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**The Role of the Social Care Worker in
Interventions into Unacceptable Sexual
Behaviour in People who have a Learning
Disability**

Marilyn de Santos

**Ph.D. Social Work
University of Edinburgh
2013**

Declaration

This is to certify that the work contained within has been composed by me and is entirely my own work. No part of this thesis has been submitted for any other degree or professional qualification.

Signed:

Abstract

This thesis concerns the role of the Social Care Worker in interventions into unacceptable sexual behaviour in people who have a learning disability. It takes as point of departure ways in which support organisations and individual members of staff become aware that a service user's sexual behaviour needs to be addressed. This raises issues about the service user's human rights, confidentiality, and the concept of what it is to be 'professional' which can affect information sharing between support organisations and also between fellow support workers. In the case of the latter this relates to the workers status within the organisation, relations of power/knowledge which also has implications for the status of these workers as 'professionals'. The thesis goes on to determine the support workers' perceptions of what Bourdieu has termed, their 'field'. That is to say, those behaviours they feel they can address without consulting health professionals. In addition to this, criteria used to decide when it is appropriate to consult health professionals is also described which thus demarcates their 'field' as perceived by the social care workers. The subsequent roles of the SCW whether working with or without input of health professionals is then discussed in terms of the individual worker's 'proximity' or working relationship with the service user in question, and also their status within the support organisation. Findings suggest that some front-line workers who can claim closer 'proximity' to the service user may not have the same level of information about the behaviour as their managers who work off-site and do not have their direct care. Consideration is then given to accounts of situations in which input from health professionals is sought but is not forthcoming leaving SCWs and their organisations to deal with the behaviour in-house. Some of these such as sexual assault and rape are thus being treated in the community when otherwise the individuals concerned would be treated in locked NHS wards. Thus a new 'field' emerges requiring of the SCW a level of responsibility and skill that goes unacknowledged. The thesis ends by considering the feelings of workers involved in interventions into unacceptable sexual behaviour and concludes with recommendations on the education and support

these workers require. Acknowledgement of the work they do and re-assessment of their status as workers is also recommended.

Acknowledgements

This has been a long journey but not a lonely one. First I would like to thank my supervisors Susan Hunter and Heather Wilkinson for their wisdom, encouragement and patience. I feel very fortunate indeed to have had their support. I am also grateful to the postgraduate administrative team and the valuable assistance they have given me over these last four years. My fellow PhD students also deserve mention for letting me off-load woes every now and again and share a laugh or two. Special thanks go to Dr Andressa Gadda for her unstinting moral support. Thanks are also due to the ESRC who funded this research.

In the course of this studentship I made some new friends including those I met in connection with the Australian aspect of this work. This would have been far more difficult if I had not had the help of Sam Murray of ASID. Having discovered how difficult it can be to gain access to people to interview, I must also acknowledge those helpful gatekeepers who were willing to try to recruit staff on my behalf, as well as the workers themselves who volunteered. As well as gratitude, I have great admiration for these individuals and the work they do. It was a privilege to meet them and hear their stories.

I have been blessed with good friends. They have kept me going with their warmth, laughter, and more than a little sympathy when things were not going to plan. Sadly, last year I lost two who were and are very dear to me, Fiona Morgan Costa and Viv Blanchard. They will never know how much their friendship meant and how much I owed to their wisdom and support. Lastly, I would like to thank my husband Rafi. We met the same week that I was awarded the ESRC grant for this studentship so he truly has been with me every step of the way sustaining me with his love.

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Chapter 1

Problem Definition

1.1 Research topic

This research is concerned with the role Social Care Workers in Scotland and Melbourne Australia play in interventions into unacceptable sexual behaviour in people who have a learning disability. In many cases the organisations for which they work will not have a clear policy to which these workers can refer for guidance. Thus this work will commence with a review of policies with regard to such guidance, updating that done in Scotland in 1996. No similar review was done on the Australian policies in question so these will be analysed for the first time. Research will then continue by determining the factors involved in becoming aware of the behaviour; those concerned in deciding whether an issue needs to be addressed, and factors which decide whether the matter can be dealt with in-house or when it is thought necessary to bring in the services of a health professional. The roles of the SCW in both situations are described and contextualised by the worker's status within their organisation and their working relationship with the service user in question. The status of SCWs as perceived by society in general is also considered. Lastly, these workers' feelings about their involvement in the modification of service users' unacceptable sexual behaviour are also described.

1.2 Australian context

In Scotland, UK government policy in the late 1980s advocated the closure of NHS hospitals for people who have a learning disability with the purpose of moving them into the community where they could be supported to live a better, where defined as normal, quality of life. In terms of community living, Australia, along with the US and the UK was at the forefront of the change from institutional care to care in the

community for people with learning disabilities (Mansell 2005).¹ Additionally, as in Scotland, Australian support services have a procedure they call ‘Life Planning’ (in Scotland ‘Person Centred Planning’), which is about the development and maintenance of independent living skills yet exclude those of intimacy (Chivers & Mathieson, 2000). Similarly, these writers also note that Social Care Workers in Australia, in spite of training in Sexuality and Relationships, still seek the help of health professionals when confronted with such service user issues (ibid). In Scotland Social Care Staff are for the most part untrained in dealing with service users’ sexuality so look to health professionals, particularly community nurses for advice. The workers may also have misgivings about dealing with these matters themselves because of service users’ parents’ different perceptions of care and health worker roles in this matter (Sangster: 2007). What follows are Social Care Workers’ accounts, from both locations, of working with and without health professionals to modify service users’ unacceptable sexual behaviour.

With regard to terms used in each location, whilst we in the UK refer to individuals having a learning disability in Australia the term intellectual disability is used. Similarly, whilst we in the UK use the term Social Care Worker, (SCW) those who work in Australia are referred to as Disability Support Workers (DSW). The term Key Worker which is used in the UK becomes Core Worker for those similarly employed in Australia. For the sake of consistency, in all these instances, the UK versions will be applied in this research, unless as specifically used by the interviewee.

1.3 My context

I have worked as a Social Care Worker with people who have a learning disability for over 10 years. In that time I have been surprised and dismayed that the sexual lives of these service users are not usually accounted for until there is a problem that has to be addressed. This not only pathologises the individual but can serve to perpetuate cruel myths about people who have learning disabilities as sexual

¹ In 2007 there were approximately 120,000 people who have a learning disability living in Scotland. Most of these individuals lived at home or in supported accommodation. Perera *et al* (2009)

predators. Rarely is the information that a service user has had any sex education, or their level of sex education recorded, even in those few instances where it has been provided (Sangster, 2007). Furthermore, given the nature of learning disabilities in which advice about all manner of things may need to be reinforced, sometimes on a daily basis, it is questionable whether this is being applied generally to matters of sexuality. More remarkably, services can fail to record incidents of unacceptable sexual behaviour, including attempted rape (ibid). Such omissions set both the individual, and the organisation that otherwise supports them, up to fail. Where a victim is involved, they also suffer. Given that the ethos of care is now 'normalisation' (the former ethos was containment) in which service users can have their own tenancies and paid employment, it seems strange that 'person-centred' plans rarely take the service user's sexual needs into account. It would seem that for this particular group of individuals the shadow of sex as a taboo subject still falls across their lives.

1.4 Scope of research

Although my research concerns people who have learning disabilities of both sexes, men are more likely to act out behaviours that are sexually inappropriate or abusive (Lindsay *et al*, 2006). For those born of a more sexually conservative generation in which the sexuality of people with learning disabilities was often denied, ignorance is more prevalent (Sangster, 2007). Such ignorance in older men with learning disabilities can mean that this group is regarded as a particular problem by both care and health staff (ibid). They may have been brought up in an age in which people were more reticent about discussing sexual matters or they may have lived in long term institutions prior to living in the community, thus lack knowledge of what is appropriate and acceptable.

Regarding women, it is recognised that in the general population of the UK that they are less likely to get a custodial sentence for committing an offence (Hayes, 2007). The numbers of women who have learning disabilities and who sexually offend form a very small section of this population (Allam *et al*, 1997), and according to Hayes, are more likely to be jailed for prostitution-related offences which it could be argued,

constitutes self abuse as opposed to abuse of others. For the purpose of acquiring sufficient respondents I will interview Social Care Workers who have experience of service users' unacceptable sexual behaviour including those whose service user is over 16 years of age, is male or (more unlikely) female, and who has or has not been reported to the police.

1.5 Outcome of this research

In undertaking this research I hope to provide findings which will thus inform the policies of organisations and the training of Social Care Workers as well as their status as workers. In so doing, the quality of life of those who display unacceptable sexual behaviour may be improved through greater freedom in the community and by being perceived by others in a more positive light. Appropriate policies and adequate training of Social Care Workers will also lead to greater public safety whilst the knowledge and confidence and public's perception of the Social Care Workers themselves could be enhanced.

Chapter 2

Literature Review

2.1 Definition of 'learning disability'

The Scottish Government's Policy Document *The Same As You* (2000), defines learning disability thus:

“People with learning disabilities have a significant, lifelong condition that started before adulthood, that affected their development and which means they need help to:

Understand information

Learn skills; and

Cope independently” (3)

This is different from having a learning *difficulty* which means that individuals have problems with one particular aspect of learning:

“but otherwise can cope without support. For example, those who have difficulty with reading, writing or numbers but otherwise have normal cognitive development” (mhtml: accessed 31/08/2009).

2.2 Definition of sexuality

In their policy on Sexuality and Relationships, one Scottish support organisation defines 'sexuality' as follows:

“Sexuality is a term used to describe the aspects of us that are associated with sexual thoughts, feelings and behaviours. It can be considered in terms of physical expression, self-image, emotional development, social circumstances, sensuality, spirituality and personal identity”.

Further this policy advises staff that:

“All individuals with support needs have sexuality and should be supported to foster this where possible. For people with profound or multiple disabilities it might not be

possible for this to be expressed physically through having sex with others or even by themselves through masturbation. However it is entirely possible for all people to explore and express sexuality through other means such as close friendships, being held, or through non sexual sensual stimulation.” (Loretto, 2011: 4).

As this definition makes clear, expressions of individuals’ sexuality can take many forms and is not simply about our biology. Weeks (1995) writes that he rejects the essentialist biological explanation of sexuality in favour of social construction thus he writes:

“We have all too readily believed that sexuality is the most natural thing about us, that our drives are fixed and inherent, that our identities are dictated by that nature and those drives, and that a history of sexuality must be no more than an account of reactions to those basic biological givens” (5).

Rather, he argues, sexuality should be understood in its historical and cultural context and in terms of power relations. Certainly in Western society the considerable influence of Christian teaching has served to promote heterosexuality as the ‘natural’ and only acceptable way of acting out sexual needs. The law in the UK criminalising homosexual activity was a classic example of creating and enshrining norms of behaviour. However, Weeks goes on to assert that our bodies are not *tabula rasas* on which a society inscribes its sexual ideals and that biology is still relevant to our sexual behaviour. I concur with Weeks on this point and would argue that the Gay Rights movement and the drive to gain acceptance of homosexuality would simply not exist since every individual would be ‘programmed’ to express their sexuality in a given (heterosexual) way. Rather, we are the product of both biology and the culture into which we are born.

In terms of sexuality and its expression, people who have learning disabilities are no different to anyone else. In my Masters research interviews with Social Care Workers brought forth accounts of service users expressing their sexuality in various ways which included, heterosexual, homosexual, bisexual, transvestite, autoerotic and fetishistic ways (Sangster, 2007). When we talk of sexuality then I would suggest it is taken to mean the ways in which an individual’s drive to be sexually active is manifest. Yet no matter how legal a given expression of sexuality is, it

remains the case that not every instance of that legal activity is acceptable, and by this I refer to times when the activity impinges on the rights of others as in the case of molestation or rape, or involves exploitation of those who are vulnerable as for instance is the case with paedophilia.

Riddell and Watson (2003) quote Crow who asserts that even when social barriers to disability are removed a personal barrier to inclusion in 'ordinary life' remains. As someone who has a physical disability Crow writes,

“our experience of impairment means our experiences of our bodies can be unpleasant or difficult . . . for many disabled people personal struggle related to impairment will remain even when disabling barriers no longer exist” (4).

In this instance, the reference is to physical disability and its relation to conventions of physical attractiveness and actions. However, with a learning disability, such physical barriers often do not exist and so barriers to sexual relationships can exist outside the individual rather than within them. Lack of opportunity, lack of knowledge, carer's caution in the name of safety of the individual and that of others are thus more likely to be the barriers between people who have a learning disability and a sexual relationship. Of course, this does not mean that their need/drive to be sexually active diminishes.

2.3 Use of the term 'unacceptable sexual behaviour'

McCormack *et al* citing Brown & Turk define sexual abuse as occurring when:

“sexual acts are performed on, with, or sometimes by someone who is unwilling or unable to consent to those acts, or who has been unduly pressured into consenting within an unequal relationship” (2005: 220).

This applies to all perpetrators, learning disability or not. Masturbation is illegal when done in public view, but is not illegal when someone does it privately. However in the latter case, if it is done to excess and to the exclusion of other activities or leads to personal neglect it will still be considered a problem. Similarly it is not illegal to have sexual intercourse in your own living room, but it may be

offensive to others if they are in the room at the same time. Ward, Trigler and Pfeiffer (2001) define what they referred to as ‘sexualised challenging behaviour’ which, they describe as: “sex acts involving non-consenting partners, sexual behaviour that is public or intrusive, and/or sexual behaviour that presents danger to the individual or others” (294).

In their research which takes as its point of departure the stance that all challenging behaviours, sexual or not, are functional, these writers set out to empirically define the term as experienced within Irish learning disability services. Coding service user files and interviewing support staff led them to identify two broad categories; self- and other-directed behaviours. The former consists of masturbation and self-touching in public: exposure that is non-targeted and what these authors describe as ‘bizarre sexual behaviour’, and also looking at internet porn in a public location². Those behaviours regarded as ‘other-directed’ include, touching a staff member or other person - sometimes in an aggressive manner - or between service users when there is a question over mutual consent; also verbal and written communication to staff and finally, inappropriate exposure which is other-directed. They use the term ‘sexualised challenging behaviour’ which they further define as consisting of: “a continuum of self and other-directed behaviours related to touch, exposure and communication which they view as distinct from sexual offending” (ibid).

2.4 Motivation

Ward, Trigler and Pfeiffer also found that for staff, one of the issues around these behaviours includes not being able to say if a sexually challenging behaviour has amounted to abuse. This is a central problem that often involves staff making a judgement call regarding the service user’s motivation, i.e. was the behaviour sexually motivated and was it done to take advantage of another’s vulnerability? Lockhart *et al* (2009) explain that research has also been fixated with differentiating acts as inappropriate or abusive. They write:

² It may be argued that some individuals derive sexual pleasure from the fact that they are viewing internet pornography in full view of others. This, I would contend, can also be ‘other directed’.

“Research has been limited to a focus on ‘sexual offending’ and ‘abuse’, terms which are often criticized in their applicability to people with intellectual disabilities given their connotations of criminal intent or insight” (293).

Sajith *et al.*, also argue that:

“whether these behaviours are considered as challenging behaviour or sexual offending is determined by a number of factors including the involvement of the criminal justice system” (2008: 1079).

Yet involvement with the Criminal Justice System is preceded by someone else’s judgement call, and as Wilcox (2004) asserts, the public perception of people who have learning disabilities is either that they are sexual innocents or sexual deviants with the result that people who find them engaged in any type of sexual activity respond in widely varying ways. In the case of masturbation, Wilcox concludes, that when done in public view it may be treated as a criminal act without realising that the perpetrator has neither the knowledge nor the private space for appropriate masturbation. To be sure, even when people with learning disabilities are appropriate in their sexual behaviour it can draw negative responses from others.

Tarnai (2006) asserts that sexual acting out can be for many reasons, for instance, deficits in the cognitive functions of impulse control and judgment; being unable to communicate that clothes are ill-fitting; health problems like tight foreskin; attention seeking or peer influence. Other possible factors include boredom or anxiety. Wilcox offers yet another explanation and quotes Day who writes:

“their sexual offending is essentially the consequence of crude attempts to fulfil normal sexual impulses in the absence of normal outlets compounded by poor adaptive behaviour, sexual naivety, poor impulse control and social ineptness” (91).

With regard to the former Tarnai argues that:

“problems arising from expressing sexuality are not a direct consequence of cognitive disabilities. They result from the everyday dependences of persons with cognitive disabilities on others, and from attitudes of parents, educators and caretakers regarding their own ideologies about sexuality of persons with cognitive disabilities and the importance they attach to sexuality in those persons’ lives” (151/2).

What Tarnai suggests here is that a person with a learning disability should be regarded as innocent in that all their sexual behaviours including those that would otherwise be labelled as abusive can, rather, be deemed inappropriate because these individuals have simply not been given even basic sex education or opportunity. Certainly, the fact that such perpetrators often lack the guile to hide their actions (Tudway & Darmoody, 2005) could be construed as evidence to support this argument. Mitchie *et al* thus term this behaviour ‘counterfeit deviance’ (2006).

Yet Tarnai also points out that it is often weaker people in the community who are targeted by the men as victims of their sexual activities, which suggests some level of awareness that what is being done is reprehensible though the culprit may not understand the reason why. Additionally, Allam *et al* (1997) write that whilst many offenders who have a learning disability display poor impulse-control this is not to say that offences are not planned prior to being committed. Indeed, they add:

“some individuals are capable of undertaking meticulous ‘grooming’ behaviours, particularly of children. However, they are seemingly able to move much more readily from situations which trigger arousal into committing the abuse in a very short space of time” (158).

Ward, Trigler & Pfeiffer’s use of the phrase ‘sexualised challenging behaviour’ was created by them in order to infer that all sexualised behaviour in this service user group must be assumed to have come about through their innocence rather than intent. Nevertheless, it is as Fairbairn asserts, “In determining an act as abusive, the motivating force that lies behind the abuser’s behaviour is important” (2002: 21). Indeed, the course of action taken to modify the behaviour depends exactly on establishing the motivation. Thus in light of the difficulty in establishing service users’ motivation, which is in any case, outside the remit of this body of research, it is more useful then to follow Beebee when he borrows Thompson & Brown’s term ‘unacceptable’. This encompasses sexual behaviours that are both inappropriate and those that are abusive, as well as being sexually or non-sexually motivated. Use of this term also serves as Beebee points out, to acknowledge the potentially harmful effects of such behaviours on those who are exposed to them (2003).

In any case, illegal or not such behaviours need to be addressed. To this end policy documents such as *The Same As You*, *National Care Standards: Care Homes for People with Learning Disabilities*, and The Scottish Social Service Council's *Codes of Practice for Social Service Workers and Employers* direct organisations to support all their service users to lead normal, socially acceptable lives. As is the case with criminal sexual behaviour, that which is not considered by staff to be an offence receives 'patchy' responses. This mitigates against the individuals' chance of leading a 'normal', socially acceptable life.

2.5 Prevalence of unacceptable sexual behaviour

Commenting on the percentage of young people with learning disabilities who display harmful sexual behaviour, Almond & Giles (2008) suggest that:

“this could be due to imprecise definition of ‘Learning Disabilities’, testing problems, and the impact of trauma and neglect on young people’s development leading them to be placed in the category ‘Learning Disabled’” (228).

Commenting on the percentages of police arrests, Yacoub & Hall (2008) note that previous research has shown that although it is common practice amongst gay men, both with and without a learning disability to have sex in public places, people with learning disabilities may be more vulnerable to police arrest. Further, Swango-Wilson (2008), makes the point that when calculating the extent of abusive behaviour in this service user group, it should be remembered that women with learning disabilities do not always recognise that they have been abused so any expectation of accurate figures of those whose behaviour is unacceptable is futile. However it remains the case that some people who have a learning disability display sexual behaviour which needs to be addressed.

Almond & Giles (2008) write that while offending in general is uncommon among people who have a learning disability, sexual offending seems to be over represented. ‘Respond’ a charity that provides therapeutic support for victims and perpetrators of sex crimes who have learning disabilities add that as such young people account for 30 – 50 % of those who display sexually harmful behaviour (Respond: accessed

12/05/09). Regarding all sex offenders over the age of 16, Day (1993) found that over a 40 year period the rate of imprisonment for people who have a learning disability ranged between 12 – 46%. Aside from this wide discrepancy it should be remembered that most sex crimes committed by men with learning disabilities do not get reported to the police (van den Bergh & Hoekman, 2006), and those men who are reported are rarely charged (Vaughn, 2003). Thus the actual numbers of perpetrators can hardly be exact but for the purposes of this research it will be accepted that the figures are as Lindsay *et al* (2006) assert, ‘significant’.

2.6 Interventions

In the case of abusive sexual acts being perpetrated by people with Learning Disabilities against Social Care Workers themselves, research has found that in many cases such situations are dealt with in-house or even left unaddressed by staff members or the organisations they work for (Tudway & Darmoody, 2005). A similar situation exists where the victim also has a learning disability. Yet as Tarnai (2006) insists: “over tolerance is not an attitude that serves normalization of the lifestyle of persons with cognitive disabilities in society, in the community” (165).

Nevertheless historically interventions have ranged from being highly questionable to downright barbaric. Tarnai writes that treatments of inappropriate masturbation has included hand smacking, forcing the individual to drink lemon juice, and in the case of one nine year old Australian boy, castration. As Beebee asserts:

“Ethical considerations are vital to ensure that the intervention supports an individual’s acceptable sexual expression, while the effect of unacceptable behaviours should not be ignored and aversive interventions should be avoided” (2003: 10).

In any case Lambrick & Glaser (2004) advise that the first task of assessment of the person with a learning disability is to determine whether the behaviour was due to a lack of knowledge thus what they label ‘inappropriate sexual behaviour’ or if there are more serious underlying criminogenic processes such as sexual deviance manifest. As argued above, if this can be done then it will indicate the type of intervention that is required.

2.7 Types of intervention

2.7.1 Drugs

Sajith *et al* (2008) note that currently psychological therapies are the most prevalent intervention to modify problematic sexual behaviour. These they add are used for both those with and without a learning disability. These writers add that pharmacological treatments have also been advocated, especially for those who have committed serious sexual offences and pharmacological drugs are also used for managing risk in serious sex offenders in the community. However, they note, little research has been done into efficacy of the drugs though known side effects can range from fatigue, and in extreme cases, to death. Moreover, Sajith *et al* note that where trials into the efficacy of these pharmaceuticals involve user's self-reporting their effects, the results in such circumstances must be questionable. These writers also highlight the ethical problems associated with the use of drugs. They state that in their suppression of aberrant sexual behaviours the drugs may also suppress normal sexuality and its expression for the convenience of the individual's carers. For these reasons psychological interventions are the preferred method of modifying unacceptable sexual behaviour.

2.7.2 Behavioural therapy

Psychological interventions are based on behaviour management, sex education, strengthening appropriate sexual behaviours and training in social skills and assertiveness (Sajith *et al*, 2008, See also Wilcox, 2006). A version of Clinical Behavioural Therapy has been modified for people who have learning disabilities and is the current favoured approach because it is thought to be effective in reducing recidivism (Lindsay (2000) in Sajith *et al*). Yet this is only available in specialist centres (*ibid*), and, I would add, by appointment.

2.8 From policy to practice

2.8.1 Introduction

Hill (1997) describes the path of a policy thus:

“from a general commitment to action, through the formal enactment of a law, to the establishment of a series of guidelines to implementing ‘street-level’ *interpretations* (my italics) and thus eventually an ‘output’” (141).

In this research the path from policy to practice is concerned with the implications of the former in relation to service users whose sexual behaviour is unacceptable, and ways in which this is manifest at the level of practice. On occasion, recommendations framed within a policy can reveal lack of foresight. As Hill continues:

“The central problem is that while some policies pass out of the legislative stages with very clear rule structures enabling implementation deficits to be easily identified, others are much less fully formed” (ibid).

For example, and in the context of this research, is a policy about the support of a vulnerable adult understood by organisations to include those who are also perpetrators of sexual abuse? In this example there may be a need to elaborate exactly who counts as ‘vulnerable’ within the policy, and hence its laws and guidelines.

2.8.2 Policy

2.8.2.1 Scottish policy

In Scotland the government undertook a review of services for people who have a learning disability entitled *The Same as You* (2000). Resulting recommendations for improving these services form the government’s current policy on the care of people who have learning disabilities, which they describe as “fundamental to the delivery of local authority services” (Scottish Government, accessed 26/8/2009). In the body of the review the document states that:

“People with learning disabilities should have the following. Welfare to help them live lives which are as normal as possible. . .

. . . and helps them to be included and accepted with local communities.” (4).

Comment is also made about the more complex needs of those who have great difficulties with social development; who are in trouble with the law or who are aggressive and display socially unacceptable and challenging behaviour. Services are thus encouraged to “make sure an appropriate risk assessment is carried out and that treatment and ongoing support are provided as far as possible within the community” (18).

These sections of the review give rise to the following recommendations, which, via laws and guidelines, are set out to inform individual support agency’s internal policies. Thus:

Recommendation 22: “The Scottish Executive’s National Care Standards Committee is currently developing standards for residential and nursing care homes for all care groups including people with learning disabilities. These standards should look clearly at assessing and managing risk in working with vulnerable people”

Recommendation 23: “All local authorities in association with health boards NHS trusts and other agencies should develop policies and guidelines on protecting vulnerable adults. . . .”

2.8.2.2 The state of Victoria’s policy

The city of Melbourne is situated in the State of Victoria, Australia and so is subject to State, as well as national policies. The United Nations’ *Declaration on the Rights of Disabled Persons* drawn up in December 1975 under the Charter of the United Nations and proclaimed by their General Assembly, pledged to promote: “higher standards of living, full employment and conditions of economic and social progress and development of all the Member States’ disabled citizens” (State of Victoria, accessed 5/7/2010).

Thus the Declaration proclaims the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged. With particular relevance to this research is the further directive that:

“Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever their origin, nature and seriousness of their handicaps [sic] and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal or as full as possible”,

And further, that they have the right to:

“...functional treatment ... to medical and social rehabilitation ... counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration” (ibid).

This maxim applies to all individuals who have a learning disability including those whose sexual behaviour is unacceptable.

In keeping with this, the *Australian Human Rights Commission Act 1986* (Australian Government, accessed 5/7/2010) established the body *Human Rights and Equal Opportunity Commission* in order to oversee the *Declaration's* directives. The *Commission* met these with the introduction of various Acts such as *The Disability Discrimination Act 1992*, which seeks to ensure equal opportunities in, for example, employment and education (Australian Government, accessed 5/7/2010). Whilst such Acts were drawn up at the level of the Commonwealth (i.e. Australia-wide) individual States such as New South Wales and Victoria were simultaneously drawing up State Laws which also reflected the directives of the *Declaration*³.

2.9 Law

2.9.1 Scotland and the state of Victoria - consent or abuse?

When an individual who has a learning disability has poor or none existent communication skills it is imperative that support staff establish whether they are participating in sexual activity with another because they consent to this, or whether they are in fact being abused. This is essential in the identification of both victim

³ Those who discriminate can be prosecuted and convicted under either Commonwealth or State Law, but not both.

and culprit. In Scotland the *Adults with Incapacity Act* (2000) states that where there is doubt about an individual's ability to consent to a sexual act either because of the level of their disability, lack of knowledge, or by their level of communication, organisations are compelled to assess the individual's capacity to give consent in this particular context. If organisations are unable to do this then they must refer to a court of law to make a decision. Referring specifically to people who have a learning disability, State Law of Victoria is also concerned with an individual's capacity to consent to sexual activity. Guidelines on the DHS intranet entitled, *Personal relationships and sexuality: Disability Service*, state that the ability to give consent is defined by the individual's awareness of the nature and consequence of the act they are consenting to (2006). To express this another way, the Supreme Court of Victoria have decreed that, it is when a person, in this particular case a woman:

“has not sufficient knowledge or understanding to comprehend (a) that what is proposed to be done is the physical act of penetration of her body by the male organ or, if that is not proved (b) that the act of penetration proposed is one of sexual connection as distinct from acts of totally different character” (quoted in Graydon,).

This is known as the ‘Morgan’ direction (ibid). Graydon adds that this was further elaborated in 2005 when a jury in a similar case involving a woman, was directed:

“if the complainant has knowledge or understanding of what the act compromises and its character ... then she has all that the law requires for capacity to consent. That knowledge or understanding need not be a sophisticated one. It is enough that she has sufficient rudimentary knowledge of what the act comprises and its character to enable her to decide whether to give or withhold consent” (ibid).

Graydon notes that in the Court of Appeal this was regarded as a correct statement of law. As the author comments, this standard of knowledge is much lower than that required under Victorian law to give informed consent to therapeutic treatment, and is also lower than criteria in other countries such as the US. Although cases cited here concern penetrative sexual acts, ‘indecent acts’ against a person with intellectual disabilities are also illegal (*Crimes Act* 1958; Section 39).

In Scotland, when a person has capacity to give consent but cannot because they are being coerced, the *Adult Support and Protection Act* (2007) empowers local

authorities to remove the vulnerable adult to a place of safety or bar their abuser from coming in contact with them. In Australia, the *State Disability Plan* deals with the matter of coercion. According to the Intellectual Disability Rights Services in Victoria an individual can take out an Apprehended Violence Order against another who is physically or mentally abusing them. Nevertheless this requires the person with the intellectual disability themselves to be pro-active in either accessing the law for themselves or approaching others to act on their behalf. If they are very frightened of what the abuser will do to them then they may not take any action at all. The OPA (Office of the Public Advocate) also run a Community Visitor Programme in which volunteers who have the power to do spot checks on organisations, and can interview service users, report back any concerns they have about an individual's support. If an individual who has a learning disability lives at home they may be subjected to abuse by a member of their family and Victoria's Plan for Community Safety and Security (2010) outlines intentions to conduct a review of its *Family Violence Protection Act 2008* to include making interventions where non-family members are abusing individuals (Section 15).

2.9.2 The Law and protection of victims

2.9.2.1 Scotland

Recommendations, based on mention of treatment and support in the text of *The Same as You*, can be taken to include amongst the vulnerable those whose behaviour is challenging or an offence. In terms of staff practice then how do these policy directives inform the law regarding protection and support? Where there is a question over whether the individual is a willing partner in a sex act or its victim, the *Adults with Incapacity (Scotland) Act 2000* makes provision for agencies and their agents to intervene in matters of welfare of an adult who is suspected of not having the capacity to act on, make decisions on, or retain memory of a decision because of their learning disability (City of Edinburgh Council, November 2008). Going by the opinion of those who know the person well or, ultimately, the Courts, the individual's capacity to give consent is gauged. By this law inability to give consent in one situation does not necessarily indicate an inability to give consent in another. Furthermore, this law can also find for the 'accused' if the ability to give consent is

confirmed. Thus the vulnerable ‘victim’ and the innocent ‘abuser’ may find protection in this law.

As mentioned above, Hill pointed out that ‘implementation deficits’ can become apparent in the working of a law enacted to realise a policy’s recommendations. Such is the case in the drawing up of the *Adult’s Support and Protection (Scotland) Act 2007*. Essentially this law recognises the fact that even where a person has indisputable capacity to make decisions these cannot be realised if others coerce them with, for example, threats or violence. Where this is suspected to be the case the local authority can access the individual under threat for interview to try and establish the facts. Where confirmed, the local authority can invoke a Removal Order to place the individual in a place of safety (with their permission), or can get a Banning Order to remove the abuser(s) from the individual’s home.

2.9.2.2 State of Victoria

In keeping with the spirit of the Declaration, the State of Victoria brought forth their ‘*State Disability Plan 2002 – 2012*’ which sets out policy regarding the life-style expectations of people who have a disability. At its heart of course, is the concept of ‘Rights’ and a commitment to “strengthen the disability support system so that people’s individual needs can be met” (5). The Plan advocates the introduction of the individualised support model based on a person’s needs and choices and promises that by 2012 these individuals will be as much a part of society as anyone else. Part of this includes the acknowledgement of the vulnerable and sometimes exploitable nature of having a disability since special mention is given to the level and nature of support that should be ensured where people are experiencing physical, emotional or sexual assault or harassment. Where this leads to the involvement of the Criminal Justice System, the Plan states that its agents must respond to people with a disability in a more effective manner. An improved response must be given to people with a disability who offend as well as those who are victims of such abuse. In all these respects Victoria’s Plan is comparable with Scotland’s ‘*Same as You*’ Policy, and sets out to eradicate the dismissive way in which people who have a learning disability have been treated in their encounters with the CJS.

