of the life-world and existential concern for human well-being to nursing care. This humanising framework centres care, its meaning and method of delivery, on the perspective of the person receiving the care: it values what it

means to be human and seeks the means to act on this concern (Galvin and Todres, 2013). I contend that this conceptual framework is as relevant to social work as nursing for, although social workers rarely provide care themselves, not only do they purchase, organise, oversee and commission such care but they also, crucially, undertake assessments exploring the service user's intimately personal experience and needs. A humanising approach to social work enables practitioners to focus on what matters to service users, exploring suffering and well-being from the perspective of the life lived from the inside. The application of the humanising approach to social work practice offers a new understanding for practice. In terms of sexual well-being, this means enabling social workers to explore the unique meaning given by service users to their sexual experience, wishes and identity with an understanding of what makes us feel human.

The eight dimensions of humanisation in relation to my findings and social work practice with physically disabled people:

Galvin and Todres' theoretical framework identifies eight dimensions of humanisation which contribute or detract from well-being. It is founded on the experiences of well-being and suffering within the life-world dimensions. Recognition of these experiences leads to knowledge about what constitutes humanisation and dehumanisation and forms a value base for "considering the humanising and dehumanising elements in care" (Galvin and Todres, 2013, p.10). But the parts of the framework are interrelated, not discrete; they all lead to the same outcome: human well-being. If social work with adults is to genuinely focus on well-being, this framework becomes a useful guide for thinking about how the quality of social care can be judged. Each dimension is on a continuum with dehumanising occurring when 'one or more dimension of humanisation is obscured to a significant degree' (Galvin and Todres, p.11).

The findings and literature do not neatly fit into the framework, with some aspects being more relevant than others and some aspects overlapping. I do not want to impose an artificial structure on the findings and thereby lose their meaning, therefore some parts of the framework have more details from the findings than others. In addition, as a social worker I am attuned to certain aspects of the

framework, such as agency, which have particular resonance which with my professional experience leads me to emphasise those aspects.

Humanising

Dehumanising

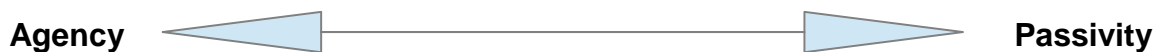
Insiderness  **Objectification**

Each individual has a view of “living life from the inside” it is a personal world and this subjectivity is “central to humans sense of themselves” (Galvin and Todres, 2013, p.12). Objectification is the experience of being made into an object through labelling, systematising or being dealt with in ways which do not account for insiderness. Use of professional jargon to fit people into systems is an everyday example of objectification.

Personal identity is lived from the inside but becomes externalised by the narratives to which we are exposed and through which we interweave our own narratives. The literature describes the dominance of the medical model of disability with its increasingly technological interventions (Oliver, 1990b; Oliver and Sapey, 2006). This model influences both the external conception of what it means to be disabled but also how the individual internalises the external messages in their conception of the meaning of disability (Simcock and Castle, 2016). Amy experiences the duality of a strong personal identity, her intelligence strengthened by the familial narrative celebrating and defending difference. Yet she is also objectified as a rare case of a medical condition and is photographed, examined and operated upon as an object of curiosity and learning for others. She expends emotional effort reconciling this duality. She wishes to contribute to knowledge generation, allowing her body to be objectified, but also recognises her emotional need to be part of a peer group of young students, participating in their activities. A humanised approach would explore this duality, recognising areas of objectification which do not reduce her sense of humanity and those which do.

Jack's experience also adds insight into the insiderness -objectification continuum. His sense of insiderness is quickly apparent when spending time with him. He has a strong sense of identity with clear opinions and is able and keen to make choices, which he communicates passionately. However, his communication system depends on others engaging fully and being prepared to explore his meanings. His lack of independent communication puts him at risk of harm (in reference to the risk indicators in the safeguarding section of the literature review) and allows for objectification; labelled as non-verbal, dependent and vulnerable. Kevin also expresses objectification in his comments on exclusion from the workplace due to the unpredictable nature of his condition; he feels himself labelled as a 'scrounger' when his self-perception is one of willingness to work hard but the workplace is not suitably flexible.

The Care Act's emphasis on the individual as their own expert and the value of inclusion of personal perception within the assessment is compatible with the humanising approach to how life is lived on the inside. How this can be used to enable humanisation is discussed in section two.



Exercising our ability to make choices and being held accountable for those choices is an essential part of being human and it is how we experience freedom (Galvin and Todres, 2013, p12). The alternative is passivity where choices are made for us, thereby diminishing our freedom and personhood.

The concept of risk and how it is constructed within a society directly relates to agency. As discussed in the literature review a society, such as the UK, which is both risk averse and promotes a prescribed concept of dependence, dehumanises those it deems dependent by removing choices involving risk (de Than, 2015). All six participants in this research expressed their agency, however, elements of passivity were also apparent due to the complex interactions between themselves and their environments. This illustrates the complexity of human experience and

that humanisation is not a simple or linear process but is always moving according to human change. For example, Jack is completely dependent on others for all his needs and this puts him at risk as he cannot protect himself from harm. However, he feels that his ability to express his needs and wishes is enough for him to demonstrate his agency. But because listening to him requires effort he is made to feel agency or passivity depending on the listener's response. The other participants, and people featured in the literature, similarly experience various levels of imposed and learnt passivity where, for example, paternalistic carers have excluded the individual from decision making (Simcock and Castle, 2016). Compromises to agency impact on personal dignity as people's capacity for control is reduced (Hasler, 2004). This is discussed in detail in relation to the Care Act's personal dignity well-being domain in the following section of the discussion chapter.

The expectation of others informs the individual's capacity for agency, a point which relates to the performances disabled people are expected to give as discussed by Liddiard (2013c) where:

“disabled people learn to respond to the expectations of non-disabled culture in ways that range from acting the passive disabled bystander, the grateful recipient of others' support, the non-problematic receiver of others' disabling attitudes”

(Goodley, 2010, p. 92, cited in Liddiard, 2013c, p.3.)

Sex has not typically been a topic focused on by the disability movement which instead has concentrated on liberating disabled people from the paternalistic, often overprotective attitudes of society, and enabling all forms of social inclusion (for example: Oliver, 1996; 2004; Shakespeare, 1996; Barnes, 1996; Barton, 1996; Swain and French, 2003). The notion of sexual citizenship has been largely absent from the disability movement and social discourse (Morris, 1991; Shakespeare, 2003; Kungaude, 2010; Shuttleworth, 2010), which has resulted in the absence of any claim on state services or funding for sexual well-being. This research, in

contrast, highlights the importance of sexual well-being to human well-being which is now a focus within social policy (Bacon et al., 2010; Aked et al., 2010). Without acknowledgement of the importance of sexual citizenship, which means belonging to a society which gives rights to information, education and access to services (Kanguade, 2010), the concern for sexual well-being has been avoided in social policy. Because sexual citizenship also involves the responsibility to abide by the codes of that society (Kanguade, 2010) it is also a means of enabling agency.

Social work can aid the promotion of sexual citizenship but this requires training, awareness raising and tackling the lack of easily available information, in formats suitable for everyone. Without information consent is not possible and, therefore, agency is inhibited (de Than, 2015).



“We are more than the sum of our parts” (Galvin and Todres, 2013, p13), but can be reduced to a list of characteristics or types used to categorise (for example, the term ‘disabled people’ used as a homogeneous category denying diversity).

The participants experience themselves as unique sexual beings and whilst Penny and Betsy are passionate about empowering others to achieve sexual well-being, not all recognise the sexual nature of others with physical impairments. This reflects the homogenisation of disabled people as asexual discussed in the literature (Tilley, 1998; Milligan and Neufeldt, 2001; Liddiard, 2013a; Owens, 2015). The participants are socialised into the same culture and are subject to the same dominant discourses resulting in negative views of disability, so it would be unreasonable to expect the presence of an impairment to necessarily lead to an alternative view. Media portrayals of sex reinforce a homogenised form of sexual behaviour which denies diversity (Dune and Shuttleworth, 2009). The participants commented upon this although Jack remarked that the media provides a useful pool of ideas on which to imaginatively draw.

The promotion of uniqueness within the humanising approach compliments the

focus on the individual in personalisation policy (SCIE, 2012a). It offers a philosophical perspective rather than the economic utility of personalisation (Beresford, 2013).

Togetherness  **Isolation**

Humans are generally social beings. Isolation disrupts our connections to others and can lead to alienation and isolation (Galvin and Todres, 2013, p14).

Togetherness is core to the definition of sexual well-being offered in this research as connection with others is identified as fundamental. The literature also highlights that social connection is vital to well-being. However, my findings demonstrate the reduced opportunities for social interaction disabled people experience due to restricted access and limited money. Betsy values the social activities in which she is able to participate but doubts this opportunity is available to others due to financial constraints on social care budgets. Participants expressed a sense of difference which creates isolation from the 'norm'. The necessity for carer support at all times underlined this difference for Jack. He is physically with someone, yet does not experience a sense of 'togetherness' because this is enforced company rather than people wanting to be with him. This sense of difference removes the creation of harmony created by a sense of place and can become a form of dislocation from society.

The lived experience of people with physical impairments demonstrates the still limited reach of equality legislation as access and opportunities to participate in the community remain restricted by services such as expensive transport and the perception of negative societal attitudes. Participants discussed the loneliness resulting from lack of access to social opportunities but also from self-imposed limitations, thus closing down options for making human connections. The participants live in a rural area, in small towns or villages where transport and social opportunities are limited. This adds a different perspective to urban-based research. Geographical isolation limits the potential for togetherness. Connection with others is an element of sexual well-being, so social work seeking to address

sexual well-being needs to facilitate a sense of togetherness.

Evidence indicates that relationships, especially romantic ones, are a positive influence on well-being (Markey et al., 2007). Research also indicates that physically disabled people have fewer intimate relationships and enter long-term relationships later (Wiegerink, 2006). Amy's experience of the absence of romantic interest negatively impacts on her self-esteem, affecting her projections of her future self. The emphasis on relationships within society adds a further negative narrative to physical disability.

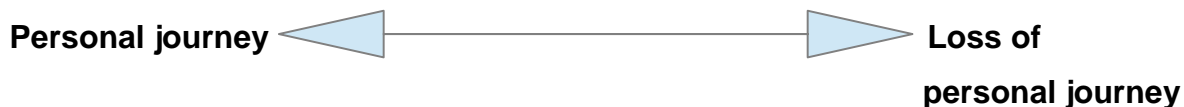
Feeling attractive can be empowering, aiding the self-confidence to engage with others. Both the research findings and literature highlight the value of non-sexual physical contact and the positive emotional impact of attraction, flirtation, closeness and acceptance (Shakespeare, 2000).

Sense making  **Loss of meaning**

To be human is to care for the meaning of things, events and experiences of personal life. Dislocation from oneself can occur if this is disrupted. Internalised and dominant narratives influence how we view ourselves, but if we become dislocated we feel as though we are numbers or statistics rather than human (Galvin and Todres, 2013, p.15).

Adjusting to change is a demonstration of sense making and romantic relationships can have a positive influence on adjustment (Esmail et al., 2007; McCabe and McDonald, 2007; Handley et al., 2015). Penny provides insight into her adjustment in conjunction with her partner as her impairment led to them having to rewrite their future. Hope is a positive sense-making force for Zack who expresses his hope for a cure – this motivates him to continue. However, it also diverts him from adjusting, or making sense of his changed circumstances in which he feels he has lost his story. Amy also expresses the lack of hope she feels in achieving romantic connections which is experienced as a barrier to her well-being. She struggles to make sense of a future where her desire to have a relationship and family is

thwarted by her belief that others see her as an unsuitable partner. Lack of hope leads to fear of risk taking, Amy, Zack and Kevin state that it is better not to try to meet romantic partners rather than risk rejection which will negatively impact on their self-esteem.



Life is a journey to be understood as a before, and a next. To be human is to be connected to a sense of continuity so when the journey is disrupted loss is experienced (Galvin and Todres, 2013, p.16).

The dominant medical narrative conceives disability as a tragedy which interrupts personal journey and must be avoided or corrected rather than considered as part of a naturally changing life course (Morris, 2001). This dominant narrative was evident in the perceptions of the participants, for example, Zack reflects on this notion, stating that his sexual self was 'on hold' pending the finding of a cure for his disability. For Amy, her anticipated sexual life has been frustrated leading her to review her expected life-course. Memory links the personal journey and can be used positively as a well of contentment to draw upon, but can also be a source of discontentment, longing and frustration. Both uses of memory were evident in the findings, for example, Jack's re-inhabitation of past sexual encounters while for Zack, previous sexual activity served to underline present difference.



This is where the sense of at-homeness is meaningful. The physical environment impacts significantly on the sense of privacy, dignity, homeliness and hopefulness. But places are more than simply environment – they are created by what occurs

within them (Galvin and Todres, 2013, p16).

To enable sexual well-being people require a sense of a safe place where privacy is respected and where there is a sense of belonging and dignity (Galvin and Todres, 2013). But it is more than physical environment – it is about having emotional security (Galvin and Todres, 2013). Kevin comments on his lack of at-homeness in his personal environment. He feels insecure in his tenancy and this affects his ability to plan ahead, which includes developing intimate relationships. This is especially relevant for residents of care institutions where privacy and security can be difficult to achieve. Even Jack, who lives in his own home, struggles for privacy due to the presence of carers. In contrast Betsy, referring to her professional experience, describes how privacy can be achieved within care settings but this is dependent on staff accepting people's well-being needs.



Humans have physical bodies and it is through these physical entities that we act within the physical and social world (Galvin and Todres, 2013, p.18).

Embodiment is a fundamental element of sexual well-being which involves physical, sensual pleasure. The notion of a separation existing between the mind and body devalues embodiment and reduces the body to something external to the self (as discussed in the literature review). Impairment is an embodied experience which can bring into focus the taken-for-granted physical functions and disrupt one's life journey. Physically disabled people report that services can view them as a selection of deficits to correct through aids or rehabilitation (Oliver and Sapey, 2006) and this reduces any sense of being human. A humanising approach involves giving people the opportunity to define their understanding of the impairment and how they wish to respond to it rather than assumptions being made about what rehabilitative goals should be set. The reductionist view of the body supports the notion of external meaning, for example, being able to walk independently is associated with self-confidence and the use of a wheelchair is a

symbol of dependency (Shuttleworth, 2000). However, the individual may have an alternative view, perhaps that a wheelchair offers access to social activities.

A humanised approach to care recognises the embodied nature of humans and explores what the individual's body and their experience of it means to them. This may involve enabling the individual to reconnect to, and find some pleasure in, a body which has become alien through change (Galvin and Todres, 2013). For example, for Zack this would involve enabling him to explore the sensual pleasures he is able to experience now, helping him move from thinking that sexual pleasure can only be found through the activities he used to be able to do. This links to the discussion within the literature about societal emphasis on coitus and the need for information about and portrayal in the media of alternative sexual activities (Davies, 2000).

Contextualising insights from my findings and the literature within the life-world dimensions and humanising care framework has added clarity about how humans experience well-being and how this can be made useful in the promotion of the conditions which enable human well-being. I now progress the discussion to consider how humanisation assists social work focused on sexual well-being by examining the well-being domains of the Care Act which offer the opportunity to explore service user's sexual well-being. I discuss the findings and literature in relation to these specific Care Act well-being domains as sources of insight and illustration.

2. Sexual well-being, humanisation and the Care Act 2014

The meaning of sexual well-being and plausible insights discussed in the previous section illuminate the lived experience of disability in contemporary society which makes clear that disabled people still experience barriers to inclusion, and this impacts on well-being. As well-being is fundamental to social work with adults through the well-being principle I now move on to draw on the findings from participants and the wider literature to discuss how the Care Act could be used by practitioners to address sexual well-being. This discussion informs the

development and design of the practitioner learning tool.

The following analysis of the Care Act 2014 assessment identifies where sexual well-being aligns with the outcomes of the Act and how social workers could use it to consider sexual well-being using a humanising approach. This analysis demonstrates how sexual well-being is intrinsically related to well-being, and is therefore of crucial importance to well-being-informed social work practice. Opportunities to explore sexual well-being are offered within both the outcome and well-being domains of the Care Act 2014 assessment (see Appendix 4). By using the opportunities practitioners can foster positive attitudes in disabled people towards their sexuality and help develop sexual esteem (Milligan and Neufeldt, 2001). Assessment is an intervention in itself (Department of Health, 2014, 6.2) and should be the starting point for practitioners to enable service users to assert their rights and explore the meaning of well-being, something they may not be familiar with prior to assessment.

Personalisation is built into the Care Act assessment process and the humanising approach of Galvin and Todres (2013) discussed in the previous section contributes a philosophical dimension to personalisation and the notion of human well-being. For example, a social worker exploring Jack's needs collaboratively with him might, if Jack wants to, discuss the impact his sexual frustration has on his mental and emotional well-being. They would examine the factors in his life leading to this frustration, such as his apparent inability to access clubs where he feels he could express his sexuality. A humanised approach would add depth to this examination, enabling the social worker to use their capacity for empathy to think about which factors in his life enhance his feelings of being human. In this case, this might be through his expression of agency by enabling him to find a suitable club and arrange transport.

Sexual well-being and the Care Act 2014 well-being domains

a) Personal dignity

For social workers to assist with personal dignity an understanding of what it means to the individual and the barriers they experience is required. The updated Care Act Guidance (2016) defines dignity as ‘being treated as if you matter’ (Department of Health, 2016, glossary), which focuses on how a person is treated rather than how they view themselves. Without a sense of self-worth the expectations of treatment from others will be low (for example, feeling that ‘I do not deserve better’) (Mayers et al., 2003). The findings illustrate the damage the sense of poor self-worth has on emotional well-being with Kevin feeling he has to hide away at times. Therefore, I contend that a humanised approach to personal dignity should include self-worth which requires an exploration with the individual about how they can develop. The significance of sex and desirability to the sense of self-worth is evidenced by research on the psychological impact of sexual well-being (Westgren and Levi, 1999; Taleporos and McCabe, 2002; Grossman et al., 2003; Rockliffe-Fidler and Kiemle, 2003; Mills and Turnbull, 2004; Popovic, 2005; McLaughlin and Cregan, 2005; Wiergerlink et al., 2006). When sexual self-worth is damaged:

“the individual’s self-view, satisfaction with life, capability to experience pleasure, willingness to interact with others and ability to develop intimate relationships may be limited. When damage to sexual self-esteem is severe, this can constitute a disability that significantly interferes with the individual’s functioning”

(Mayers, et al, 2003, p.269).

This suggests that damaged sexual self-esteem or worth can lead to the sort of needs which social policy is seeking to delay or prevent (Department of Health, 2016). Kevin’s loss of confidence negatively impacts on his sense of dignity, making him feel ‘unworthy’, resulting in passivity where events happen to him rather than through his active exercise of agency. Zack, too, experiences a sense of life happening to, rather than with, him. Promoting sexual self-esteem which aids

confidence becomes an imperative in preventative-focused social work. This means enabling the individual to feel sexually competent, attractive and acceptable to others (Mayers et al., 2003) by acknowledging their sexual identity and working with them to find ways to express their sexuality.

However, the findings and literature indicate that the way disability is currently socially constructed and reported is detrimental to self-worth (Simcock and Castle, 2016). This has become especially relevant since the economic crisis of 2008, when media reports on disability became increasingly negative (Briant et al., 2013). The notion of disabled people as 'folk devils' has become apparent, with media reports commonly associating disability with benefit fraud and becoming more supportive of government policy to reduce benefits (Briant et al, 2013). This has led to a "re-evaluation of who is and who is not deserving of benefits" (Briant et al, 2013, p.880): the deserving and undeserving. Amy and Betsy are especially aware of this negative conceptualising of disabled people and express their concern for their own economic well-being and that of other disabled people who are subject to work capability assessments. Due to the fact that disability has been defined variously according to historical and cultural context (Shakespeare, 2006) its definition can be redrawn to serve the purpose of the definer. This has significance as the legal definition, which can alter, is linked to service entitlement, including welfare benefits (Briant et al., 2013). The negative narrative of disability illustrated by Briant et al., 2013 impacts on self-worth and psychological well-being, and influences the context in which disabled people live creating a more hostile world (Quarmby, 2011). Social workers have to be aware of this impact, seek to counter the narrative and acknowledge it in Care Act assessments if they are to genuinely reflect a disabled person's situation.

To work in a humanising way agency must be promoted by keeping the person's voice central at all times. Agency is linked to human dignity so "when agency is taken away one's sense of personhood is diminished" (Galvin and Todres, 2013, p.12). Empowering people to assert their agency, including defining their personal meaning of dignity, is crucial. The capacity for agency is dependent on being able to make informed decisions, making the provision of information essential. The

participants expressed their frustration at the limited information regarding sexual well-being, although Penny did have information related to sex and spinal injury. In addition, disability can interfere with accessing information, for example, Jack relies on others to find and provide the information he requires. Social workers need to be able to access the knowledge and information service users need, which includes the time to research and seek information in appropriate formats.

Both the findings and literature illuminate the gendered conceptions of desirability which impact on dignity and self-worth. Social norms become internalised so that a form of internalised ableism or discrimination develops (Grossman et al., 2003), including how female beauty is constructed in terms of male desire (Tilley, 1998). Despite understanding this, being conversant with feminist arguments, the influence of the beauty ideology has a vice-like grip on women's minds as demonstrated by Amy who wages an internal war between her head (which knows that beauty is a construct) and heart (which wants to conform to the beauty standard illustrated in popular media). The notion of disabled women being considered 'damaged goods' as reported by Tilley, 1998; Walters and Williamson, 1998; Howland, 2001 and expressed by both Amy and Betsy is corrosive to self-esteem and contrary to the concept of equality enshrined in legislation (de Than, 2015), yet still endures. Kevin also uses this specific term to describe himself, removing the gendered quality and instead identifying 'damaged goods' as a view about all disability. Kevin's experience echoes the accounts of disabled men within the literature who face prejudicial views because they are considered to have deviated from social scripts based on physical attractiveness leading them to consider themselves unworthy of affection (Walters and Williamson, 1998). Zack's comment on being a 'sad old git' reflects experience of disabled men who compare themselves to social norms of masculinity and are consequently more likely to remain socially isolated (as Zack is) as they cannot live up to their own ideals (Shuttleworth, 2000). Such a notion is profoundly damaging to self-worth and dignity and psycho-emotional well-being and social workers need to be able to assist people to review their thinking.

Disabled women such as Penny who has children, responsibility for elderly parents, and a business negate the view that disability leads to dependency and destabilises societal norms. But this can be met with hostility as she relates in her encounter with a member of the public who questions her ability to be a good mother. Disabled people able to draw on other ideals such as interdependence and the prioritising of emotional intimacy are more open to change and social integration (Shuttleworth, 2000) and social workers can assist with this by exploring alternative views of disability such as the affirmative and social models as well as respecting diversity.

The humanising approach emphasises the uniqueness of individuals (Galvin and Todres, 2013) rejecting forms of homogenisation. For social work, this means working in a genuinely person-centred way which involves moving towards a rights-based and affirmative model of disability (French and Swain, 2008) where responsibility for the definition of meaning is taken from the professional 'expert' and passed to the individual. Humans undertake sense making about their personal identities throughout their lives. It is a constant negotiation working with and against the cultural constraints our societies provides. Using the affirmative model as a starting point, social work can aid physically disabled people to counteract the negative narrative of disability and positively construct their identities. Establishing peer support networks is an effective means of undertaking this enablement (French and Swain, 2008), a point that Penny emphasises in her discussion about her work with people who have spinal cord injuries.

Social workers can be active participants in changing the negative stereotypes and narratives by being knowledgeable about the issues which impact on the lives of physically disabled people such as gender issues, notions of beauty, loss of agency, risk aversion and human rights contraventions (for example, by not enabling sexual expression (de Than, 2015)).

A humanising model which enables agency and emphasises uniqueness involves risk enablement as it empowers service users to make decisions regarding their sexual behaviour. For example, in work developing Jack's sexual self-esteem this

might involve arranging methods of masturbation or accessing pornography.

b) Physical, mental and emotional well-being

Humans are sense makers, we look for significance and make explanatory stories (Galvin and Todres, 2013). The participants' accounts illustrate how they make sense of their life experiences. This is done within a social context, so external messages are also integrated into the sense-making narrative, for example, Zack 'makes sense' of his current situation by conceiving of it as a pause in his known life until a cure is found. The humanising approach explains that when sense-making is negative or even removed in part or wholly, for example, by illness, people become dislocated and a sense of meaninglessness prevails. Kevin experiences this dislocation from the connections of employment and peer groups, poor mental and emotional well-being results from this negativity and meaninglessness. A humanised approach enables sense-making, reconnecting people to their life journey by exploring what this now means to the individual, making sense of their past and anticipated future.