Victoria's *State Plan* engendered new Acts and also caused a review of those in existence. For example, *The Disability Act* (2006) was brought in to improve services to people who have a learning disability. Again, based on the principles of human rights and citizenship, the *Act* provides guidance for service providers on how they may re-orientate the nature of their support. By means of Individualised Planning (Equivalent to Scotland's Person Centred Planning) support is now about self-determination, community membership and citizenship rather than confinement (Disability Forensic Assessment and Treatment Service: 2009). Additionally, in terms of improving the safety of vulnerable individuals, the *Crimes (Sexual Offences) Act* 2006, introduced a new section to the *Crimes Act* 1958 which outlaws the sexual penetration of, or indecent acts upon, people who have a 'cognitive impairment', perpetrated by staff or medical or therapeutic services (51:1/2) and from service providers' staff (52: 1/2). Furthermore, where cases come to court, the *Act* gives directives for facilitating the giving of evidence of individuals with learning disabilities, be they witness, victim or accused (23: 1A, 1B, 1C, 1D). One element of this is to ensure that people with learning disabilities have a voice in encounters with the CJS, is the introduction of the *Independent Third Person Program* run by Victoria's Office of the Public Advocate (OPA). Its purpose is to provide individuals who will assist those who have a learning disability or mental illness who are being interviewed by the police. It is the Third Person's responsibility to ensure that police are aware of the interviewee's lack of understanding of their rights or circumstances in these situations. The Third Person also assists with communication and helps appoint legal services where necessary⁴. Independent of the police and run on a voluntary basis, training and registration is done through the OPA. Support is mandatory and available to victims and alleged offenders, as well as witnesses who have a learning disability. The introduction of the Independent Third Person in Australia, and in Scotland the Appropriate Adult, is a means of overcoming difficulties, usually communicative, experienced by vulnerable people in these situations.

⁴ Independent Third Persons do not however advise the individual they are helping on how to deal with the matter in hand.

2.9.3 The Law and support of culprits

2.9.3.1 Scotland

Following on from recommendations made in *The Same as You*, how does the law act to protect those with a learning disability who also offend? Where the individual charged with an offence has a mental health problem and/or a learning disability then the *Mental Health (Treatment and Care) (Scotland) Act 2003* (henceforth referred to as the Act) also applies⁵. Under the Act, a Local Authority is obliged to provide or secure provision of services for those who have what they refer to as a ‘mental disorder’. Such provision must include the opportunity for these service user groups to “lead lives which are as normal as possible” (Part 4: Ch 2: 25: 2b). Further, services must be designed to “promote the well being and social development of the person” (Part 4: Ch 2: 26: 1a). These directives follow policy to the letter.

Where a culprit continues living in the community Local Authorities are required to enquire whether “because of their mental disorder, the safety of some other person may be at risk” (Part 4: Ch 2: 33: 2d). Steps may then be taken via the authority’s Medical Officer to remove the individual to a more secure setting if this is found to be advisable. However, the law does not offer guidance on what support organisations should do with the individuals known to the law but considered a low enough risk to continue living in the community. Nor does it provide guidance on what to do about individuals who are in danger of coming under the scrutiny of the law because of unacceptable sexual behaviour. For this, we need to look at national guidelines.

2.9.3.2 State of Victoria

Victoria’s *Disability Act 2006* has as its objective that all individuals who have a disability should “live free from abuse, neglect or exploitation” (13). To this end the Act directs that disability services “be provided in a way which reasonably balances safety with the right of persons with a disability to choose to participate in activities

⁵ The Act as currently framed, does apply to people with a learning disability and some offenders with learning disabilities can find themselves subject to its provisions. The Adult Support and Protection (Scotland) Act may also apply if they meet the three point test.

involving a degree or risk” (2 (n)). This statement contains the promise of both safety and empowerment. Pertaining to individuals whatever their disability it may also be understood to refer to the risks involved in forming relationships, sexual and otherwise. Section 58 (4) of the Act provides Residential Services with advice that: “the need to ensure that there is a reasonable balance between rights of residents and the safety of all residents in the residential service”. Again, this applies to services whatever the disability and whatever the activity.

Victoria’s *Disability Act 2006* also contains extensive guidance regarding interventions involving service users whose behaviour challenges. This may be taken to include those whose sexual behaviour puts themselves or others at risk. As in Scotland’s *Mental Health (Treatment and Care) (Scotland) Act 2003*, the Victorian equivalent of the Medical Officer – the Senior Practitioner - has special powers that include deciding when it is necessary to use restrictive interventions, or compulsory treatment by service providers (27 (1) a). In addition to investigating situations, the Senior Practitioner monitors cases and the support engendered (27 (1) b). Further, the Practitioner can advise when to stop treatment but must provide assistance in developing an alternative strategy (27 (3) c). Where treatment by the service provider is recommended an Authorised Program Officer must be identified from within the support organisation. They ensure that any restrictive intervention that has been advised by the Senior Practitioner is administered in accordance with the Act (*Disability Act 2006: Restrictive Interventions Implementation Guide*, 139 (1). In Australia this marks the move towards a therapeutic approach to jurisprudence (Disability Forensic Assessment and Treatment Service, 2009). In terms of service users whose behaviour poses a significant risk of serious harm to others and who are thus in danger of committing a criminal act, a service provider’s Authorised Program Officer can apply for a supervised treatment order (STO). On satisfying certain requirements this will be granted and the service user may be referred to DFATS for services which come under the Community Programme and/or Consultancy Programme (ibid). The former provides specialist treatment services for people who reside in the community as well as those who are young and in custodial settings and

adults incarcerated in correctional settings, whilst the latter is an advice and support service offered to those organisations that support them (ibid).

2.9.4 Guidelines

2.9.4.1 Scotland

The Scottish Commission for the Regulation of Care has published the *National Care Standards: Care Homes for People with Learning Disabilities* (Scottish Executive: 2005) which sets the required standards for all providers of care and support to those who have a learning disability. So what does it advise by way of supporting this service user group in cases of unacceptable sexual behaviour?

Initially, service users are assured that they have a right to “be treated equally and to live in an environment which is free from bullying, harassment and discrimination” (6). Thus those who are abused and those who act in an unacceptable manner are afforded the same consideration, respect, and level of service. Additionally, Standard 5 of the guidelines states that

“You [will] experience good-quality support and care. This is provided by management and staff whose professional training and expertise allow them to meet your needs”, which includes “managing risk” (20).

As in keeping with the new ethos of care this should be less about containment and more about enabling people to live in the community⁶. Standard 5 concerns support arrangements including staff developing “with you a personal plan that details your needs and preferences” (23). Although the nature of needs is not elaborated the commitment to treat all equally means that the care needs of those whose behaviour is unacceptable must also be met. This can involve “any measures of restraint which staff may have to use for your own safety or the safety of others” (ibid).

The *National Care Standards* document appears to give full consideration of service users’ rights and support needs. However, it may be argued that this becomes questionable when confidentiality becomes an issue. Standard 9 which concerns

⁶ Restraint can be used legally but its use is subject to strict conditions and “will not be used until other interventions have failed (unless legally required)” (Scottish Executive, 2005: 31).

protecting service users' interests assures the service user that "staff record and investigate any accidents or incidents, including any episodes of restraint, telling, relatives, carers, or other representatives *if you want them to*" (my italics) (31). Yet guidance at Standard 10 asserts that "If any information cannot be kept confidential you will be told why not and who has the right to see it" (32). This addendum is protective of others giving them the information they need to keep safe. The abusive individual will also be less likely to be put in temptation's way and be charged with an offence as a consequence. In short the individual's needs in terms of community acceptance will be met at all times. Part of meeting this need is expressed in Standard 10 which advises that: "If your behaviour challenges ... you [will] receive good professional support to understand and, if possible, change your behaviour" (32). *Codes of Practice for Social Service Workers and Employers* (SSSC: 2005).

Clear instruction to meet the needs of all service users, whatever that may amount to, is expressed initially in the recommendations made by *The Same as You*, and informs resulting laws and guidelines. Yet responses at the level of service delivery to unacceptable sexual behaviour remain 'patchy'. This may possibly be due to the nature of individual organisation's policies which fail to advise their workers on steps they should take when one of their service user's sexual behaviour is unacceptable. Since a survey on this aspect of organisation's policies has not taken place in Scotland since 1996 (L. Brown) it will be of interest to discover whether this situation has changed for the better.

2.9.4.2 The state of Victoria, Australia

The State Government of Victoria's Department of Human Services oversees Disability Services in Victoria and sets the standard for them in accordance with the *State Disability Plan* which applies to both its own service provision and also NGO services in the State of Victoria. These standards are in keeping with those laid out in the DDA 2006 and direct that e.g.

"support options are planned, developed, implemented and reviewed in a manner that builds opportunities for individuals to participate in the life of the community" and also "enables the achievement of valued roles in the community

(State of Victoria, accessed 5/7/2010).

Services outcome standards set within the *Disability Act 2006* are indicated by the experiences of those who use them. Meeting these standards means that support services must ensure that “each individual has the ability and potential to achieve a valued role in the community” (Victorian Department of Human Services, 2007:1). Further, “Each individual has rights and responsibilities as a member of the community” (ibid). What this calls for is tailored support for each service user which in the case of those whose sexual behaviour is unacceptable presents a serious challenge for services given prevailing public perceptions of the sexuality of those who have a learning disability. Nevertheless support must be geared to allow as much untrammelled access to a life in the community as is possible whilst simultaneously encouraging the normalisation of the service user’s behaviour.

With specific reference to service user’s sexuality, the DHS has published guidelines entitled *Personal relationships, sexuality and sexual health policy and guidelines* (2006). In addition to promoting the rights and responsibilities of all individuals who have a learning disability, the policy includes advice to the front-line worker on procedures when service users display inappropriate or abusive sexual behaviour. This policy covers DHS support staff but is also available to other support organisations to use as it stands or adapt to their particular circumstances. From the policy to the laws to the guidelines for service providers comes the central tenet of individual organisation’s policies on all aspects of service users’ lives including those on Sexuality and Relationships.

2.10 Cultural context

2.10.1 Society and people who have a learning disability

Weeks explains that it was concern over the poor health of soldiers sent to fight in the Boer War that first turned the British Government down the path of eugenics in an attempt to create a strong and healthy fighting force (2000). In order to keep people with learning disabilities from breeding with ‘healthy’ British subjects, institutions were built to house these contaminating ‘defectives’ and keep them segregated from the rest of society. This strategy for ‘improving’ the national stock

continued into the 20th century. Thompson quotes the Mental Deficiency Act (1913), which states that:

“prevention of mentally defective persons from becoming parents would tend to diminish the number of such persons in the population; and that consequently there are still grounds for placing mental defectives of each sex in institutions where they will be retained and kept under effectual supervision as long as may be necessary” (2003: 33).

It was not until the 1970s that Wolfensberger developed ideas of ‘normalisation’ for people who have learning disabilities (Race, 1996) which amounted to a belief that “Mentally handicapped people have a right to enjoy normal patterns of life within the community” (Jay Report, 1970, quoted in Race, 33). Although in the following years there was a move from living in institutions to life in the community, there was no corresponding change in attitudes towards the sexual rights of people with learning disabilities. As Thompson concludes: “The control of the procreation of women with a learning disability persists to the present day . . . although the availability of contraception has provided an alternative to segregation” (34).

2.10.2 Perceptions of the sexuality of people who have learning disabilities.

In segregating people with learning disabilities in this way it is as Milligan & Neufeldt (2001) note that: “Traditionally, individuals with learning disabilities have been thought to have little social judgement and are thus incapable of responsible sexual relationships” (92). This perception continues, as evidenced by Grieve *et al* who, writing in 2008, assert that:

“Previous studies have shown significant levels of stigma towards people with learning disabilities . . . This is particularly the case in relation to the sexuality of people with learning disabilities” (76).

As Keywood (2003) asserts, these service users are treated like child-like innocents or over-sexed predators. Even given these exaggerated perceptions it seems strange that service providers often fail to have a policy concerning management of unacceptable sexual behaviour (McMillan: 2008). As a result service users can

continue to offend and individuals continue to be victimised. This does nothing to allay the perception of people with learning disabilities as having ‘animalistic appetites’. Men who have learning disabilities can be especially demonised because of their sexual behaviour. Yet as Lambrick & Glaser note:

“many sex offenders with an intellectual disability will have spent most of their lives subjected to stigma, ostracism and inappropriate or inadequate messages regarding basic issues such as sexuality and relationships” (2004: 382).

Mee (2010), conducted research which involved collecting accounts of the past from men who have a learning disability. One man who lived in an institution for many years spoke about being threatened with punishment if he danced with women at ‘socials’ which were held there. As Mee points out:

“It is important, however, to recognise that this is not just a case of the ‘bad old days’. The underlying perception that led to people being cast in these roles [sexual innocents or predators] casts a shadow over the present; so, for example, an adult person in a community services setting today might not be allowed to form sexual relationships and might be punished if they try.” (38)

Indeed, Almond & Giles (2008) found that young people who have a Learning Disability are subject to more scrutiny and observation and that behaviours not regarded as a problem in the general population, e.g. excessive masturbation can be viewed as a problem when the individual has a learning disability. As Swango-Wilson (2008) further suggests, the sexuality of people who have learning disabilities is often shaped by inaccurate information and unpleasant experiences. Additionally, Tarnai (2006) writes of inappropriate masturbation that there is an over-representation of adolescent males in case studies he researched. As he goes on to explain, during puberty, sexual maturation creates a stressful situation for caregivers and quotes Hammar *et al* who write that: “anxiety and concerns around puberty result in anticipation of problematic behaviours and tend to interpret any wriggling, scratching or clothes tugging as masturbation” (163). In short, care givers can create problems where none exist because they anticipate problematic sexual behaviour in this service user group.

2.11 Treatment in the community

2.11.1 Introduction

Whilst there has been a plethora of research done on men with learning disabilities imprisoned for sexual offences (Keeling & Rose, 2006; Mitchie *et al*, 2006; Craig & Hutchison, 2005; Courtney & Rose, 2004), literature has also suggested that most men who commit sex crimes which are discovered never get reported to the police (van den Bergh & Hoeckman, 2006). Further, even when reported, the men were rarely charged, and those who are were did not often get convicted and sent to prison (Vaughn, 2003). Men who did go to prison could be put on programmes to reduce recidivism with varying degrees of success (Langdon & Maxted 2007) before being released back into the community. Additionally, Wheeler & Jenkins (2004) with regard to those who were charged, maintained that one management option was to decide the place of treatment based on an individualised structured assessment which could suggest that it was not always necessary for treatment to take place in a secure or semi-secure setting. It may be surmised then that since most treatment took place in the community there were strong implications for the role of Social Care Workers. Furthermore, whilst the above mentioned authors referred to service users who were sex offenders, treatment in the community also applied to those whose behaviour was defined as being sexually problematic but not an offence. Social Care staff also had a duty of care to these people which included ensuring they act appropriately for their own sake as well as for that of others.

2.11.2 Critique of treatment in the community

Given that most treatment of unacceptable sexual behaviour of people who have learning disabilities is treated in the community, it is ironic then that as Wheeler & Jenkins further assert, they are more likely to continue offending where their care is in a large or even small community institution because of the following factors; no socio-sexual training for service users, and also because of the high level of incompetence in the management of men with learning disabilities who sexually abuse. Additionally, Brown & Stein (1997) found that when perpetrators who have a learning disability abuse several victims this indicates a service failure for other vulnerable service users. They also note that since most of these culprits fail to

conceal their behaviour they are more easily found out and that there is no evidence to suggest that services subsequently acted effectively to prevent or contain it. The situation may be further exacerbated by the fact that Social Care staff training was often inadequate in both content and availability (Sangster, 2007: 14). Furthermore, Wheeler & Jenkins refer to a general lack of clear policies as a factor when offending persists. Clearly then there is a need to examine the nature of treatment in the community of people who have a learning disability and whose sexual behaviour is unacceptable in order to improve support organisations' procedures and the Social Care Workers' practice. This in turn will improve the quality of life of the service user and also in cases of abuse, the safety of others.

2.11.3 Inadequate policies

Within the field of Social Care agencies come in for particular criticism for their lack of policies and guidelines in relation to coping with service user sexuality (McMillan, 2008). For example, Brown and Stein with reference to what they term 'so-called peer abuse' assert that service agencies can fail to address such issues. This results in service users, predominantly men, repeating offences because of lack of appropriate intervention, and this, the authors maintain, is the norm. Lack of clear policy also affects the Social Care Worker. Robertson & Clegg (2002) in a study of risk assessment management of men who sexually offend suggest that failure to develop specialist risk assessment skills may compromise risk management by community staff. Where policies do exist, the message that underpins them is simply that of constraint and containment, rather than education and facility. In 1994, H.Brown found that those that existed were framed by a discourse that suggested that "one implicit role of services is the regulation of sexuality and the creation of sexual boundaries" (p.123). This refers to the sexual behaviour of all service users, not only those whose behaviour is unacceptable. Sexual mores have changed since this was written and as such, affect what is deemed unacceptable by the general public today. It is now twelve years on since Brown and Stein condemned service agencies for their lack of clear directions for staff faced with addressing service user's issues around sexual behaviour. Further, since L. Brown surveyed Scottish policies in 1996 (report published in 1998), Care Commission Guidelines and Scottish law have been

reviewed several times with regard to sexuality and people who have learning disabilities so changes in the nature if not the number of organisation's policies ought also to reflect these developments. L. Brown's research also found that policy documents tended to focus on short rather than long-term approaches to reducing challenging behaviours yet in the case of modifying unacceptable sexual behaviour this can take 2 – 3 years (Bell, 2002; Lambrick & Glaser, 2004). As Bell explains with service user's behaviour change the pace is limited and slower than is the case with others precisely because of their learning disability.

2.11.4 Prevalence of policies

Policies relevant to this study include those of Scottish organisations and UK-wide organisations which operate in Scotland and also those pertaining to Melbourne Australia. In L. Brown's research in 1998 which consists of a literature review on challenging and inappropriate sexual behaviour of people who have learning disabilities in Scotland, she found that 26% of organisations surveyed failed to respond when asked if they had policies and guidelines on personal and sexual relationships and sexual abuse. Of those who responded, (64%), less than half had a policy and guidelines on both sexual abuse and on sexuality and personal relationships, and of these, more than 50% failed to provide guidance on interventions for those who displayed unacceptable sexual behaviour (36). Furthermore Christian *et al* (2001) found when they asked workers if they had read their agency's policy that 52.4% of staff said that they had, 19% were undecided, and 38.6% said they had not read it. Here, I would argue that the 19% who were undecided may be added to the 38.6% who said they had not read the policy since if you cannot remember reading it then this is equivalent to not reading it at all. However, it cannot always be assumed that a lack of policy results in a lack of good practice because individual members of staff, who have the appropriate attitude, using their common sense and experience, could well provide an excellent service in some situations.

2.11.5 The effect of a lack of policy on staff responses

In light of poor, ambiguous, or non-existent directives from support organisations it is hardly surprising that front line Social Care staff have shown, at best, uneven responses to inappropriate or abusive sexual behaviour (Hill-Tout et al, 1998). Even where service user's sexual behaviour is acceptable it is as Christian *et al* (2001) note, that agencies without sexuality policies leave the decision-making to untrained staff. Workers may also be stultified by fear of management reprisals for using their initiative in taking on service user's sexual issues (Sangster, 2007). Furthermore, Lyall *et al* (1994) conducted research in which they found that in questioning staff of the 30 establishments they studied only 3 said that they would report sexual assault or indecent exposure. Further, they found that staff at one residential establishment said that they would hesitate to report rape whilst staff in another organisation would consider the circumstances before reporting rape to the police. Certainly, Social Care Workers can fall heir to problems because of this. The *laissez faire* approach to service user's sexual behaviour in some Learning Disability Hospitals has meant that individuals who have moved into life in the community have lost the 'sexual freedoms' they once enjoyed, some of which were self-directed and some of which were abusive of others (Sangster, *ibid*).

Given that more than ten years have passed since L. Brown brought out her report on the state of Sexuality and Relationship Policies in Scotland, and that no previous research has been done into the content of policies in Melbourne, this work will take this as its starting point. That each policy contains a section regarding the protection of victims of sexual abuse is now a given considering the recent plethora of laws brought out in both locations. . However, what is of concern in this research is whether policies now provide guidance for staff on how to proceed when a service user displays unacceptable sexual behaviour.

2.11.6 Management's approach

2.11.6.1 With regard to the status of the victim

Whether or not a policy exists, Thompson, Clare & Brown (1997) found that an organisation's response can depend on whether a member of the public is involved, especially if it concerns children. Although a huge moral obligation applied in this situation, arguably some organisations' hands were forced by the involvement of those they cannot control because as already demonstrated, where the victims were also service users, response has been patchy to the extent that even rape went unreported. Similarly, management's reactions were patchy where members of staff were subjected to the behaviour. Whilst victims who have a learning disability are susceptible to abuse because of their vulnerability, the reason for staff being subjected to the behaviour may be different. In terms of the relationship between SCWs and the service user, Thompson, Clare & Brown (1997) describe the paradoxical nature of the relationship where the former is female (which was mostly the case in the past) and the latter male. They explain that whilst service users may regard the female worker as caring and motherly towards them, which through their gender placed them as lower in status because they are female, their role also carries the element of authority – the person 'in charge' – and thus of higher status in the relationship. Nevertheless, these authors suggested that male service users could have simultaneously misread the woman's warmth and friendliness which is a necessary component of building a rapport and believed that she was interested in him sexually. The man's behaviour, they reasoned, may also have reflected sexist culture which was prevalent in our society with regard to men's attitudes to women. Thus the dynamics of such a relationship may have left the worker shorn of any status and where their manager was male he may then have believed that the female victim had in some way led the service user on.

2.11.6.2 Response depending on the nature of the behaviour.

There were other reasons however for a lack of response to service user sexual behaviour, although it may be argued that some of these related back to the lack of clear guidelines. For instance, McCarthy & Thompson (2000) distinguish between 'inappropriate' sexual behaviour and 'sexual abuse' and note that the former is

usually considered to be less serious. Thus it may go unrecorded, unaddressed, and so continue. McCarthy & Thompson further note that concern for the victim with regard to doctor's examination or police questioning can also deter staff from taking any action. Staff may have had similar concerns for the culprit, although Lindsay notes, these individuals are more likely to be motivated to stop aberrant behaviour if the police do become involved (in Wheeler & Jenkins, 2004). Wheeler & Jenkins add that staff might also fail to respond to unacceptable sexual behaviour because they put it down to the individual's ignorance rather than being sexually motivated. Where staff mistake sexually motivated behaviour for something more innocent, they may even unknowingly reinforced the behaviour e.g. if staff give a service user a comforting cuddle it may be misconstrued by the latter and used by him/her for sexual fantasies (Wheeler & Jenkins: *ibid*).

2.11.7 Overcoming patchy responses

Writing in 1994 on the subject of Social Care Staff's dealings with service user's issues around sex and relationships H. Brown asked, "What would it take to actively support people with Learning Disabilities?" (139) and conclude that this will require changes at all levels. At an individual level, she continues, it would mean the Social Care Worker taking a proactive stance in being willing to help service users meet potential partners or maintain existing contacts. As part of this process, Brown foresaw that this would require a framework whereby Individual Programmes or Service Plans could include a dimension on sexuality which "seeks to wed people's aspirations to their knowledge and understanding" (139). However, more recent research indicates that not only are staff unaware of their service user's existence or level of sexual knowledge, but also that service users' sexual aspirations are not usually included in their "Person-centred" plans (Sangster, 2007). H.Brown foresaw the outcome of neglecting the subject of service user sexuality as resulting in their sexual alienation expressed as challenging sexual behaviour. As she concludes:

"Policies and staff guidelines have been an important starting point but need now to be translated into individual service level contracts so that people's rights are safeguarded and they are not subjected to the whims of individual home owners or managers"
(139)

Recent evidence suggests that this situation has not changed (Tudway & Darmoody, 2005).

2.12 Existing research into SCW's practice: SCW involvement in treatment

2.12.1 Care culture

There are many reasons why staff might not report service user's illegal sexual behaviour to the police and these are listed above. What is not mentioned is the culture of care work. Social Care Workers can be assaulted, sometimes on a daily basis. They can be slapped, kicked, punched and suffer verbal abuse from service users who display challenging behaviour. Workers in the medical professions are also subject to these levels of abuse from some patients. However, theirs' is a different and comparatively short relationship with the abuser since their profession is essentially about 'fixing' rather than supporting the individual him/herself. Unacceptable as this situation is, health professionals are not subject to continuing harassment by an individual they see almost every working day.

As elaborated above, people who have a learning disability are subject to the same laws as anyone else, e.g. if a service user hits a worker, the worker can have them charged with assault. This very rarely happens. Instead, management plans are put in place so staff can 'handle it' whatever motivates the behaviour. Thus there is a culture of acceptance of 'bad' behaviour and a culture of dealing with it in-house or bringing in help from health professionals to treat the person in the community rather than go to the police. Yet as has been explained above, service response in this area has been patchy (Hill-Tout, 1998) so there is a need to know when the behaviour is regarded as being in need of addressing and subsequently, the Social Care Workers' involvement in its modification. Since unacceptable sexual behaviour is an on-going issue for support services this research will continue by considering the factors involved in organisations deciding that intervention is necessary.

2.12.2 Existing research into SCW practice

Research into current practice of SCWs is limited. Moreover, McConkey & Ryan (2001) note that most research regarding Social Care Workers on the subject of the sexuality of people who have a learning disability focusses on workers' attitudes. In their own study, these researchers used a self-completion questionnaire to determine staffs' experiences of issues around service users' sexual behaviour. Using seven scenarios gleaned from a focus interview, staff members were asked to use a Likert Scale to indicate how confident they felt about their handling of these incidents where they themselves had experience of them. Simultaneously workers who had not had experience of a scenario were asked to gauge how confident they thought they would feel about dealing with the situation. Thus they had been asked to give a reaction to a hypothetical situation. McConkey & Ryan conclude that workers with relevant experiences gauged themselves to be more confident to situations they had encountered in the past compared to situations they might encounter in the future. This points to a fundamental lack of confidence when it can only be claimed with hindsight yet McConkey & Ryan do not go on to find out why the workers feel this way about their possible interventions. More importantly from the point of view of finding out about service user support in the community, those with experience of a scenario are not asked to give an account of the action they took.

In her research Simpson *et al* (2006) sought to gain insights into staff attitudes and perceptions regarding sexuality and relationships in order to identify areas of support required from their service managers and service leaders. Following a focus interview in which she set out to determine staff attitudes towards service users' sexual behaviour; their own knowledge of sexuality; their employers procedures in these situations and whether these were put into practice, Simpson designed a self-completion questionnaire to identify areas of support staff required. The focus group exercise consisted of Simpson presenting respondents with four typical but hypothetical scenarios in order to encourage discussion. The scenarios did not include anything illegal or any apparently abusive behaviour. This it may be surmised is what the researcher wanted the interviewees to first establish as part of their response. Whatever the motivation the result was the development of a self-

completion questionnaire which like McConkey & Ryan's research did not seek to engage with the worker's own experiences and subsequent actions.

The work of McConkey & Ryan and also that of Simpson represents research most relevant to my study yet these are essentially quantitative studies which in both cases do not allow for respondents' own experiences and accounts. Muir & Gibb (2006) point out that there has been an inordinate focus on the resettlement process involved in the shift from institutional care to that in the community without a corresponding large scale effort to study the effects of this on those individuals concerned. It is assumed, they suggested, that service users' lives have improved for the better based on observational evidence that had not been tested. In terms of their sexual behaviour in the community setting however, as explained above, research has shown that some individuals with learning disabilities, particularly older men, do not have the same sexual freedoms they had in the institutional setting (Sangster, 2007). This leaves a problem to address which calls for the input of the Social Care Worker.

2.12.3 Why should the SCWs role be researched?

So what do we know of the Social Care Worker's real-life role in the treatment of service user's unacceptable sexual behaviour? Although they advocate treatment in a community setting Wheeler & Jenkins fail to make specific mention of the Social Care Worker's role in this. Similarly, in a Case Study of the treatment in the community of a sex offender who has a learning disability, Hill-Tout *et al* (1998) outlined the input of the Clinical Psychologist, the Psychiatrist and the Senior Social Work Practitioner but omitted the role of the Social Care Worker (see also Craig & Hutchinson 2005). Nevertheless, a role is implied. It may be thought to include, providing behavioural histories, accompanying the service user to counselling sessions, generally helping the service user to live peaceably in his community (see Hill-Tout); supporting the service user during investigation into abuse; allaying factors which may contribute to the continuation of unacceptable sexual behaviours which can include drugs, alcohol, anxiety, depression, boredom, resentment, feelings of deprivation (Joyce, 2003). Further, Social Care Workers are on hand to reinforce treatments recommended by experts that seek to address denial, motivation,

cognitive distortion, empathy development, intimacy/loneliness, sexual and non-sexual fantasies, social functioning, and relapse prevention (Wheeler & Jenkins, 2004).

L. Brown (1998) wrote that education programmes on sexuality and personal relationships aimed at people who have learning disabilities are viewed as a means of reducing their vulnerability to sexual abuse. She adds that programmes on what is socially sexually acceptable, along with behavioural interventions, also act to modify unacceptable sexual behaviour in people who have learning disabilities. Thus sexual knowledge both protects and empowers. McClimens & Coombes (2005) ask who is best placed to disseminate sexual knowledge to people who have a learning disability, whilst I have argued above that Social Care staff are best placed for this because of their familiarity with the service user and because of their daily contact with them.

Thus treatment reinforcement on a daily basis would take place within the residential or day care service. This necessitates the knowledge, judgement and skills of the Social Care Worker. As Beebee citing Walsh (2000) writes: “Carers’ responses to incidents of unacceptable sexual behaviours can be seen as the most common and effective form of direct education as they are closely linked to the events” (12). Additionally, since both Wilcox (2004) and Sajith *et al* (2008) comment on the lack of appropriate assessment tools that are in use of both pharmaceutical and psychological treatments I would suggest that the Social Care Worker because of their daily contact with the service user, might be just such an ‘assessment tool’. Furthermore, Lambrick & Glaser state that what they term the ‘premaintenance’ process takes about 3 years, and add, that “programmes need to be consistently re-informed within and across client’s day-to-day environment” (2004: 389). This ‘environment’ is peopled by Social Care Workers. Yet these workers are subject to such observations as that made by Hames & Carlson (2006) who reckon in their estimation that SCWs can be trained to accompany service users to appointments. Such narrow ambition, I would argue, amounts to a high level of misrecognition of SCWs’ existing skills and the potential to extend these even further.

SCW's 'back-stage' role in terms of a service user's treatment is vital to the service user's quality of life. As already alluded to and as Hill-Tout *et al* point out, members of the public have heightened perceptions about sexual behaviour, particularly of men who have learning disabilities. They add that this is dangerous because the men could end up in an "over-restrictive environment" where they would have a "slim chance of discharge" (1998: 163) if their behaviour so much as offends sensibilities as well as if it breaks the law (See also Milligan & Neufeldt, 2001). Thus Social Care staff have an enormous responsibility to the men, no matter that it has gone unacknowledged. Thus there exists a need to research Social Care Workers' lived experiences of modifying service users unacceptable sexual behaviour.