Continuity of the self is a significant factor in well-being (Galvin and Todres, 2013) so social workers need to be mindful of enabling continuity for the person through periods of transition including in the event of a new disability or deterioration of a physical condition. This could be achieved, for example, by aiding Zack to connect his 'old' self to his 'new' self, finding aspects which have remained the same whilst valuing the new perspectives his impairment has brought. Whilst the Care Act assessment includes scope for biographical accounts and personal narrative, this can be overlooked when limited social work time makes focusing on immediate need the priority. A humanised approach reinforces the necessity of interventions having meaning to the life 'viewed from the inside', otherwise interventions lack relevance or impact. Therefore, personal narrative is essential in ensuring the effectiveness of interventions and social workers can assist in sense making, by exploring the narrative accounts.

Psychological well-being is linked to physical and sexual esteem (Taleporos and McCabe, 2002; McCabe and Taleporos, 2003), therefore, to improve well-being

strategic plans to improve body and sexual esteem are necessary. The literature evidences that:

“sexual esteem, body esteem and sexual satisfaction were strong predictors of self-esteem in people with physical disability. If people with disability were sexually satisfied and felt good about their sexuality and their body, they were more likely to have high levels of self-esteem. Further, for people with physical disability, if they felt good about their body and were sexually satisfied they were less likely to feel depressed”

(Taleporos and McCabe, 2002, p182).

The literature also indicates that physically disabled people with more severe physical impairments have lower levels of sexual esteem and sexual satisfaction and higher levels of depression (McCabe and Taleporos, 2003). This relates to Jack’s expression of ‘inner turmoil’ where his frustration is felt but cannot be acted upon independently. Social workers need to be aware of the connection between well-being and sexual self-esteem and work to alleviate the negative effects by exploring meaningful ways of developing self-esteem, for example, identifying positive role models, connecting people to networks of peer support, as highlighted by Penny, or investigating opportunities where a service user can express their sexuality (for example, going on a date).

One of the most significant ways social workers can build sexual self-esteem amongst the people with whom they work is recognising people as sexual beings. This is because the notion that physically disabled people are asexual is damaging to well-being as “sexual expression is a natural and important component of self-concept, emotional well-being and quality of life” (Milligan and Neufeldt, 2001, p.92). Being deemed asexual is a form of harm which denies personhood and agency (Stevens, 2010). Sexuality is “often the source of our deepest oppression” (Finger, 1992, cited in Shakespeare, 2000, p161) and if the Care Act is to address well-being the narrative of asexuality needs to be challenged. It is a narrative which becomes normalised, evidenced by Taleporos and McCabe (2003) who found that people with physical disabilities commonly believe that they are less sexually

desirable than able-bodied people and that their disability seriously limits their sexual life. This is a point echoed by Amy, Kevin, Betsy and Zack, each of whom stated that they felt unattractive and undesirable, although not asexual. The emphasis on coitus, which may not be possible for some disabled people, reinforces the narrative of asexuality, so other types of sexual activities need to be made known. However, very little work is done in promoting alternatives to penetrative sex (Davies, 2000).

Recognising physically disabled people as sexual and making sexual well-being an acceptable topic with the promotion of sexual citizenship is core to well-being-focused social work because sex is having an increasingly important role in modern society in the construction of the self, meaning sexual intimacy has become an essential part of self-constitution (Dunk, 2007). Therefore, disabled people claim that sexuality is “a bid for full subjectivity” (Shuttleworth, 2000, p.280). Part of this well-being-focused work involves raising consciousness amongst service users and their networks about the external messages which may close down opportunities, for example, that disability equates with passivity. Jack illustrates this when discussing his experience of being overprotected by family and service providers whose protective care becomes a form of dehumanising restriction. The participants, like many others, wish to discuss their sexual needs (Aizenberg et al., 2002) and to have their sexual identity confirmed, and some expressed relief and appreciation when professionals affirm their sexuality (Walters and Williamson, 1998). However, some of the participants did state that such a discussion would be limited to those individuals whom they trust.

A humanising approach seeks to counteract the negative narrative of asexuality by exploring with the person what sexuality means to them. This involves engaging in sense making, meaning that social workers need to be aware of the components of the negative narrative of disability in order to confront it (Shakespeare, 2000; Tepper, 2000).

A further issue to psycho-emotional well-being is the significance of positive role models to positive self-development and their assistance in increasing access for

physically disabled people to opportunities for sexual expression through increasing the visibility of disability (Milligan and Neufeldt, 2001; Grossman et al., 2003). Amy stated how the lack of role models influenced her own self-conception. However, the role models have to be realistic in order to be positive as Penny states in her discussion about the promotion of elite paralympic athletes leading to unhelpful expectations of disabled people. Social workers can assist by identifying appropriate role models.

c) Protection from abuse and neglect

The barriers to social workers addressing sexual well-being include safeguarding concerns (de Than, 2015). As discussed in the introduction, my work is of relevance to safeguarding because it focuses on individuals identified as at risk because of their need for social care support services. However, the literature and my findings reveal that the individual's conception of risk is different from the professional's (Furedi, 2011; Faulkner, 2011). The Care Act 2014 responds to this as it embeds a person centred approach which emphasises:

“ having conversations with people about how we might respond in safeguarding situations in a way that enhances involvement, choice and control as well as improving quality of life, well-being and safety. It is about seeing people as experts in their own lives and working alongside them”

(Local Government Association, 2014, p.4).

This concerns the empowerment of service users to be fully involved in safeguarding planning and in control of the outcomes. Such an approach compliments humanisation, as it demands consideration of, and action upon, what the experience of 'being safeguarded' feels from 'life on the inside' (Galvin and Todres, 2013). For social workers, this means engaging with people about matters which will improve their quality of life and safety, including their sexual well-being.

The Care Act promotes prevention of abuse which evidence indicates is:

“not about over-protective paternalism or risk-averse practice. Instead, the prevention of abuse should occur in the context of person-centred support and personalisation, with individuals empowered to make choices and supported to manage risks”

(Faulkner and Sweeney, 2011, p.3).

In terms of sexual well-being this could concern sexual relationships or activities where there is risk of harm but the person wishes to continue those activities or relationships. According to their accounts the participants were not experiencing relationships involving risk at the time of the interviews, so safeguarding was not a theme discussed. However, this is an issue to be included in the learning tool as it is fundamental to social work practice. To approach safeguarding co-operatively, social workers require skills of openness and honesty to help explore and understand the risks so the person can make informed decisions (Faulkner and Sweeney, 2011). Making Safeguarding Personal (2012) indicates that from a person-centred perspective, the benefit of protecting people from relationships, even ones in which harm has occurred, can be outweighed by the psychological harm of ending the relationship. Instead, what is wanted is intervention to stop the harm but not necessarily the relationship. In addition:

“The very process of engaging with them (people subject to safeguarding Interventions) often gave them a sense of control and self-esteem that enabled them to better safeguard themselves”

(Faulkner and Sweeney, 2011, p.11).

This quote is fundamental as I contend that addressing the issue of sexual well-being in social work with adults gives people the information and sense of control to better safeguard themselves.

This point is confirmed by research identifying factors which contribute to risk of sexual harm: *not having enough knowledge about sex and sexuality;*

- *being unable to make decisions;*
- *low self-esteem.*

(Hollomotz, 2010, p.21).

Vulnerability to sexual risk is located in the relationship between the person and their environment where some people are empowered and others are disempowered (Hollomotz, 2010). Social work concerns the empowerment of service users. In terms of sexual well-being this involves the instrumental role sexual citizenship has in protection from abuse and neglect (Kanguade, 2010). Humanising practice promotes personal agency by enabling people to be active participants in their lives, make choices, be held accountable for those choices and exercise their rights, that is to become citizens. By promoting the concept of sexual citizenship, for example, through sex education including the provision of information, social workers aid social justice both through social inclusion and enabling service users to protect themselves (Richardson, 2000; Shakespeare, 2000; Grossman et al., 2003; Shuttleworth, 2010; de Than, 2015).

However, sex education for physically disabled people has been criticised as inadequate (Shakespeare, 1996 and 2000; McCabe, 1999; Owens, 2015). Social workers cannot assume that people have the information from previous sex education to enable their sexual well-being. The participants stated that they have been given little, if any, information about how their impairments might impact on their sexuality or relationships. Raising awareness is crucial to protection from and prevention of abuse and neglect (SCIE, 2011; Department of Health, 2016) and social workers have a role in informing, empowering and advocating for those at risk of harm (Coulshed and Orme, 2012). Social workers aid service user protection and the promotion of sexual well-being by focusing on service users' agency, sense making and insidership to understand how they perceive sexual well-being, how they wish to express their sexuality and their rights to do so. The enduring narrative of disability leading to asexuality is a form of harm which denies full humanity and results in the sexual disenfranchisement of disabled

people (Richards et al., 1997; Tilley, 1998; Walters and Williamson, 1998; Shakespeare et al., 1996; Oddy, 2001; Kaufman, 2007; Owens, 2015) affects the ability to establish sexual relationships. A humanised approach enables social workers to consider what this means by exploring with service users what sexual well-being means to them and how their sexual selves can be expressed. For example, this might involve preparation for dates being part of the care and support plan.

d) Relationships

The quality of an individual's social relationships is one of the strongest indicators and predictors of well-being (Markey et al., 2007; Helliwell et al., 2015). This includes romantic relationships, although marital/intimate relationship stress is an indicator of poor well-being.

“Contemporary social sciences now widely recognise the decisive role of interpersonal relations, particularly those that are genuine, in the development of a good life....Some scholars have defined relatedness as a primary need essential to well-being”

(Helliwell et al, 2015, p.141).

In addition, relational networks are a crucial aspect of self-protection as social isolation puts people at risk due to lowered self-esteem and removal from the protective networks of support (Nosek et al., 2001; Bournemouth, Dorset and Poole Local Authorities, 2015). Well-being in the humanising framework includes togetherness, acknowledging that good quality relationships are beneficial to mental and physical health (Galvin and Todres, 2013). Penny's strong family relationships illustrate how relationships enhance self-esteem and the love she feels provides security. But the nature of meaningful relationships depends on the service user and their humanising 'view from inside'. A relationship may not have to involve direct contact to be meaningful such as Amy's online friendships.

Social workers can emphasise and strengthen bonds by exploring service user networks and enabling the development of social links to reduce isolation. This is a

challenge in a rural area where transport links are limited. However, the internet offers the potential to create and maintain alternative routes to connection. Work addressing the social structural causes of isolation at a strategic level is also necessary to improve disabled people's access to opportunities of togetherness (Shakespeare, 2000; Shuttleworth, 2000; Oddy, 2001; Grossman et al., 2003). Relationships, therefore, should be a focus of care planning as research shows that joining social groups reduces morbidity and are a key factor in prevention (Handley et al., 2015).

Disability can also change the established roles of exchange and reciprocity within relationships (Parker, 1993; Shakespeare, 2000; Oddy, 2001; Chance, 2002; MaCabe and Taleporos, 2003; D'ardenne, 2004; Hwang and Johnston, 2007) which upsets the balance of the relationship and may lead to re-evaluation and even separation (Parker, 1993). Betsy demonstrates this in her description of the different expectations she and her husband now have of each other and how she struggles to reconcile him being both her carer and husband, resulting in the end of their sexual relationship. Established roles such as 'breadwinner' can be disrupted and partners may readjust in destructive ways, for example, by changing concern to pity (Parker, 1993). Zack's experience of marital breakdown reflects the destruction a lack of adjustment can cause which illustrates how the survival of a relationship relates to the extent partners can negotiate adjustment to their changed lives (Parker, 1993). The loss of his role as a worker affected both how he saw himself and how his partner viewed the relationship, which led to irreconcilable differences. The ability to talk and even joke about sexual difficulties is helpful, something Penny comments on in her account of her peer support work, which includes laughing at bodily functions. Social workers undertaking well-being-focused work could use a humanising approach to explore the situation from the viewpoint of 'the inside' and assist people to re-evaluate in a constructive way, facilitating communication which aids adjustment to change (Parker, 1993; Richardson et al., 1997; Grossman et al., 2003; Esmail et al., 2007).

Well-being focused social work needs to be aware of and challenge the dominant discourse of the ideal family, with marriage rewarded in social policy (for example,

tax incentives and the political rhetoric of 'hard working families') as this can lead to a negative self-perception by those outside of such relationships. For disabled single people this is compounded by limited access to the usual methods of social contact such as sport, bars and clubs (Oliver, 1990b; Oliver and Sapey, 2006; French and Swain, 2000; Myers and Milner, 2007). In addition, social expectations are normative and reinforced by cultural meaning, for example, without autonomous, normative mobility and communication it is seen as difficult to establish relationships (Shuttleworth, 2000), reinforced by a negative view of dependency which is associated with unattractiveness. This lack of opportunity means people miss out on chances to develop the skills of dating, which then feeds the lack of confidence illustrated by Amy and Kevin. They perceive that their disability will exclude them from being considered as potential romantic partners and therefore it is better not try rather than face rejection. This anticipated rejection can lead to a retreat from social life (Milligan and Neufeldt, 2001) and social isolation reduces defences by reducing self-esteem and the protection social networks offer (Nosek et al., 2001). It is a destructive cycle of isolation feeding the lack of confidence, which then reinforces isolation.

Social workers can work in ways that improve service users' sexual self-confidence, by acknowledging the aspects of a person's situation which impact on their confidence and esteem, then seeking ways to address these. This might be, for example, facilitating access to social events or working with someone on how they might start a conversation with someone they find attractive. In addition, social workers can consider with service users other forms of social networks such as employment, voluntary and paid. The efficacy of such interpersonal work is evidenced by research which demonstrates the value of relationships in the recovery from, and prevention of, ill health (Markey et al., 2007).

This section has focused on how the Care Act 2014 assessment process offers social workers the opportunity to explore sexual well-being with service users in a way that considers life viewed from the inside. To do so relies on interpersonal skills with the exploratory work being situated within a human-to-human relationship. However, social work activity is becoming increasingly regulatory in

nature (Pollack, 2010) due to severe funding cutbacks and changes to the education and regulation of the profession (Community Care, 3.2.16; Department for Education, 2016). This means time for relationship-based work is limited, with other functions prioritised (Jones, 2014). However, if the government is genuine in its promotion of well-being as a means of social progress, social workers have a unique contribution to make due to access to marginalised, difficult to reach groups, often at times of crisis when humanly sensitive, timely intervention can avert further harm.

The first two sections of the discussion chapter have focused on a humanised understanding of sexual well-being and its relevance to the Care Act, the primary purpose this research study. However my critical engagement with the literature and practice of development work have also highlighted the well-being needs of practitioners and the dehumanising effects of the the hostile environment in which social work operates (evidenced by professional life expectancy being only 7.7 years (Holmes et al., 2013) and the recruitment and retention of social workers becoming a significant concern (Carter, 2016)). Exploration of the humanising conceptual framework has led me to reflect on its relevance to social work practitioners and I conclude my discussion chapter with a consideration of how the humanising approach provides an enduring rationale for practice which has the potential to reconnect social workers to the motivational factors inspiring them to enter and continue in practice – to reconnect to a concern about human well-being. The conclusion of the discussion returns to my personal narrative which has been woven throughout this thesis, illustrating the personal nature of D Prof study.

3. Search for a well-being focused rationale for social work practice

3.1 A humanising approach to social work

My life in social work practice is echoed by the accounts from hospital patients in Galvin and Todres' (2013) work. Some patients report that their experience of receiving care feels like something is missing, that the care is technically proficient but lacks a deeper relational dimension. I contend that a similar absence of

compassion, based on human-to-human relationships, is apparent in social work practice which is populated with technical interactions and free market economic systems which commodify care (Lymbery, 2013). Service users are conceived of as customers with personalisation primarily concerned with increasing choice and control rather than the quality of the care experience (Lymbery, 2013; Beresford, 2013). Outcome success is measured by reduction in dependency rather than accounts of lived experience (Beresford, 2013), while technology increasingly separates humans from their environments and capitalism turns people into commodities denying their humanity (Habermas, 1990). Without compassion, defined by Webster's dictionary as the sympathetic consciousness of others' distress together with a desire to alleviate it, social work becomes a technical exercise of welfare administration.

The humanising approach integrates "humanisation as a value, well-being and suffering as a focus and relational embodied understanding as a professional capacity" (Galvin and Todres, 2013, p.8). It is a way of connecting biomedical conceptions of care (view from the outside), which are necessary in the treating of illness, to the experiential (view from the inside), which is often overlooked by busy services. The humanisation approach seeks a balance between technological and systematised forms of care with life-world and humanising forces in order to create a philosophical foundation for humanised forms of care. It offers a way of relating to people in a way that explores the experience of suffering and well-being from the inside, the personal life-world of service users. It also acknowledges both the agency and vulnerability of individuals so power can be passed to service users to enable them to be truly engaged in their care, whilst accepting that life is tenuous and change is inevitable for everyone, making the human condition dynamic: we are all in process. For social work practice this means empowering service users to increase their quality of life as they define it, not just 'correct' the impairment through aids or rehabilitation.

The well-being principle of the Care Act 2014 offers social workers the "professional space" (Jones, 2014, p. 493) to make a unique contribution and engage with service users, rebuilding their confidence and competence after years

of managerialism and care management. The humanising framework provides a conceptual explanation of well-being which can turn this principle into something useful as it provides a structure and philosophical basis to prioritise a notion of person-centred care which is deeper than the traditional concept of choice and control: it provides a philosophy for practice which responds to the humanity of both service user and practitioner, focusing on “something less measurable, but keenly felt” (Galvin and Todres, 2013, p1). This is more than person-centred care which emphasises a consumer model. To be truly person-centred a philosophy of the person, well-being and care needs to be explicit and made known. This rationale leads to a distinctive understanding of the type of knowledge that is needed for care professionals; an embodied relational understanding, a knowledge for “head, hand and heart” (2013, p.5). This relates to the types of knowledge relevant for social work practice which embraces: “research, theory, emotional, law, policy and procedural” (Manthorpe, 2015, p. 212).

However, because humanisation has been developed in response to specific critical incidents which have highlighted a crisis in health care, it relates to, but is not the same as, personalisation in social care and this impacts on its applicability to practice. Humanisation, which concerns human-to-human relations, offers a relational model or approach which practitioners can use in their social work encounters. It enables consideration of the meaning of lived experience but it does not include the wider social and structural concerns which social workers must take into account (Parker, 2007), such as inequality and discrimination.

3.2 Why do I (we) need a new rationale for practice?

Inhabiting the dual identities of researcher/practitioner offers unique insights unavailable without lived experience of both worlds. Having taken a step away from social work practice and active research in order to complete this thesis means I have entered a different world: that of the reflective writer. In this world I endeavour to articulate and make useful, deeply felt learning gathered from a life in practice where interaction with service users regarding matters of profound significance (relating to quality of life and death) has contributed to my personal world view. My

research has interacted with, changed and destabilised this practice life-world provoking professional anxiety and existential homelessness. These same symptoms are reflected in the professional distress I recognise in other practitioners and are echoed in the literature which reports on the high turnover of social work staff, burnout, stress and limited professional lifespan (Holmes et al., 2013). Whilst professional distress has many causes, including poor management, high caseloads and the emotional dissonance created by differences between ethical/practice codes and daily practice, this research is my own contribution to help social work connect to its fundamental concern: human well-being. By focusing on an issue which matters – sexual well-being – and the development of an evidence-based practitioner learning tool linked to relevant social policy, my research becomes a bridge between the aspiration of social work to seek social justice for, and inclusion of, a marginalised group (physically disabled people), with the operation of day-to-day practice. My research offers a means to use social policy, specifically the Care Act 2014, in a way which improves the quality of life for service users, whilst also enabling practitioners to engage in work which connects them with a shared human concern (sexual well-being).

My personal relationship with social work has undergone two significant battles during my D Prof journey. The first battle involved the cumulative effects of more than 20 years in social work practice with adults during which time I have experienced multiple agency reorganisations and redefinitions of the social work task including care manager, personalisation, social worker as gatekeeper, broker and resource. The second battle related to a developing appreciation of the political nature of social work, with the social worker enacting social policies shaped by the dominant political discourse founded on political values at odds with my own. As stated, this has resulted in profoundly destabilising my professional and personal identity, creating a sense of cynicism. Cynicism has become a characteristic of social work:

“Empirical research highlights the tendency for many social workers to complain about their intensely bureaucratic and stressful work environments, ongoing and often disorientating departmental

reorganisations, deskilling, increasing workloads and responsibilities, staff shortages, and retention and recruitment problems. In addition, staff complaints are made about resource constraints and the strained relations that often develop with management, service users, carers or colleagues”

(Carey, 2014, p.128).

I have witnessed increasing targets, audit trails, emphasis on measurable evidence and IT systems which are always hungry for more data. I contend this results in data being collected and measured because we have the technology to do so rather than the data serving any useful purpose.

However, I retain a commitment to the value of social work as mediator between the state and service user and advocate for marginalised groups. I agree with Carey (2014) that cynicism can be used positively to ‘encourage practitioners to challenge normative practices and consequentially provide better support to users and carers’ (Carey, 2014, p129). In my own case, this sense of cynicism about social work’s potential to effect positive change in the current social context has prompted a search to find a reinvigorating philosophy for social work practice that can transcend and endure the uncertainty brought about through political and social change; a philosophy to underpin practice in all its diversity that is able to accommodate social work’s concern for macro-level issues such as social justice, anti-oppressive practice and human rights, as well as the intimate micro-level human-to-human encounters built on empathy. It is a search for a philosophy to motivate practice which recognises humanity at its fundamental level, stripped away from cultural overlays, and which appreciates uniqueness whilst recognising commonality. My requirement is for a philosophical and theoretical framework able to enhance professional resilience, to regain the professional space where social work’s unique contribution can be made. I agree with Jones (2014) that:

“Alongside the realities of Rationing and Risk, social workers should seek to regain the remit and space for the third ‘R’ of Relationships”

(Jones, 2014, p. 496).

It is in the personal domain that social workers have the power and discretion to effect change. The humanising approach to relationships offers a way of thinking about what aids well-being in a holistic, multi-dimensional (the dimensions of the life-world) way. My research findings, with their revelations of the intertwining internal and external worlds of experience, have led me to focus on what it means to be human; what humanises and dehumanises us, and how this can be applied to social work practice. The findings reveal the importance of trust in order to enable the exploration of sexual well-being. This requires a relationship based on respect and an empathetic understanding of the other, which the literature indicates has been largely absent in work with physically disabled people (Oliver and Sapey, 2006). The findings confirm many of the reports within the literature and this is a disappointing indication of how little progress has been made in establishing sexual citizenship for all.

Using this concern for human well-being as the rationale for my practice development project, the humanising conceptual framework as its philosophical foundation and the well-being domains of the Care Act as its structure, along with the findings of my own research (thereby making the tool directly relatable to practice), I now progress to the development of the learning tool.

Chapter 7 Practice Development Part 2: Developing a Learning Tool

My research has demonstrated that sexual well-being is a matter of deep concern and significance to human well-being. I now turn to the question of how to design, present and disseminate this knowledge in a way which is effective, whilst maintaining respect for the data, keeping it connected to the lived experience of the research participants who volunteered their time and disclosed sensitive information about themselves and their situations. Reflecting on personal insights from the practice development work I undertook in relation to establishing the Research Interest Group (RIG), I realise that the power of RIG lay in its collaborative approach. This aided implementation and delivery as shared purpose creates ideas, mutual commitments and expectations of self and others which were motivational. In contrast, although I have consulted with participants, practitioners and academic supervisors about the sort of learning tool required, and will undertake the design and content with a participatory approach, responsibility for its creation lies with me alone. This responsibility is both advantageous as it gives me the freedom to apply for funding to whom and when I wish, but is also daunting as not only do I have ethical responsibility to the participants and other contributors, social work professional standards demand a high-quality product which is respectful, meaningful, useful and completed in a timely manner.

The idea of creating a learning tool has emerged from the findings and literature. I have found the revelations of life-world distress and well-being disclosed during the interviews and clarified by analysis emotionally powerful and resonant. The revelations have compelled me to find a way to communicate the messages beyond my own practice and an academic audience who might read this thesis or subsequent journal articles. But this emotionally stimulated compulsion to communicate to an audience who can use the information to positively improve people's lives needs to be matched with the necessity to meet specific doctoral learning outcomes. Therefore, my practice development project, like my personal identity, is situated within multiple roles which are imbued with internal personal

meaning and external significance:

- as a student I must meet prescribed targets and turn the knowledge I have personally gained into an external product (thesis and practice development project/product) in order to progress;
- as a professional I must contribute to work place learning and the application of social policy;
- as a human-being I must respond with compassion to human experiences of distress and well-being.