2.13 Work and status

2.13.1 'Habitus'

In terms of status and identity within the caring professions that of the SCW ranks arguably lowest of all. Not only are they viewed thus by others but so they regard themselves⁷. Such status within the caring professions may be explained using Bourdieu's concepts of habitus, field, capital and doxa. Bourdieu asked the question "how can behaviour be regulated without being the product of obedience to rules" (In Maton, 2010: 50). Essentially the term refers to an accepted pattern of being and practices. For example, whilst a working class child may expect to find a job on leaving school and have children by his/her mid twenties, a middle or upper class child may have expectations of first going to university and putting off having children until their late 30s or early 40s once they have a well established professional career. Thus habitus is in a way a self-fulfilling prophecy based on our place in society at birth rather than something imposed on the individual, that is to say, by habitus Bourdieu does not infer that individuals are merely victims of a given set of circumstances. As Maton sums up, the phrase that applies here is that something 'is not for the likes of me'. For Bourdieu, as Maton continues, habitus thus explains how social structure and individual agency are reconciled. And

⁷ One interviewee remarked that she was 'only a support worker'. This I would suspect is not an uncommon perception shared by these workers.

concludes that: “the habitus is thus both structured by conditions of existence and generates practices, beliefs, perceptions, feelings and so forth in accordance with its structures” (51). Further, as he points out, for Bourdieu, habitus sits in an unconscious relationship with his further concept of ‘field’.

In using the term ‘field’ Bourdieu refers to social spaces which as Thompson explains are “designed to protect insiders (and) constitute(s) self-contained worlds” (2010: 70), for example that of the judiciary. Of necessity, these little worlds are defined by regular practices and stipulations of entry. In this example, these include specific academic attainment and the claim of ownership of specific knowledge and practices pertaining to advising and representing others with regard to the law. As Thompson continues, “Social agents who occupy particular positions understand how to behave in the field” (ibid). Access to a particular field can depend on an individual’s capital. By this, Bourdieu does not mean their economic circumstances, although he also acknowledges the significance of this, but to what he calls ‘symbolic capital’. As Bourdieu explains:

“In particular it defines as disinterested those forms of exchange which ensure the *transubstantiation* whereby the most material types of capital – those which are economic in the restricted sense – can present themselves in the immaterial form of cultural capital or social capital and vice versa” (in Moore, 2010:101, original italics).

Thus practices and status can also define an individual whose life-style is the habitus of a particular field. For example, an individual may study to be a doctor, and be rewarded not only in a financial sense but also by being afforded universal respect, deference, and connections (social capital). Additionally his/her habitus would include practices of, e.g. hill walking and going to the theatre (cultural capital). By way of comparison, an individual may leave school and become a minor civil servant; not enjoy universal respect, deference, nor connections (little social capital), play football and go clubbing (little cultural capital). Such symbolic capital, Bourdieu suggests, has many forms for example as mentioned, cultural capital (theatre/clubbing), linguistic capital (RP/ regional accent), and further, that as Moore points out: “Each field of symbolic capital reproduces the system of unequal

relations in the economic field (relations of class and power) and in doing so reproduces the fundamental structure of social inequality” (2010: 104). As Moore further explains: “although the formation of *habitus* takes place initially within the family, the domestic *habitus* . . . for Bourdieu the most important agency is education, where capital assumes institution form” (105 original italics). Thus Bourdieu argues that society cannot only be understood in terms of economic class but should also be considered in terms of culture and educational contexts (Bourdieu, 1977). He writes:

“Academic qualifications, like money have a conventional fixed value . . . {and} the cultural capital in a sense guarantee once and for all does not constantly need to be proved. Once this state of affairs is established, relations of power and domination no longer exist directly between individuals; they are set up on a pure objectivity between institutions, i.e. between socially guaranteed qualifications and socially defined positions . . .” (187/8).

Moore adds that Bourdieu regards the domestic habitus and agency of education as being continuous with each other. In other words, an individual’s economic status at birth defines to a very large extent, the fields with their defining social and cultural capital that are available to them in adulthood

Universal acceptance of status and value thus socially ascribed to different fields and their practices can be explained by Bourdieu’s concept of ‘doxa’. This has parallels with Gramsci’s concept of hegemony and also Marx’ ‘false consciousness’. It describes the way in which designated status and values are arbitrary and how this goes unchallenged because it is not recognised by members of a society (Deer, 2010). In short, the status quo is accepted because it seems to be natural in its order rather than socially constructed. As Deer sums up:

“Explicit physical force is replaced by implicit social habits, mechanisms, differentiations and assumptions, the “natural” strength and legitimacy of which reside in the misrecognition of the arbitrary nature of their socio-historical emergence and reproduction” (2010: 121).

2.13.2 Field/jurisdiction

‘Field’ as a concept refers to the area of practice as well as to the particular competences involved, thus the concept of skills may be expressed in another way. Abbott uses the term ‘jurisdiction’ (in Macdonald, 1999, 15) which I would argue describes an area of practice. In the case of care work ‘jurisdiction’ equates to legitimate claims to maintain and improve another’s quality of life. In the case of people who have a learning disability, this currently amounts to enablement. When particular academic qualifications also inform jurisdiction then in the mind of the qualified individual and in the minds of others, only the qualified individual may justifiably claim the ability to perform the tasks to which it relates. For the most part this is true, for example, who could administer an anaesthetic without first having been trained to do so? However, this begs the further questions of who is selected for this training, and why? Further, and more importantly where this research is concerned, what makes one skill more valued in a society than another? Deer has pointed out above the fact that values are not inherent but are socially ascribed. The status quo is thus maintained on a general failure to acknowledge and challenge the worth of these socially ascribed values. However, this is not to say that we cannot offer explanations why some aspects of our society are valued more than others.

2.13.3 Bourdieu and the concept of ‘the professional’

In our society some types of employment are referred to as being a profession, and those in these professions, professionals. An example here is the ‘field’ of medicine and the doctors whose job it is to have a working knowledge of medical practices (its embodiment). However, having the tag of ‘professional’ on to your job title is not sufficient to render an individual as a professional in the sense that it may be regarded as also a sign of high status in our society. For instance, we can talk about a professional hairdresser but in terms of status we are not also talking about the person as one who belongs to one of ‘the professions’. Bourdieu regards those professions defined as such – the doctor, the lawyer etc. – as the result of power struggles based on being regarded as a scarce resource which is maintained as such by restrictions on entry to the ‘field’. Although Bourdieu avoids the charge of economic reductionism in his concept of ‘habitus’, he nevertheless acknowledges the

importance of the economic to the level of education available to an individual. Thus access to the academic qualifications required to join one of the professions is restricted, usually to those whose family already belong to a particular ‘habitus’. As a line of work difficult to access, a profession is thus imbued with ‘symbolic capital’, that is to say, is of high status. This is justified by requiring the individual to gain difficult to come by qualifications in order to gain access. Schinkel & Noordegraaf (2011) sum up Bourdieu’s work saying that consideration of professionalism as a form of symbolic capital is:

“not a structuralist approach but one that is power centred . . . {and} emphasises professionalism as a scarce symbolic resource, an object of a process of consecration and a source of legitimate forms of acting and interpreting” (67).

Power relations infer power struggles and Bourdieu refers to the dynamic as opposed to a static aspect to what is meant by the concept of ‘professional’. As Schinkel and Noordegraaf further summarise, for Bourdieu: “the very idea of ‘formal content’ of ‘professionalism’ is constantly as stake” (ibid) Thus Bourdieu insists on the arbitrary nature of the ‘professions’ given that they come about through power struggles and are not, as is generally accepted, part of some natural order. As a result, Bourdieu rejects the notion of there being jobs which can be distinguished as being ‘professions’ in favour of the concept of ‘field’ as explained above. Nevertheless, Schinkel & Noordegraaf argue that the term ‘professional’ is still useful if those who use it maintain a critical distance from what they refer to as the ‘native’ point of view. They argue:

“it is also possible to regard professions as occupational fields in Bourdieu’s sense, and as themselves enmeshed in a larger field of struggle between such professional and extra-professional or newly professionalizing fields” (80).

The approach taken in this research will therefore be based on Bourdieu’s concept of ‘field’ whilst account will also be taken of what Schinkel & Noordegraaf refer to as ‘occupational fields’ and the struggle between ‘the professional’ and ‘newly professionalizing fields’.

2.13.4 Gender work and status

Evans (2002) cites Kimmel and Messner when they define gender as “that complex of social meanings that is attached to biological sex [that] is enacted in our daily lives” (441). To be sure, cultural differences demonstrate that gendered roles are socially constructed rather than biologically driven (Adams & Savran, 2002).

Although Bourdieu applies his concept of habitus to class, Virkki (2008) uses it within the context of gendered difference in social groups and their practices.

Describing habitus as “the site of individual internalization of the rules of the game in a specific field” (76). She cites as example the way that social workers and nurses [and SCWs] occupy an ‘emotional habitus’ which parallels the values and rules of caring work. Virkki concludes that it is through this emotional habitus that gendered social inequalities are reproduced. Thus as Huppertz (2009) asserts: “. . . caring is considered a natural and innate feminine pastime. These associations enable women’s employment and excludes men” (53).

In the world of paid employment Huppertz found that many women with a longer history of working in nursing or social work gained this employment precisely because of their gender, thus converting, she insists, their symbolic capital into economic capital. Within the context of employment, this leads her to conclude that although femininity is embodied it is also a learned competency which enables women to “know the field, and play it well” (ibid). So what exactly does this feminine caring field entail? It has been likened to the mothering role (Huppertz, 2009; Poole & Isaacs, 1997) which can be further defined as being empathetic and intuitive (Huppertz, ibid) ‘touchy feely’ in nature and also characterised as being soft-spoken and gentle (Evans 2002). However, as Huppertz further points out, since these attributes are considered to be innate aspects of the female as opposed to the learned skills of the male, our society values them less, and one might add, pays them less.

Thus no matter how important the ‘feminine’ approach is considered to be in the caring professions, it is as Poole & Isaacs note that this work which is accepted by both giver and receiver as unpaid in the home is also accepted by both giver and receiver as poorly paid in the patriarchal work place. This situation serves to

maintain the caring professions as a predominantly female domain in a society in which the 'feminine' continues to be subordinate to the 'masculine' (Huppatz). Nevertheless, Evans (2002) comments that despite nursing being traditionally women's work men are entering the profession in record numbers, a fact which challenges gender stereotyping because these men also enter nursing with the aim of caring for others (Taylor *et al* 1983 cited in Evans). Men are also entering Social Care Work and I would venture that this may be related to structured decline of the manufacturing industries in the UK and its replacement with service industries. Couple this with the fact that the care sector does not usually demand applicants to have relevant, or indeed any, qualifications. This argument is partially borne out by McConkey *et al* (2007) who found that men were more likely to have entered the profession from non-care settings. That said, the men's wish and ability to care for service users is generally not in question and Wilson (Unpublished PhD, 2009) comments on the vital role male SCWs play in male service users' expression of their masculinity because they "influence, reinforce, and characterise masculinity" (213). Furthermore, he differentiates male and female caring where the former is expressed through "male banter, warmth, mutuality and bonding" (226). Nevertheless, in spite of the growing number of men in the field, the care worker's pay and status is low compared with other care-related, regulated occupations.

An explanation for pay and status differentials amongst the caring professions may be found in the nature of the work involved rather than the similarity of purpose. Macdonald (1999) points out that:

"Sociologists generally take a model of rational, formalised scientific knowledge as their starting point in the study of the epistemological base of the professions and then elaborate in relation to a number of other features of professions and their social context" (157).

In similar vein Sturdy *et al* (1992) note that skills are often conceptually divided into those that are objective (technical) and subjective (social). These differentials are not value free however, for the former is associated with male dominated occupations and the former with female. These writers quote Littler who elaborates that "It is

useful to distinguish between the two forms of a social construction theory of skill”

(4). Using the terms ‘strong’ and ‘weak’ Littler adds that the former:

“applies where it is not job content but control of supply through employers’ or workers’ entry barriers which indicate the skill level as being high. In the ‘weak’ form most jobs have significant skills but this is recognised and rewarded as ‘skilled’ only to the extent of the capacity of the workers to define it as skill” (ibid).

Here, Littler applies Bourdieu’s concept of field, and especially hints at the role of education (cultural capital) in debarring others from its access.

2.14 Work and identity

2.14.1 Health professionals

Of course it may be stated that any practitioner in the health professions does care work since their *raison d’être* is to help people have a better quality of life. Yet there is a conceptual fissure between perceptions of medical doctors and psychiatrists compared to, say, nurses and occupation therapists, not to mention between the latter group and social care workers. At one time the practices we now associate with the physician were the sole preserve of men (Macdonald, 1999).⁸ However, nowadays women are well represented in the profession. It may be noted, however, that it was the lack of access to levels of knowledge and the learning of technical skills that once kept women from joining becoming doctors.⁹ The status of doctors in our society is ascribed by Foucault to their key role in the 18th century project of modernity which included the promotion of the hygienic, healthy, (and thus productive) population. Of this he writes that “The doctor wins a footing within the different instances of social power” (1980: 176), indicating the high status of the medical doctor not just for individual patients, but for society itself. This said, acknowledgement must be made of the seven year programme of knowledge acquisition they undertake which

⁸ 7th January 2012 marked the 100th anniversary of the death of Sophia Jex-Blake who was Scotland’s first woman doctor. Her 25 year campaign played a major part in opening up women’s access to university education and the medical profession. (Edinburgh Evening News, 7th January, 2012: 28).

⁹ Fees may now keep the less well off from attending university courses and becoming physicians thus denying them access to the knowledge and skills that they need.

includes 3 years of practical application¹⁰. As individuals our attitude towards doctors may be thought of in terms of what Giddens has described as ‘passive trust’ (Open University website accessed 9/01/2012). Here, Giddens refers to the fact that we are apt to trust doctors with care of our health simply because of their job title and the expectations which go with this title.

Unlike Social Care Workers, nurses also have a positive place in the public imagination. Quoting Daniels & McKinlay, Macdonald (1999) writes, “most . . . professional ‘traits’ {are} shown to have an ideological tinge or even to be characterized as ‘mythology’” (4). Regarding ‘mythology’ nurses have a strongly defined image, for example, a British hospital drama on television which had nurses as the main focus of the story was called *Angels* and for many years there was a Christmas morning broadcast from a hospital where a choir of nurses sang carols to patients (*Angels!*). Just as medical doctors are legitimised by the Royal College of Physicians, so too is the nursing profession through the Royal College of Nursing. Of course the nursing profession is also defined by skills. Although the job has of course its caring ‘feminine’ side, through its association with administering drugs and using medical instruments, nurses also have objective (technical) skills and belong to an order and status of worker of which numbers are limited by compulsory training which is now provided at the level of higher education. As such, nurses may also be said to have ‘strong’ skills and so a defined field or area of jurisdiction.

2.14.2 Identity and status of SCWs

As stated above, SCWs do not have a particularly positive image in the public imagination. One that springs to mind is that of the carer in the television comedy ‘Little Britain’ who though kindly and well meaning, is rather sloppily dressed and not very bright¹¹. This image is reinforced by utterances such as that made by the

¹⁰ This makes 7 years training in all, the same time that it took to train a 16th century wood carver.

¹¹ A recent Panorama programme concerned the ill-treatment of residents who have a learning disability and who lived in a privately owned home in Bristol. Such cruel treatment of vulnerable people has further damaged the image of the SCW. That said, the ring- leader was a trained nurse. (BBC, accessed 4/12/12)

(now ex-) MSP Colin McGavigan who referred to care workers as ‘the great unwashed’¹². So it is that SCWs can clearly be seen as belonging to those who in Littler’s categories have ‘weak’ skills. As mentioned this is because of the likeness to women’s caring work in the home which requires no qualifications beyond being female and applying for the job. Macdonald in his reference to that other ‘female’ profession, nursing, insists, “as caring is something that everybody underrates in the context of the family. This (again) devalues the occupation” (1999: 135). Thus devoid of qualifications and restricted skills, the job of SCW comes pretty low in terms of social capital. Given the lowly status of SCWs it is hardly surprising that workers refuse to acknowledge or take on support duties surrounding service user’s sexual behaviour, acceptable or not, (Bazzo *et al*, 2006; Bell & Espie, 2002). This is because reflected in the eyes of others they may have seen this as being ‘not for the likes of them’ (Sangster, 2007).

Having said this, if SCWs lack qualifications and perform tasks which are not valued in society should they work closely with a particular service user, they will become, in time, an ‘expert’ in that individual. This in terms of the latter’s understanding, communication level and style, and also what does and does not motivate that person. Since Bourdieu’s concept of habitus influences their boundaries of jurisdiction, i.e. those acts and skills which form their particular social standing, it also directs their social relations such as those that can develop between the SCW and their service users. Craft & Brown (1996) contend that support staff are powerful forces in the lives of service users and they cite Bandura who writes that this power encompasses everything from their physical environment to spoken and unspoken feedback they give about service users’ behaviour. This would include their sexual behaviour.

2.14.3 The SCW’s status within the support organisation.

In terms of habitus/jurisdiction, the higher the position in an organisation, the higher the level of knowledge of the industry, and the more power to make

¹² Kirkintilloch Herald, 6th October 2010: p5

decisions, though there is less direct contact with service users. As McDonald explains:

“If the state is the external feature of the professional project, [in this instance The Scottish Government and in Victoria the Department of Human Services which define policy around the care of vulnerable adults], then ‘the sine qua non of its internal structure is knowledge’ (1995: xiii).

This includes knowledge of the service in question and staff management. Yet the relationship between a service user and staff transects the vertical personnel structure of organisations in situations where an, or it may be argued, the, important element of knowledge required to address a situation is knowledge of the individual him or herself (See Fig 1, below).

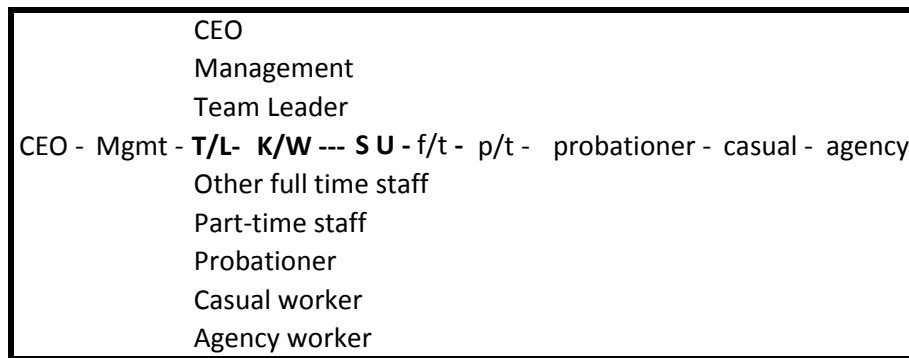


Figure 1

Though much of a support worker’s duties involve physical labour, and includes supporting an individual to make a meal, or is based on knowledge of the individual, such as deducing what is troubling them when they behave in an uncharacteristic way, there is also a large element of emotional labour involved in the support of another human being. In her book *The Managed Heart*, Hochschild refers to what she terms emotional labour as that in which there is “a profit motive slipped under it” (Hochschild, 1983: 10). Here Hochschild uses the example of the work of the air hostess whose job includes being polite to strangers even when the latter are being rude or hostile. This, of course, is not to say that true emotions like affection are never to the fore in a work situation and Hochschild writes of these in relation to

migrant workers employed to look after the children of parents in the affluent West¹³. In the case of care work, over time, genuine affection and caring for the service user can also develop into a relationship which goes beyond and enhances the usual concept of what is 'professional'. This said, such a relationship depends heavily on spending time with an individual and getting to know them well, which not every member of a support team is able to do. Thus it would be expected that some SCWs will have a stronger working relationship with the service user than others.

2.14.4 SCW Status and relationships with service users

As mentioned above, the status of SCWs ranks low in the sphere of the caring professions and within their own care organisation, hierarchies also exist. Nurses who rise through the ranks have noted that promotion involves an emotional as well as physical distancing from patients. Such is the cost of 'professionalism' as more qualified and experienced individuals' input becomes more administrative in essence (Malone, Berkowitz & Klein, 1965). As in the Health Service so with Social Care where managers' duties concern overseeing the service rather than direct involvement with service users. Should the latter have issues it is the care worker, especially those designated as the individual's Key Worker who is closest to them and their circumstances. Dealing with the service user's problem involves a deep understanding of the individual, especially where they have a learning disability. Awareness of the situation, the service user's understanding of it; their level and style of communication, and further, their likely response to attempts to resolve the issue are prerequisites in attempts to find a solution.

2.14.5 SCWs and management

A further relationship in which SCWs are involved is with their management. This again is hierarchical but unlike that between worker and service user, is much more clearly defined. Power to act or not on information belongs with management, the latter choice often being the case according to Lyall et al (1995) who found that at that time only 7 out of 30 managerial staff would report sexual assault, and

¹³ In *Global Women: Nannies, Maids and Sex Workers in New Economy*, (2003) B Erenreich & A R Hochschild (Eds.), Metropolitan Books: New York.

statements made by my interviewees who said that in the past their concerns regarding service user's sexual behaviour had been swept under the carpet and that no action was taken to modify the behaviour in question (see appendix i). However this was not the only reaction managers could show when they were informed by workers that an individual's sexual behaviour was causing concern. Workers could find themselves in a difficult situation for even mentioning to management that there was a service user's sexual behaviour required addressing. For example, one worker I interviewed for my MSc dissertation was threatened with the sack for suggesting that a service user who was sexually active would need condoms. Although this happened twelve years prior to interview so traumatised was he by the backlash that he said even today he would handle such matters with great caution (Sangster, 2007). Thus the power of management could serve to silence the worker and in the end reinforced their hierarchical relationship. However, where managers are prepared to have the service user's unacceptable sexual behaviour addressed they will also have a role to play in this. Because this research concerns the modification of behaviour of individuals with often extremely complex needs, consideration of the roles of all the SCWs who support them needs to be contextualised in terms of their working relationships with these service users and also within the context of the worker's status within their organisation.

2.15 Benefits of multi-agency work

In the past institutions not only provided service users' 'social' care but also their health care where medical interventions were necessary (Barber: 2011). Today, those service users who live in the community with the support of an agency or their parents make use of NHS services which are available to all. Thus they can have the support of multi-agency teams which can include doctors, psychiatrists, psychologists, nurses, speech therapists, etc. Like services in Australia which are subject to the Australian Government Social Welfare Commission 1975, a strategy based on multi-agency collaboration, those in Scotland, are subject to the Scotland Community Care and Health (Scotland) Act 2002, which expresses the intention to expand local joint and pooled budget arrangements between NHS and local authorities" (HMSO, accessed 01/09/10). Richardson & Asthana (2006) quote van

Eyk & Baum who list the advantages of multi-agency working as: “the improvement of services including the prevention of people falling ‘through the gaps’ [and] provision of best quality and most effective care for people who require multiple services” (658).

Where people who have a learning disability are concerned multi-agency working can be for various reasons including joint meetings on specific topics and referrals to other agencies (McConkey, 2005). McConkey adds that one of the benefits of this is that agencies learn from each other. This seems to be particularly relevant where non-specialist health professionals are concerned. In his study in 1997, Bollard (1997) found that 72% of GPs felt that their knowledge of this user group was limited and their knowledge of specialist services available to them was likewise very poor (see also Marshall: <file:///E:/New folder/nurse6.htm> accessed 14/09/2011). Indeed, all generic health services have come in for criticism with regard to their treatment of people who have a learning disability (Jukes, 2004; Dinsmore & Higgins, 2011; Jones et al, 2008). In his research undertaken for MENCAP, Dinsmore (2011) identifies several health care issues giving rise to concern. For example, lack of specialist knowledge can lead to what is termed ‘diagnostic overshadowing’ as health care professionals mistake genuine symptoms for aspects of the individual’s learning disability and so leave them untreated. Generic services, he continues, also fail to take account of carer’s (both paid and unpaid) opinions and comment. He cites the work of Foley & McCutcheon (2004) in which investigation shows that listening to carers is an effective way of detecting pain suffered by patients who have a learning disability. These writers also found that hospital routines can also mean that patients do not get their medication when they need it nor is information made available in ways accessible to these patients (ibid). Generically trained health professionals may also find issues of communication and understanding the needs of service users difficult (Jones *et al*, 2008). Under all these circumstances it is as Juke (2004) assures us that health inequalities continue for people who have a learning disability when they have reason to call upon generic health services. This situation appears to be on-going in the UK since Dinsmore, writing in 2011 comments on the lack of knowledge and poor attitudes of non-

specialist health workers towards this service user group. Service users themselves have remarked on the poor quality of service they receive from this quarter (Gates, 2011).

Yet specialists in the area of learning disabilities are available, including, for instance, psychiatrists, psychologists, nurses and counsellors. Although the nature of care these health professionals give is specialised and includes core skills there is also a degree of overlap particularly in the case of physios, OTs and nurses (Lillywhite & Atwal, 2003). Work done by SCWs may also overlap with these although this may be because there is no other choice since they lack formal training and it is not part of their work remit (Jones *et al*, 2008).

The chapter concerning accounts of inter-agency collaboration will commence from describing reasons why SCWs decide that consultations with health professionals is required and the subsequent roles they play in the modification of the service user's behaviour. This will also be contextualised by their status in the support organisation and their working relationship with the service user. The relationship between the SCW and health professional will also be examined in terms of ways in which perceptions of status and skill affects inter-agency work.

2.16 SCWs feelings about their work

It is also necessary to consider the Social Care Workers' feelings about their current role in modification of service users' unacceptable sexual behaviour. J. F. Brown concurs with the statement of Bell and Lambrick & Glaser quoted above, in that in researching interventions for behaviour change in general she concludes that: "Interventions can fail before they've had time to be effective particularly in the field of learning disabilities where individuals take longer to learn" (2005: 117).

Citing Woods & Cullen, J. F. Brown adds that staff found it difficult to maintain these programmes over a long time, which needs high levels of effort to sustain (*ibid*). She continues by quoting Felce (1998) who maintains that staff orientation is important because to do anything we need both skills and the motivation to use them.

However, the motivation of lowly paid care staff to engage in demanding and long-term therapeutic interventions is a key factor in the ultimate success of the programme. This leads Brown to conclude that staff's thoughts and feelings about the clients' behaviour will have an important role to play in the outcome of a therapeutic programme. Writing from the stand point of unqualified health workers who were selected to tutor sex offenders who have a learning disability, Sandhu *et al* (2012) endorse Brown's sentiment. Yet they further conclude that some workers were more therapeutically minded than others and that competence in this appeared to be a personal characteristic rather than the result of years of experience. They further identified the personal quality of 'emotional intelligence' with this competence. Thus this research seeks to address the following questions. What are the positive and also the negative feelings SCWs have concerning their work with service users whose sexual behaviour is unacceptable, and how does this inform the work they do?

2.17 Sum up

Why might the Social Care Worker's role be important to the process of modification of unacceptable sexual behaviour in their service users? These workers are in the company of the service user every working day and as such have the opportunity to built up understanding, communication, trust and rapport with the individual whereas health professionals such as the nurse (specially trained or otherwise) can only be seen by appointment. This places the Social Care Worker in a central role of reinforcing behavioural therapeutic interventions which must be on-going and consistent. Indeed, the Social Care Worker is central to the role of identifying that the behaviour needs to be addressed since they will often be the first to witness it or be told about it. To date no research has been done into how the Social Care Workers handles real situations in which a service user's sexual behaviour is unacceptable, when they need to bring in help from a health professional or how they feel about their level of involvement in the service user care. Furthermore, the value, and the valuing of the working relationship between front-line worker and the service user has not been considered in any situation including when the former is involved in the modification of the latter's unacceptable sexual behaviour. Having the Social

Care Workers' own account of their experiences will add to knowledge of treatment in the community, and help identify areas and situations in which more training and support for the worker is required.

Reference has been made above about the lowly status of the SCW. Furthermore, as opposed to treatment taking place in the community Vaughan (2003) argues for the development of a long-stay secure service that offers a range of secure measures for individuals who have a learning disability and whose sexual behaviour is unacceptable. These behaviours, he insists, "are difficult to contain within a typical community setting" (113: author's italics). Nevertheless, the reality is that McKenzie *et al* found that out in the community SCWs were dealing with: "the range of behaviours (were) similar in nature to those displayed by individuals detained under the Mental Health Act at the health care houses, and included rape, sexual assault and exposure" (2011: 63). When this is the case SCWs and their organisations can choose either to avoid their duty of care, or seek to extend their habitus/jurisdiction in order to cope effectively.

Chapter 3

Research Strategy

3.1 Methodology

3.1.1 Ontology

Smith (1998) defines ontology as being the relationship between knowledge and reality so is concerned with the question, “What can really exist?”(279). Thus it is an account of being rather than knowing. Smith goes on to comment that empiricists do not accept that it is possible to distinguish between the things we experience and the mental construct we use to understand the empirical level. As Bryman elaborates, this “implies that social phenomena confront us as external facts that are beyond our reach or influence” (2004:16). Aptly here, he gives as example, the organisation, which he describes as:

“ . . . a tangible object. It has rules and regulations. It adopts standardised procedures for getting things done. People are appointed to different jobs within a division of labour. . . The degree to which these features exist from organisation to organisation is variable, but in thinking in these terms we are tending to the view that an organisation has a reality that is external to the individuals who inhabit it” (ibid).

What Bryman implies here is that rather than organisations having these implicit characteristics, the form it takes is the construction of social agents. That is to say, it does not have an immutable reality we can state as fact, but that it has been constructed and can also change through social agency. For example, the current concept of ‘care’ for those who have a learning disability is one of inclusion which demands the resituating of care from isolated institutions to the community. Along with this comes the concept of ‘support’ which has changed from a notion of keeping safe, fed, clean and contained, to one of empowering the individual. In effect this manifests as encouraging service users to see as much as possible to their own physical needs, foster the development of skills and interests, and facilitate inclusion in the community. It is therefore feasible to analyse work involving the care/support of service users who have a learning disability in constructionist terms as described above.

3.1.2 Epistemology

Crotty explains, that epistemology concerns the “philosophical grounding for deciding what kinds of knowledge are possible” (1998: 8). According to Carter & Little (2007) in research this influences the implementation of method in three ways. Initially it affects the relationship between researcher and researched in that the latter can be cast as the subject to be studied or as an active contributor. Epistemology also influences the way in which quality of method is demonstrated, for example, through use of triangulation or choosing to undertake a structured interview which can be repeatedly used to the letter, or the researcher can incorporate memos of decision making processes into the research findings, etc. Finally, Carter & Little suggest that epistemology influences form, voice and representation in the method, i.e. whether the researcher is present in the research through including an account of her subject position or whether she is absent from the work – an objective ‘non-presence’.

In epistemological terms this research is approached from what is termed an interpretative perspective which as part of the post modern turn suggests that there is no single ‘truth’ but, rather, a multiplicity of subjective ‘truths’. In research terms this implies that there is “no one truth to be discovered by an impartial . . . scientist [objectivism], but many truths awaiting discovery” (Padgett, 1998: 6). Interpretivism relates to this because it refers to the concept that meaning is not fixed but constructed by different people in different ways even in relation to the same phenomenon (Crotty, 1998). This would include the researcher, the interviewees, and also the person who reads the research. How then can this be useful in furthering knowledge and informing practice to the benefit of the service users, their carers, and the world at large? Padgett (1998) points out the logic of postmodernism can be taken to an extreme and the ‘many realities’ approach becomes a hall of mirrors in which nothing is knowable. Here she cites as example that under postmodern reckoning we can never verify how many were killed in the Holocaust because this event can be interpreted from many standpoints, none of which are privileged. So how might we ‘privilege’ one utterance over another? As Robson explains: “People, unlike objects of the natural world, are conscious, purposive actors who have ideas about their world and attach meaning to what is going on around them (2006: 24).

Does this mean then that knowledge gleaned about one individual cannot be generalised to others? If this was the case then no knowledge can be generalised and therefore has no use outside of that individual. However, when research subjects already share things in common – their work, the nature of a particular task as part of that work, the societal mores and laws in which they all operate – then it is possible to generalise to a *workable* degree. As Miller and Glassner (1997) insist:

“what matters is to understand how and where the stories are produced, which sort of stories there are, and how we can put them to honest and intelligent use in theorising about social life” (111).