As part of the D Prof study the practice development element must meet the demands of academic rigour, specifically the learning outcomes specified within the Bournemouth University Doctor of Professional Practice programme. Those outcomes most applicable to the practice development element being to:

- *draw on and from their professional practice experience, knowledge and understanding to identify an appropriate area of professional practice or service delivery in need of enhancement through research and practice development;*
- *complete all research and practice development stages leading to the generation of new knowledge, understanding or insight into their professional practice context;*
- *undertake a critical analysis of evidence from multiple sources of data in order to contribute to the development of new ideas, approaches or techniques illustrating contemplative scholarship in professional practice;*
- *communicate complex concepts, ideas, recommendations for professional practice or service improvement with clarity, reflective sensitivity and analytical confidence to specialist and non-specialist audiences.*

(Bournemouth University, 2015b)

D Prof study concerns creating knowledge for a workplace. By becoming useful to practice, as well as meeting academic outcomes, my work contributes to the knowledge economy. I am also linked to the knowledge economy at a more personal level, for although I did not undertake the D Prof for the purpose of career progression, but rather for personal growth and the fulfilment of academic ambition (it has been about me becoming the kind of person I aspire to be), I was aware from the outset that the limited number of social workers educated to doctoral level would mean that I would become a rare 'commodity' and therefore a move away from front-line practice would be a likely outcome. Whilst leaving front-line practice has been an emotional wrench, the progress of my research has co-coincided with reforms to the profession to which I have found it difficult to reconcile; therefore, a move into an academic position where I may be able to assist practitioners has been personally timely.

Linking to my research approach I take a pragmatic stance to turning my research knowledge into a 'commodity' useful to practice and apply the same problem-solving cycle (Gray, 2010) discussed in Chapter 2, and used in relation to the creation of RIG.

A problem-solving approach to the development of a practice learning tool:

Problem-solving stage (1): Problem definition

The problem my research has identified is: the sexual well-being of users of social services is an important topic related to human well-being but one that is often overlooked in social work practice due to personal and social barriers. Therefore, how can practitioners be enabled to address the topic of sexual well-being?

Successfully engaging people with the learning tool requires consideration of who I anticipate the consumers of this knowledge to be. As a D Prof student pursuing knowledge for practice I have focused throughout the research on practitioners as my primary audience. However, the term 'social work practitioner' represents a vast

array of individuals who have taken various educational routes into practice and bring their specific preferred learning styles as well as accumulated learning experience to every training situation. The learning tool has to be accessible to those practitioners who are unfamiliar with research engagement whilst also stimulating for those used to seeking and applying knowledge to practice. In addition, practitioners are members of every demographic group hence the tool's usefulness is dependent on its sensitivity to multiple perspectives.

Problem solving stage (2): Data collection and analysis

Elements of the practice development work in establishing RIG, as previously discussed in Chapter 2, have contributed key data as I think forward and develop my research findings into a future practice learning tool. Key data refers to:

1) Practitioners face barriers to engagement with research and learning as discussed in Chapter 2 including:

a) Research skills and confidence amongst practitioners – the lack of research skills in qualifying and post-qualification training reinforce the perceived separation between research and practice (Orme and Powell, 2007; Webber, 2015). The learning tool needs to be responsive to this issue by demonstrating its roots in practitioner research, demystifying the process leading from a practice-focused question to in-depth research activities to learning tool.

b) Time to engage – staff have limited time to engage in research and learning so to counteract this the tool needs to be designed as bite-sized chunks which can be used as a structure for a training event, smaller practice discussion event or a quick reference guide.

c) Incentives and support and **d) Research enabling organisations** – practitioners are required by registration to engage with learning and research (stated in the Critical Reflection domain of the Professional Capabilities Framework (Appendix 5)), but in the current social work environment practice skills are prioritised over learning activities (Lyons and Manion, 2003). Therefore, intrinsic

motivation to engage with research is required such as personal development or professional curiosity, as there are few external incentives (Staudt et al., 2003; Bywaters, 2008; Sharland, 2012). The creation of an attractive, flexible learning tool that can be used in small or larger groups, in bite-sized chunks or as part of longer training events, provides a unique instrument that can be used as social workers require. As a product of a research study supported by my employer it is a demonstration of organisational investment in research and may be a stimulus for other practitioner research.

e) The location of research in practice: the practice/theory divide – formally presented academic work can be inaccessible and appear inapplicable to practice (Coulshed and Orme, 2012), so the learning tool will present information in a condensed, interactive format using reflective questions to create links between the information and practice.

f) Accessing research – Research is often presented in expensive academic books and journals. To be accessible the tool will be an easily read series of interactive cards with links to online information. The first print run will be free and given out as part of the dissemination plan (discussed below) but further copies may incur a charge.

2) Barriers to practitioners discussing sex

As discussed in the literature review practitioners can be reluctant to discuss sexual well-being issues (Walters and Williamson, 1998; Guest, 2000; Weerakoon, 2001; McLaughlin and Cregan, 2005; Shuttleworth, 2010; Dyer and das Nair, 2013; Blackburn et al., 2015). These barriers cannot be an excuse for inaction as practice which refuses to address the issues which matter to people is dehumanising (Galvin and Todres, 2013). The tool will acknowledge these barriers and provide reflective exercises through which a practitioner's own values can be explored (for

example, small group discussions regarding in what circumstances one's sexuality needs to be declared). The tool aims to equip practitioners with the knowledge and confidence they require to be able to meet the first two levels of the PLISSIT model discussed in the following section.

To engage practitioners so they can raise awareness in the topic of sexual well-being, the information and learning must be presented in an emotionally and intellectually engaging way which invites curiosity and empathetic connection. This relates to the power of research focused on lived experience. It is service users' accounts of their experience which are so evocative, often provoking emotional responses and prompts to action to address social injustice (Milligan and Neufeldt, 2001; Schlesinger, 2003; Grossman et al., 2003). Representation of the findings in humanly sensitive ways creates an embodied relational understanding; knowledge for 'the head, hand and heart' (Galvin and Todres, 2013, p150). Therefore, each card will feature a relevant quote from the findings (with participant's permission and anonymised) or the literature. In addition, a successful application for funding for the development of the tool would make it possible to fund any of the participants interested in co-producing the tool as experts by experience.

I acknowledge that some practitioners will object to sex being discussed and without policy guidance consideration of sexual well-being cannot become a compulsory part of well-being-focused social work. Therefore, other work is required to influence policy including involving Lyn Romeo, Chief Social Worker, Department of Health, in the conference/launch event discussed below.

Problem solving stage (3): Improvement planning

The learning tool:

The discussion in Chapter 2 considering McCormack and Garbett's (2003) work on the functions and activities of practice developers in relation to the Research Interest Group is equally applicable to my work on the practitioner learning tool as I seek to:

- **facilitate and promote change** in practitioner and organisational attitudes towards sexual well-being;
- **translate and communicate** knowledge about the topic;
- **educate** by providing relevant information and stimulate reflection; and
- respond to the **external influences** on the lives of physically disabled service users.

The purpose of the learning tool is neither to provide in-depth training about sexual well-being nor to train social workers as sex therapists, which requires a specialist professional qualification. Rather, the aim is to assist social workers to become humanising, sexual well-being enablers when required by service users, as allowed by the Care Act 2014, using data from lived experience to animate the topic and evidence the need for practitioner openness. Links to useful information will be included so practitioners can access further resources. The existing PLISSIT model is helpful in developing the purpose and use of my learning. PLISSIT represents four levels of sex counselling and therapy which encourages professionals to deal with patients' sexual concerns at the level according to their experience:

- 1) *P: permission giving; to open the topic up to discussion.*
- 2) *L.I: limited information giving.*
- 3) *S.S: specific suggestions.*
- 4) *I.T: intensive therapy.*

(Weerakoon, 2001)

The learning tool focuses on the first two levels of the PLISSIT model: the first level involves the social worker being 'perceived as someone to whom clients can talk to about issues related to sexuality' (Dunk, 2007, p5). For this, the worker recognises that talking about sexuality is relevant to everyday life and is a legitimate topic within social work encounters. To meet the demands of the second level of the PLISSIT model, workers require knowledge about sexual issues, human physiology and sexual values to be able to offer limited information:

“This involves the practitioner giving the client enough information for them to perhaps alter their perception of a sexual concern. A concern that masturbation is ‘abnormal’ is an example of a client issue that a social worker may be asked about in the course of their work with a client”

(Dunk, 2007, p.6).

Social workers should ensure that they use reliable sources of information (such as those in Appendix 2), and that service users know how to access information when they wish (Blackburn et al., 2015).

The development of the learning tool also draws on the work of the Sexual Health and Disability Alliance (SHADA), a multi-disciplinary network of academics and professionals working with disabled people across the UK, which advocates for the sexual citizenship of disabled people. I was, and remain, the only social work member of the network and so I have been able to offer a different perspective to their work. I have contributed to SHADA’s online Sexual Respect Tool Kit (found at shada.org.uk), which is an awareness-raising tool for all professions. The information specifically relevant to social work practice is limited due to its multidisciplinary approach, however, contributing to the development of the Sexual Respect Tool Kit was a stimulus for my learning tool designed specifically for social work students and established practitioners responding to the barriers to research engagement discussed above.

The learning tool will take the form of a deck of interactive cards to provide information and stimulate discussion amongst practitioner and social work student learners. The content of the deck will be formed collaboratively with stakeholders, specifically the research participants (if they wish), practitioners recruited from the Pan Dorset Academy and RIG network, Bournemouth University colleagues and students and SHADA. However, the deck of cards will include such activities as a reflective ‘wool and stones’ exercise where learners create, and explain, a simple representation of a typical working day with stones signifying points in the day

where they have experienced 'humanness' and being dehumanised. Such an exercise, which starts with the learner's own experience, stimulates discussion about the humanising and dehumanising of ourselves and others. Other cards will feature an exploration of the barriers practitioners face in discussing sex and ask learners to consider ways of overcoming such barriers or their ability to assist service users with their sexual well-being concerns in appropriate ways. I anticipate the deck comprising of between 40–50 cards, some of which will be information only, others more interactive. This complements the work undertaken by Dr Lee-Ann Fenge, Dr Kip Jones and Christina Hicks of Bournemouth University and their advisory board of participants entitled Methods of Diversity Raising Awareness of issues of Older Lesbian, Gay, Bisexual and Transgender People (Fenge et al., 2012). They produced a series of cards and trained 'champions' within health and social care organisations in their effective use. This work has provided a successful model of research dissemination on which to base my own learning tool. The links they have established with local provider organisations are equally as relevant to my work. I will also work with the Sexual Health and Disability Alliance (SHADA) along with the participants of my research to finesse the content and design of the learning tool to ensure its relevance and the quality of the content. The SHADA network extends across the country and provides a route of dissemination where 'champions' can be trained to use the cards within their own organisations.

Making the finished product is a piece of post-doctoral work requiring funding (an application will be made to the Big Lottery), however, the elements of learning will be based on the following key headings and I have designed sample cards included as Appendix 6.

Diversity: its definition, legal requirements and relevance to work with disabled people.

Well-being: its meaning and relevance to social work practice.

Thinking about sexuality: both the sexuality of the practitioner and service user, their sexual rights, sexual citizenship and the meaning of sexual well-being as found from the findings.

Sexual esteem: the importance of acknowledgement of sexual agency, dignity and

respect.

Thinking about disability: diversity, models of disability and disability discourse.

Disability and sex: to include information about the positive impact of sex on pain, how different positions are manageable, safe and pleasurable, the availability of technologies and aids and the impact of medication on sexual function. Also covers information about catheterisation, continence and sex.

Acceptance and professional values: the damage to disabled people from cultural representations of disability, assumptions and 'disable-ism'.

Social issues: including pornography.

Policy and legal context: to include equality, consent, safeguarding, use of trained sex workers, and the duty of care.

Service provision: sexuality in relation to domiciliary and residential care.

Resources: links to online and written information, policy and services.

(This content list includes information adapted from Blackburn, 2015.)

Problem-solving stage (4): Dissemination and implementation

Dissemination of practitioner-led research is problematic with research often remaining localised (McLaughlin, 2007). Being aware of the following barriers assists in the development of the dissemination and implementation strategy.