This line of thinking is not without its detractors. Alveson writes that:

“Qualitative researchers still present interview statements as if they were pathways to the interiors of those being interviewed or mirrors of social practice, although it is broadly recognised – also among positivists – that data need to be interpreted to say anything” (2002: 4).

Yet whatever interviewees think they have expressed, and however interviewers interpret this, both refer to concrete events or effects in the world. As Crotty goes on “to talk of the construction of meaning is to talk of the construction of meaningful reality” (10), thus drawing together constructivist ontological and interpretive epistemological stances which complement each other. Robson elaborates on this by explaining that “In particular, (their) behaviour depends crucially on these ideas and meanings (24). That is to say, abstract phenomena such as ‘meanings’ have material consequences or palpable effects. Why is this concept of reality not consistent with objectivism? Because palpable though reality of a phenomenon is, there is also the awareness that it can change or disappear, i.e. it is neither immutable nor eternal in that there is no ‘essence’ to the phenomena as defined in quantitative methods by those who research the natural sciences. In any case, as Webb asserts: “Social science is like science in the sense that it is marked by constant debate and dispute over fact, theory and method” (1995: 96/7).

What this statement amounts to is an acknowledgement that ‘objectively’ acquired knowledge, even in the ‘pure’ sciences shifts and changes or can be seen from

different perspectives. I might add that accounting for every affective variable in quantitative practice can also be regarded as pretty futile as new discoveries often lead to the reconsideration of previous ‘facts’. In taking an interpretative approach this is not to succumb to what might be termed the excesses of postmodern thought in which all is in flux, for as Padgett reminds us: “The arid detachment of the postmodern movement appears inappropriate and potentially harmful amid the crises in social and health-care services that beset the poor and the vulnerable” (7). It may be concluded then that rather than making ‘truth’ claims we simply set out to discover that which is useful to the lives of ourselves and others within the context of our particular historical and cultural circumstances.

3.1.3 Qualitative methodology

Quantitative methods are characterized by the passive respondent; dependence on replicating research procedures precisely in order to confirm findings, and the concept of the objective researcher. These are attributes which define the positivist approach to research in which researchers seek to discover a pre-existing reality in a manner akin to that used in the natural sciences (Strauss & Corbin, 1994).

Qualitative methods on the other hand involve the active respondent, triangulation by comparison of data and the declared subjective position of the researcher and is in keeping with constructivist ontology and interpretative epistemology. Strauss & Corbin (1990) write that some areas of study are particularly suited to qualitative research and give as example the uncovering of individual experiences of phenomena which this method allows. Thus they maintain researchers gain intricate details that are difficult to access using quantitative methods such as a questionnaire.

My research concerns the role SCWs play in a given situation but with myriad contexts, for example, the worker’s employer’s policy, experience, training, attitude – the service user’s sexual behaviour, level of disability, history etc. It is also important to find out about the worker’s confidence and how this is informed by these aspects including how s/he perceives her/his abilities and competences. It is also necessary in this work to give an account of myself and declare my subjective position as a researcher who is also a SCW. I do this in order that readers can

approach this work with a fuller understanding of its genesis. This is also in keeping with the ontological and epistemological approach taken in this work.

Thus this is an emic study since it is concerned with the lived experience of respondents and Padgett states that in such instances qualitative methods are more appropriate because they allow the respondent to explore and express their experiences in their own words. As Padgett continues, this is a heuristic device, i.e. it puts meaning in context. Moreover, qualitative methods are naturalistic, favouring *in vivo* observations and interviewing of subjects thus appropriate in conveying the complex world of respondents using “thick description and assuming a dynamic reality” (3).

Qualitative methods are also fitting in situations where the research topic is a sensitive one, i.e. in research such as this in which the worker’s approach to service user sexuality is central, closed questions may be regarded as inappropriate or insensitive (Lee, 1993) since they do not allow the respondent to contextualise their answers from their own perspective. That is to say, an action may seem inexplicable when looked at outside of its context which gives its whys and wherefores.

Qualitative methods can also be used to evaluate outcomes of processes but unfortunately the time constraints of a PhD. studentship places this outside the scope of this research. Nevertheless it is useful in determining these processes at work. In all then, qualitative methods are as Allan (1991) asserts appropriate to exploring topics especially those calling for respondents’ own understanding of events, and as such, Padgett assures us, are also most appropriate for gaining in-depth understanding.

My project is thus in keeping with ESRC guidelines concerning the uses of Social Work research which advises that researchers should “Highlight the quality of lived experience and advance practical wisdom” (ESRC, F15: 4.1, accessed 12/09/08). Such a statement seems to place the researcher between the horns of qualitative and also quantitative strategies. Lived experience certainly includes an individual’s palpable actions, but these are driven by the complex contexts of both the individual

and the situation in question. Quantitative methods fall somewhat short when we need to know the ‘why’ rather than the ‘what’, and as Anastas & Mc Donald (in Robson, 2006) have pointed out, are no less prone to being interpretative. As such a qualitative approach is more effective in untangling such complex contexts giving prominence to “understanding the actions of participants on the basis of their active experience of the world and the ways in which their actions arise from and reflect back on experience” (Allan, 199:177). As Allan continues, this requires a more flexible approach from the researcher than quantitative methods, such as questionnaires allow. Thus the epistemological approach in this research is that knowledge is subjective, so utterances must be considered in their context or from subject positions (O’Sullivan, 1994) including that of the researcher.

3.2 Qualitative approach

Within the discipline of qualitative studies a selection of strategies are available for data analysis and as Stark & Brown Trinidad remind us: “A judicious choice of method guides the research toward the intended aims and helps ensure that its products are useful and well received” (2007: 1372). To re-iterate, exploring the role of the SCW in modifying a service users’ unacceptable sex behaviour is the aim since this area is under-researched. The question is how best to go about this? Which qualitative method is most appropriate to the aims, objectives and practicalities of this study whilst incorporating my ontological and epistemological position?

3.2.1 Grounded theory

Initially, the method used to analyse data collected for this research was done by means of Grounded Theory. More specifically, I used this method as devised by Strauss & Corbin (1990) as opposed to that set out by Glaser in which the latter regards research preparation by literature review as a source of researcher bias in the process of letting the data ‘speak for itself’. In terms of my research, the formers’ version of Grounded Theory had many aspects that commend its use in that:

- a) This is the recommended method when a subject is under-researched;
- b) Its processes are both inductive and deductive which aids the process of generating theory;

- c) Being both inductive and deductive it encompasses the process of triangulation;
- d) It involves the use of memos regarding decisions on interpretation which have been made thus, it is argued, is reproducible,
- d) And it involves the use of memos in which the researcher's reflections on different aspects of the process, including note of her subject position in relation to the research are set down in writing.
- e) Lastly, Grounded Theory is a systematic method; an important aspect when a lot of data are to be analysed.

This said, there is a fundamental difference between undertaking a PhD and using Grounded Theory, even in the form developed subsequently by Strauss and Corbin. A doctoral thesis requires the researcher to set out their stall from the beginning, detailing the questions they want to address and this is not the way Grounded Theory can be approached since categories must be allowed to 'emerge' rather than be hunted down. Indeed, those who claim to have delivered a Grounded Theory project can be rather coy regarding the questions they subsequently ask when tracking down a category so it is difficult to tell whether they have given more importance to a category than it actually warrants; that they have introduced an element of bias. Perhaps the category is part of an interviewee's experience, but hardly one that is central to it and likely to 'emerge' when using a less focused interview style.

Additionally, the method is dependent on the researcher having enough interviews, initially to determine workable avenues to explore in subsequent interviews and then to be able to saturate the data. Try as we might predicting the number of those who will volunteer for interview, especially given the time restraints of completing a PhD, and the sensitive nature of the study, is not possible. Nevertheless, given the advantages listed above and encouraged by the fact that others, from whom I could learn, had used Grounded Theory to successfully complete their thesis, I set about to use it in my research.

3.2.2 Changing method

There seemed to be many good reasons for choosing Grounded Theory for my research, especially the form developed by Strauss and Corbin since its process allows for first undertaking a literature review which is mandatory in the PhD process. Indeed, unless the researcher has a solid history and reputation in the field, it is difficult to imagine anyone attracting funding using Glaser's version which rejects the idea of research informed by a literature review and ideas *a priori*. This said it may be argued that the selection of an area to investigate comes itself with ideas and expectations of outcomes, albeit that they occur to us without conscious effort.

With the intention of using Grounded Theory I set out to undertake 30 interviews in Scotland and as many in Melbourne as recommended by Robson (see above). This said I was prepared to accept 20 volunteers from each location as a minimum requirement thinking that this would also allow for saturation. In Scotland I contacted 41 organisations in 4 chosen areas which included 4 regional councils. Of these, 5 organisations and 1 City Council responded positively resulting in 9 volunteers for interview. In Melbourne, I contacted 25 organisations and was contacted by a further 2 that has seen my advert for gatekeeper contacts on the DPV website¹⁴. Of these 27 only 4 agreed to pass on my request to staff for volunteers, and in the end I got 10 volunteers but from only 2 organisations.

Why was response so poor? In Scotland a couple of organizations contacted me to say that the current economic climate and accompanying cut-backs meant that they had too much going on internally to consider playing a part in my research. Perhaps they were also sensitive to any negative outcomes from my research (although confidentiality was assured) reflecting on them and affecting their funding from their Social Work Departments. After corresponding for a few weeks and also meeting up with members of their staff, two organizations seemed very keen to get involved, but then stopped responding altogether. One of the regional councils did grant me access to their gatekeepers and one did get in touch with me before similarly dropping off

¹⁴ Disability Professionals Victoria.

the radar. One gatekeeper from a charity organization told me in a phone call that he would get a member of his staff to be interviewed but then never got back in touch. Perhaps because I said that for ethical reasons his employee would have to volunteer for interview. For the most part though, I got no responses to my letters, emails and phone calls.

In Melbourne, I was fortunate to have a contact through ASID¹⁵, an association through which I'd previously given a conference paper on findings from my MSc dissertation. He added to the small list of service providers I'd gleaned from browsing the internet. Additionally, he gave me contact names and sent out emails to gatekeepers recommending involvement in my research. I duly contacted these gatekeepers; initially by email from Scotland, and once in Melbourne by phone, email, and also by paying visits to talk with staff. Again, a couple of gatekeepers who showed initial interest failed to keep in contact, and also where access had been granted, no volunteers came forward for interview. What surprised me – and it is something that may also have applied to Scottish organization I had contacted by email (for details of the person in the organization to whom I should address my request for volunteers) - was that one of the gatekeepers who got in touch voluntarily told me that he had not received some of my emails and put this down to the fact that his organization's computer firewall was rejecting any emails with the word 'sex' in them. Another gatekeeper refused access because he believed my research exploitative of service users. I did of course reply explaining that the aim of my research was to inform and improve practice but got no further response.

Whatever the reasons in Scotland and in Melbourne, I ended up with too few interviews to be able to saturate categories, a process central to analysis using Grounded Theory. Thus I was compelled to reconsider other methods with which to approach my data.

¹⁵ Australasian Society for Intellectual Disability.

Prior to deciding to use Grounded Theory, I had read about and considered the use of Phenomenological Hermeneutics. From what I had read it seemed worthy of consideration since it involves the close examination of individual's experiences (Baszenger & Dodier, 1997). Further, this method is used to determine the meanings and common features of an experience based on the concept that:

“The truth of the event, as an abstract entity, is subjective and knowable only through embodied perception; we can create meaning through the experience of moving through space and across time” (Stark & Brown Trinidad, 2007: 1374).

This alludes to the importance of context to Phenomenological Hermeneutics which is also important to this thesis given the variety of experience and experiences of support workers. Thus, I thought at the time that this method would be appropriate to my research since my aim was to gather worker's lived experience from their own perspective. Use of this method also concerns uncovering an event's core elements, an important aspect when a subject is under researched. However, material I read on the use of Phenomenological Hermeneutics advocated 'bracketing' out the researcher. As such: “The researcher must examine herself in order to identify personal biases and remove all traces of personal involvement in the phenomena being studied” (Patton in Marshall & Rossman, 1995: 82).

What this amounts to is the researcher making an account of, and removing herself from the research process in order to avoid bias in the collection or analysis of data. This results in what Patton and others believe in and advocate - objective research. As stated above I take a constructionist/interpretive approach to research arguing that objective research is not achievable since individuals cannot escape their subject positions.

3.2.3 Phenomenology

Koch (1994) explains that distinction can be drawn between Husserlian transcendental phenomenology and Heideggerian hermeneutic phenomenology which has implications for the methodology and method researchers use. Referring to research into nursing, it is as Walters asserts: “Most nursing discourses

concerning phenomenological research technique has failed to discriminate between the different philosophical traditions underpinning these research approaches” (1995: 781).

Although both forms are interpretive and so initially appropriate to qualitative method the Husserlian version has been described as positivist (Koch, 1994; Walters, 1995). As Koch elaborates, Husserl’s transcendental phenomenology is based on the mind-body split known as Cartesian duality, which, she explains, “offers a mechanistic view of the person” (1994: 828). Indeed, Dreyfus (1987) describes Husserlian phenomenology as: “the culmination of the Cartesian tradition that thinks of man’s relationship to the world in terms of subjects knowing objects” (in Walters, 1995: 792). Thus phenomenology as articulated by Husserl amounts to: “study of phenomena as they appear through the consciousness” and “recognition of experience as the ultimate ground and meaning of knowledge” (ibid).

Husserl uses the concept of ‘life-world’ to refer to lived experience which amounts to the effects of an individual’s culture upon them. So imbued are we with its traditions, ways of perceiving the world, and also its mores, that individuals regard aspects of life as given; as common-sense. This is similar to Derrida’s insistence that we are always already in-formed as members of a given culture and phenomena have to be deconstructed in order to understand the cultural meanings that underpin them. Husserl’s goal is similar in that he wants to uncover the underlying structures – ‘consciousnesses’ or ‘essences’ – that underpin a culture’s take on their world and evaluate their part in their construction of meaning. As Koch sums up: “... the enquirer using Husserlian phenomenology always asks about the meaning of human experience. Reality is the life-world” (828).

Koch goes on to explain 3 concepts central to Husserl’s phenomenology. The first is ‘intentionality’ which she defines as an “idea (was) based on the assumption that our own conscious awareness was one thing of which we could be certain” (828). This then is the foundation of our knowledge of reality. The second aspect is Husserl’s main aim which was to uncover the structures or ‘essences’ that constitute

consciousness. Framed within Cartesian duality Koch comments that the resulting mind-body split is explained metaphorically as body as container for the mind wherein symbolic representation occurs. Thus Koch argues that it is through Husserl's search for 'essences' that he claims to be objective. As Walter's notes, "Husserl's phenomenology was conceived of as the foundation for a rigorous science of absolute knowledge" (1995: 792). The third concept is that of 'bracketing', and here Husserl appears to contradict his own theory of knowing the world. Of this Koch cites Shultz when he writes that Husserl added the ultimate level of transcendental phenomenology, bracketing not only the individual world but also the individual consciousness. This is referred to as 'phenomenological reduction' which Walters explains involves reducing the complex problems into its basic components by, as a researcher, eliminating one's prejudices about the world (1995: 792). Koch goes on, "to bracket things in this way is not so much a matter of doubting their existence but of disconnecting from them" (ibid). In effect this amounts to the researcher claiming validity through objectivity by denial or bracketing out their own subject position. Thus Husserl's transcendental phenomenology, although generally regarded as an interpretative device, is as Walter's states: "referred to as eidetic reduction, i.e. bracketing [is] where he attempted to achieve a vision of consciousness totally untainted by interpretations, i.e. to let the facts speak for themselves" (1994: 609).

Koch contends that within nursing research the concepts of phenomenology and hermeneutics are used inter-changeably whilst Walters (1995) also comments on the fact that "these two vastly different philosophical approaches . . . assume homogeneity of phenomenological philosophies" (791). This she adds, results in the development of a single phenomenological nursing research method. This in spite of the fact that within Social Science the concept of the knowing subject has been seriously questioned over the last 30 years or so. Yet it is apparent that such confusion does not appear to be confined to nursing research. In their text book aimed at researchers in general entitled 'Designing Qualitative Research', Marshall and Rossman (1995) describe phenomenology in precisely this uniform positivist manner.

Heidegger, a pupil of Husserl, questioned the Cartesian basis of the latter's approach which he found problematic. As a result Heidegger revisited Husserl's philosophy to consider its ontological status (Koch, 1995). Developing phenomenological hermeneutics, Heidegger identifies 2 main concepts; historicity of understanding and the hermeneutic circle. To understand these Koch recommends that researchers first grasp further concepts, namely, 'background', 'pre-understandings', 'co-construction' and 'interpretation'. 'Background' refers to the culture the individual is born into which determines what they consider to be 'real'. In Heidegger's theory there is an assumption that these background meanings, skills and practices cannot be made completely explicit. 'Pre-understanding' is the meaning and organization of a culture which exists before we are able to understand. As Koch elaborates: "Pre-understanding is a structure of our "being-in-the-world" [which is similar to Husserl's concept of 'life-world'] [However] It is not something we can eliminate or bracket, it is already with us in the world" (831).

Yet Heidegger cannot be accused of being deterministic. His further concept of 'co-constitution' is the way in which we are simultaneously constructed by and constructing of our 'world' which we construct according to our own experiences and background. We simply cannot stand outside it, and as Koch notes, through this process: "It is possible to find common meanings where the role of the situation, and personal concerns offer a relational view of the person" (831).

According to Koch, Heidegger's concept of 'interpretation' is achieved by the researcher accounting for a person's background understanding framed within its 'historicity' to which we must always make reference. In this way, the accusation that Heidegger's stance is deterministic is refuted since contexts differ and so 'reality' can also differ. This framework of interpretation is the "fore-conception in which we grasp something in advance" (831). For example knowing that an individual was born before or after a major war may affect interpretation, and being aware that the researcher was born before or after a major war may also affect that interpretation. Koch quotes Bleicher who writes:

“The circularity of argument is apparent in the conception of interpretation moving within the fore-structure of understanding what is already understood – characterizes the hermeneutic or existential-ontological circle” (ibid).

Since both researcher and researched inhabit a shared culture at a shared moment it is as Taylor suggests that: “There is no outside, detached standpoint from which to understand the cultural world, we are dealing with interpretations and interpretations of interpretations” (quoted in Koch: 831). Koch sums up this aspect of Heideggarian phenomenology when she notes that: “All claims to understanding are, for Heidegger, made from a given set of fore-structures which cannot be eliminated but only corrected and modified. Hence the famous ‘hermeneutic circle’” (832).

With Heidegger the shift in philosophical debate is from the epistemological stance of Husserl to one that is ontological (Walters, 1994). Husserl’s is an attempt “to achieve a vision of consciousness totally untainted by interpretation in which the knowing subject . . . lets the facts speak for themselves” (608). Rather, Heidegger takes the hermeneutic, interpretive approach in which Koch asserts, it is still possible to let facts speak for themselves but these facts are of necessity interpreted. Thus, states Koch, for Heidegger only as ontology is phenomenology possible and “analysis of particular existential facts proceeds from an interpretation of the relevance it has to existence” (609). This she concludes leads to new ontological understanding of being. Heidegger’s approach appears in keeping with the assertion made above that rather than the postmodern notion of the existence of multiple truths becoming a hall of mirrors, truths created and thus understood in a specific culture at a specific time and in specific situations can be essential to that time, culture and situation – and no other.

Initially use of hermeneutics pre-supposes prior understanding on the part of the interpreter. Indeed, Heidegger, according to Walters (1995) insists it is only possible to interpret something according to one’s lived experience, and later, that he believed that research was enhanced by the researcher’s beliefs which he regarded as an important part of the research process which is legitimized as a result. Analysis of data involves revisiting it several times to search out recurring themes in order to

uncover the hidden experiences of those under inquiry. As Walters after Heidegger goes on to explain, coming from the same group as you are researching gives additional closeness to their lived experience. In Walters' case she is a Critical Care Nurse investigating aspects of the Critical Care Nurses' experience. She states that from recurring themes emerge the ontological qualities that embody the experience of being-in-the-world for the group under investigation. As Walters insists, this is not a special process but one that people use in making sense of, or understanding, their everyday world.

Use of phenomenological hermeneutics also avoids subjectivism because of the inter-subjective shared experience and interpretations of the researcher and the researched. Thus, insists Walters, the researcher does not have to 'get inside the mind of the subject' to achieve understanding. Using Heidegger's approach thus acknowledges the contribution of the researcher's experiences to interpretation. Should this differ from that of the researched then Thompson suggests that the researcher keeps a journal explaining her own position since:

“the theory or interpretation that emerges from the data are influenced by the conceptual leanings (biases and prejudices) and interpretive background used, consciously or unconsciously, by the scholar” (in Walters 1995: 794)

Walters also points out that hermeneutic interpretation of everyday activity also recognizes the situated meaning of the action, not abstract or causal relationships between actions, and is unique because of this. As social agents of a shared culture we thus understand the meanings and purposes these actions serve. Understanding is also a product of what we already know and concepts that arise from the enquiry in question. Thus new understanding develops and is refined (Packer cited in Walters 1995). Koch further notes that Heidegger does not provide a method but that understanding is reached through a fusion of the dialectic between the pre-understanding of the research process, the interpretive framework and the sources of information. To this effect Walters (1994) describes her collection of data as taking the form of 'experimental conversations' in which researcher and those being researched reach shared understanding of events. In Heideggerian tradition this also means that the researcher keeps a journal in order to account for her own context and

experiences, and also methodological and practical considerations. This is similar to the Grounded Theory practice of memo writing although it may be argued from a Heideggerian point of view that future researchers reading your findings will come to them from a different background and range of experiences and that this is to be expected and accepted.

Phenomenological Hermeneutics may be regarded as appropriate to this research for the following reasons:

- a) In terms of the specific situations under investigation here Heidegger's concept of 'Sorge' is particularly important. Of this Walters (1995) notes that his concept of 'Dasien' or 'being-there' emphasizes the situatedness of our reality thus analysis takes as its point of departure the interpretation of being-in-the-world, the most fundamental element of which is 'sorge' which translates as 'care'. This Walters elaborates "is about Being and caring for things, and other people" (783), and it may be understood that individuals form societies through the need for mutual support in one form or another and as a species we seem compelled to the social.
- b) Phenomenological Hermeneutics is used by Walters in her studies of nursing because of this central concept. Thus I would argue that it is also apt in research into support working which is founded on the care of one human being for another. Like Grounded Theory, Phenomenological Hermeneutics is also recommended for use in situations where the subject is under-researched (Annells, 2006). Annell's quotes Wilson and Hutchison who insist that "The rich and insightful detail of hermeneutics provides a depth of personal understanding that creates a dialogue and a beginning for a conversation" (56).
- c) Heidegger also emphasises the importance of the fit between researcher and what they are researching, considering this to be the starting point for hermeneutic enquiry. With this in mind I, as an experienced Social Care Worker, can use my existing knowledge and understandings of what it is to work in this field to inform the quality of interview and analysis.
- d) Emphasis on contextualization allows the research to address the complexity of the subject area.

- e) Unlike Grounded Theory, 'categories' do not have to be 'saturated' although common themes are sought. What this does is remove the need to acquire 30 + interviewees as is recommended in the case of Grounded Theory by Robson; a number difficult to meet where the subject area is such a sensitive one.
- f) In seeking common themes in existing transcriptions of interviews rather than using the interview process to focusing down on a core category, as is the practice in Grounded Theory, the priorities of the interviewees are allowed to emerge. Thus the respondent's priorities become apparent, not those of the researcher.
- g) This method includes acknowledgement of the interpretation process of the researcher, participant and also the reader.

Thus Phenomenological Hermeneutics is relevant and suitable to answering questions which concern SCWs' experiences that constitute the greater part of this enquiry. However, due to reasons which are explained in Chapter 10 in the section on reflexivity, the first question on the contents of organisations' policies will be reviewed with regard to their explicit contents.

Question 1 - Since organisation's policies are to be reviewed with regard to their overt rather than covert content, Phenomenological Hermeneutics will not be used for their analysis. Rather, this will be a matter of simply reading them to find out what they do and do not say about advising staff on procedures in situations where a service user's sexual behaviour is unacceptable.

Questions 2 – 5 uses Phenomenological Hermeneutics to examine scenarios in which the service users' unacceptable sexual behaviour becomes apparent; the factors involved in deciding to deal with the behaviour in-house and those involved in decisions to consult a health professional; roles undertaken by SCWs in both scenarios and also the SCWs' feelings about involvement in the modification of the service user's unacceptable sexual behaviour.

The use of Phenomenological Hermeneutics is, I would argue, entirely appropriate to this research since it concerns the worker's own account of their experiences and this

method is directly concerned with the respondent's accounts of this. Taken within their contexts, as Walters assures us, using Phenomenological Hermeneutics situates meaning of the action rather than produces abstract or causal relationships between actions. Given the myriad of possible contexts involved in the situations under research here use of Phenomenological Hermeneutics is of particular use given the exploratory nature of this work into an under-researched field.

Use of Phenomenological Hermeneutics also allows participants to decide what is significant in relation to my subject area unlike Grounded Theory which sets out with an open agenda which is subsequently narrowed or 'focused down' by the researcher. Use of Phenomenological Hermeneutics on the other hand, even though data is a co-construction, allows interviewees to express what is significant to them. It is then the job of the researcher to find what accounts may have in common. Meaning is also a co-construction and as Walters explains, Phenomenological Hermeneutics is a method in which involvement of participants is considered to be an important component in the overall interpretation process, where new meanings can surface and better interpretations achieved.

Heidegger recognized the importance of the researcher being an 'insider' because it is only possible to interpret something if it is also part of your own lived experience. Because of this the researcher can use prior knowledge of the field to inform, discuss and explore practices they have in common with the interviewee in ways that an 'outsider' could not. This is especially true where the field is under-researched and few texts are available. Thus it is argued, coming from a shared culture we come to the data with a measure of understanding which is then enhanced by further information provided by the interviewee, in dialogue with the knowledgeable interviewer, that in turn develops or refines existing knowledge.

3.3 Changing aims

Poor responses to my request for interviewees also had impact on the aims of this research specifically that of making a comparison between workers' experiences in Scotland and Melbourne, Australia. Related to the lack of numbers was a

polarization of the status of workers who agreed to be interviewed in these countries. Whilst those from Scotland consisted of a Manager, Team Leaders and Key Workers, those from Melbourne included a Manager, Team Leaders and Key Workers, and of other front-line staff, Full-time, Part-time, and Probationary Workers. Thus no comparison could be made between these localities in terms of Full-time, Part-time and Probationary Workers since there were none of this rank included in interviewees from Scotland. This said status, knowledge and roles of these workers from Melbourne confirmed one of the findings from my MSC dissertation which concerned Scottish workers. For this reason I have decided to include rather than compare the accounts of the workers from Melbourne in this thesis, since to do so positions 'proximity' as a central concept.

3.4 Validity

Qualitative research is regarded as a lesser method than quantitative. As a variety of the former, Phenomenological Hermeneutics is also subject to criticism for lack of scientific rigor. Reliability means applying the same procedure in the same way to produce the same measure. Used at a different time to the unaltered phenomena the procedure should produce the same results (King *et al*, 1994: 25). This approach is based on the concept of the researcher as objective observer and the existence of immutable facts. With regard to objectivity, given that 'bracketing' oneself as a researcher is not only impossible but counter-productive in Heidegger's reckoning how does a researcher using his version of Phenomenological Hermeneutics justify their findings? In Heideggerian analysis there is no object-subject dichotomy and no 'fact' exists independent of interpretation thus validity as featured in positivistic sciences is an illusion (Walters, 1995). Rather, it is as Robson argues, having a grasp of the issues is of benefit during interview since the researcher can pursue lines or introduce prompts which will help the interviewees give greater detail in their accounts. He asserts: "without a firm grasp of issues (theoretical, policy etc.) you may miss cues; not see contradictions; [nor see a need for] further evidence" (2006: 169).

A further advantage of having ‘insider’ status is that I can immediately find common ground with interviewees by disclosing my own status as a Social Care Worker. This may act to reduce the effect of any perceptions interviewees may have of me as a ‘brainy’/privileged researcher which could result in their distrust (Miller & Glassner: 1997). Instead, I hope to claim what Robson terms ‘street credibility’ in order to elicit open, frank responses to my questions thus enhancing its credibility.

Walters (1995) cites Jasper who uses quantitative terms when he insists that achieving validity in phenomenological research concerns both participant and researcher. In the case of the former, use of participant validation and of the latter, inter-rater reliability, is recommended. Yet as Walters points out, these methods are based on the assumption that it is possible to achieve valid or true interpretation of human actions. In practical terms of this research neither means is possible because the time schedules of both myself and my participants does not allow for this level of involvement. Neither is inter-rater validity possible since this work concerns a PhD. However, Robson writes suggesting that validity in qualitative research is possible and involves showing that you have been thorough, careful and honest (ibid). Arguably Phenomenological Hermeneutics provides the most detailed account of its processes since it emphasizes the importance of the interviewer having ‘insider’ status to enhance the work. Such status is thus declared and as with Grounded Theory, decisions are recorded and form an audit trail giving arguably the fullest account of the process of any research method be it qualitative or quantitative.

Given that the Heideggarian approach is based on the belief that all ‘facts’ are arrived at through interpretation be it that of the participant, researcher, or reader. Walters continues that in order to present a credible account the written account of the research should include participants’ quotations which illustrate the researcher’s interpretation. The final interpretation is, however, only considered as tentative rather than an absolute truth. She suggests therefore that researchers are obliged to provide enough information about the research process to enable the readers to make their own interpretations. However much detail the researcher is able to supply, “The ‘correctness’ of the interpretation, (however), is judged by the reader” (794/5).

3.5 Method

Carter & Little (2007) define methodology as providing justification for the method the researcher chooses for her project (as related to chosen epistemic stance and the nature of the enquiry itself), and the method as the technique for gathering evidence. They quote Kaplan who describes the aim of methodology as:

“to describe and analyse . . . methods throwing light on their limitations and resources, clarifying their pre-suppositions and consequences . . . to help to understand, in the broadest possible terms, not the products of scientific enquiry but the process itself”(1318).

Marshall & Rossman (1995) note that social research: “long dominated by methods borrowed from the experimental sciences . . . now present a sometimes confusing array of appropriate alternative research methods” (1). As these writers continue:

“researchers often face at least three challenges in conducting qualitative research, namely, to develop a thorough, concise and elegant conceptual framework for the study; put together a plan and design that is systematic and manageable yet flexible, and finally, to integrate these into a coherent document that convinces the funding body or examiner that the study can be done and will be done” (5/6).

3.5.1 Means of data collection

In broad terms the aim of this research is to explore the lived experiences of Social Care Workers in situations where service users’ sexual behaviour is unacceptable and in need of modification. These experiences include instances where collaboration with a health professional is thought necessary and also when it is not. An emic study, this research seeks to elicit the workers experiences in their own words.

Whilst data collected by means of observation and interview as used by Ethnographers would have the benefits of encountering such situations first hand thus providing rich data, it is simply not possible because of constraints of time, matters of service users’ confidentiality and consent and further, the need for me as an individual coming into the service users’ living environment having to apply for clearance through Disclosure (Scotland) on each and every case. This would add an extremely heavy burden on the time factor involved in completing a PhD. As Stark & Brown Trinidad (2007) sum up: “Although observation can be a rich source of

data it is often impractical in health research because of the potential for intrusiveness and logistical difficulties” (1375).

Furthermore, ethnography is concerned with research into cultures in order to generate a typology of cultural classification (Marshall & Rossman, 1995). Whilst SCWs do have a shared work culture an aspect of which may be ways in which individuals in this group regard themselves in relation to nurses, it is not the aim of this research to ‘reduce’ their work to a culture but to gather a wide spectrum of different experiences from different contexts. In short, to determine differences as well as similarities.