Barriers to dissemination and implementation

i) Implementing a tool which is designed to be used independently from its creators results in the risk of its being used poorly, even inappropriately, leading to potential harm through misinformation. To mitigate against this the collaborative creative team will draw on expertise from conference contributors including Claire de Than (co-director of the Centre for Law, Justice and Journalism at City University, London, part of the SHADA network), local authority mental capacity advisors and local authority safeguarding adults leads to ensure the information is accurate. In addition, the recruitment of champions within organisations who will promote the resource will assist in managing its use. Access to such a range of expertise and organisations reflects the advantages of 'insider' research.

ii) Practitioners may respond positively to the tool, however, without management

and colleague support it is very difficult to integrate new ideas into practice (Rolfe et al., 2001), hence the necessity of gaining stakeholder support for the learning tool. In addition, the primary purpose of the tool is to inform and challenge practitioner attitudes, to make them think about the conversations they have with service users and promote humanising methods, rather than introduce a new procedure or way of 'doing social work'.

iii) Practitioner research is criticised for being 'a travesty of science where the unqualified engage in confirming their own common sense' (Hughes and Hitchcock, 1995, p114). The development of the Professional Doctorate addresses this barrier through the application of rigorous academic standards to 'insider' research, thereby giving practitioner research credibility (Boud and Tennant, 2006). Furthermore, recognition of the diverse sources of knowledge required for social work, including practice wisdom, service user knowledge and research (RiPFA, 2013) make practitioner research relevant and vital. This, along with Croisdale-Appleby's (2014) identification of the role of social workers as social scientists, which contributes to the profession's knowledge base, challenges this barrier.

iv) Successful implementation of the learning tool is dependent on its perceived relevance by the stakeholders including employers, practitioners and service users. Local authorities now have responsibility for public health (Department of Health, 2012) and the successful implementation of the learning tool involves demonstrating the significance of sexual well-being to health and well-being. To this end I have devised the following implementation strategy drawing on the links to organisations and individuals which I have made during my doctoral journey.

a) I will be working with the Pan Dorset Academy to launch, promote and disseminate the tool. The development of the Academy has involved senior managers from three local authorities and health services, senior learning and development officers and principal social workers all of whom are influential within their organisations. Gaining their support will influence the success of the tool. In May and June 2015 I applied for, and was successful in gaining, grants from my then employer and a university postgraduate development fund to organise a

sexual well-being conference, hosted by Dorset County Council. Speakers were selected according to expertise in specific aspects of practice as detailed below. However, a delay in organising the conference occurred when the safeguarding trainer was no longer able to contribute and finding an alternative has proven to be problematic. This delay coincided with the most recent agency reorganisation and consequent change in my own professional role. My intention to hold the conference remains, and this will now be part of my post-doctoral activities. It will be part of the developing Pan Dorset Academy programme of events and offers the opportunity to launch the learning tool.

b) Piloting the learning tool with postgraduate and undergraduate social work students at Bournemouth University.

c) Following the routes used to disseminate and implement the Methods of Diversity Deck (Fenge et al., 2012), I will contact local disability organisations, as well as the networks of which the research participants are already members, to offer demonstrations and recruit champions. SHADA also offers an extensive network of national disability organisations from which to draw collaborators and champions.

d) Dissemination and implementation through the SHADA network.

e) Dissemination and implementation through the Dorset Sexual Health Service to whom I presented my work in 2014 and where I have been invited to return.

f) Dissemination and implementation through the Humanising Care network and annual conference at Bournemouth University where I presented my work in 2015. I was invited to return.

I am enthusiastic about applying for funding and implementing the learning tool using the strategy above. I also anticipate that barriers I have not yet considered will occur because I am as inexperienced with implementing a learning tool as I was with the work developing RIG. However, I consider the ability to deal with the

unexpected and to critically approach problem-solving activities as part of the skills developed through D Prof study.

Chapter 8: Reflections and conclusion

This chapter offers an overview of my doctoral journey and my final reflections.

As stated in Chapter 2, undertaking doctoral study means embarking on a journey of change as new ideas challenge and inform, leading to one's identity splintering and reconstructing (Scott et al., 2004). I have been particularly influenced by notions of attitudes which transcend theory or methodology and become part of personal identity informing one's stance in, and approach to, the world (examples from this work include the phenomenological attitude (Finlay, 2008) and the ethical attitude, which do not rely on prescribed codes or formulas but lead to a way of being (Mauthner et al., 2002; Doel, et al., 2010)). The humanising attitude (Galvin and Todres, 2013) has particular resonance with my personal and professional world view with its valuing of lived human experience and concern for well-being. I have found these notions of positive attitudes helpful in reconstructing myself throughout my learning journey. Having encountered and embraced the humanising attitude halfway through my journey I see my earlier work as a period of searching and my later work as a period of humanised sense making. I therefore approach this final chapter with a humanising attitude, applying the humanising/dehumanising conceptual framework to myself and my work.

As I have stated throughout the thesis, it is attitudes towards the sexual well-being of physically disabled people which my research is seeking to challenge, inform and, indeed, to humanise.

1. The achievement of aims and objectives from the study:

The overall aim of this work has been to explore the meaning of sexual well-being for physically disabled people and the implications for social work practice. My thesis concerns the following objectives:

- to critically examine existing knowledge of social work, sexual well-being and well-being;
- to explore the social work task with disabled people through a personal narrative;
- to gain a deeper understanding of sexual well-being and the lived

experience through a phenomenological approach;

- to develop a practice-based learning tool.

I approached my objectives concurrently, allowing each to stimulate thinking about the others. I examined existing knowledge by critically engaging with different types of literature concerning social work, disability, well-being and sexual well-being. I purposefully embraced diverse forms and sources of literature because knowledge for practice is diverse, encompassing the lived experience of service users and practitioners, as well as academic literature and research. I sought and examined the current debates in professional social work practice and the critical issues regarding disability and sexual well-being, reflecting on the impact these debates have had on my professional and personal identities. This has included consideration of the distress to service users and practitioners when dehumanising forces (such as the sexual disenfranchisement of physically disabled people, or the limited capacity for relationship-based practice) have led to experiences of existential 'homelessness', isolation or loss of meaning. I have highlighted the uncertainty of the social work role and the ambiguity between policy, theory and the reality of daily practice. It is this ambiguity which led me to experience a sense of meaninglessness and loss in respect of my personal journey, discussed within the narrative sections woven throughout the thesis, and which leads me to the completion of my second objective; a reflective narrative of my experience as a social worker working with physically disabled people. This narrative considers the difference between the assumptions made about policy and practice, assumptions which are not always shared (for example, social workers might assume their purpose is to improve people's lives, whereas policymakers might assume the purpose of social workers is to exercise the law). My search for a method of human sense-making has informed both my ongoing development as a research-minded social work professional as well as the nature of the practice development aspect of my D Prof work.

I have met the third objective through gaining original insights and new knowledge from research participants through unstructured interviews and using a phenomenological approach to analysis. This approach generated data that was

rich with meaning about unique life-world experiences. I have gained insights that have affected my practice and practice development work. Using the phenomenological approach has highlighted the benefits of drawing on lived experience for understanding the impact of social policy in ways which have both intellectual and emotional resonance. The power of this qualitative evidence has created the motivation to devise a practitioner learning tool in order to communicate the findings to practitioners who can influence the content and nature of social work encounters.

2. Limitations of my research and the practice development project

I originally intended to interview ten participants in order to capture as much depth and variation as possible for a lone researcher. However, I was not able to find ten people prepared to discuss the topic from among the limited population of physically disabled social service users in my local geographical area. The small sample group restricts the breadth of the findings. Had time and resources allowed, it would have been beneficial to widen the geographical area for participation.

The quantity of data produced through the unstructured interviews was extensive and phenomenological analysis of such a large amount of data was a skilled undertaking. As a 'novice' researcher I learnt how to 'do it' as the research progressed, although I acknowledge that the findings presented are my interpretation (shared with and verified by the participants) and it is possible that another researcher would have reached different conclusions. However, the aim of this research was to co-construct the discussion of the experience of sexual well-being, and my unique perspective as a social worker, known to most of the participants, may have enabled a much greater depth than would otherwise be possible.

The pre-existing relationship between me and all but one of the participants potentially influenced their willingness to contribute. While this may have been considered as leading to potential bias, it also was very clear from participants' accounts that their willingness to share so much information was because they

knew me and we had already built up a trusting relationship. With additional time and resources I could have recruited participants unknown to me via the snowballing method and would have considered approaches to building trust with other individuals.

All of the research participants live in their own homes and I could have included participants living in residential homes whose voices are not only 'muffled' by the social status of disability but are often silenced and made hard to reach by their accommodation status. This was not done because I wished to avoid any tokenism, or distraction from the primary theme of physical disability, resulting from too diverse a participant population in terms of their circumstances.

Undertaking this research over an extended period of time and on a part-time basis has meant that multiple research activities have occurred concurrently, including examination of the literature and interviews. In retrospect, it would have been helpful to have concluded the literature review prior to undertaking the interviews so that I was fully informed of the issues identified within the literature. However, I appreciate that this could have resulted in me imposing a structure on the interviews to serve my research purpose, a debate featured in the methodology section.

The organisation and delivery of a conference was an overambitious goal both in terms of the timescale and for a lone researcher to organise. While organisational support was made available through the learning and development department, concurrent agency restructuring severely limited this support. The unexpected withdrawal of a conference presenter and then time spent trying to find a replacement speaker delayed the conference to the extent that it became impossible to organise while I was still in post. The contents of the conference would have contributed to the learning tool.

I had developed links with the College of Social Work and presented my work to the adult faculty as well as contributing written work to the online magazine (Lee, 2014) and being a member of the Knowledge Exchange Committee, all of which

presented the means to disseminate my work. The closure of the College is both a professional loss and a loss of diverse routes to reach other practitioners and influence policy.

Merging the voices of my multiple roles as student, practitioner and researcher has created a limitation. I recognise that while my interpretation and application of information to practice, and embedding the whole of my narrative in practice, is very helpful, positive and a requirement of a D Prof (and, indeed, why I chose to do one) it has led to integration within my work to the point where differentiating or separating the different voices is difficult. This has resulted in a degree of ambiguity about which aspects of my work have derived from which role.

3. Key messages and the implications for professional practice arising from this thesis

The primary message emerging from this thesis is that sexual well-being is key to physical, mental and emotional well-being. The introduction of the notion of well-being into social policy through the Care Act offers social workers the opportunity to address the issues which really matter to people, including sexual well-being, however, this is challenged from a number of fronts.

Well-being is a contested term used according to the meaning assigned by the user in their context (Ereaut and Whiting, 2008). Without clear definition this ambiguity means well-being-focused assessments will be approached, undertaken and interpreted differently by service users, organisations and social workers. This increases the current lack of clarity around the social work role (Moriarty et al., 2015a). The humanising conceptual framework adds a philosophical depth to well-being and social workers could use the humanising/dehumanising domains to explore service user's own interpretation of well-being.

Well-being is promoted in the Care Act through the extension of personalisation which is focused on consumer choice and control rather than relationship based social work (Beresford, 2013). This removes the potential for exploratory,

collaborative problem solving.

For government to achieve increased well-being across the UK population, and for the well-being principle of the Care Act 2014 to become embedded into social work practice, a genuinely holistic approach which values the layered aspects of human nature and need has to be demonstrated in social policy. Government states that well-being is a desired policy outcome (Department of Health, 2014), yet the impact of austerity policy on social organisation, policy priority and public discourse appears to be undermining the potential for improving well-being amongst certain groups within the population. Evidence indicating the negative impact of inequality across all of society (Wilkinson and Pickett, 2009 and 2010) means the pursuit of factors which positively contribute to the many and not just the dominant few is required; this means the inclusion of marginalised groups.

The concept of well-being as applied within the Care Act is in danger of becoming simply an outcome target, disconnected from lived experience and its foundation in the philosophy of being. However, practitioners are in control of the nature of the relationships they forge with service users and can reclaim well-being by recognising its place in the values and ethics of practice. In addition, practitioners can produce evidence from practice about the wider implications of well-being, specifically the impact of social conditions and inequalities on well-being. If government is serious about increasing national well-being, social workers are well placed to provide the evidence of the effects of social policy on citizens. To achieve this, practitioners and social work agencies need to recognise the essentially political nature of social work, in order to critically consider their roles and engage in research to provide lived experiential evidence.

To do this, social workers can use the Care Act 2014 well-being domains to analyse and challenge the dominant discourse of sexuality and disability. One method of achieving this is to promote the concept of independent living, something which is core to the well-being principle of the Care Act 2014. The guidance states that:

“The well-being principle is intended to cover the key components of independent living, as expressed in the UN Convention on the Rights of People with Disabilities (in particular, Article 19 of the Convention). Supporting people to live as independently as possible, for as long as possible, is a guiding principle of the Care Act”

(Care Act Guidance, 2016, 1.19 (renewed)).

Article 19 of the UN Convention on the Rights of Persons with Disabilities (2006), entitled ‘Living independently and being included in the community’ requires governments to take action to facilitate disabled people’s ‘full enjoyment’ of this right and their ‘full inclusion and participation in the community’ (Parker and Clements, 2008, p509). Social workers can use this to inform practice as it provides a clear agenda for social work with physically disabled people and gives substantial scope for advocacy (Parker and Clements, 2008). This includes promoting disabled people’s participation in work, training and recreation, control over day-to-day life and contribution to society, all of which are well-being domains within the Care Act assessment.

Social workers, like other professionals, can be reluctant to address sexual well-being. To overcome the barriers practitioners require training to provide information and raise their awareness and confidence. The training should include reflection on their own understanding of sexual well-being and their personal sexual values.

4. Where now?

a) Recommendations for further practice development arising from this research:

1. Sexual well-being as a topic becomes a focus within CPD along with well-being training.
2. Social work practice focused on well-being needs to be mindful of the influences of social structures and inequalities on lived experience.
3. Practitioners and employing agencies should take responsibility for finding out about sexual well-being and its relevance to practice.

4. The humanising framework becomes the rationale for practice.

b) Recommendations for further research into the experience of sexual well-being and how policy influences this. This includes:

1. The sexual well-being experiences of residents in residential and nursing care and the impact of the Care Act 2014 on well-being and person-centred care.
2. A deeper understanding of the lived experience of disability and sexual well-being through in depth qualitative research.
3. Practitioner-led research engaging seldom-heard groups to provide wider evidence and knowledge about sexual well-being and disability.
4. This user-generated evidence to be used to inform both local and national agency policy and practice.

5. Final thoughts

I liken the experience of undertaking a D Prof to that of becoming a parent: you might observe others going through a unique change process, building a relationship with their child, suffering sleepless nights of self-doubt, but until you enter the doctoral pathway yourself you cannot truly appreciate its destabilising but also reconstructive effects (Scott et al., 2004). Doctoral study is an emotional roller-coaster (the urge to press delete occurring to me frequently) and, reflecting on my journey, I recognise that I have developed and changed during a period of self-reconstruction affecting my professional attitude and confidence. Despite frequently questioning my ability and whether I am 'good enough' I have endured, and now appreciate my tenacity. I understand my tenacity is built on a self-confidence which, were it not for this doctoral study, I might not otherwise have discovered. But aspects of self-doubt remain and these will continue to be motivational forces ensuring I continue to gain "pleasure in learning, testing (myself) out, proving (my) ability, gaining confidence, and self-fulfilment" (Leonard et al., 2005, p138) in my post-doctoral work. This ongoing work will benefit from my growth in confidence and self-esteem, and my becoming more reflective, analytical and critical.

During the period of study I have shared my work through a number of conference presentations and publications (two published and one pending), which have contributed to my personal and academic development and increased awareness and knowledge about the topic of sexual well-being. These activities bestow a sense of belonging to the academic community, of academic credibility and, for me, signify movement away from front-line practice. Each occasion has been a test of whether I am 'good enough' for doctoral study. Reflecting on ending my doctoral journey I perceive that perhaps the greatest personal impact has been my review and recommitment to fundamental social work values of empathy, equality and human respect. My work on sexual well-being has been about attitudes towards disabled people which result in inequality and discrimination, attitudes which are often unconsciously built on hierarchies of power. The extended period of austerity has been used as a justification for reinforces negative attitudes resulting in my increasing political awareness, specifically regarding the impact of social policy on service users and social care professionals. This has led me to become increasingly aware of the need to enable curiosity, criticality and reflexivity and curiosity in myself and others: that is to challenge attitudes, the ultimate goal of my research.

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Legislation and Guidelines

Care Act 2014

Data Protection Act 1998

Disability Discrimination Act 1995

Equality Act 2010

Human Rights Act 1998

Mental Capacity Act 2005

NHS and Community Care Act, 1990

Sexual Offences Act 2003

Case Law

Re MM (An Adult); Local Authority X v MM [2007] EWHC 2689 (Fam)

Other references

Dating websites:

Dating4Disabled – www.dating4disabled.com/

Disability Dating – <http://disabilitydating.com>

Special Bridge – www.specialbridge.com/

Appendix 1

Dorset County Council Adult Services Social Work Research Interest Group

Terms of Reference

Context

Social work is a professional occupation utilising knowledge drawn from diverse related disciplines including psychology, sociology, social policy and political theory. An essential element of knowledge creation is research; the collection, analysis and testing of evidence. Registration with the Health and Care Professions Council (HCPC) requires social workers to engage with research (Standards of Proficiency 13.3, 13.4, 14). It is part of each practitioner's professional responsibility to ensure that their practice is evidence based and up to date with theory and knowledge. This is a dynamic endeavour with practitioners being both consumers and creators of research and knowledge.

The Research Interest Group recognises the complexities of social work practice and the significance of different types of evidence that is generated by both quantitative and qualitative methodologies, including reflection and practice wisdom.

In a "'Health Check' survey carried out in 2012, staff reported low levels of awareness of resources to support them in accessing information and research, and frustration with IT systems that block useful websites. Many said that they would like dedicated time to devote to keeping up to date with current research and that additional help on how to access research and evidence would be welcome. In recognition of these concerns, and as a proactive response to the HCPC registration requirement, the Dorset County Council Adult Services Research Interest Group was formed in 2012. The group acknowledges and seeks to address the impediments to practitioner engagement.

Aims

- To enable social work practitioner participation in the critical consumption and creation of research by facilitating access to research support and resources that are available from Dorset County Council.
- To discuss and address issues of concern in relation to practitioner engagement.
- To exchange ideas, strengthen skills and share examples of good practice to develop practitioner involvement in research.
- To organise practitioner development events four times a year which will include the promotion of local, recent and current research through presentation and discussion.
- To encourage a research-minded workforce.
- To act as ambassadors for the Research Interest Group and the essential role research has in professional social work.
- To help guide the development of recommendations for further work.

Ways of working

The Group will meet a minimum of four times a year. Minutes of the meeting will be kept and agreed by all members of the Group who attended the meeting. Members may be contacted between meetings for advice should the need arise. From time to time, sub-groups may be formed to work on specific issues as appropriate. From time to time, individuals may be co-opted to provide specific advice and expertise as required. Meeting topics will be generated by members of the group. The chair for each meeting will rotate between members of the group; this will entail:

- 1) Devising the agenda prior to the meeting.
- 2) Chairing the group meeting.
- 3) Receiving any feedback from group members after each meeting and communicating this.

Membership

The research interest group will be made up of registered social work practitioners

and managers from across the county representing adult services teams including Amanda Grant, representing and reporting to Dorset County Council's Learning and Development Department, and Ann Harris and Sarah MacBeth, representing and reporting to Dorset County Council's Research Department.

Terms of reference to be reviewed annually at the first meeting of each year.

Appendix 2

Reliable sources of information for practitioners' use:

ASAP Ask a Sexual Advocate Professional: www.advocacyprofessional.com

The British Association of Social Workers: www.basw.co.uk

British Institute of Learning Disabilities (BILD) – information, publications and training: www.bild.org.uk

Brook Advisory Services – deals with under 25's sexual health and wellbeing: www.brook.org.uk

The Care Quality Commission: www.cqc.org.uk

Elfrida Society – provides resources and sexual training: www.elfrida.com/publications.html

fpa – provides support in sex and sexual health to professionals throughout the whole of GB: www.fpa.org

People First – independent self-advocacy for people with learning difficulties: www.peoplefirstltd.com

Sex Education Forum – advice and publications on developing sex and relationships education policies: www.sexeducationforum.org.uk

Sexual Health and Disability Alliance (SHADA): www.shada.org.uk

The Sexual Respect Toolkit: www.sexualrespect.com (has links to organisations dealing with particular conditions, including multiple sclerosis).

Bywater, J. and Jones, R., (2007) *Sexuality and Social Work*. Exeter. Learning Matters.

Sexual issues in social work by Steve Myers and Judith Milner (2007).

Myers, S., and Milner, J. (2007) *Sexual Issues In Social Work*. Bristol: BASW.

Appendix 3

Research participant letters and information

DCC

Letterhead

Potential participant's address

Dear

An exploration of the meaning of sexual well-being to people with physical disabilities

I am looking for up to 10 people with physical disabilities who use social care services in Dorset who would be interested in taking part in research about what sexual well-being means. It is an opportunity for you to 'tell it as it is' from your perspective.

This will form part of my part-time Professional Doctorate research.

Interviews will be carried out between January and April 2013 at a suitable location of your choice.

Interviews will be up to 1.5 hours in duration, but can vary according to your needs and will be at mutually convenient times.

Interviews will be informal and based around the theme of what sexual well-being means to you.

If this sounds of interest please read the enclosed information sheet. Feel free to discuss it with someone you trust before making up your mind.

If you have any questions, please contact me on 07763 06948 (this is a mobile number that I alone have access to, so is confidential) or email s.a.lee@dorsetcc.gov.uk.

If you do not have any queries and wish to take part, please sign and return the consent form in the enclosed stamped addressed envelope. I will then contact you to make an appointment.

Full confidentiality is guaranteed. This research has ethical approval from Bournemouth University and Dorset County Council.

Yours sincerely,

Sally Lee, School of Health and Social Care Bournemouth University/Social Worker Dorset County Council

Letterhead

Potential participant's address

Dear

An exploration of the meaning of sexual well-being to people with physical disabilities

I am looking for up to 10 people with physical disabilities who use social care services in Dorset who would be interested in taking part in research about what sexual well-being means. It is an opportunity for you to 'tell it as it is' from your perspective.

This will form part of my part time Professional Doctorate research.

Interviews will be carried out between January and April 2013 at a suitable location of your choice.

Interviews will be up to 1.5 hours in duration, but can vary according to your needs and will be at mutually convenient times.

Interviews will be informal and based around the theme of what sexual well-being means to you.

If this sounds of interest please ask a relative, friend or carer to contact me on 07763 06948 (this is a mobile number that I alone have access to, so is confidential) or email s.a.lee@dorsetcc.gov.uk and I will arrange to visit you to provide further information about the research and collect your consent if you wish

to take part.

Full confidentiality is guaranteed. This research has ethical approval from Bournemouth University and Dorset County Council.

If you require someone to assist you with your method of communication I would be grateful if you would ask them to be available when I visit.

Yours sincerely,

Sally Lee, School of Health and Social Care Bournemouth University/Social Worker Dorset County Council

PARTICIPANT INFORMATION SHEET

- You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve.
- Please take time to read the following information carefully and discuss it with others if you wish.
- Take time to decide whether you wish to take part. Thank you for taking the time to read this information sheet.

As you already know, I am a social worker with Dorset County Council.

For the last two years I have been studying part time with Bournemouth University doing a research degree.

I am writing to you to see if you would be interested in participating in this research. Please have a read of the information below and let me know if it is of interest to you.

What is the purpose of the study?

To explore the meaning of sexual well-being for people with physical disabilities in Dorset.

Why have I been chosen?

You have been chosen because either you have previously told me you are interested in this subject or I think it might be of interest to you. I am seeking to hear from people who may not have had the opportunity to speak out about what living with disabilities in Dorset in the 21st century is really like.

I am approaching people in diverse circumstances, ie men and women of different ages, disabilities and relationship status in order to explore what sexual well-being means from a range of perspectives.

I am really interested in getting a range of views, positive and negative, so even if this topic does not seem of immediate relevance or interest to you I am still keen to hear from you. I will be there to listen and learn from you, not to make any judgements about you or your lifestyle.

Do I have to take part?

No, participation is voluntary and even if you initially agree to take part but later change your mind and want to withdraw, that is fine. I will destroy all the information you have provided up to the point of withdrawing if you want me to.

What do I have to do?

Sign and return the consent form in the enclosed stamped addressed envelope. I will then make contact with you so we can discuss the research further; if you are interested we can then arrange a meeting.

I will come to you when it is convenient for you, or if you prefer we could meet at a neutral venue such as a friend's house or a cafe.

Talk to me about what sexual well-being means to you. I would like to record our interview, which I will then transcribe so we can both read it and make sure we agree with the content. The interviews will be at your pace and can be done over a number of meetings.

I am aiming to interview around 10 people between the ages of 18 and 65 and it may be that you know someone in Dorset with physical disabilities who uses social care services who you think would be interested in taking part too; if so, I would be grateful if you would pass my details to them.

What are the possible disadvantages?

This is a sensitive topic and could be distressing for you as upsetting memories or currently difficult situations may be spoken about. Please discuss this with someone you trust before you become involved.

You know me as a social worker but as far as this work is concerned I am a researcher interested in your thoughts. This means I will not be visiting you to discuss services or to make arrangements for you. I will let your allocated worker know of your involvement so they can support you.

Once the research is published it cannot be altered.

What are the possible benefits of taking part?

It is an opportunity for you to 'tell it as it is' from your perspective; to get your voice heard.

The experience of exploring your perspective is likely to lead to personal insights, to get to know yourself better, and may lead to new things because of this increased self-knowledge.

It is an opportunity to take part in something innovative which has the potential to change perceptions.

The information gathered may lead to change in the way sexual well-being is understood by you personally, your family/friends, myself and my colleagues. It will be used to inform social care practice and attitudes and improve social workers' understanding of the lives of people they meet.

The information you provide will form part of published literature and will contribute to knowledge about what life is really like now.

Will my taking part in this study be kept confidential?

Yes. If you wish you can choose a pseudonym which will be used in all the written work and presentations, but you can reveal as much or as little about your personal identity as you wish.