One method that provides personal accounts but does not call for the direct involvement of respondents is to use extant material such as photographs, letters, diaries, records etc. Any individual who has been through the health or care systems will have a written record. Subject to the same needs to establish context e.g. of time, culture etc., use of these records avoids the problem of reliance on respondent’s memory although gaining access to the records still presents the problem of service user’s consent. Again, where the person has a learning disability, the additional problem of their capacity to give consent may be an issue. A further and considerable problem with using data from records is that often they are incomplete or ambiguous. For example in my research project towards my MSc I found that in written accounts violent sexual behaviour could be glossed over; trivialized, even omitted. Records can also contain use of coy and therefore misleading language such as ‘had an accident’ to describe ejaculation (Sangster, 2007). For these reasons use of service user files would not be feasible as a strategy in realising my research aims.

3.5.2 Interview

As Yates asserts, “when finding information out about people – the best way is to ask them!” (2004: 156) Yates goes on then to define the word ‘interview’ as literally meaning the development of a shared perspective and understanding between two or more people (ibid). Where qualitative method is concerned he adds that the main

concern is to discover the speaker's perspective, i.e. to see the subject through their eyes. Focus groups may be used in quantitative studies to determine categories and themes to be covered in a survey (Robson, 2006). In qualitative research focus groups may also be used to explore the subject area and can be particularly effective for allowing the unexpected aspects to surface in what can amount to a 'brainstorming' session. This makes use of a focus group worth considering in my research. However in discussing service user sexuality questions of confidentiality arise. Whether in a small town or large city, service users access the same services and often attend the same events even when their main care service is provided by different organisations so it could be quite easy when hearing another worker's experience to surmise who is being referred to even when details like name and sex are changed. There is also the possibility that more confident speakers in the group will hold the floor preventing the experiences of their less vocal colleagues from being included in the data.

When should in-depth interviews be used? "As with all selection of method a mix of practicality, theory and epistemology will come into play" (Yates, 2004: 158). Given that the role of the Social Care Worker has only been implied in previous research the in-depth interview facilitates emic research. Thus it is a practical method for finding out about a subject area since it involves direct *in vivo* enquiry. In-depth interviews also provide data from which theories can be developed and further, contain an acknowledgement and acceptance that individual's perceptions create their personal truth. As Yates argues, in-depth interview is appropriate where the aim of the research is to gain in-depth understanding and detailed description of an individual's experiences, how individuals give meaning and express their understanding of their experiences, to find out why events occur and to explore the complexity, ambiguity, and specific detailed processes taking place in a social context.

Whilst more time is required in conducting one-to-one interviews this method offers a more effective way of eliciting the widest range of accounts and rich detail. Since my topic is under-researched, using the flexible in-depth interview will allow for its

fuller exploration (Allan, 1991). That is to say, in the person-to-person situation I can follow up any unexpected or unpredictable turns in the conversation, as they arise, with further questions. Thus using in-depth interviews, it may be argued, produces a more developed account of experiences than any quantitative method because it allows also for interviewer's clarification. My questions can be rephrased if the respondent does not understand, and similarly, I can ask for clarification where I feel an answer is ambiguous or I simply do not understand the response. Additionally, in one-to-one interviews I believe it is easier to establish a rapport with the interviewee which will increase the possibility of the interview being a positive and productive experience for us both.

Arskey & Knight (1999) have noted that in-depth interviews also offer the opportunity for respondents to reflect and gain insights into their practice and conclude that the power of the interview includes its use to:

“examine the context of thought, feeling and action and can be a way of exploring relationships between different aspects of a situation. Interviewing is a powerful way of helping people to make explicit things that have hitherto been implicit – to articulate their tacit perceptions, feelings and understandings” (32).

Given the sensitive nature of the research topic, the use of in-depth interviewing will thus serve both interviewer and the Social Care Workers as access to the latter's beliefs and motivations behind the actions they describe.

In-depth face-to-face interviews are also appropriate when talking of sensitive issues such as is the case in this study. Being able to gauge a respondent's feelings about a question and to either leave it or rephrase it in a more acceptable way is simply not possible with a questionnaire (Lee, 1993: 101). It may also be beneficial in such situations that I am a female and that my respondents will also mostly be women. As Lee continues, females are generally more comfortable when being interviewed by a female researcher.

Use of a semi-structured interview schedule will also help focus the interviewee (and interviewer) on the subject in hand whilst also acting as a prompt for opening the

interview up for further comments and related issues. Semi-structured interviews can also serve to elicit matters, particularly those important to the interviewee that the interviewer might not have anticipated (Bryman, 2004). Thus ‘thick description’ is acquired.

3.5.3 Sample

Because of the specific experiences being studied in this research, a purposive sample will be taken of those Social Care Workers who are presently, or who have been in the past, been involved in deciding the nature of these behaviours and also involved in addressing them. Since this research can only meet its aims through interviewing Social Care Workers, the sampling method is described as being Purposive, i.e. it is not representative of the general public and not randomly chosen (Robson, 2006). As Bryman further explains, “Such sampling is strategic and entails an attempt to establish a good correspondence between research questions and sampling” (333/4).

3.5.4 The research sites

Research will involve support agencies for people who have Learning Disabilities in four Scottish areas, namely, City of Edinburgh, City of Glasgow, Fife, and Scottish Borders Regions. These areas have been chosen because together they are the equivalent of Melbourne Australia, in terms of population size. As mentioned above, both Scotland and Australia are at similar stages of closing down hospitals for people who have Learning Disabilities and finding them alternative accommodation in the community.

3.5.5 Procedure

Initially, support organizations in both Scotland and Australia will be approached in order to request copies of their policies on Sexuality and Relationships. Some organisations have their own Sexuality and Relationships policy whilst others use those which others already exist e.g. the one which was written by their Local Authority service provider such as City of Edinburgh’s *Making Choices, Keeping Safe*. Some organisations have no policy on the subject but it is important that I

emphasise that this need not prevent them taking part in the research. I need to emphasise in my introductory letter that they should not feel themselves criticised by this omission since their inclusion in the study will lead importantly to an all-round account in terms of the research aims. All appropriate support organisation operating in the City of Edinburgh, the City of Glasgow, Fife, and Borders Regions, and also the City of Melbourne will be approached to seek permission to ask their Support Workers to volunteer for interview. These organisations may be run by Local Authorities, charities or voluntary organisations.

Permission will also be sought to approach members of each organisation's Social Care staff to recruit suitable interviewees. In cases where Local Authorities provide a support service for people who have learning disabilities, External Research Ethics forms will have to be submitted in order to get permission to speak to their staff. An outline of the research and its aims will be sent to relevant gatekeepers within the organisations. Where the gatekeepers consent to their staff being interviewed, further copies of the research outline will be sent to the organisations for dissemination to their workers along with details of the interview process; an assurance of confidentiality, and a short letter introducing myself. I will then conduct semi-structured one-to-one interviews with each of the volunteers after giving a written and verbal account of the research and its aims, the former of which is to be signed by both interviewee and interviewer as note of consent to the interview taking place.

3.5.6 Data analysis

For reasons listed above, the method of data analysis that was thought most appropriate to this research was Grounded Theory. This involves the researcher examining transcripts of interviews closely to determine common themes. Questions asked at subsequent interviews are then devised to find out if there are indeed themes common to all workers' experiences. Thus these 'emerge' from the data. Once it became apparent that insufficient interviews had been forthcoming in order to allow this to happen it was then necessary to find an alternative form of data analysis which could be applied. Thus, Grounded Theory was used initially to separate respondents'

answers and comments into their particular question group. These were then sorted into their different types of response. That was as far as it was possible to use this particular theory of analysis. Having re-read accounts of various methods of data analysis it was decided that Phenomenological Hermeneutics best lent itself to the task, particularly as developed by Heidegger. His is an interpretative rather than positivist approach as devised by Husserl, and is thus more in keeping with the philosophical basis of this research. Furthermore, Phenomenological Hermeneutics takes as its point of departure people's lived experience and emphasises their contextual aspect. This was important in this study given that the concept of 'proximity' was used to describe the context of those who were interviewed in terms of their status within the organisation and also their working relationship with the service user in question. Thus Social Care Workers' roles in interventions into service users' unacceptable sexual behaviour was given further refinement within these concepts. An additional reason to use Phenomenological Hermeneutics concerns the importance Heidegger places on the need for the researcher to be an 'insider'. This, he asserts, enhances the validity of the research through knowledge and insights that 'outsider' researchers cannot bring to the process of interviewing subjects and interpreting their utterances.

3.6 Problems and challenges

3.6.1 Subject area

Because this research concerns the sensitive area of sexuality in the lives of vulnerable individuals, problems may be foreseen. One such potential problem could be that of access to Social Care Workers for interview, i.e. gatekeeper employers must be willing to grant access to their workers and the workers themselves must agree to be interviewed. A further potential problem arising is that interviewees may be self-selecting in that only those who are willing to support service users with issues of their sexuality may volunteer for interview. Whilst it is central to this study that interviewees talk about their experiences, much value may be had in discovering reasons why workers may not get involved and how they avoid getting involved. For example, do they refuse outright because they do not like to talk about 'things like

that' or do they interpret service user's sexual behaviour as innocent and not in need of modification?

3.6.2 Subjectivity

Reinharz (1997) maintains that the researcher brings a variety of 'selves' to the field . On reading her research notes she observed that she referred to herself in different ways as different aspects of herself became salient over and across time. She identified about 20 different 'selves' which she categorised in three ways; a research-based self, a brought self, and a situationally created self. The first category included, for example, being someone who was sponsored and someone who was a good listener. The second category included being a mother and being an American, whilst the third category included for example, being a worker and being exhausted. Whilst aspects of her 'brought self' such as being a mother served to help her acceptance by those she was researching, other aspects in this category such as her 'academic self' were slightly more problematic. As she concludes, "The researcher does not know in advance what attributes will be meaningful in the field" (18). From my own point-of-view I would hope that being a Social Care Worker will be viewed positively by interviewees making them feel at ease and have confidence in me and the research project, but I cannot take this for granted.

3.6.3 Insider status

Although integral to Heideggerian Phenomenological Hermeneutics, Robson notes that being an insider also has serious disadvantages. For instance, he explains that interviewing work colleagues can be an uncomfortable experience for both parties since confidential information which may be appropriate to the research may affect your working relationship with the interviewee, i.e. they will be asked to disclose information to you as a researcher that they would not otherwise disclose to you as a work colleague. Further, Robson notes that once you publish your findings, you have to live with any mistakes that you make. He explains that this will be particularly embarrassing for the interviewer who then has to face work colleagues on a daily basis. Perhaps the biggest disadvantage of insider research though is the likelihood of bias from either/or interviewer and interviewee. Am I only hearing

what I expect to hear? Are they only saying things they think I want them to say or which will place them in a good light? Great and continuing awareness of the possibility of these situations arising will be required in order to avoid any such bias distorting the research findings. Additionally problems of bias relating to my 'insider status', may be addressed by use of a reflexive approach to practice and since the particular qualitative method I am using is Phenomenological Hermeneutics I can provide readers with an explanation of my practice and conclusions. Further, I will not interview any colleagues with whom I work directly.

3.6.4 Researcher

Richard Sennett (1978) maintains that individuals in today's society emphasise the private aspect of life at the expense of a public, socially engaged way of living. In what he regards as this narcissistic state, individuals are constantly engaged in "this fruitless search for an identity composed of materials from within" (9). To illustrate his point he uses the analogy of an inexperienced interviewer who is "anxious to show that they regard their subjects as real people, not just as 'data sources' (9/10) that in attempts to demonstrate that they think of their subjects as equals will match the interviewee's personal revelation with one of their own. Sennet regards such behaviour thus: "Treating someone else as a 'real person' in this situation becomes like a market exchange of intimacies; they show you a card, you show them one" (10).

Interviews I conducted in research for my MSc dissertation also concerned Social Care Workers and I have to confess that I frequently offered stories of my own during interview. My intention, as I remember it, was sometimes to demonstrate that I had understood or that I needed to tease out subtle nuances from interviewer's accounts using examples of my own. I did not then consider that I was as Sennett insists, searching for my identity, though I may have been trying to send out a message to the interviewee that I was empathetic to their situation and shared their experiences. The latter situation could of course feed into the former and further, could happen on a subconscious level. It is certainly something I will have to be

aware of during interview and account for in analysis asking myself why I introduced a story and what effect it had on the interviewee's subsequent utterances.

3.6.5 As woman interviewing women

The interview process also has the potential to raise positive emotions like camaraderie which I hope very much will be the case. Yet this too needs to be reflected upon. Social Care Work is predominantly the domain of women. Finch (1984) comments on the ethical dilemma facing women researchers who interview other women. She comments that we have to consider, "the extreme ease with which . . . a woman researcher can elicit material from other women" (166), in part, she writes, because it offers them a rare opportunity to talk about themselves and their experiences. Further, they are more used to accepting intrusions such as interviews into their personal lives. Let us call this the 'good girl' syndrome – a polite and responsive way of behaving when finding yourself at the thinner end of an uneven power relation – eager to please, or at least, not get into trouble. A further point Finch makes is that women often lack the opportunity to talk with others like themselves, and certainly, especially where a Social Care Worker is employed to support a single service user, her/his daily contact with colleagues will be restricted to quick 'hand-overs' to on-coming staff. Finch maintains that the friendly female interviewer happening on such a respondent will find it easy to get the individual to talk. Conceding that some men may also be adept in getting women in such circumstances to talk to them, Finch maintains that where the interviewer is also a woman, then an added dimension comes into play because "both parties share a subordinate structural position by virtue of their gender" (170). As such, she argues, women, in contrast to men, are more likely to impart information which favours public interest over their own. This, she continues, is because:

"Most women are unlikely to be in a position where they can anticipate the outcome of research in this way, since they have little access to the public domain within which the activity of research can be contextualised" (175).

I'm not totally convinced by this argument which in effect casts women as naive and child-like. However I agree with Finch when she further advises that researchers

must be aware that aspects of their data could be used to undermine interviewees' interests so it is important that I reflect on each aspect of the research process including ways in which my findings could be used.

When a researcher offers her own stories at interview, it could also be an attempt to redress any perceived power balance within the interviewer/interviewee relationship. Munro *et al* (2002) and Plummer (2001) write of the power differences in the interview situation between interviewer and interviewee. The former writers opine the tendency to anonymize the researcher in findings and also remark that it is arrogant to assume that researchers hold all the power in the interview situation and that as a result they will be met with deference. From this stand point it would also be considered advisable for the researcher to make account of themselves in research findings by declaring their subject positions.

3.6.6 Sensitivity

It is not only knowledge of practical aspects of Social Care Work that I bring to this research. Having a 'brought self' of Social Care Worker I am also aware of the emotions involved in working closely with service users. In the role of interviewer this may serve to elicit an emotional response in me which enhances the research process. Wilkins (1993) writes of the emotional/autobiographical aspect of social research and notes: "...our emotional responses constitute key *cognitive* and *analytic* resources in the 'here and now' of the research setting and are capable of yielding important sociological insights" (94). Still, I have to consider the interviewee and the possibility of 'poking the wound'. As Wilkins reminds us, the researcher is active in making the moment so it is up to me to handle potentially upsetting but telling subject areas with awareness, empathy and sensitivity.

3.7 Ethical concerns and practical issues

3.7.1 Ethics

Padgett (1998) describes good research as achieving “a delicate balance act” (33). Careful consideration of the impact of the research on the interviewees; on the lives of those whose stories they relate, and on myself as researcher, is therefore required.

In terms of the SSPS Self-Assessment this research is graded at Level 1 in that I have carried out the School Ethics self-audit in relation to my proposed research project and can confirm that no reasonably foreseeable ethical risks have been identified¹⁶.

Ethical standards of City of Edinburgh, City of Glasgow, Fife Council, Borders Council and Melbourne City Council will also have to be met in order to approach their staff for permission to interview. As a member of staff of City of Edinburgh’s Social Work Department as a Social Care Worker to people who have a learning disability, I will not be interviewing anyone from the service of which I am part. This is done to avoid breaches of confidentiality since I may be able to guess who is being discussed in interview, and also to avoid any element of bias caused by familiarity with interviewees or bias when analysing data.

To those who are interviewed I owe an obligation to supply details of myself as the researcher and also the organisation, University of Edinburgh, which I represent. Interviewees are also due an assurance that their participation is voluntary and that they can refuse to answer particular questions or withdraw safely from the research at any time. Assurance must also be given of their own and their service users confidentiality. Regarding my own welfare as the researcher, I will avail myself of the University Counsellor should I find myself emotionally affected by the data I collect.

¹⁶ This situation has been reviewed in Chapter 10 which includes a review of research methods used.

Padgett (1998) writes that most funded research projects allow for small monetary payments to be made to interviewees. This 'gift' encourages participation and compensates respondents for their time. This seems only fair when asking people to volunteer to be interviewed in their own time when they are already busy working in a full-time job or unpaid in the home. Padgett goes on to advise that to offer too little is insulting to the prospective interviewee, whilst to offer too much looks like coercion particularly if the person is not particularly well-off. However, As Russel *et al* sum up, offering payment is in keeping with a consensus that reimbursing participants for their time is consistent with a duty of respect and not intended as an inducement (In Yacoub and Hall, 2008: 7)

3.7.2 Costs and resources

Expenses incurred in the course of this research will include incentive payments to respondents; travel expenses within Scotland; travel to and within Melbourne Australia; accommodation and living expenses within Melbourne Australia. I am fortunate in that such expenses form part of my ESRC funding award.

3.7.3 Dissemination

All organisations that agree to give access to staff will receive a Summary Report of findings and be advised of my email address should they wish to be sent the full document as an attachment. A Summary Report and offer to email the full document as an attachment will also be sent to respondents. I will also offer the thesis as an attachment to the Scottish Care Commission. I will also look for suitable conferences to which I can present the research findings and further, will try to organise workshops for organisations in Scotland. Additionally, I will submit papers based on my findings for publication in appropriate journals.

3.8 Research aims

This study is an attempt to fill a gap in understanding treatment in the community of people who have a Learning Disability and whose sexual behaviour is unacceptable. It focuses on the role of the Social Care Worker in this treatment from the initial acknowledgement that intervention is necessary to involvement in the treatment

itself. A gap also exists in understanding the ways that the Social Care Worker and the health professional work together to modify unacceptable sexual behaviour in this client group.

This study cannot make conclusions about the ultimate success of treatments since these take 2 – 3 years of pre-maintenance and so falls outside the PhD time limit. This leaves scope for future research which I hope very much will be taken up. Research findings may be used by the Scottish Care Commission to implement a policy recommending that all support organisations should provide their staff with a policy or guidelines specifically on addressing unacceptable sexual behaviour in service users. This could result in all support organisations having a policy which (if implemented) would help put an end to ‘patchy’ responses to these situations thus promote good practice. Finally, it is hope that this study will add to knowledge of treatment in the community so that the life of those whose sexual behaviour is unacceptable is improved to the extent that they are no longer ostracised by society. If this is the case then public safety will also benefit.

3.9 Overview of scenarios

Service user	Description	Worker
Ray	Uses binoculars to look at children	Edward/Rose/John
Tom	Obsessed with female staff/assault	Rose/John
Bill	Sex toys	Rose/John
Luke	Aroused by dancing and rhythmic songs	Jacky
Anna	Inappropriate with female staff	Louise
Frank	Sexual interest in cars	Grace
Fraser	Children – staff must always be with him	Beth
Chloe	Promiscuous especially with taxi drivers	Wendy
Dale	Generally unacceptable and has convictions	Charles
Clark	Wants to go to strip clubs	Grace
Trev	Looks up women's skirts	Jean/Beth

3.10 Case pathways

In the workers' accounts that follow, some have been of a complexity that has warranted frequent mention. In order to provide clearer understanding of these, detailed accounts of the pathways taken in these cases are now provided.

Grace - Frank

Frank is independent and mobile. In the past, he has tried to involve other service users in sexual activity by sneaking into their bedrooms at night. Although one of these service users has moved house, he and Frank continue a sexual relationship which appears to involve Frank getting bitten. Members of staff were already aware that he liked to cuddle and touch cars. As a matter of course, a member of staff followed him on one of his excursions into town to make sure that he was safe. She saw him start to cuddle a car but then he began to rub himself against it in a way that appeared to be sexual. This was confirmed when Frank climbed up onto the roof of the car and, as Grace explained, "hump the car". Frank, in his trips uptown has also been known to stand waiving money about and Grace cannot be sure whether he is looking to attract a sexual partner this way. He refuses to talk about it. This was a recent event and when I interviewed Grace she was keen to get a sex therapist involved. However, Frank's parents don't want any outsiders involved. Rather, they want him removed to a service where he can be closely supported 24 hours a day. Thus in the meantime, Grace is looking to get Frank on a course on the day that he usually goes uptown by himself.

Wendy - Chloe

When Chloe first came into the support service from her parents' house it was already recognised that she has a high sex drive. At one time she had a boyfriend who also has a learning disability and who lived in the same supported house. However, his aggressive behaviour towards other residents resulted in his removal to a support service in a different locality some distance away. Thus the relationship is only maintained by their phone calls. Chloe needs use of taxis on a regular basis to take her to her work and other activities. She has been in the way of chatting to the drivers in an inappropriate manner which has sometimes led to sexual intercourse.

Similarly, a male volunteer was once discovered naked in her room. A counsellor worked with Chloe because of this behaviour but their sessions finished some time ago. The behaviour returned and staff resumed the counsellor's instructions but at time of interview they were considering consulting her/him again. However, they could not be sure that treatment would be any more effective than the last time. Wendy suggested that it is a relationship Chloe wants rather than just sex but she sees this as a way of forming a relationship.

Jacky - Luke

Luke and his brother came into their current support service from an institution for people who have a learning disability. Some of his actions and requests seemed very odd but not sexual, until Jacky noticed that when she agreed to do what he termed the 'chicken dance' in order that he would go in his bath, Luke became sexually aroused. This led staff to consider other bizarre behaviours as sexual, which they turned out to be. One of these is his requests for others to recite rhythmic poems and songs, which, it transpired, he also found sexually arousing. On this realisation, staff stopped doing his 'chicken dance' and reciting these poems when he asked them to. In response to this, Luke would ask unwary individual's to write the poems down and he would then get another unwary individual to read the poems to him. Luke also gets sexually aroused by loud noises like music and in particular the noise children make on a bus when going to school. In response to this staff try to get him to avoid buses full of children but if members of staff become aware that he is getting excited then they let him know that they are both leaving the bus. Luke also acts in a sexually inappropriate way if children walk by when he is out in the garden. Workers have to be very aware of him and his behaviour at these times and will stand out of sight listening ready to distract him or to tell the children to go home, if he becomes inappropriate. His condition is such that health professionals find it extremely difficult to work with him since he has a low attention threshold and will not listen to them or stay on the subject. Thus Jacky and staff have to put the strategies together without health professional input.

Edward, Rose and John – Ray

Members of staff heard Ray speaking in a sexually inappropriate way about children. Their manager was informed and when he went round to talk to Ray about this and to find out what was going on, he saw Ray looking out his window, through binoculars. He was looking at children in a local playground. Edward and Key Worker John sat down with Ray to discuss what he was doing. Ray agreed that his behaviour was wrong and that he would not do it again. Nevertheless, because this was potentially a very serious situation, a CLDN was called in to make an assessment of Ray's behaviour. After consideration of Ray's circumstances and habits it was concluded that he would not actually physically go after children and harm them in any way. This proved to be so, but then quite by accident another member of staff played a tape recording Ray had made for his language class and heard him talking about what he would sexually like to do to little girls. He also sounded as if he was masturbating. The CLDN team were immediately called back in and Social Work informed and Ray then started both group and individual therapy to help him understand that this behaviour was unacceptable and also criminal. He has also been taught coping strategies should he find himself in a situation in which he could potentially harm a child. This involves phoning Rose right away, talking through and adhering to, an avoidance strategy. At time of interview, this was working. However, Ray has himself reported to staff that he's been making tapes again talking about what he'd like to do to children and again the CLDN has been called in. They have concluded that this in effect acts as a safety valve for Ray and that he is not in danger of carrying out any of the deeds he mentions. Staff reported that he is making good progress with his therapy and that he also now has a girlfriend.

Rose, John - Tom

Tom who has schizophrenia as well as a mild learning disability moved into his own tenancy from a residential service. This move greatly improved the quality of his life since he no longer had to share with 19 others and can come and go as he pleases with the support of 3 members of staff, one of whom was a woman. Because of difficulties recruiting suitable staff the woman got more shifts with Tom than usual and he became increasingly attached to her. He started behaving inappropriately

towards her and did not like it if she spoke to anyone else when they were out and about. He began to insist that they stay in his house for the whole duration of her shift so that he could have her sole attention. Rose took over as Team Leader around this time and felt that she had to intervene. She thought that it would be unfair on Tom to take the woman out of his team altogether so she discussed the situation with him, explaining the boundaries around the relationship between service users and their paid staff. Rose also added more team members, both male and female to have a bigger mixture of staff and for a while this seemed to stop his inappropriate behaviour. However, it started up again and he would tell other workers to go away. Again Rose had a word with Tom and explained that it was a waste of support time if he only wanted the woman to whom he was attracted to sit in his house with him for 8 hours at a time watching TV. Instead, because Tom was actually a very able individual who had a job as well as his own tenancy, Rose decided that his support should only consist of help preparing meals and overseeing his medication. Once this was done, the staff member could leave. Then one night Tom came home from work to find a male member of staff on shift to support him, rather than the woman who had been expected. Tom physically attacked the worker accusing him of hurting the woman in question. The worker's ribs were broken and he was badly bruised. He managed to phone John who was at that time Tom's Key Worker. John was working with another service user at the time. John, in turn phoned Rose to let her know what had happened. The police and a doctor were also called in. Because of the serious nature of his behaviour the doctor wanted Tom to go to hospital voluntarily which at first he was unwilling to do. However, John managed to get him to realise that it was better to go voluntarily otherwise he was going to be sectioned. In hospital Tom saw a psychiatric nurse who worked with him until his discharge from hospital. Tom's support team was changed initially to 2:1 staff ratio and was all male. Tom's progress has been gradual. He has continued to talk about the woman wanting to see him and crying because she can't see him. For this reason a psychologist has written a social story for him about different types of relationships. Tom has also threatened to sexually attack other women if the woman he is attracted to is not re-instated in his support team, although he has also been made aware of the consequences he will face if he does this. Tom is also regularly attending sessions with a psychiatrist. Because

they all live in a small town where sooner or later Tom was going to bump into the woman, a strategy has been put in place in order that she can acknowledge him but also quickly leave his company. This appears to have worked so far.

Chapter 4

Policies

4.1 Introduction

The first question in this research concerns the existence of, and the extent to which, the contents of support organisations' policies on Sexuality and Relationships offer guidance on the support of service users whose sexual behaviour is inappropriate.

This is to review L.Brown's work in Scotland undertaken in 1996 and to examine for the first time the contents of similar policies of support organisations in Melbourne Australia.

4.1.1 Policies in context

Sexual abuse, particularly of children, is not new in the Western world but it is only comparatively recently that the subject has been brought out into the public domain. Its prevalence seems remarkable given previous levels of silence. Vulnerable adults including those who have a learning disability have also been targeted by abusers. Lack of understanding, communication skills and power (both physical and social) renders such individuals easy targets for those who would exploit them. In attempts to secure their safety and well being organisations like the Care Inspectorate and the Mental Welfare Commission in Scotland have been set up to oversee delivery of their support services. Additionally, measures have come into force such as Disclosure (Scotland) which sets out to ensure that those who work with vulnerable individuals have not been charged or convicted of crimes which may affect their work. Of particular note was the introduction of the Adult Support and Protection (Scotland) Act 2007, which was introduced to protect vulnerable adults from financial, physical, emotional and sexual harm. In essence this Act dealt with the possibility that a service user though having the capacity to give or withhold consent could be prevented from doing so by various coercive means. For example, a woman with learning disabilities might initially refuse sexual intercourse but acquiesce when threatened with physical violence. The Act came about following a particularly

harrowing case in which a woman from The Borders Region, Scotland, who has a learning disability, was systematically abused, financially, physically and sexually. The Mental Health (Care and Treatment) Act 2003 sets out legal procedures and practice regarding individuals with mental health problems and/or learning disabilities who commit offences including those of a sexual in nature. However, as noted above, presently those whose sexual behaviour has been unacceptable including those who sexually abuse do not always come to the attention of the courts, for the various reasons mentioned above. This leaves SCWs with these individuals' care out in the community and they will look to their policies for guidance on how to go about this.

In her report concerning Scotland in the year of 1998, L. Brown found that of the 31 support agency policies she received on sexuality and personal relationships, just over half failed to offer workers guidance regarding those whose behaviour was unacceptable. Rather, the focus of these documents was on protection of victims and the need for sex education. Given that an individual with a learning disability is more likely to be a victim of abuse as opposed to being an abuser, this is understandable in terms of avoiding labels associated with general perceptions of this service user group. Nevertheless, support of abusing individuals and those whose sexual behaviour is inappropriate comes essentially under the directive that support staff have a duty of care to them as well as those they may offend or abuse. Brown further reports that only 6 reports offered guidance to staff that recommended adopting a behavioural approach. No corresponding document is available for the situation in Victoria, Australia. Although only 6 policy documents were received in the present study (4 Scottish and 2 from Victoria) it is nevertheless necessary to consider them as part of the general context from which respondents tell their stories.

4.1.2 Designated sections

In all six policies, unacceptable sexual behaviour is referred to in both direct and indirect ways. For example there may be a designated section on masturbation or there may be tangential reference through advocating the service user's need to respect the rights of others. Of the former, the subjects of masturbation, pornography

and prostitution are the aspects of sexual behaviour which are most mentioned in dedicated section of these policies. Whilst it may be argued that masturbation in public spaces is the most common form of unacceptable sexual behaviour encountered by staff, it could also be argued that where pornography and prostitution are concerned, these are more likely to involve service users requesting staff for assistance in their procurement¹⁷. Thus these three behaviours are more visible to the service and arguably more easily dealt with in-house. In all instances the policies concerned offer guidance to staff on relevant procedure. Designated sections are also given over to non-specific behavioural situations for example, where the service user is at risk of re-offending, when a service user is at risk of developing unacceptable sexual behaviour, and procedure involved whatever the nature of the unacceptable sexual behaviour.

4.1.3 Direct reference to unacceptable sexual behaviour

Although they may not have a designated section as described above, policies refer directly to unacceptable sexual behaviour in sections which are aimed at the support of all service users. One particular area mentioned in all policies relates to indices of abuse. All stress that behaviours such as those that are overly seductive do not necessarily indicate that abuse is the cause, and suggest that staff consider such behaviour as a sign that some service users are victims rather than culprits, and that this calls for a different response. A further area in which unacceptable behaviour is referred to directly within a section is that of consent. Here, organisations advise their staff when it is acceptable to breach confidentiality and that is where sharing information with colleagues is essential in order to ensure the safety of the individual or their potential victims.

4.1.4 Indirect reference to unacceptable sexual behaviour

Indirect reference to the support of service users whose sexual behaviour is unacceptable is also made. For example, staff are encouraged to explain the responsibilities as well as the rights involved in sexual activities, or are asked to

¹⁷ It is not prostitution per se that is illegal but procurement and use of these services which is deemed criminal in Scotland. Prostitution is not a criminal offence in the State of Victoria.

consider the possibility of the use of coercion where there is a sexual relationship between a different ability couples.

4.2 Sum up

Because of the small number of policies involved in the above review, it is not possible to estimate the percentages of organisations which have a policy on Sexuality and Relationships in Scotland or Melbourne. Nor is it possible to approximate how many will give direct or even indirect guidance on supporting individuals whose sexual behaviour is unacceptable. Neither is it possible to compare Scottish policies with those of support organisations in Melbourne. This said, and as might be expected, policies in both locations have all got detailed sections on supporting victims of abuse.

Policies, as codes of practice define the ‘field’ in which workers operate. ‘Duty of care’ is the umbrella term for that which constitutes the embodied practices associated with the ‘field’ of the SCW, and must be considered as an absolute. Yet some areas of care are picked out for particular mention whilst others are ignored. Although this is not the intention of policy makers, this omission, nevertheless, allows situations including sexual abuse of service users, to continue, by means of justifying workers’ and indeed their manager’s failure to deal with the situation because ‘it’s not my remit’¹⁸. Contemporary policies must continue to include guidance for workers on how to approach situations of abuse, but this must include a section on how to support the service user who sexually offends as well as victims of sexual abuse.

In the next chapter this work will continue with an examination of how SCWs define their duty of care when a service user’s sexual behaviour is unacceptable. In Heidegger’s terms, how they define their ‘field’. Limits to the ‘field’ are also defined by workers’ perceptions of situations in which they feel it appropriate to consult Health Professionals in these situations.

¹⁸ It is ironic that Edward had to defy management and ‘break the rules’ when he supported the service users’ to be sexual. (see appendix i)

Chapter 5

Knowledge, the concept of ‘professionalism’ and the ‘field’ of social care

5.1 Introduction

With or without appropriate guidance in the form of an organisation’s policy, on discovery of a service user’s unacceptable sexual behaviour, SCWs are faced with decisions. Does the situation need to be addressed and if so what should they do? Moreover, are they able to do it? This chapter deals with questions two and three of the research project and so considers situations in which workers become aware that the service user’s sexual behaviour is in need of modification and also the factors involved in deciding when to deal with behaviour in house and when to consult a health professional.

Initially situations in which support organisations and/or their staff realise a service user’s unacceptable sexual behaviour is in need of modification are described. Whilst some of these are spontaneous, others, which involve the sharing of information, may be regarded as relating to a concept of professional practice characterised by the prioritization of the service user’s right to confidentiality. The chapter then goes on to describe conditions which relate to the decision being made that workers can deal with the behaviour in-house and those that relate to the decision to consult a health professional. In so doing, what is revealed is the SCWs’ notion of who should be doing what. That is to say, what becomes apparent is what these workers consider to be their own ‘field’ but also its limits, or the points at which they believe the situation is more appropriate to the ‘field’ or jurisdiction of the health professional.

5.2 Ways in which workers gain knowledge of the service user's unacceptable sexual behaviour.

Organisations and their managements' reluctance to get involved in service users issues around their sexual behaviour have generally changed. This is illustrated by the very existence of policies on Sexuality and Relationships as well as the existence of, for example, groups that exist specifically for people who have a learning disability, such as *Respect*, an organisation based in London but which is also on-line, that offers help and advice on sexual matters to this service user group. Such changes reflect greater openness in our society where sex is concerned and an acknowledgement of the equal human rights of people who have a learning disability. It may also be the case that members of present management are more likely to have come up through the ranks at a time when normalisation became the purpose of support rather than containment¹⁹.

Analysis will take as its point of departure recent experiences of supporting service users who display unacceptable sexual behaviour beginning with ways in which these workers realise that there is an issue to be addressed²⁰. If the service user comes into the service then those in the management team may be the first to be aware of any such behaviour carried over from the home, from the service user's parents or through records provided by previous support services. If the behaviour first becomes apparent in their present service, then it is most likely that the direct care staff will be first to realise that there is an issue to be addressed. These scenarios will be described and analysed from a perspective of power relations and the sharing of knowledge.

¹⁹ There is irony here. Containment amounted to keeping abusers away from members of the public but not from fellow service users who would become their victims.

²⁰ For these workers' accounts of their past experiences see Appendix i. These confirm existing articles but also provide new information on the subject.

5.2.1 Spontaneous awareness of the service user's unacceptable sexual behaviour.

It can be the case that the unacceptable sexual behaviour can become apparent after the service user has been with a service for a few months or even years. Without prior knowledge of their unacceptable sexual behaviour, either because of inadequate notes and information, or because the behaviour only developed in the present service means that it may become known through its discovery by staff which may come about by several means. It may take place in public surroundings – communal living spaces, Day Centre buildings etc. – where it is a matter of initially observing what service users are doing and establishing that the behaviour is indeed of a sexual nature. Sometimes this will be obvious, for example one interviewee spoke of a couple of service users who were:

“Not 100% sexually active [no penetration involved] but [the couple] were having oral sex and this and that” (Dawn: Melbourne).

Another worker recalled of her service user:

“Yes, I think she probably did when she stayed with her family. As I say, she did quite often [masturbate} and sometimes there was other people there. They found it really embarrassing and sometimes other people who stayed in the house – their parents would be coming in. And I mean - it was constantly” (Tina: Scotland).

Occasionally knowledge of one behaviour leads to realising the existence of another. One SCW spoke of a situation where a colleague had voiced concern over comments Ray was making about little girls. The Service Manager, Edward, decided to drop by to talk to the man to try and find out more about this. He was not expected and came across Ray standing at his window looking at children in a local school playground through binoculars.

“[I] discovered him in his kitchen observing out the window with binoculars and he was pretty surprised and acted caught out. . . I said, ‘Were you using them?’ And he became very agitated.”

Observation of the behaviour in question can also come about through the worker's routine duty of care. As another worker related:

“[Frank] goes out on a weekend on his own and . . . a staff member followed him just to see if he was OK – just to see he’s safe. But the staff member caught him with cars. He’s got a thing about cars and he was rubbing himself against the tail pipe. . . and caught him getting up on top of the car – on the roof of the car and humping the car” (Grace: Melbourne).²¹

Attempts to address the behaviours mentioned above can only proceed if the members of staff in question, in these instances front-line staff, are committed to the concept of duty of care which informs their ‘field’. Their subsequent actions are then the embodiment of this ‘field’.

Perhaps the most unfortunate circumstance in which unacceptable sexual behaviour becomes apparent is if it is observed and reported by a member of the public, and most especially if children are involved. One interviewee related just such an incident and some of its consequences:

“ I think this client just made an inappropriate gesture to the boy and the mum saw it through the window and it turned into a beating [when] the boy’s father was notified at work and he came over” (Gary: Melbourne).

Although it was not the case in this instance, McCarthy & Thompson (1997) showed that many men who have a learning disability who come to the attention of the Criminal Justice System have a history of sexual behaviour that was known of, but also ignored, by staff. In Bourdieu’s terms such instances exemplify staff failure to recognise the ‘field’ they inhabit. Of course unless obviously sexual, behaviours may be open to interpretation and further, there may be a need to establish whether they are sexually motivated. However, where the worker has knowledge of behaviour that will cause offence or amounts to a criminal offence then there is a clear duty of care to support the individual in ways that protect him as well as any existing or potential victim.

²¹ Sexual attraction to cars, which is also found in individuals who do not have a learning disability, is called mechaphilia. Not illegal in itself, police involvement would only occur when it involved someone else’s property and/or offended public decency. That is to say, if done in private and with your own car no law would be broken.

5.2.2 Staff subjected to the behaviour

Thompson, Clare & Brown (1997), as mentioned above, have written in particular detail about the attitude of male service users towards their female staff because they become confused by the women's dual role as authority figure and the caring, friendliness which underpins the support they give. Thus male service users can misread the signs of this and regard it as an invitation to a relationship of a more sexual nature. This was certainly the experience of some of my interviewees who have themselves been subject to the behaviour in question. Louise (Scotland) with reference to Anna said:

“A service user that I supported for a while and I had an extremely good relationship with - there were times . . . she would be slightly inappropriate just in the way she would approach me and touch me”.

Workers can also be aware that the service user has become emotionally attached to them and with this attachment comes a sexual element. As Rose (Scotland) explains of Tom:

“He became really attached to the female member of staff and it kind of tipped over into being, inappropriate, and he would touch her hair and want to sit next to her”. Eventually, “touching the lady and obsessing about her”.

Another respondent told of a similar instance where:

“When a couple of staff walk in it's very – stressed and he behaves probably inappropriately to a certain degree” (Jean: Melbourne).

Vera (Melbourne) had also been subject to a service user's sexual advances:

“I was doing my Activity Night . . . he was just trying to sit down and cuddle me.”²²

²² Interestingly, these accounts all came from female staff members although not all service users they referred to were male. In Louise's case the female in question had come into her service from a learning disability hospital where the sexes were strictly segregated and so the only possibility of having a sexual relationship was with other women. Same sex relationships can also develop between heterosexual male service users when they have no access to females with whom they can form a sexual relationship (Wilson: 2009).

Thus the friendliness of staff, male as well as female, may not be regarded by service users as part of the embodied practices of their field, but mistaken for an invitation to a more intimate relationship. Vera's case is particularly note worthy since the behaviour to which she was subjected was already known to the organisation. Yet since she was still a probationer in this service, management had not informed her that this might happen, nor how she should respond. This practice is a feature within the support services and is due to managers' concerns about service user confidentiality.

As well as being their human right, confidentiality is also characteristic of the concept of 'professionalism' (Hershberger 2010, accessed 06/06/12). Yet guidelines and policies in both Scotland and Melbourne state clearly that a service use's human right to confidentiality may be waived when there is a possibility of harm being done to either the service user or others. As to the notion of professionalism, even within what has been termed the 'liberal professions' (Schinkel & Noordegraaf, 2011), i.e. those long established such as the medical profession, confidentiality may be waived, for example, if it is in the public interest (Brooks, accessed 11/08/12). An example of this is when an individual has been wilfully spreading HIV which is a criminal offence. Thus it may be concluded that in Vera's case her manager was acting on the basis of a mistaken concept of what it is to be 'professional'. Additionally, Vera's acceptance of her manager's failure to provide information may be described as an example of 'doxa' or her, not to mention her manager's, internalisation of a concept of what it is to be professional.

5.2.3 Information provided about the service user's unacceptable sexual behaviour

The social care work in question here concerns adults defined as anyone over the age of 16. This implies that because of the comparatively recent replacement of institutions with homes in the community that service users will have come into their present support service from either their parent's home (and this includes adults in their 40s and 50s) or from another service provider. As such, verbal details from the parents or written records from the former service should be available to the new

organisation especially on matters of safety, as this information about Fraser illustrates:

“I think it was really always within our knowledge from the family that there was an issue . . . I believe looking back historically we always knew that we had to be aware of this person around children” (Beth: Melbourne).

On the other hand it may also be the case that a service user’s past behaviour is implied rather than referred to directly. For example, Chloe’s support worker recalled that: “She had a hysterectomy years ago probably because of her sexuality more than anything” (Wendy: Melbourne). In talking of ‘sexuality’, Wendy is referring to Chloe’s sexual behaviour and her subsequent experience of this would lead to this conclusion. However, information does not come with a guarantee that all details will be included. Parents may be reluctant to inform the service of any kind of relevant behaviour which they fear may result in their child being refused a desperately needed service (Sangster, 2007). In relation to present research one interviewee commented that: “In some cases the person will come directly from home. Obviously relatives and parents will withhold information to get the service” (Gary: Melbourne). Parents in this situation may not understand the remit of support services which is underpinned by their duty of care. It is also an underestimation or misrecognition of the work that SCWs do.

Churchill & Livingstone (1997) write that:

“In many ‘routine’ cases not all the relevant information is provided on admission and the gaps may be filled in later without apparent harm. This is not so when considering the admission of a known or suspected abuser when ignorance is foolhardy and potentially dangerous” (129).

Nevertheless, I would add that even where the service user’s behaviour harms no-one, his dignity and community presence may be jeopardised if staff are unaware of the support he needs. As one worker commented:

“Some people have hardly got anything [notes] and others have got a shopping trolley full”.

Where the former is the case, this respondent added:

“If we didn’t get a lot of information we went up to the institution to talk to the person – to talk to the staff . . .” (Laura: Scotland).

She further indicated that talking to staff could be more enlightening than talking to management because the latter say:

“This is Joe Bloggs, and he’s 50 . . . rather than opposed to the staff who’re inclined to give you the negative stuff – throws himself out of the wheelchair” (Laura: Scotland).

Negative though it may be, the information provided by staff does give future workers an indication of the support the individual requires, and is simultaneously recognition of the needs of the worker. However, this serves as further evidence of some manager’s misguided concept of the law regarding confidentiality and what it is to be a professional.

Sometimes organisations do provide some relevant information in order that on-coming services are aware of the level and nature of support required. Though useful, however, it is not always complete even in cases where the service user has been involved with the Criminal Justice System. As in Laura’s account above, Charles also has experience of receiving incomplete information about an on-coming service user. As he explains, in Dale’s case:

“He came here with an idea of some of the things and pretty much an understanding of how – you know the things that happened to him – how much risk he posed.”

It is also the case that organisations will not share information on a service user to whom they both give a service. As Beth (Victoria) remarked of Fraser:

“There has been incidents I believe at [his] day service – but then again, I’m not entirely sure of the details” (Beth: Melbourne). (See also Sangster, 2007).

Again, unquestioning adherence to a concept of professionalism which includes complete confidentiality means that necessary information is withheld, resulting in a lack of consistency in service user's support.

5.3 Reasons for choosing to take an in-house approach to dealing with the service user's unacceptable sexual behaviour

On occasions, using a multi-agency approach involving health professionals is not considered to be necessary. In these instances organisations and their staff cope with the situation on their own, since they have judged these situations as belonging to their 'field'. This section of the chapter proceeds with workers accounts of the factors involved in thus demarcating their 'field'.

5.3.1 Need for in-house strategy: the management plan

Whether an individual develops the behaviour in question before or after going into his present support service a general strategy, or management plan, regarding encouraging appropriate behaviour is necessary. This is to be expected as part of the support services' remit and as an aspect of their duty of care. For example, Charles was Team Leader, when Dale, who has a history of unacceptable sexual behaviour came into his organisation. He and his team decided on their general approach to his care prior to his arrival. Charles explained that for him:

“... there only is the in-house approach and that is person-centred, building self respect and about giving somebody a life. And that's how you're going to lessen these tendencies and give somebody a positive life by helping them develop self respect and self esteem.”

In-house strategies are also required in order to try to prevent situations escalating to a point that health professionals in-put is thought necessary. In Ray's instance, John (Scotland) explained:

“Before he used to have a habit – tell-tale signs. When we were out somewhere he would stare at people, usually females, and it could get quite uncomfortable. He used to stare constantly at them.”

5.3.2 'Less serious' behaviour

In some situations workers felt confident in their ability to deal with a service user's behaviour without going to see a health professional. Tina (Scotland) and her colleagues felt that they could modify a service user's uninhibited masturbation in-house. Louise (Scotland) was similarly confident that she could deal with the situation in which a female service user would touch and talk to her inappropriately. The team Beth (Victoria) works with made a similar judgement about the nature of a service user's unacceptable sexual behaviour and their ability to deal with it. When asked if she and her colleagues were handling the situation in which a service user was being sexually inappropriate towards female members of staff by trying to look up their skirts, she replied:

“ Yes, because – it's not like he's offending . . . He's just – I sense there's a large amount of sexual frustration in his behaviour and anxiety.”

5.4 SCW's perceptions of the health professionals' 'field'

A further question in this research concerns reasons why workers from support organisations decide that a consultation with a health professional is necessary when a service user's sexual behaviour is unacceptable. In the past institutions not only provided service users' 'social' care but also their health care when interventions were necessary (Barber: 2011). Today, those who live in the community with the support of an agency or their parents make use of NHS services that are available to all. Thus service users can have the support of multi-agency teams which can include doctors, psychiatrists, psychologists, nurses, speech therapists etc. Services in Australia are subject to the Australian Government Social Welfare Commission 1975, a strategy based on multi-agency collaboration. Similarly, local authorities in Scotland are subject to the Scotland Community Care and Health (Scotland) Act 2002 which expresses the intention to “expand local joint and pooled budget arrangements between NHS Scotland and local authorities” (Scottish Government, accessed 01/09/10). Richardson & Asthana (2006) quote van Eyk & Baum who list the advantages of multi-agency working as: “the improvement of services including

the prevention of people falling ‘through the gaps’, [and] provision of ‘best quality and most effective care for people who require multiple services’ (658).

This includes people who have a learning disability and whose sexual behaviour is unacceptable.

Although there may be a degree of overlap in some cases situations in which support workers seek the input of health professionals in interventions into service users’ unacceptable sexual behaviour, fall into three broad categories. These are, ‘As a matter of course’, ‘Specialist Consultations’ and ‘Emergencies’. The first may be based on existing situations or relationships between agencies, the second because information is required on a new or unknown development and the last where the safety of others, including the service user himself, is at serious risk.

5.4.1 As a matter of course

The use of health professionals may be the decision of the support organisation or it may be mandatory in that external bodies insist on health professionals’ involvement. Both decisions are made on the strength of expectations of embodied practices associated with those who inhabit the medical ‘field’.

In some instances such is the relationship between agencies that even in a situation which might be dealt with competently by support staff, they automatically look to the health professionals for input. As Louise (Scotland) explains,

“Any organisation that I’ve worked with has always had a very good relationship with the learning disability nurse and they’ve always been very accessible to us and any organisation I’ve worked with or any position I’ve been in.”

Input from health professionals may even be mandatory. Where a service user has a history of challenging behaviour, sexual or otherwise they may be subject to a CPA which as Charles (Scotland) describes is a multi-agency body which is:

“put in place to make sure that all relevant professionals are present . . . It’s meant to be a group approach – the psychiatrist, the psychologist, police, housing – the team that supports the individual”.

In the case of Charles' service user this team was already in place when the young man called Dale came into his service and the medical professionals were regarded as one of the necessary elements of that team given the history of his behaviour.

Although not subject to a CPA service users may likewise come into a service with on-going support from a health professional or team. This may be because a behaviour is already in the process of being addressed or could be because it is subject to regular review. As Jean's (Victoria) account illustrates:

“He's got psychiatrist appointments . . . he's been under [treatment] for quite a while but at the moment he seems a lot calmer . . . and he'll probably be reviewed again in six months time”.

Similarly a service user can have a history of problematic behaviour and their support agency has a long standing relationship with a health professional or team because the behaviour recurs from time to time as in the following experience:

“I think if we had another situation like the last one – if it blows up again – we would go and get [guidance on safe sexual behaviour] reinforced by somebody other than us to make her realise just how serious it is” (Wendy: Victoria).

In this instance the workers seek support and input from a counsellor whose 'field' is a source of expertise for Wendy as well as an acknowledged figure of authority for her service user Chloe.

5.4.2 Medical expertise

Health professionals may also be consulted as a matter of course where behaviour may be brought on by a medical condition which on the surface appears to be sexual, for example when a service user is continually touching his penis. Here it is a matter of eliminating other possibilities before seeking support with issues of sexual behaviour. This is especially the case where the service user has little or no vocal communication skills to express pain or discomfort. Maggie (Victoria) explains:

“If we have several bad days we start to look at things like medical issues – like being constipated or having a urinary infection for example. . . . People don't do things for

no reason. It's just a matter to decipher what it is I guess, and use the support of doctors."

Rose (Scotland) spoke of a similar situation:

"So we were noticing that there was faeces on the bed and we started finding things like pencils, toothbrushes . . . so initially the first step is to find out if there's any medical reason for this. So we had to speak to him and we kind of knew it was for sexual gratification. That was my feeling and that of the team's feeling that he should go and see a doctor, and he [the doctor] said that there was definitely no medical reason for this happening."

On occasion it is clear to members of staff that a situation is beyond their knowledge and/or experience and that consultation with a specialist health professional is required. In the case of Tom who became obsessed with a female member of staff, the initial problem was how best to withdraw her from his team without causing him too much distress. John (Scotland) reported that:

"We got the learning disability team involved and they were really good. The community nurse – he used to go to sessions – so many sessions. These involved discussing relationships with the service user and emphasising what is and what is not appropriate. Also along with his support team the community nurse provided sex education".

A worker from Victoria told of a similar situation which had recently come to her attention. However in this instance knowing which health professional might be able to help is proving more difficult since the service user has mechaphilia. Like masturbation this would not be a problem if done in private but unlike masturbation, it is a rare form of sexual activity and so more problematic in terms of modification. Although still in the process of discussing the situation with her team and management, Grace was considering bringing in a sex therapist to work with the service user and his support team. She remarked that:

"The person we can speak to is a sex therapist who I met when I went to this forum. There was this lady there that specialises in disability and sex therapy and she would be a good person to sit down with".

On occasion health professionals will refer the service user on having done all that they can, having reached the limits of their own expertise. This was the case with Tom. His behaviour escalated when the female worker who was the object of his attention was withdrawn from his support team causing him to threaten to sexually assault any woman he might meet if the worker was not reinstated. John (Scotland) his Key Worker elaborated:

“The learning disability team seemed to think there wasn’t much more they can do with him now but the psychiatric department [are now involved]. He realises what he’s done. He doesn’t blame himself . . . and he calls it ‘the boy – it’s the boy inside him doing these things’”.

Health professionals can also be called in to run assessments on learning disability conditions which may impact upon the individual’s awareness and understanding of their sexualised behaviour. Jacky (Scotland) explained:

“We called them in [again]. One is assessing him for autism. He has autistic tendencies. That’s what’s been diagnosed and I can only go by what they say. Some folk have got more autistic tendencies that they can’t get out of so we’ve got a psychologist coming in to assess that.”

5.4.3 Safety issues

Respondents were particularly concerned to call in health professional expertise when the safety of others and/or the service user in question was at risk. There is a particular sense of urgency if the behaviour is aimed at children. Although the initial assessment of Ray was that the support he was getting at the time was sufficient to keep children safe, subsequent escalations of the behaviour which involved the man recording himself saying what he’d like to do to little girls caused staff to take further measures. As Rose (Scotland) recalled:

“We went back to the community learning disability team and said we really need some intervention here and we need it pretty quickly”.

In some instances there is recognition that the service user will require long-term input from health professionals in order that they do not target children. Beth (Victoria) explains how the service user can take ownership of such treatment:

“And he himself has been supported to have lots of counselling which he still goes to and he will talk openly if he’s concerned about something he will take out his book about it and discuss it and so we’re all in the loop of where he is and all of that”.

Violence towards staff, though often accepted by them as simply part of their job, can become too serious to ignore. Rape and sexual assault are obvious manifestations of sexual violence. Less obvious is violence towards others that is the result of sexual frustration. Referring to Tom, Rose (Scotland) said,

“He came in from work and a male member of staff who was there to support him with his medication and his evening meal – [the worker] came in for about 10 minutes and was attacked quite severely and sustained two broken ribs and was quite bruised”.

This was Tom’s reaction to the male worker being on shift rather than the female member of staff he had been expecting.

The safety of the service user himself can be in question, not only because of threats of others should they observe the behaviour in question or the possibility of going to jail, but also through doing himself some physical damage. Laura (Scotland) spoke of the service user who also had a mental health problem and went through periods of masturbating continually and openly. In this case there was a standing arrangement that when this happened and staff could no longer manage the situation he would go into short stay psychiatric care and return to his home once he was at the low end of his bi-polar episode.

5.5 Sum up

Workers may become aware of a service user’s unacceptable sexual behaviour because they have witnessed it. Awareness may also come about through being subject to the behaviour, particularly where this involves female staff whose caring ways may be mistaken by the service user for sexual interest in him. However once the behaviour becomes apparent it is not necessarily brought to the attention of all staff who have the individual’s care since within support organisations knowledge of such details are treated as being confidential and confidentiality an aspect of the individual service user’s human rights. Yet this may be waived where there is a possibility of ‘harm’. This misunderstanding of the law around confidentiality may

also relate to management's conception of what it is to be 'professional'. This concept of professionalism and confidentiality also applies between support organisations who may fail to provide a level of information to on-coming and sister services, preventing them from providing appropriate support.

Support organisations, regardless of the information they have on in-coming service users, must compile a management plan based on what they know. This is done in order to support the service user to the best of their knowledge and to provide a smoother transition for the individual in question. Thus it is an embodied manifestation of the 'field' that is support work. Confidence expressed in ability to support the service user who masturbates openly, or who touches someone inappropriately, is further embodied manifestation of the 'field', or to borrow Bourdieu's expression, they have "a feel for the game" (Noordegraaf & Schinkel (2011). This said, it is self- misrecognition to describe such work as 'it's not like he's offending'. Indeed, these behaviours are criminal offences and their discovery could have extremely serious consequences for the service user if he was left to continue. Managing such behaviour in effect incurs a high level of responsibility for SCWs.

The 'field' of the health professional as defined by SCWs as having the following characteristics. Members of this group are acknowledged at individual, organisational and societal level as a legitimate source of specialist medical knowledge (cultural capital) and are thus a 'higher' authority to which SCWs can refer. Their medical expertise, including in some cases special training in working with people who have a learning disability, are particularly thought necessary when a service user's behaviour poses danger to the service user or others.

Having given accounts of situations in which SCWs decide which types of service user's sexual behaviour they can deal with in-house and those in which they seek input from Health Professionals, in the following chapter this work continues with accounts of the roles these workers take on in these circumstances. These roles are the embodiment of the SCW 'field'.

Ch 6 'Proximity'

Redefining the SCW 'field'

6.1 Introduction

Above are cited accounts of how a service user's unacceptable sexual behaviour becomes known to the support organisation and its staff, and also the factors involved in the decision to either deal with the matter themselves or consult a health professional. The point of departure for this chapter is a description of the SCWs' roles in the process of modifying the behaviour, i.e. the embodied practices of the SCWs' 'field'. Included here are those undertaken on first realising that modification is necessary. Additionally, this chapter covers staff roles when it has been decided that working with health professionals is not necessary as well as when it is. Roles taken on by workers in these situations can be regarded²³ as being their 'field' or jurisdiction as defined above by Thompson (2010) as "little worlds . . . defined by regular practices . . ." (44).

Furthermore, these workers' roles are contextualised by their status within the support organisation. Simultaneously, these roles are examined in light of the worker's relationship to the service user. That is to say, by the amount of daily contact, or the extent to which they know the service user and the level of information they have about the service user's unacceptable sexual behaviour. The nexus of worker's status and knowledge of the service user I have termed 'proximity'. The chapter concludes by outlining factors which serve to limit workers in their efforts to help modify service users' unacceptable sexual behaviour, some of which may be regarded as a misrecognition of the skills which are integral to the SCW 'field' and which improve the chances of the service user's successful engagement with health professionals and potentially the outcome of treatment.

²³ Bourdieu would not regard Social Care Work as a profession as is understood when we talk about 'the professions'.

6.2 Staff role when matter dealt with in-house

Where no information about a service user's behaviour has been given to their on-coming service, it may be presumed that because of their almost daily contact with the individual that the SCWs are the most likely of all who work in the support organisation to be either subject to the behaviour or first to come across it.

Therefore, becoming aware of a situation is involuntary. Of more relevance here are the initial actions of the workers. Without the added in-put of health professionals, whether this is by choice or not, support staff must respond to a service user's behaviour. To do nothing, would be to breach commitment to their duty of care.

Situations staff encounter can be familiar to them but they can also find themselves having to support individuals in circumstances for which they have very little, if any experience or guidance. Nevertheless care work is their 'field' and it is this care that is at the heart of their practice.

6.2.1 Managers

6.2.1.1 Investigation

When a serious situation arises such as the one mentioned above involving Ray who looks at children through binoculars, staff are expected to involve their managers as a matter of course because of their status which is underwritten by experience and knowledge. This was the case in this incident when Edward had been called in to investigate following a staff member voicing concern over comments Ray had made about children. Although Edward knew of Ray he had never worked closely with him, but nevertheless took on the investigative role as part of his managerial duties. After confirming suspicions the manager's involvement in the case became that of a liaison officer, as he explains:

“It seemed such a serious situation. It was taken very seriously within the organisation. I contacted my line manager who had a discussion about it and we agreed to speak to the person's care manager²⁴ - speak to the community learning disability team for advice and speak to the in-house expert at head office to get some advice” (Edward: Scotland).

²⁴ A Care Manager is employed by the local authority's Social Work Department to oversee vulnerable individuals' care. They may or may not be qualified Social Workers.

At this point Edward's direct contact and involvement with the service user ended. This case is in contrast with one involving the manager of a Day Service. Because of the nature of their work location managers often have direct daily contact with service users, thus it is not uncommon for them to know their service users well. Working alongside of the service user and being familiar with their ways means that managers may themselves notice that a service user's behaviour needs to be addressed. This can be of particular importance when service users have a profound learning disability which more often than not is accompanied by poor or non-existent verbal communication skills. One respondent's comments highlighted the benefit of having a close working relationship with the service user. Day Centre Manager Maggie (Victoria), being *in situ* referred to going through the process of investigation before concluding the nature of a service user's apparently sexually motivated behaviour. She explained:

“I'm lucky enough to work with the same clientele each day. They're long term. They're not just here for a couple of weeks. But in that time I usually get to know them quite well so I know what a good day looks like, and I know what a bad day looks like”.

Where someone appears to be having more than one bad day, she continued, her role then is to investigate the problem. Where this includes, service users, for example, openly touching their genitals, the task is then to investigate whether the cause is medical or sexual. Thus she described the need to find out what the service user's issue is before calling in a health professional, as she explained:

“When people start displaying behaviours that they don't normally display then there's usually a reason for it. People don't do things for no reason. It's just a matter to decipher what that is. I've worked with the person to eliminate something they're not happy about . . . I've eliminated all these things and we've put in place positive supports and if it's not working then we tend to go down the medical aspect.”

Thus Maggie is involved directly in in-house treatment of the service user should they find that there is no need for in-pat from a medic. On the other hand, manager Edward (Scotland) who was called in to investigate Ray's behaviour following reports that he had been talking inappropriately about children, is not directly involved in cases which are deemed to be less serious.

6.2.2 Team leader

6.2.2.1 Educator and advisor

As might be expected part of the support role includes advising service users on different aspects of their lives. In terms of sex education the fact that the front-line worker is in almost daily contact with the service user this presents many occasions that Brown & Craft refer to as ‘teachable moments’ (1997). These are especially useful when the individual has been sexually inappropriate or abusive. Team Leaders can be the worker on-the-spot and thus in a position to advise service users when they behaviour inappropriately. This is important because the advice can become meaningless to the service user if proffered at a later time, since he may not have the capability to associate the advice with the event in question. When Louise (Team Leader: Scotland) was subject to inappropriate language and touching by a service user, she handled the situation successfully by advising her there and then that this was not acceptable.

“She would make inappropriate comments, but fortunately again, it was just a matter of talking to her about what was appropriate and what wasn’t and how uncomfortable it made me feel – and she stopped doing it.”

Interestingly this worker trained as a nurse but when asked if this had any bearing on her decision to manage the service user’s behaviour on her own she replied:

“I don’t think that the fact that I came from a nursing background would have made any difference to the way I handled it, because I knew the person”.

Thus Louise’s status as a support worker having full-time care of the service user was of more value to the situation than her nursing experience.

Occasionally though, there may be situations in which the authority of a Team Leader is used to emphasise to the service user the importance of the matter in question. In this example the advice had to come later from the team leader once she was called in to deal with a situation involving a man with a mild learning disability. When Tom got sexually attracted to a female member of staff the team leader’s role was to explain to him why this was inappropriate. She recalled:

“We sat and had a conversation about – this isn’t good, you pay these people to work for you so you can’t have all these attachments to people and it’s not appropriate to have that sort of relationship with someone you pay” (Rose, Team Leader: Scotland).

Nor is advice around sexual behaviour always about the do’s and don’ts of it all. Some advice concerns the service user’s own protection. The team leader, knowing of Ray’s propensity to talk to everyone about everything going on in his life, had to advise him not to tell his neighbours and others he met about what he had been doing. As Rose explained:

“Initially he was wanting to tell everybody he saw [and was advised] look for your own safety . . . people won’t like that. We know that nobody else knows that so you need to keep that information private. And that was another dimension that you needed to support him to keep that information confidential” (Rose, Team Leader: Scotland).

6.2.2.2 Devising strategies

Team leaders do not always get the information that they need in order to support the service user adequately from the outset, so need to respond when the behaviour becomes apparent. Similarly, they may also have to devise strategies in response to an existing service user developing unacceptable sexual behaviour. Until Tom’s behaviour escalated to the point that he hit a male member of his support team, Rose (Scotland) devised the strategy which involved, as noted above, explaining to him the nature of the staff/service user relationship. At this point in developments this was done in preference to withdrawing the woman from his service because Rose realised that this would have been extremely distressful to him.