However, if disclosure of illegal activity is made during any discussion I am obliged to pass this on to the relevant authorities (eg, social services, police), or if you make me aware of any significant harm being done to yourself or others, again this

has to be reported so people are protected.

I will store all the recordings and transcripts in a secure place for up to 36 months. Recordings will be deleted once the transcripts are completed and the participants agree the content. Electronic copies of the transcripts will be stored on computer memory sticks in the same place (a locked box in my home) which only I will have access to.

Your contribution to the research will be acknowledged in the written work and presentations anonymously unless you give permission for your real name to be used.

What will happen to the results of the research study?

The information will be collected, stored securely, transcribed and analysed by me and will be used in a number of ways:

The results may be used for articles in disability organisation literature or professional journals and presentations at conferences.

The results will be presented to Dorset County Council staff and used as the evidence needed to potentially develop new services and/or used for staff learning. This could spread to other local authorities too.

The results will be used to inform my own and my colleague's working practices. I will keep you informed about these different things as the research goes on. I would be delighted if you wanted to be involved in the presentations.

The results will also form part of my written work for the Professional Doctorate qualification. This means it will be part of the published thesis, copies of which are held at Bournemouth University and the British Library. There is also online access to doctoral theses via university libraries. It will (hopefully!) become a resource for people interested in this subject.

Who has reviewed the study?

I am undertaking this research as a student at Bournemouth University. My work is

supervised and reviewed by Dr Lee-Ann Fenge and Dr Bethan Collins for Bournemouth University. Ann Harris at the Dorset County Council Research Department has awarded ethical approval on behalf of the council and it has been reviewed by the University Research Governance Committee.

Contact for further information?

If you would like further information or have any questions about the research before deciding whether or not to participate please contact me on 07776 306948, (this is a mobile number which I alone have access to) or

Dr Lee-Ann Fenge, Associate Dean, School of Health and Social Care, Bournemouth University, Royal London House, Bournemouth BH1 3LT (01202) 962114; lfenge@bournemouth.ac.uk

Dr Bethan Collins, Programme Co-ordinator, School of Health and Social Care, Bournemouth University, R602 Royal London House, Bournemouth BH1 3LT (01202) 961390; bcollins@bournemouth.ac.uk

If you are interested in taking part in this research please return the consent form in the enclosed SAE addressed to:

Sally Lee
Social Services
Bath Road
Sturminster Newton
Dorset
DT10 1DR

Once received I will contact you to arrange an appointment.

Thank you for considering taking part in the study

Appendix 4

Care Act 2014, Part 1 Section 9, assessment of an adult's need for care and support

The Care Act assessment includes a three-stage process of determining eligibility which is set out in the Care and Support (Eligibility Criteria) Regulations 2014 and the Department of Health Care and Support Statutory Guidance, 2014:

1. Needs

The adult's needs arise from, or are related to, a physical or mental impairment or illness.

2. Outcomes

As a result of the needs, the adult is unable to achieve two or more of the following outcomes:

- a) managing and maintaining nutrition;
- b) maintaining personal hygiene;
- c) managing toilet needs;
- d) being appropriately clothed;
- e) maintaining a habitable home environment;
- f) being able to make use of the home safely;
- g) developing and maintaining family or other personal relationships;
- h) accessing and engaging in work, training, education or volunteering;
- l) making use of necessary facilities or services in the local community including public transport and recreational facilities or services;
- j) carrying out any caring responsibilities the adult has for a child.

3. Well-being

As a consequence, there is, or is likely to be, a significant impact on the adult's well-being, including the following:

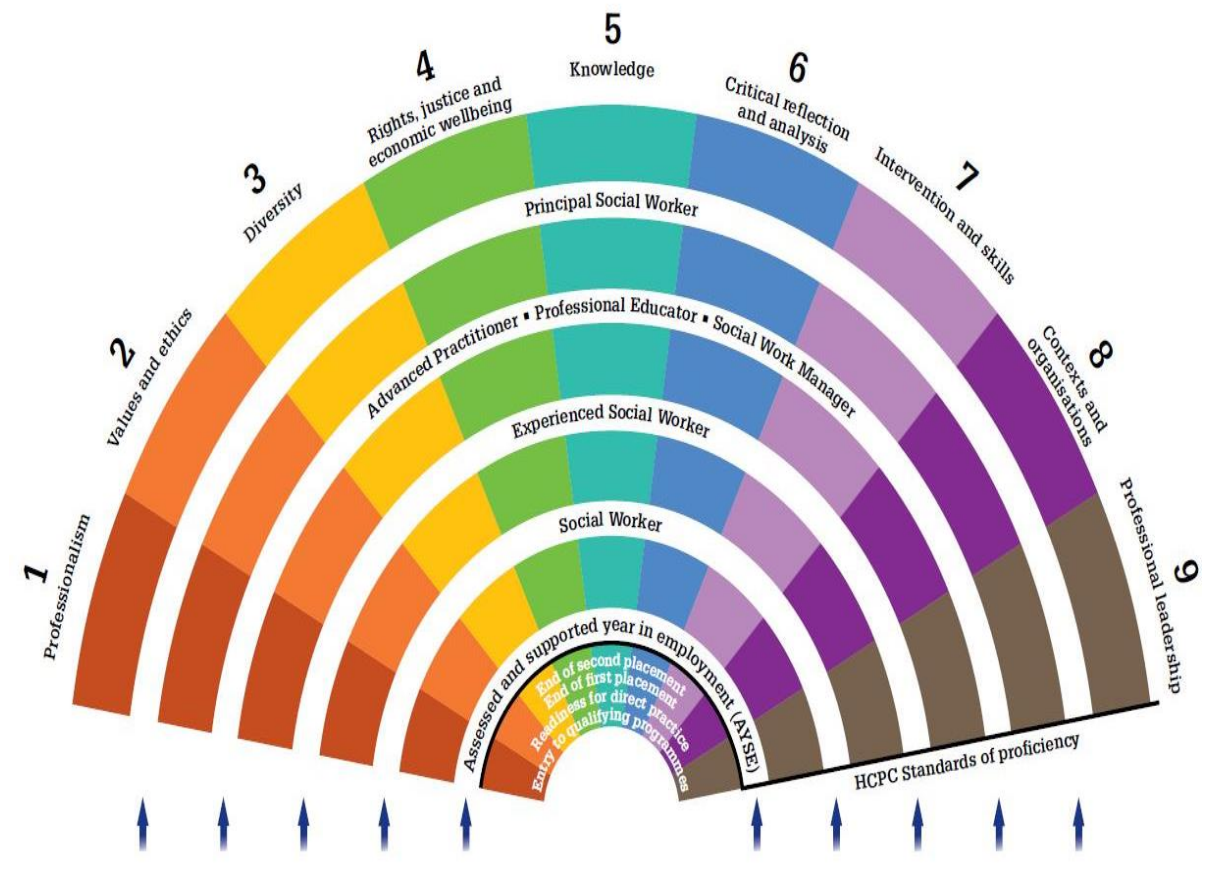
- a) personal dignity (including treatment of the individual with respect);

- b) physical and mental health and emotional well-being;
- c) protection from abuse and neglect;
- d) control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- e) participation in work, education, training or recreation;
- f) social and economic well-being;
- g) domestic, family and personal relationships;
- h) suitability of living accommodation;
- i) the individual's contribution to society.

(Department of Health, 2016)

Appendix 5

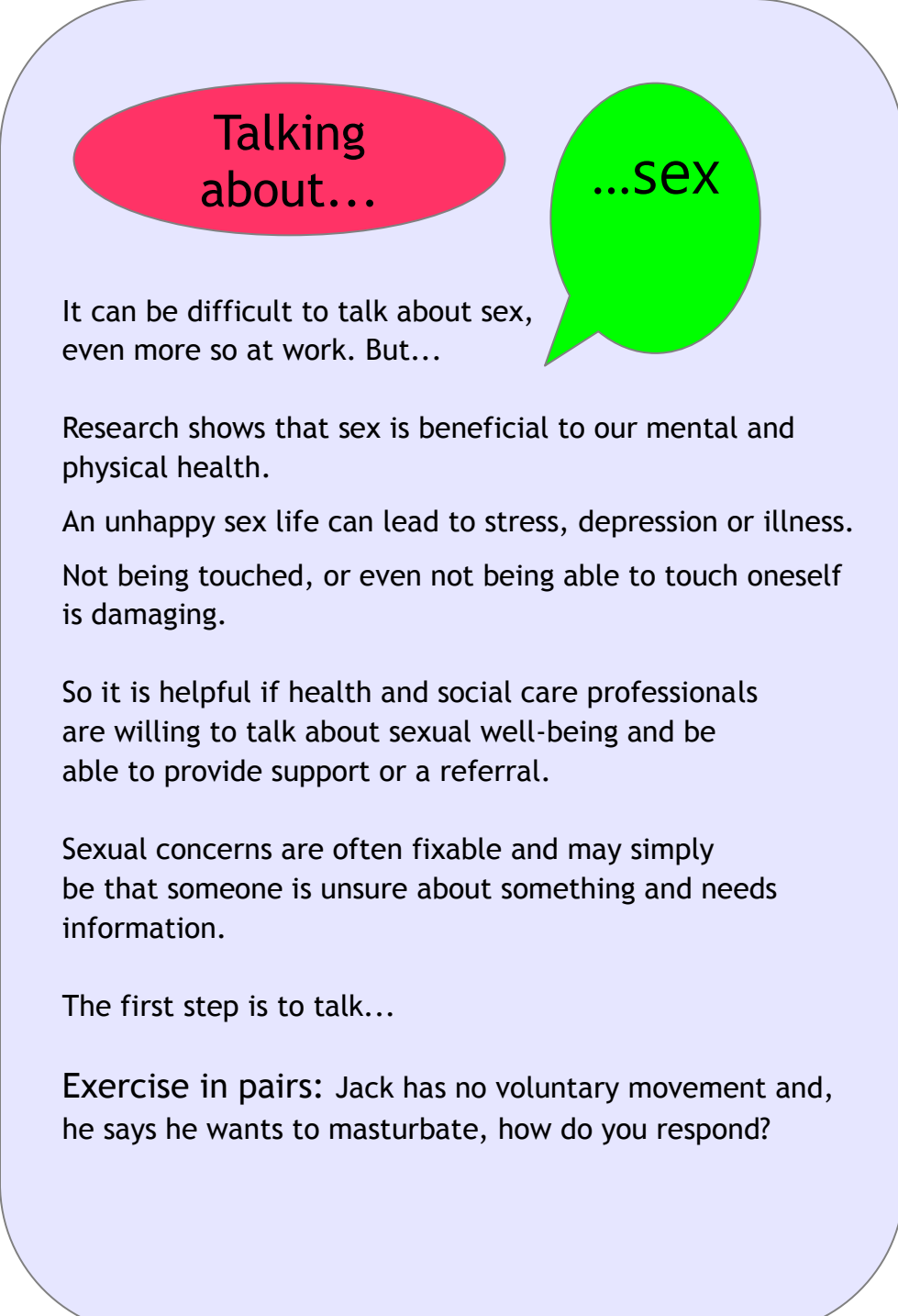
The Professional Capabilities Framework (The College of Social Work, 2012)



Appendix 6

Sample learning tool cards

These examples are limited in style and content. The final set of cards will be professionally illustrated and produced, and the content collaboratively agreed.



Talking about...

...sex

It can be difficult to talk about sex, even more so at work. But...

Research shows that sex is beneficial to our mental and physical health.

An unhappy sex life can lead to stress, depression or illness.

Not being touched, or even not being able to touch oneself is damaging.

So it is helpful if health and social care professionals are willing to talk about sexual well-being and be able to provide support or a referral.

Sexual concerns are often fixable and may simply be that someone is unsure about something and needs information.

The first step is to talk...

Exercise in pairs: Jack has no voluntary movement and, he says he wants to masturbate, how do you respond?

Barriers to talking about sex

It can be embarrassing talking about sex, but thinking about it can be more difficult than doing it.

Some reasons professionals give for not talking about sex:

No time

Fear of offending someone

Thinking there is no solution

Thinking the person would start the conversation if they wanted to talk about sex

Think of any other reasons and, using the information from these cards, ways of overcoming these barriers

By giving people the opportunity to talk about their sexual well-being you are recognising the whole person, and gaining a greater understanding of their health and care support needs.

Assumptions

Research shows that it is often assumed that disabled people aren't sexual.

Acknowledging our assumptions and sharing them with others can help us become more aware.

Make a list of the assumptions about sex and disability you are aware of.

Talk about:

Where have these assumptions have come from, and why do you think people have them.

How can this be used to develop an understanding of how normative assumptions operate in society?.

How can assumptions be challenged?