Knowing the service user also means that you can base strategies for coping with the behaviour on what you know about them and their ways. With regard to Luke who liked to dance ‘like a chicken’ to invoke sexual arousal, the Team Leader who was simultaneously his key worker, and who was thus familiar with his other curious behaviours realised that some of these were also sexual in nature. Jacky explained that he also enjoyed a particular rhythmic scan of some poems and songs and would get staff to recite or sing them also finding them sexually stimulating. Since she knew that the service user involved all staff members in reciting his poems, her

immediate strategy once she realised what was happening was to let all other staff know that they should no longer comply with his requests to do so. As she explained,

“It was only after we realised ‘the chicken’ was a sexual thing that we started to notice other things were – [rhythmic poems like] ‘bumpity bump’ – then we stopped doing that line and reading poems that had wee rhythms”.

What would otherwise be considered an innocent if strange activity was thus reviewed and a strategy put in place as described above. In this instance Luke developed a counter strategy of his own in response to this which the support team then addressed successfully.

“What he would do was try and get somebody else outside the organisation to write the poems for him. And he flashes [the pieces of paper]. If you’re going to the shop he’d bring them out and ask the counter staff to read them” (Jacky, Team Leader: Scotland).

6.2.2.3 Interpreter

The roles of Team Leaders and Key/Core Workers can overlap where the former work directly with service users or, if they have risen through the ranks, may have worked closely with individuals before being promoted. Sometimes it is not a matter of knowing a good day from a bad but just knowing the service user’s mode of communication or relying on an established relationship, as the following account exemplifies:

“[Bill] can’t speak verbally but he uses his own kind of style of Makaton²⁵ and he can create signs at a moments notice. See if something catches his attention – he’s quite a clever guy – he just invents a sign for it and you need to know him quite well to communicate with him freely” (Rose, Team Leader: Scotland).

Knowing him and his communication style well meant that this team leader was able to understand that he required the use of a sex toy if he was not to hurt himself using inappropriate objects to satisfy himself sexually. Roses’ insights into Bill’s unique

²⁵ Makaton is a version of sign language which is taught to people who have a learning disability and whose verbal communication skills are weak.

communication style meant that later she also understood when, like wise, he was requesting a different sized sex toy.

6.2.3 Key worker

6.2.3.1 Investigation

Until staff can be certain that in-put from a health professional is necessary, they must first establish the nature, if not the cause, of the service user's behaviour, especially if it is one they have not previously encountered. As front line staff, Key Workers are also well placed to investigate the nature of a service user's behaviour. John (Key Worker: Scotland) whose Team Leader is Rose, also spoke about the situation with Bill, prior to realising he wanted a sex toy, as he explained,

“We found that he was actually using the book. So this went on for quite a while and we weren't sure what was happening. So we kind of found out the ins and outs of the thing.”

Although in this case a health professional was eventually called in this was to endorse the support team's intent to get him a sex toy. Grace (Victoria) also spoke of Frank's Key Worker's involvement in investigating his behaviour when he went out on his own and was observed taking what looked like a sexual interest in cars.

6.2.3.2 Advisor

Key Workers are of course also on-hand to give advice. When Tina (Scotland) came across her service user openly masturbating in public areas, she advised her that although masturbation is not a bad thing, it was important to do it in private.

“So that was something we had to work through with her that if that's what she wants to do that's totally fine but it's not appropriate to do it when there's other people in the room.”

In Ray's case the first role direct support staff took on in this situation was educational. Although his behaviour was first seen by a member of management it was felt necessary that this SCW who was also the man's Key Worker, should be involved in the initial response to the behaviour. He takes up the account:

“I was the main support worker at the time and we [himself and the manager] spoke to [Ray] and he was quite willing – after talking to him and assuring him and explaining the dos and don’ts – basically what’s appropriate and what isn’t [use of binoculars and interest in children]” (John, Key Worker: Scotland).

John, like Rose, also advised Ray against telling all and sundry about his behaviour.

6.2.3.3 Counsellor

In the course of their relationship the Key Worker can gain a better understanding of the individual and their situation. At the same time, the service user can learn to trust the worker realising that the support they are given can be relied on and is based on their best interest, no matter what the situation. In this atmosphere of trust and understanding the service user can feel free to express himself openly knowing that he will not be judged. Add to this the knowledge the worker has of the service user gained from working closely with him. This is illustrated by Key Worker John’s account of working with Ray when he explained,

“... so through that just speaking to him and gaining his confidence he started to talk about his feelings that he had about kids – and in his mind he sees – he’s not got any judgement about age limits – like a 6 or 18 or 24 year old – he hasn’t got any judgement about age limits even though – you could speak to him but there’s more disability there than you would think. You could be talking to him ok and then he’ll lapse into talking like a 6 year old – it’s just the frame of mind he’s in” (John, Key Worker: Scotland).

Having this information regarding his feelings and also the deceptive nature of his communication level provided a starting point for addressing Ray’s behaviour.

6.2.3.4 Motivator

Understanding on the part of the Key or Core Worker and trust on the part of the service user makes for an effective working relationship where the latter depends on the former for the quality of his life. This stands true for any situation where decisions are to be made. Where the service user’s initial response is to avoid doing something that is in their best interest the depth of trust they have in the worker will be key in persuading them to do it willingly. Complementary to this is the worker’s understanding of the service user that provides them with the best way of handling

the situation. When Tom assaulted a support worker because the female member of staff to whom he was sexually attracted had been withdrawn from his service, he refused a doctor's request to go to hospital for a psychiatric assessment. It was John his Key Worker who got him calm enough to accept that he had to go. He said:

“So I spoke to [Tom] myself and by this time he was really calm and he was fine and said he would go to hospital with myself and another main support worker .” (John, Key Worker: Scotland).

6.2.3.5 Protection

When a service user is known to be interested in children sexually, staff fear that members of the public might witness this. Although their first concern is for children's safety, they have a duty to keep the service user free from harm as well. Hence John explained to Ray that:

“It might be appropriate to use binoculars if you were out bird watching but not in the middle of a housing estate. It's a low flat and the pavement's right next to it so anyone passing could see what he was up to”. (John (Scotland)).

6.2.4 Other workers

6.2.4.1 Advisors

Other workers who are full time but not key workers for the service users in question were also able to advise them when necessary. Dawn (Melbourne) was present when a couple of service users began openly to get intimate, and so was able to advise them on the need for privacy: “We encouraged them that when they want to do that they do it in private.” Similarly Beth (Melbourne) responded to situations in which Trev looks up female staff's skirts, by letting him know there and then that this was unacceptable. Gary (Melbourne) had worked for his organisation for over 10 years and his input to addressing the unacceptable sexual behaviour of a service user who masturbated in public also concerned using an on-going strategy of encouraging the man to go to his room to do this. Another worker gave her account of discovering a service users' behaviour which was known to other members of staff. The incident in question concerned Vera and the service user who was trying to embrace her (see

above) and thankfully she was able to handle the situation by instructing the man to go to his room. She explained what happened after she had reported the incident:

“My manager said next time you’d better be careful if something happens to you. Just immediately call to someone because in that place we had no sleep-over person . . . But we have ‘on-calls’ so that obviously this was my first experience. I didn’t know about these things – the procedures but then my manager said that if something happened next time you just ring the ‘on-call’ and just inform all these things to the ‘on-call’. (Vera: Melbourne).

She had not been given information about the man’s behaviour prior to the event because she was still a probationer with the service. In this instance it is interesting to note that the advice she was given concerned self-protection rather than information on ways the man’s behaviour might have been modified.

6.3 When health professionals are consulted: staff role; status; and ‘proximity’

SCWs roles in the modification of service users’ unacceptable sexual behaviour when health professionals become involved also constitute the embodiment of the ‘field’ of care work. What follows are workers accounts of the level of their involvement in these situations and how this affects their role.

6.3.1 Managers

6.3.1.1 Initial contact with health professional

Whatever the situation, the first role of the social care worker is to give information on the behaviour to the health professional in the initial consultation. Support workers may also have to act as the voice of the service user should they be unwilling or unable to converse with the health professional. Indeed, Walmsley (2004) has commented that the care worker is to the person who has a learning disability as the wheelchair is to someone who is paraplegic. In cases cited here initial contact with a health professional, when a service user’s behaviour caused serious concern, was undertaken by those in managerial positions. Although as Edward (Scotland) states they in turn have themselves to refer upwards, they are also the ones who make initial face-to-face first contact with those from the medical

profession in these circumstances. This is particularly the case when there is an emergency situation, thus:

“I contacted my line manager who had a discussion about it and we agreed to speak to the person’s Care Manager – speak to the Community Learning Disability Team – for advice and speak to the in-house expert at head office to get some advice.”

Following this, Edward is no longer directly involved in the case apart from keeping informed of the situation. Maggie (Melbourne) also makes initial contact with health professionals, although in her case this includes follow-up situations in which she sets out to establish whether the behaviour is sexual or medical in nature.

6.3.2 Team leaders

6.3.2.1 Initial contact with health professional

Team Leaders interviewed also made initial contact with health professionals and like Louise (Scotland) quoted above, have enjoyed a positive working relationship with them. Rose (Scotland) had just become Team Leader of Tom’s support team when he assaulted a member of her staff. Although the team had already been working with a CPN over his infatuation with the woman on his support team, this was a new situation and Rose recalled:

“So [the assault] had to change absolutely everything. Absolutely everything changed then. Obviously we had to contact the hospital to get an emergency assessment from a psychiatrist”.

It was also Rose who made initial contact with their CPN and Care Manager to discuss buying a sex toy for Bill because this was not a decision she was allowed to take on her own. Jacky (Scotland) also made initial contact with a psychologist when she realised what Luke’s ‘chicken dance’ was about. As a result of this initial contact it follows then that Team Leaders also liaise between the health professional and support staff.

6.3.2.2 Reporting back to health professionals

When the health professionals’ involvement is instigated by behaviour that gives cause for serious concern then Team Leaders are required to give them feedback. For

example, Dale was already involved with a health professional service (and also his Care Manager) and so Charles and his team are required to complete monitoring reports on the service user's sexual behaviour which are then circulated at Dale's CPA meetings.

6.3.2.3 Informing staff of strategy

In other cases Team Leaders will be involved in discussions after making initial contact. Rose attended a meeting where she was talked through a strategy devised by a psychologist for Tom which she then passed on to his direct support staff. She explained:

“We'd a psychologist involved who wrote up social stories for Tom. They're like cards and communication like Tom understands. He can read big writing if it's in simple language – so a social story about my relationship with my staff – ‘I pay my staff to work with me. They do not miss me when they're not here’”.

Members of front line staff were required to work with Tom using these stories whenever he started to refer to having a relationship with the female member of staff.

6.3.2.4 Specific roll in the strategy

On occasion, Team Leaders are set particular tasks as is the case with Rose for Ray who now phones her to let her know he is following the health professional's advice on what to do if he finds himself in situations where there is a possibility of interacting with children. Ray phones Rose when he thinks it necessary to let her know how he had avoided such situations:

“He would phone me and say –‘I was walking to work this morning and a wee girl was coming towards me and I turned round and went the other way and I want you to know that that's what I done and was that the right thing to do?’ You know, looking for reassurance” (Rose: Scotland).

The approval she expressed helps Ray feel that he was doing well; that he is doing the right thing. Although her status as Team Leader is important to this development, since she is in effect an authority figure, the fact that they share a long

work-related relationship is arguably even more important. As Charles (Scotland) remarked on the positive effect of having had a long relationship with Dale:

“You can’t fix anybody. We’re going to take all this understanding and it’s only because of the strength of rapport in that relationship . . . he’s just getting on with his life.”

6.3.3 Front-line staff

6.3.3.1 Subsequent appointments

Initial contact will of necessity involve discussions of the case but subsequent meeting may mean that other members of staff will be involved. CPA meetings take place when there is a serious issue concerning a service user. Those who attend include everyone who may have a bearing on the issue which can be psychiatrists, CLDNs, physiotherapists etc. Members of the individual’s family can attend as well as members of the social care team. In the case of the latter, this may be the service manager, Team Leader and also the service user’s Key Worker. For example, John attended a CPA meeting to discuss how the incident with Tom was to be approached. He said: “We had various meetings and went to the CLDN team”. Key and fellow front-line workers also have the task of supporting service users on their visits to appointments with health professionals.

6.3.3.2 Implementing strategies

Once an inter-agency team is in place it is necessary for suggested strategies to be implemented. All front-line staff who have the care of the service user in question are responsible for this, especially the Key Worker. They and other direct support workers are mostly involved in implementing strategies devised by the health professionals although all staff having contact with the service user, for example, agency and those brought from another part of the service when there is a staff shortage are required to do so. Strategies may include giving sex education and explaining about relationships using whatever communication style is most suitable to the service user; playing relaxation tapes, continual 1:1 or 2:1 staff ratio, or administration of medication. The account above of Tom and his social stories is one example. Similarly, staff who have the support of Fraser know that they must stay

with him all the time when they are out in the community because of his past behaviour towards children (Beth: Victoria).

6.3.3.3 Instructing other front-line workers

Staff members are not always told of the strategy directly from the health professionals or from members of their management team, however. Informal instruction may be provided by existing members of staff to those who are new to the service in what may be regarded as their ‘teachable moments’.

6.3.3.4 Monitoring and reporting

All staff who are assigned to work with a given service user will usually have to fill in a Daily Recording Sheet. This will include Key Workers, and other workers whether full-time, part-time, probationer, casual or agency. This is standard procedure in which aspects considered of particular note in the individual’s life, e.g. their diet, activities, health and mood are recorded on a daily basis. The record provides up-to-date information to on-coming support staff. Over a longer period of time these records can also be used to indicate both positive and negative development in the service user’s life. When a health professional becomes involved with the service user they may require staff to monitor the effectiveness of any treatments they recommend.

6.3.3.5 Medication

Finally, the outcome of consulting a health professional may result in the daily task ascribed to whoever is on shift to administer regular doses of medication. Jean from Melbourne supports a service user who gets aroused in the presence of certain female members of staff and has been prescribed drugs. She said that: “We’ve actually had to give him medication to calm [the service user] down, but it hasn’t been too much of a big deal lately”. Yet staff may not know what the service user’s medication is for. Part-time, casual, probationary or agency staff, may be left unaware that a service user has an issue with his sexual behaviour so may also be denied information regarding treatment. As one part-time worker said of a service user, “I think he’s on tablets or something. I don’t know” (Brenda: Melbourne). Brenda is

involved in the man's daily support though it appears that her relationship with both her management and the health professional involved is a great deal more tenuous.

6.4 Limitations

Workers who were interviewed demonstrated that they accepted their roles in the modification of their service user's unacceptable sexual behaviour even in what would be considered to be highly charged situations such as those involving the possibility of sexual abuse of children. However some barriers stood between them and their commitment to support the service user effectively. Some of these related to the service user, whilst other barriers are related to the service. Each barrier prevents the SCWs' embodied practices within their 'field'.

6.4.1 Limits relating to the service user

Before care workers consider calling in health professionals they may first have to establish the nature of the behaviour. If they manage to do this, they may decide then that they can address the situation in-house. John (Scotland) worked with Bill and reported that:

“Some of the staff in the morning [found] there'd be the end of a book and it would have excrement on it. So we found he was actually using the book. [for sexual gratification].”

Rose also suspected the behaviour was sexual but could not be sure. She commented:

“So we had to speak to him, and we kind of knew it was for sexual gratification. That was my feeling and that was the team's feeling, and what he was letting me know.”

In Frank's case, his strange attraction to cars had been known about for some time, though they were not aware of the extent of this. As Grace (Melbourne) explains:

“Look, it's something we kind of knew about but I didn't think it was about sex and I just sort of – I thought he was just doing it. I really didn't think anything else of it until recently when we found out about the car-humping . . .”

Although most manifestations of problematic sexual behaviour mentioned during interview could be clearly identified as such, this was not always the case. Jacky (Scotland) and her colleagues were aware of Luke's chicken dance for a while before they realised it was sexual. "When you saw it (the chicken dance) you wouldn't make much of it, just think it was a bit weird." After realising that the dance was sexual, she started to rethink causes for other unusual behaviours he displayed and found that they were likewise of a sexual nature. Now, Grace, like Jacky, is also questioning some of Frank's other behaviours:

"He's also been known to stand at the market and he waives money around. He'll have 20 dollars in his hand – and we're worried. Is he doing that to get sex? Is he doing that just to show people he's got money? Why is he doing this?"

Uncertainty was also expressed as to the cause of service users' sexual behaviour. Anxiety is comparatively common in service users who have a learning disability. This can be over many different aspects of their lives, both sexual and non-sexual and can take many manifestations. For example, I worked with a service user who would indicate he was anxious about something by going around the house making anything that hung on the wall – pictures, mirrors etc – squint. For Beth (Melbourne), in the case of Trev, what the behaviour meant was masked by the amount of possibilities, none of them obvious. She explained:

"He's terribly anxious and stressed (in general) so again, how do you differentiate when he's non-verbal? How do we get to the bottom of where his anxiety comes from? . . . We've discussed whether there's a sexual element to that but where do you go from there? It's difficult."

A further limitation in implementing effective strategies is the level of the service user's understanding. As stated above, the very nature of a learning disability is that individuals take longer to learn. Such is the individual nature of this condition. Wendy (Melbourne) spoke of Chloe's continuing lack of understanding and its consequences:

"She's been chatting with them [taxi drivers] and saying 'Oh yes, you need to have sex'. But she's not really wanting to have sex with them. That's just a comment that she's made and they've taken that in the wrong context. She doesn't realise".

Service users, particularly those who have a mild learning disability can refuse to acknowledge their condition and so reject appropriate support²⁶. When asked if he might have been included in classes the organisation was running on the subject Rose replied, “No, because he does not consider himself to have a learning disability and he does not like associating [with others who do]”.

It may also be the simple case of the service user being unhappy about giving up the behaviour that gives them pleasure. This was the case with Tina’s (Scotland) service user when she was masturbating in public view: “She was obviously quite angry with us to begin with. She didn’t like it”.

Grace (Melbourne) had doubts about supporting Clark’s request to visit a strip club in order to address his anxieties around sex. This was a new situation for her and her team. She wondered if it would have a positive effect on him or: “He may decide that he really likes to go and he might want to constantly take himself to this place. . . He could become fascinated with this one person.” However Grace added, “But you’re never going to know if you don’t do it.”

An element of risk such as Grace describes can be present in strategies meant to change the service user’s unacceptable sexual behaviour. Although this may put others at risk, the service user himself may be in danger from others because of the way they behave. When asked if she thought her job included keeping the public safe from Luke, Jacky (Scotland) replied:

“No, I would say we’re keeping him safe. I’m trying to think, would he touch anybody? I’m not saying he wouldn’t touch somebody. I’m not sure whether he would or not. But my main thing is to keep him safe because I’m more worried about [the fact that] he can’t really control when he’s excited”.

²⁶ I don’t think this is an uncommon situation. I supported a service user who was the only one of four in his household who did not have Down’s Syndrome. Thus he only associated having a learning disability with having this condition.

6.4.2 Limits relating to the service

As explained above, previous support agencies can deliberately withhold information about a service user from his on-coming service, arguably in the name of confidentiality. Alternatively, their record keeping may have been inadequate or the service user's behaviour completely ignored. The ensuing lack of information serves to limit the new service since it is left to them to 'discover' the behaviour for themselves and then create a suitable strategy in order to cope. It is the same with fellow service providers when information gleaned in say, a day service is not then shared with, for instance, his residential service. In the meantime, the service user's behaviour may have escalated causing him to come in contact with the CJS and/or victimise someone. Without knowledge about the behaviour the service provided to the new service user is thus severely limited. However, Laura (Scotland) takes measures to overcome this situation:

“If we don't get a lot of information we went up to the institution to talk to the person, to talk to staff. I was really lucky to spend a couple of months going up to the institution to get to know the person”.

Yet confusion over the concept of confidentiality is not the only reason why SCWs may not have the information they require in order to best support the service user. As explained in the introduction to this thesis, there is reluctance on the part of the judiciary to take on and prove cases of abuse involving people who have a learning disability, whether they are victims or culprits, and this is often because of the difficulty in establishing the truth of accusations²⁷, it is simply not known whether a service user has been abused or if a service user is an abuser or not. Thus there is neither information to this effect to pass on nor an accompanying strategy to follow. Louise (Scotland) gave the following example:

“He had appeared in court seven years before [entering her service]. The police got him on an allegation that he had abused his niece. He was found not guilty but we never knew whether he did it or not”.

²⁷ Additionally, the credibility of people who have a learning disability may be doubted on the premise of their condition.

Nevertheless Louise's organisation did a risk assessment to prevent the possibility of such an incident recurring.

Lack of knowledge about how to go about addressing service users' sexuality and relationship issues may be because of the unique nature of the situation. However, this may also be due to a lack of even basic training which can deter otherwise willing workers from becoming involved in service users' issues around sexuality. In Grace's (Melbourne) case, although it was legal for him to do so, co-workers were reluctant to agree to the service user visiting a strip club and challenged Grace saying:

“Well, what is the right and wrong way? We're not trained to be discussing sex and things like this with these guys. They need someone who knows what they're talking about”.

Thus their reluctance was based on the fact that they had not been trained in this area of educational support for the service user, nor for that matter on ways the law applied to him in his particular circumstances. Similarly Louise (Scotland) explained:

“You know I can offer emotional support to somebody but I don't have any formal training in supporting somebody in dealing with sexual abuse or being an abuser. So my role has been quite limited because of my lack of experience and lack of training”.

Given that there are laws in both Scotland and Melbourne concerning the sexual behaviour of vulnerable people such as those who have a learning disability, any staff training needs to include knowledge and clear understanding of these. As explained above, organisations that support vulnerable people are subject to laws and are expected to follow guidelines. Knowing and understanding the law in, for example, human rights, fosters confidence in workers and SCWs may even find themselves in situations where they have to explain the law to service users. When Bill, who has communication difficulties, managed to convey to staff that he needed sex toys, staff were then left with the problem of communicating to him that it was not against the law or offending anyone if he used it. He had been brought up to think of sexual needs as a bad thing, which exacerbated the situation. John (Scotland) explained:

“There’s very very specific laws about not promoting sexual activity²⁸ and behaviour so what we had to do – we supported him to buy the sex aid . . . talked him through using it . . . and he keeps it in a box in his bedside cabinet with KY jelly, so it’s there for him every night in case he wants it. He had it for about 2 – 3 months and didn’t use it. When staff came in in the morning he would take it out of the drawer and put it out [unused] so that staff would look at it, and I think, knowing him – I think he thought ‘this is a bloody trick!’”

However, it was not only Bill who was unsure of the law in this case, but also those who provided his support service who had to be certain of the legality of the action they were required to take on Bill’s behalf. Rose explained that before they could buy him the toy:

“. . . it was quite a big thing for the organisation – a lot of disciplinary meetings and they eventually came to the conclusion that this is what the guy needs.”

Charles (Scotland) spoke of a similar situation in which the legal aspect was limiting because it was not understood by all those involved. Charles described such an instance made more frustrating because it was his management who misunderstood the law in question. This concerned the leisure activities of Dale who like to go out for lunch and had twice visited a casino. This brought forth stern condemnation from his Care Manager.

“I don’t think [the Care Manager] has a Scooby [clue] about anything. The guy’s [Dale] under guardianship and I mean . . . the Adults with Incapacity Act has themes that underpin it regarding what is least restrictive. I’m actually . . . a trained CALM²⁹ instructor for the physical restraints techniques . . . and they do an assignment on the Adults with Incapacity Act . . . and what this means for the use of restraint. So I’m quite aware of . . . what the legal position is on it.”

Here Charles is referring to the fact that in some situations workers can only inform service users of the advisability of doing something, they cannot physically, emotionally or financially prevent them from going against this advice.

²⁸ Edward (Scotland) gave a good explanation of what is meant by ‘promoting’. He tells his staff that if they are in a newsagent’s with a service user who is in a wheelchair and he asks the staff member to give him down a pornographic magazine, then they can legally comply with his wishes. What they must not do is draw his attention to these magazines and ask if he would like to see one. That would be considered promotion of sexual activity.

²⁹ Crisis Regression Limit Mediation Instructor.

Workers' first experience of a situation can be fraught with misgivings about what to do, especially where there are legal implications. The legal situation in Melbourne is more lenient than in Scotland with regard to the support that can be given to someone wishing to gain access to sex workers in saunas, strip clubs and brothels. Grace had doubts about supporting a service user to find out about going to a strip club as a means of sexual relief:

“Whether that’s the right or wrong thing to do? Whether we should be taking him to a sex therapist first to teach him what’s right and what’s wrong? But what is right? And what is wrong?”

Her judgement of course is partly based on her knowledge of the service user in question.

A further aspect Grace mentioned was the friction caused between workers who disagree with what might be considered a radical solution. As she continued, “And that’s where some of the staff aren’t happy because they believe that we’re teaching him the wrong things”. The reactions of fellow staff members can thus affect the service experienced by the service user. Just because my respondents were willing to take on these matters does not mean that all staff from the same organisation were willing to do so. Laura (Scotland) spoke of a team meeting geared to addressing service users’ sexual needs. She said:

“We’re sitting there saying, ‘How many people do we support? 17?’ And sitting around the meeting there’s only 2 Team Leaders who are saying this [sexual behaviour] is an issue for some service users.”

6.5 Relationships in an inter-agency setting

Above I have referred to the promotion and encouragement of inter-agency working by governments in both Scotland and Victoria, Australia. Such arrangements can be beneficial for the SCW and by extension, the service user. Before going on to refer to the limits to this relationship it is necessary to give accounts of when it works well. To do otherwise would imply that multi-agency work is doomed to fail which is not

the case. Respondents remarked on the successful nature of this and how they valued having health professionals as a resource in their care of service users:

“He (Ray) made a lot of progress and that’s down to his team and the input we’ve had with the learning disability community team, I think” (Rose: Scotland).

6.5.1 Positive

Staff acknowledge the expertise of health professionals, as in Luke’s case where as matters developed a psychiatrist was brought in who managed to establish that the service user was hearing voices telling him to do certain things, when he said to her, “You’ll have to stop the people talking about (bumpity bump) in the morning to me”. The information that Luke has an additional diagnosis of schizophrenia has subsequently helped Jacky understand aspects of Luke’s condition and why modification of his behaviour has been proving especially difficult.

It may also be the case that the health professional can come to the workplace to share information about the strategy they recommend and answer staffs’ questions: “We did have one of his counsellors come in and address the staff and answer questions and sort of talk to us about it” (Beth: Victoria). Although they professed to have no solution to his constant masturbation, health professionals did manage to arrange short-stay psychiatric care for Clive when support staff could no longer handle the situation. Laura (Scotland) noted that this was “the only sort of support we got as a team” from these health professionals.

One scenario that emerged concerned a case where the social care workers required their solution to a situation to be endorsed by a health professional in order for it to be accepted by a Care Manager. When Rose’s service user made it understood that he needed a sex toy he also insisted that his parents were not to be told about this. Rose and her management agreed to comply with the man’s request since this showed knowledge of, and respect for, his human rights. However, his Care Manager was insisting that the parents were told because he feared that the press would get hold of the story and vilify his department for what they might brand irresponsible behaviour. Rose consulted the CPN who did an assessment of the

service user's needs and agreed that Bill would benefit from having a sex toy and that there was no need for his parents to be told about this. The Care Manager accepted the CPNs assessment.

At the centre of any positive multi-agency work is the service user himself. How he perceives health professionals and any advice or treatment they may offer is vital to any progress being made towards modifying the problematic behaviour. Service users can show awareness of the health professionals' status that is generally accepted in our society. Laura gave a clear example of this.

“I've been trying for months to get [the service user] to put on side supports and I've been on to the team for months [to encourage this], but nope, [the service user] isn't having it. And a physio came in the other day and said one line, and it's like 'yes, I'll put the side support on'. So our views and opinions obviously didn't weigh heavily enough for [the service user].” (Laura: Scotland).

Wendy (Melbourne) spoke of a similar situation and offered a reason why service users might ignore the advice of SCWs:

“They get so used to you and telling them 'can you do this, can you do that?' or 'can you not do this, or can you not do that?' Sometimes it needs just that – somebody different to say, 'well this is not on.'”.

Jacky spoke of Luke whose condition made talking therapies impossible. Additionally, he would not accept guidance from SCWs. In the situation with Luke, staff had no other solution but to stop responding to his requests. After failing to prevent the continuation of this and other sexualised behaviours staff were compelled to seek the advice from a health professional, because as Jacky (Scotland) realised:

“If the staff were telling him not to do these behaviours he would get annoyed because he felt it was us that was telling him not to. We got involved with a psychologist and there was a CPN”.

In this instance members of staff were advised on ways they could alter their approach to modifying his behaviour. What this further illustrates is that the service user can understand the difference in status ascribed to different workers, and respond to them accordingly.

6.5.2 Negative

Some factors that serve to limit the possibility of multi-agency work relate to the political climate and the way in which governments prioritise service provision for service users who have a learning disability. One of these concerns the availability of specialist services for this group. Edward (Scotland) explained how he involved Ray's Care Manager in order to gain speedy access to a CLDN when Ray's behaviour caused concern. He explained that although in this instance he got an appointment within 36 hours, 8-12 weeks was the norm. Thus specialist services are not always readily available to this service user group and in some circumstances it is wholly appropriate to use those that are generic, for example, where it is necessary to rule out medical explanations for a behaviour. However, this is not always a positive experience for either the individual or their carer. As Maggie (Victoria) has experienced:

“It is (also) the case that when you go to a [generically trained] specialist or GP that they don't deal with disability very well at all. And I find that much more frustrating. Nurses, doctors, neurologists, psychiatrists – the whole lot – they need more awareness about the disability aspect, not just the mental health issue or the health issue”

One gap in their knowledge is how to communicate with service users. Maggie commented that this was about more than the fact that they address the carer rather than the individual in question but that they ask her, “What do you want from me? Do you want me to medicate? And it shouldn't be our responsibility. We're not trained to be diagnosing”. She also went on to remark on these health professionals' lack of awareness of specialist services to which they can refer service users.

Even working with medical specialists in the learning disability field can prove difficult, for various reasons. Although it has been argued that people who have a learning disability equate being good with doing as they are told rather than with a moral stance, this is not always the case (Flynn *et al* cited in Brown & Thompson, 1997). For example the individual in question may refuse to co-operate with the health professional. Nor is the lack of rapport always because of the service user's condition. Before Dale received the services of the psychologist who treated him

with respect and understanding, Charles spoke of his seven year relationship with his CPN:

“He wasn’t engaging with psychiatric services at all at that stage. It was a very very negative relationship, and just the last seven years he’s slowly getting something positive from forensic services”.

Charles added that:

“For the first 3 years I worked with him he refused to go to meetings with her. She’d be condescending to him . . . In an inflamed situation he would walk out”.

And later yet Charles commented: “He can stand her now”

It may also be the case that the service user is in denial or may want to give the health professional a more positive account of his progress than is truthful. In such circumstances the health professional should look to the support worker, if they are allowed to be present, to supply them with a factual account of events.

“Sometimes he’ll tell you things he wants you to hear. . . . Like he’ll go to the doctors and start talking about a load of stuff because that’s what the doctor wants to hear. So we say, but what about this situation? What about that? And it’s ‘Oh yes, I see what you mean’. So he knows that if he paints a pretty picture then everything will be fine”.
(John: Scotland)

It may also be the case that the service user’s condition precludes fruitful engagement with anyone including health professionals. Jacky referred to Luke’s appointments with his Community Psychiatric Nurse thus:

“I was actually in a couple of sessions with him but he just could not cope. What he would do was avoid it. They would try to get him to focus but he would – he talks continuously so if someone’s trying to talk to him he will talk continuously and not take anything in. And if they try saying ‘you have to stop right now because I’m trying to get you [to listen]’, he’ll say ‘oh sorry’ and then he’ll talk about things that aren’t even there. His social skills are not very good in that you sometimes don’t get eye contact, especially when it’s something they don’t want to discuss or they’re embarrassed about. . . . (He) will talk while you’re talking. He talks continuously. Once we get quiet, he gets quiet. So it can be very difficult. When it came to his session with the psychologist he found it all quite disturbing and we couldn’t get him to focus on any questions so they had to stop that”.

The psychologist had similar problems treating Luke, thus:

“I know that his first session with [the psychologist] was very very difficult. Luke will do everything to avoid and look for distraction – any distraction. And I think now, the first time . . . there was a staff member, a psychologist and him. That meant that he has something else to constantly focus on [the staff member]”.

Trev’s condition also prevents positive interaction with others and this is compounded by anxiety that is an element of his autism. His sexual frustration builds up because of this, as Jean (Victoria) explains:

“He doesn’t have an outlet. His disability is autism and with that they tend to like to be by themselves a lot – don’t like to mix with other people and have trouble expressing themselves and what they would like. . . . We’ve actually given him some medication to calm him down. That’s not the answer but that’s how we’ve been handling it.”

Limits to treatment where this involves counselling may be because of the service use’s lack of understanding. Gary (Victoria) spoke of a man who had been caught touching a boy inappropriately by the boy’s mother. When asked what strategy had been put in place in response to this Gary replied:

“Yes, we did get instructions on how to manage his behaviour. It was recorded and also an eye had to be kept on his well-being. So that stressed him out quite a lot too. I think as far as he was concerned he’d done nothing wrong”.

Rose (Scotland) spoke of a similar situation with Tom:

“The psychiatrist predominantly decided, and we agreed, that he needed male workers. It was too risky to put a female worker in. . . . But he reacted really badly to that. He felt he was being punished, as if we were keeping [the female member of staff he obsessed about] away from him”.

The effect of inappropriate handling of situations in the past can have a negative effect on current treatment. Tom refused to accept the psychiatrist’s version of the consequences should he offend again. Rose explained:

“So we had to be very clear with him. Twenty years in a residential service when the biggest thing that’ll maybe happen is that you’ll get a row from the manager or your mum. You move into your own place and people start treating you like an adult, and

we had to say to him, ‘You attack a lady and do anything to anybody . . . you could be arrested; you could go to jail; you could get locked up in hospital’ . . . And what he kept saying was, ‘That’s absolutely fine. My cousin’s a police officer and I’ll be fine. He’ll look after me and my mum won’t let them do anything to me’”.

Rose (Scotland) spoke of a similar legacy from the past regarding Ray’s sexual knowledge.

“The chap’s well into his 50s. He’s got elderly parents. They’re a lovely wee couple but they’re very old and its’ ‘My son has a learning disability and never had a thought about sex in his life’.”³⁰

6.6 Limits relating to the relationship between SCW and health professional

Some situations were mentioned where health professionals appeared to be excluding SCWs when dealing with service users’ issues. This was due to patient/medic confidentiality. For example, one worker remarked that therapy sessions are not always done one-to-one with the service user which brings into consideration the confidentiality of others receiving the treatment. As John (Scotland) relates, “We support [Ray] for his visits but they don’t want us to sit in with him. It was a group session”. Confidentiality is also an issue when the health professional/service user encounter is one-to-one. As such, health professional feed-back to the support service would also breach the service user’s confidentiality. For example, when asked about a CPN’s approach to treating the service user he supports, Charles (Scotland) commented, “We’re really not party to that much”.

Given that front-line workers support service users on a daily basis it seems strange that the most common area of uncertainty workers mentioned was around information about what had transpired during the individual’s session with health professionals:

21 Ironically, though Ray was keen to tell all and sundry about his use of binoculars, he was deeply concerned that his parents should not be told. His wish was respected by staff as his human right.

“They [the CLDN team] wanted to do the work with [Tom] on their own so we would just nip out to the car for an hour and come back and ask him in general about things. . . . We really didn’t know what was happening but I’d send a report to our manager” (John: Scotland).

Thus such information as he got on Tom’s treatment came through the man himself. John remarked, “He has been shown videos as well but Tom tells you something and you can’t be sure it’s what was said”. However this situation begs the question, since the service user was willing to try to tell his Key Worker what transpired in the session with the health professionals, could he not have been asked if he wanted his Key Worker present at the time? To reiterate Walmsley’s point, the support worker is to the person who has a learning disability as the wheelchair is to the paraplegic. In one instance, the worker was not even sure whether the subject of the service user’s sexual issues had been covered in his appointment with the health professional.

“Well, as I said, he is seeing a psychiatrist but I don’t really know whether [his sexual behaviour] was discussed specifically . . .” (Beth: Victoria).

While the issue of confidentiality may in some instances be accepted as a reason for not sharing what transpired during the service user’s appointment, resultant recommendations affect the role of all care staff. Yet this information was not always available to them, as is apparent from this extract from an interview.

Worker: “Every fortnight the doctor comes.”

Interviewer: “Has the doctor advised staff on how they should treat the man?”

Worker: “Yes.”

Interviewer: “So what role do you play in that?”

Worker: “Oh, I don’t really know”

Interviewer: “You’re not involved in that?”

Worker: “No,”

Interviewer: “Do you work with the person on a daily basis?”

Worker: “Yes.”

Even with knowledge of treatment, workers do not always get explanations of the reasons for this. John also gave contrasting accounts of multi-agency work involving the same service user. With regard to the psychologist and psychiatrist he said:

“It’s been really good working with the two of them. . . . We sat down with (them) and they spoke about things and we asked them if they could help us, particularly the psychologist. So they made leaflets with pictures on as well – social situations about relationships that we’d asked them to help us with.”

On the other hand, the learning disability team decided amongst themselves to leave a relaxation tape for Tom. John commented:

“We felt they could have been doing more to help. The last thing they did before they left was they gave him a relaxation tape. To me it’s just a waste of time. He has to put the tape on when he’s feeling a bit uptight. By the time it explains what it’s about – and it’s all over Tom’s head – he’s not interested. He can relax to his own music which is heavy metal, so he’ll relax listening to that rather than putting on tapes.”

Support workers may have doubts about a health professional’s suggested strategy but have neither confidence nor the opportunity to feed this back to the health professional.

“[The service user] has had one appointment and he’ll probably be reviewed again in six months time. [The doctor] was going to give him medication to calm him down but I don’t know whether that’s the answer” (Jean: Victoria).

Not all strategies suggested by health professionals are found to be effective by support workers and their feed back on this may not be requested. When asked if the CLDN had come back to find out if the tape helped, John answered ‘No’. Wendy (Melbourne) has similarly not been asked to give feedback to the service user’s counsellor. She remarked:

“We didn’t go down the path of the counsellor this time because it was the same counselling that she’d already had and we thought we would just reinforce it here ourselves to see how it went”.

Failure to request feedback is apparent here because there was no change in the counsellor’s strategy.

John's account of Tom's tape might also be included in this section. Even though he had serious doubts about the use of his relaxation tape John still felt duty bound to suggest using it. Workers may also suspect that the treatment being recommended is being used when a more effective treatment would be simply for the service user to have an outlet for his sexual feelings. Jean (Victoria) felt this was the case with Trev whose attraction to certain members of staff had become apparent.

Another Team Leader was baffled by the treatment suggested and wondered if the CPN had been listening to her account of Luke's behaviour.

“They gave us guidelines where we had to show him pictures of where it was OK to masturbate. The problem is he doesn't masturbate. He doesn't do that” (Jacky: Scotland).

One interviewee did not feel the contribution of his team and his staff was appreciated and expressed his anger that his approach to modifying his service user's behaviour was dismissed by the rest of the CPA team members, all of whom had only limited contact with, and knowledge of, the service user. Indeed, Charles was made to feel that other members of the CPA including health professionals and the Care Manager looked down on him and his team.

“One point I raised with the Community Disability Nurse – you know the CPN – she picked up what I said, twisted it, and said something back. And it was the same when any of our team spoke and it was just a mockery.” (Charles: Scotland)

Frustration can set in and affect the relationship when support staff feel that the health professional in question has not listened to what they have to say. For example Laura (Scotland) talked about the response she got when she approached health professionals for advice on what to do about the man who was masturbating constantly whilst talking about 'wee boys' and 'wee girls'. The nature of his support was such that he was never in the presence of children but he was actually losing a noticeable amount of weight because of the intensity of the behaviour:

“[We approached} the CPN and we also went to a psychiatrist and [the service user] was assessed in a short-stay psychiatric unit and again, all the feedback was that this

behaviour wasn't related sexually. [They said] it was only like making a cup of tea was a behaviour. It was really difficult to get people to admit this man was having sexual urges and you know, we needed to be supporting that" (Laura: Scotland).

6.7 Sum up

With regard to addressing behaviours in-house workers' accounts illustrate not only the ways in which roles in the modification of service user's unacceptable sexual behaviour relate to the status of the worker, but also their working relationship with the service user - their 'proximity'. What is also illustrated is the way in which this aspect of 'proximity' further defines their 'field'. That is to say, whilst all members of staff have as their remit a duty of care, when it comes to the care of specific individuals, this field is further defined by specialist skills which involve the quality of the relationship the worker has with the service user. An analogy from the medical profession would be, for example, the division of the 'field' of medicine into endocrine and vascular consultants. Whilst the differences within their 'field' concern parts of the body and their functioning. In care work, the difference is the nature of the working relationship with the service user. So it is that those who know the service user best – their Team Leader and Key Worker – perform tasks that are based on their knowledge of the individual. A good example of this is that in which Edward (manager) asked John (Key Worker) to speak to Tom to get him calmed down following his assault of another member of staff. Similarly, Rose's knowledge of Bill's unique communication style led to understanding his needs.

Regarding the input of other staff in these situations, it is apparent that their level of 'proximity' limits their roles in the modification of these behaviours. However, what is also apparent is their lack of status with regard to access to information. Again, the concept of confidentiality can be misconstrued by management who withhold information about the service user's behaviour from, amongst others, probationary staff, with the knowledge that these workers also support the service user in question. What this indicates is the way in which those in this line of work can fail to acknowledge their own 'profession' as professional, whereas within the medical 'field' probationer nurses have access to the same information as the consultant.

When health professionals are consulted in cases of service user's unacceptable sexual behaviour, SCW roles are similar in terms of their relation to the concept of 'proximity', except there seems to be a falling-off of roles where the Key Worker is concerned. Whilst managers and team leaders roles still relate to their particular level of 'proximity' to the service user, those of the Key Worker are on a par with other, less 'proximate' members of staff. Key Workers' level of 'proximity' is utilised in situation when a service user's behaviour is dealt with in-house, yet there appears to be a failure to utilise their skills when health professionals are consulted. If we ascribe value to the concept of 'proximity' then it may be the case that health professionals have failed to understand this, i.e. they have failed to acknowledge the value of the embodied practices that constitute the Key Workers specialised 'field'.

Knowledge which encompasses the full range of known sexual behaviours and their manifestation would constitute the 'field' of an expert on sexual behaviour. This is something SCWs would not claim to be. However, their experience as individual workers means that they can acquire working knowledge of a particular behaviour, how to recognise it, and ways in which it might be addressed. As to the service user's level of understanding, whilst this may be profound, the SCW who works closely with them is arguably better placed to communicate with them to a higher degree.

The availability and dissemination of information to and within a support organisation has already been discussed. Lack of knowledge can have effect even on experienced workers such as Brenda (Melbourne) who was "shocked" to find a service user fondling himself in her activity class. Even when members of staff have been with the organisation for many years they may lack information about those they support, as in Alice's (Melbourne) case who said: "I never sat in on any meetings, so I don't know anything concerning this". Additionally part-timer Vera's (Melbourne) account of her experience illustrates the point about knowledge and status when she replied to a question on the extent of her involvement with the service user who tried to embrace her. "I think the problem is – the main thing is that these people are not my key clients. I'm not a Key Worker of these people." Yet she

has their support every working day. Lack of information thus serves as a barrier to the workers' 'field'.

Lack of suitable training including that on the legal aspects of support work may also be read as a misrecognition of these workers' needs which relate to the embodied practices associated with the 'field' of care work. Certainly its provision would go some way to reducing the levels of self-doubt workers experience as a result. Suitable training might also serve to change the attitudes of some members of support staff who do not think service users' sexual behaviour is an aspect of their support remit.

To occupy the 'field' is to know the 'field'. Yet even when a worker has specialist knowledge he may, like Charles be doubted by his 'superiors', as he describes above. Yet as Hugman (1991) points out, 'subordinates' may have more skills and knowledge crucial in relation to a certain task than their management. Nevertheless those in management are considered more knowledgeable than front line-workers. In Bourdieu's terms this notion is a social construction, in this instance of what it means to be a manager (their symbolic capital), and what it means to be a front-line worker (lack of symbolic capital). This is an example of 'doxa' which amounts to social acceptance of that which is socially constructed as something that is natural.

There is little workers can do in the current political climate to ensure that governments prioritise service provision for those who have a learning disability. Similarly, where a service user's condition prevents him engaging with the health professional, there seems little that either they or the SCW can do to change this either. It is a limit to the 'field' of both occupations. That said, in situations where the service user has been brought up surrounded by silence over his sexuality, workers with whom he is in daily contact can give him sex education or if need be, they could bring in a health professional to teach him. When there is a lack of rapport between the health professional and the service user, the SCW, particularly the Key Worker may be in a position to advise them on how best to communicate and interact with them. This, because of their 'proximity' to the individual.

Similarly, if the SCW/Key Worker is present during consultations they are able to guide the service user to answer appropriately when asked questions by the health worker. These skills belong firmly in the Key Workers' 'field'.

Although Charles' experience of multi-agency working with a health professional may be an extreme example, there is ample evidence from these accounts that the skills and knowledge of the SCW are not being fully utilised. The misrecognition of their skills arguably makes for a poorer consultation than either the service user or indeed the health professional could expect. Insights and observations are lost, as is the opportunity to receive feedback on treatment from those who know the service user and his communication style, since these workers are best placed to monitor the situation.

Scenarios described above concern situations in which SCWs feel confident in addressing unacceptable sexual behaviours in-house and also those in which they choose to consult Health Professionals. Accounts of their roles and how these relate to the SCW/service user 'proximity' are also discussed. However, in Chapter 7 this thesis goes on to give account of a third scenario in which SCWs choose to have the input of Health Professionals, but this is not possible, and the subsequent roles these workers must take on.

Chapter 7

Emerging ‘field’

Where input from health professionals is sought but is not possible.

7.1 Introduction

In the previous chapter consideration was given to the circumstances in which SCWs choose to address service users’ sexual behaviour either in-house or with the support of Health Professionals. The subsequent roles of SCWs and ways in which this relates to their ‘proximity’ to the service user are also defined as well as the barriers workers experience in accessing their ‘field’. This chapter deals with a further context under which SCWs address service users’ unacceptable sexual behaviour, here defined as an emerging ‘field’.

Workers who were interviewed mentioned several situations in which they sought the expertise of health professionals but had to address their service user’s behaviour without their in-put. This was mostly, but not exclusively, due to circumstances outside the health professionals’ control. In this chapter these situations are considered in terms of SCWs now belonging to an emerging ‘field’. Garrett (2007) quoting Bourdieu writes that ‘habitus’ is ‘society written into the body’ (228). Garrett adds that according to Bourdieu history is incarnate in the body in the form of a system of durable dispositions. This does not only concern an individual’s practices but additionally their confidence, or sense of entitlement to these practices. Bourdieu relates this to positions of class in this society. Such practices clearly define ‘fields’ and are strongly associate to the concept of ‘the professional’. The status of this is ensured by protective measures such as insistence on academic qualifications in order to gain entry to the profession. This ensures that those individuals in the profession are a scarce, valuable, resource.

However, Bourdieu's is not a deterministic view of society and its structures. Rather, he regards the concept of 'field' and thus that of the 'professions' as a power relation characterised by struggle. If a 'field' defines the level of an individual's status, then so do the practices with which it is associated. Thus the struggle for professionalism is also one over the status of its associated practices. In this instance what is at stake is the health professionals' ability to do something about the service user's unacceptable sexual behaviour. However, the issue concerning the professional status of SCWs involves, amongst other things, the fact that they may find themselves working with situations that health professionals, for various reasons, cannot. That is to say that these practices are already associated with professional status whilst those who perform them are not. This chapter will now proceed to determine the circumstances under which SCWs find themselves in this situation, and the roles they perform as a result. The latter will be expressed in terms of the worker's 'proximity' to the service user before the chapter concludes with limitations to the SCWs practice in these circumstances.

7.2 Difficulty relates to health professional

7.2.1 Availability

Support Workers in both Scotland and Melbourne voiced concern about the length of time service users can wait for an appointment with a health professional. To reiterate, what this reflects is a failure of governments to prioritise funding for learning disability services. As Edward (Scotland) commented:

“We would also really want to have more time with them [health professionals] and much more in-put, but I think I'm talking about 6 – 12 weeks for issues that are not acute and require such quick attendance.”³¹

Maggie (Melbourne) also mentioned the time it can take to see a health professional:

“People don't do things for no reason and it's just a matter to decipher what it is I guess and use the support of doctors or specialists but sometimes these things take forever.”

³¹ Edward compares this with the day and a half time lapse before Ray, whose case was considered an emergency, received CLDN in-put.

Specialist health services for people who have a learning disability can be an excellent resource for service users and those who support them. However, the specialist required may not be available in the region in question. As Louise pointed out:

“We would have accessed counselling for the service user but it’s very difficult to get counsellors who counsel people who have a learning disability.”

This lack of appropriate services may have a knock on effect to those services that do exist, forcing them to spread their input a bit thinner than would be ideal. Rose (Scotland) noted that:

“The learning disability team came in and worked with Ray and the CPN came in to work with him. [The CPN} is now withdrawn and I think that’s due to the fact that they’re totally snowed under.”

Additionally the amount of time the service user spends with the health professional means that the latter is unlikely to be present during those ‘teachable moments’ unlike the SCW who works with service users almost daily. These moments are those when an opportunity to discuss a matter arise naturally in a conversation.

7.2.2 Health professional offers no solution

In Laura’s (Scotland) case, where Clive was constantly masturbating, she said that the health professionals would not accept that this was a problem requiring treatment because he was taking medication to treat cancer which also, medics insisted, was a libido suppressant. It was obvious to support staff that the man was physically and emotionally distressed because of the level of his frustration. Laura concluded:

“The only support we got (from health professionals) as a team was when that gentleman’s behaviour came to the point it was no longer manageable within that environment [and] he went into short-stay psychiatric help and then he would come back when he was at the low end of his bi-polar moods.”

Beth (Melbourne) described a similar situation in which a service user’s existing condition over-shadowed the sexual aspect of his behaviour and remained unaddressed by them. When asked to clarify a statement regarding a lack of

recommendations from health professionals and that the support team were indeed handling the situation on their own she replied, “Pretty much. Yea, I would say so”.

7.3 Difficulty relating to the service user

7.3.1 Service user’s condition

Lack of health professional in-put however is not always due to their inability or reluctance to become involved. In Luke’s case, Jacky (Scotland) remarked that it was due to his condition he could not focus and would use tactics to avoid engaging with the health worker. Furthermore, Charles (Scotland) remarked on Dale’s failure to work with a CPN because of what he reckoned was the latter’s confrontational attitude towards this service user.

7.3.2 Parents don’t want health professionals involved

Workers have also been denied the opportunity to consult a health professional on their service user’s behalf, even where there has been a possibility of children being abused. Dawn (Melbourne) said that in Fraser’s case:

“His advocate is involved, not health professionals. And the family are involved, for how we deal with this problem. His family, his advocate and our management is involved and the staff are supposed to help him – not letting him into the community by himself.”

Grace (Melbourne) also referred to Frank’s parents involvement and their preferred solution that he should be removed to a service in which he would have staff with him constantly to keep him away from cars. At time of interview this situation was on-going and although Grace wanted to bring in a specialist, no health professional had yet been consulted.

7.4 Staff roles and ‘proximity’

7.4.1 Managers

7.4.1.1. Expedite appointments with health professionals

One task which seems to be the exclusive domain of management concerns expediting appointments to the extent that this is possible. Edward (Scotland) commented that there was usually a wait of up to three months to get an appointment

with a community nurse. It was due to his involvement in Ray's case that he managed to procure an appointment a day and a half after the unacceptable nature of Ray's behaviour was established. Although Edward does not have daily contact with Ray, he nevertheless has the authority as manager to make the decision to involve Care Managers when he thinks this is required. This process calls for assessing a situation as an emergency before referring the matter to the appropriate Case Manager. With regard to this case he said:

"I knew the CLDN pretty well, I've had dealings with her on other people's cases so [I] contacted them directly but also contacted the Care Manager to ask for a referral to [the nurse] and the speed we'd like them to deal with it because there was a safety of others issue that we thought might have emerged."

As stated above, following this Edwards direct involvement was no longer necessary, although he could always be contacted should his advice be required.

Maggie (Melbourne) as manager of a Day Centre who has daily contact with service users also made a general comment about the length of time she has to wait to get an appointment with a health professional. In her case, her experience and confidence were used to procure health services in a timely manner:

"I'm very lucky to have worked in the field for quite a long time and I think it's also my personality. I'm a bit pushy like that so if I think there is something wrong I will support the family or support the house to find a resource and I suppose I go on getting better at having resources in my head as well."

Here, Maggie's final comment suggests that lack of experience can amount also to a lack of knowledge as to what is available. Time spent researching what resources are available also extends the time that support staff have to cope without input from the appropriate health professional.

7.4.2 Team leaders

7.4.2.1 Counsellor

Specialist health professionals are not always available in some areas which means support staff must cope with the situation as best they can. Louise, (Team Leader:

Scotland), faced with the reality that a specially trained counsellor was not available in her part of Scotland, found herself taking on the role. As she said, “I have to say that nobody ever said to do that but that was the role that I often took . . . All I could do was sit and listen.”

7.4.2.2 Advisor

Team Leaders were also involved in instructing or advising service users. Again, this depended on being around at those teachable moments, which is just not possible for health professionals. For example, Grace (Melbourne) has offered sex education to Frank as well as other service users. Similarly, knowing that Frank would not respond to a simple request to stop his mechaphilic practices this worker advised Frank of the consequences of using people’s cars for sexual gratification: “You can’t do that. It’s other people’s property. You just can’t do that, it’s wrong. You’ll get a bashing”. Similarly, Rose (Scotland) was able to explain to Tom why a relationship with a member of staff is inappropriate. She did this prior to him assaulting the member of staff, an incident which instigated the need to call in health professionals.

7.4.2.3 Strategies

Even though appropriate specialists may be available, staff may still find themselves short of the service of health professionals. In these situations Team Leaders also have a role to play. Rose (Scotland) described the line of action taken when, the CPN had to withdraw from Tom’s support because of his excessive work load. In response to this Rose (Scotland) had to reassess the situation:

“We’ve got a lot of support strategies in place now and we’ve got a risk assessment in place . . . but I think as far as sex education’s concerned we really need to do a lot more work [so] I’m actually going to contact his CPN again.”

In some instances appropriate health services may not be available until a situation deteriorates completely as was the case with Clive. In the meantime Laura (Scotland) and her staff were left to respond to extremely difficult behaviour as best they could. Laura thought providing Clive with a mirror in his room would help him achieve ejaculation, if he could see himself masturbate. Unfortunately, this, and

other strategies did not provide a solution to Clive's frustration and discomfort. Laura had also suggested using the services of a sex worker, but management would not allow this.

When Luke's lack of focus during appointments with the CPN made treatment impossible, Jacky (Scotland) addressed the situation with strategies which include not complying with his requests to do the 'chicken' dance or read his poems. On buses, when he singles out a stranger he wants to engage with, or if he becomes sexually aroused by the motion of the bus, or the noise of school children, then there are clear strategies in place to deal with these situations:

"There's certain guidelines we follow in certain situations. He's got to follow these guidelines or . . . we return home. Things like on the bus. He's got to sit on the inside so the staff's outside and if there's any sort of – if anybody spots that there's any kind of arousal, he's getting off the bus straight away."

Team Leaders in Melbourne are also involved in putting together strategies when they have no choice about bringing in support from health professionals. Until a place can be secured for Frank which offers 24/7 support – his parent's preferred solution to his obsession with cars – Grace has to find a way of supporting him. At time of interview Grace was contemplating making an appointment for him with a sex therapist. Meantime she is trying to find him an activity to take the place of his solo ventures into the town. A further possibility for Grace is to bring in a member of staff to accompany him when he goes out.

"What we have decided is that on a Monday – it mainly happens on a Monday from what we can gather – so what we are trying to do is get him into a programme [course] for a Monday, or have a staff member on."

Prior to getting to know a new service user staff have to have an initial strategy in place in order to provide the best support they can from the outset. Dale, although only in his early twenties, came into his present service with a history of sexual offences. The Team Leader Charles' first course of action was to call a team meeting to discuss how they were going to support him. He explained that they should take as their starting point a commitment to using a consistent approach to his

support, and to act as good role models. Later as they got to know Dale better, further strategies based on actually knowing the individual were developed and put in place alongside this basic approach. Charles explained:

“It’s like a game with him if we go somewhere and there’s lots of kids about we just say, ‘It’s a bit busy here’ – we don’t need to say it’s because of the kids – we just say ‘It’s busy here’ and he’ll go like that – ‘Nae bother’ and we go”. (Charles, Team Leader: Scotland).

Such an example demonstrates the mutual understanding that can build between worker and service user.

7.4.2.4 Protection

Team Leaders also spoke of their roles in protection. Although they may not always be directly involved in protecting the service user and any potential victim, they are aware that protection is an element of their job description, particularly where there is the possibility of serious consequences. In Melbourne, Fraser’s parents have given staff no choice over the involvement of health professionals so they have to deal with his attraction to children on their own. They are under strict instruction to accompany him, literally, where ever he goes. Dawn (Melbourne) sums up her team’s care of Fraser thus: “We support him and protect him – himself and other people.” Jacky (Scotland) has the same remit of protection which is essential to her duty of care for Luke. When asked if it was a matter of keeping him or members of the public safe Jacky replied:

“I would say him. I would say we’re keeping him safe. . . I’m trying to think, would he touch somebody? . . My main thing is to keep him safe because . . . as I say, he can’t really control when he’s getting excited. Anything can be exciting – loud noise and all that – bumpity bump – the movement and that. So I’m saying I would keep him safe.”

7.4.3 Key workers

7.4.3.1 Protection

Key Workers are also directly involved in the protection of key and other service users. One of John’s roles as key worker to Ray involved pre-empting scenarios in which he would be inclined to tell neighbours and anyone else he knew, about his use of binoculars:

“So we had to explain that people seeing you with binoculars and hearing that that’s the way you feel about children – people won’t like that.”

Dawn’s (Melbourne) remit with regard to Fraser, whose parents do not want health professionals involved in his treatment, amounts to keeping him under close surveillance when out into the community. This is in order to protect children who are his potential victims and he himself from ending up in trouble with the law.

“He’s not allowed to go out anywhere where the children are nearby – and we’re not allowed to leave him – let him go to the toilet by himself. And whenever he’s going out into the community, we have to be with him all the time.”

7.4.3.2 Strategies

Key Workers are also involved in devising long term strategies. Knowing that the tape provided by the CLDN had a long introduction which he knew the service user would not understand and get bored with, and that the relaxation music that followed was not to Tom’s taste, John, knowing Tom’s preferences, suggested that rather, he relaxes to his heavy metal CDs, which are his favourites. John reports that this has been more effective.

7.4.4 Other workers

7.4.4.1 Implement strategies

In the case of another service user who had paedophilic tendencies Gary’s (Melbourne) input was similarly to follow an on-going strategy directed by the service user’s family which involved accompanying him everywhere on every occasion. He was not the Key Worker of the service user. Similarly, Vera (Melbourne), a part-time worker also worked on an on-going strategy in which, like Gary she had to instruct a man to go to his room if he wanted to masturbate. Brenda (Melbourne) who is a part-time worker had the task of giving advice to Trev in terms of asking him to go to his room when he started touching himself. However, that was the full extent of her knowledge of the strategy in operation for this service user,

as she suggested, “I think he’s on tablets for that thing – I don’t know.”³² On the other hand Jean (Melbourne), although a probationer, was also a full-time worker whose tasks did include giving Trev his medication.

Of all my interviewees, Alice (Melbourne: Full time) was the worker who seemed to have least to do with supporting service users in her organisation whose sexual behaviour is inappropriate. When asked if she had the support of these individuals in any way she replied, “Yes, off hand. Management tell us that we should keep an extra eye on them.”

7.5 Limitations

Whilst SCWs have the responsibility for these service users which includes also that towards others that they will come to no harm, they nevertheless come up against factors which serve to limit their efforts, making a difficult job even more so.

7.5.1 Limits relating to service

Louise (Scotland) brought up the subject of a lack of training and how it limits the worker’s role:

“You know I can offer emotional support to somebody but I don’t have any formal training in supporting somebody in dealing with sexual abuse or being an abuser. So my role is quite limited”.

Effective training would also include keeping workers up to date with the law. In Melbourne, as mentioned above, sex work has recently been de-criminalised. As such, access to these services is open to all who live in Melbourne but not all support workers have been made aware of this. Where frustration seems to be at the heart of a service user’s unacceptable sexual behaviour, access to a sex worker could be at least considered as a possible solution. If staff in Melbourne were aware that this was another resource they might consider.

³² This service user is given medication for his general anxiety. As explained elsewhere, he is not being treated specifically for the sexual element of his behaviour.

Beth (Melbourne) voiced uncertainties about the cause of, and solution to, Trev's behaviour:

"[He was} attempting to look up girls' skirts and that sort of thing. But I think he's just very sexually frustrated, and that's a very difficult situation."

Yet even once the cause of the behaviour has been established the next step is to decide what to do to support the service user. As Beth remarked:

"Yes [Trev's] been discussed at a team meeting – with his anxieties – yes we've discussed whether there's a sexual element to it, but where do you go from there? It's difficult".

Jean (Melbourne) additionally remarked:

"Well I think no-one's really sure what to do."

The law can make attempts at effective support difficult. For example, those that are applicable in some circumstances may not be enforceable in others. Where a consistent approach is essential to achieving aims, such laws can work against this. Speaking in general Maggie (Melbourne) referred to the use of restrictive practices as set out for Day Centres by Victoria's Office of the Senior Practitioner (OSP).

Thus:

"I guess the OSP has no jurisdiction in the family home, so if mum and dad . . . use a restrictive intervention then obviously the OSP can't do anything about it".

Where the care of an individual is shared between the support service and the service user's parents then inconsistency in a modifying strategy will work against the efficacy of the approach as well as its assessment.

Problems can also arise around use of different policies applying to the same service user group. Both of the situations referred to in interviews concerned schisms between support organisations policies and those of their funding bodies. In both cases the latter were local authorities in Scotland. Laura gave one example:

“We also work with the funding authority’s policy as well so there are times when they’re in conflict. There’s major conflict just now but there are differences around our role to support people to explore their sexuality, but obviously within the law. There’s conflict between what we consider what’s person- centred and what the law is and what we’re allowed to do.”

Where Clive was concerned Laura hinted at a possible solution to his sexual frustration through access to a sex worker. She said:

“With him having an erection maybe fulfil that sexual desire that we thought he was seeking, but unfortunately for him we weren’t allowed to.”

Charles (Scotland) summed up his estimation of his funding body’s policy with regard to the law when he remarked: “It’s pretty draconian. They make it up as they go along.”

Staff, realising that service users are having a sexual relationship may be uncertain whether it is consensual or not. In Grace’s case this was even though the service users had maintained their relationship after one of the pair moved on to a different service provider. Although on this evidence she believes it to be consensual, uncertainty centres around the nature of their sexual activities. She commented:

“We need to start doing something, and that’s sitting both of these people down and saying ‘OK’ [what’s going on?]. Because our guy will come home with bite marks on his shoulder. . . Look, I think it is consensual on both sides. They both like each other”.

Like their counterparts in the health service, SCWs can also find themselves unable to give best service because of their workload. Some workers made comments that indicated that their work load prevented them giving the service user the level of support they required in order to deal with some behaviours:

“I really enjoyed supporting these individuals but I think I would have preferred to support them individually as opposed to in one house. Two in the house were assessed as needing 2:1 [staff/service user ration] at all times, and the other person had quite a severe physical disability, and he quite often got left ‘in the corner’ and the behaviours he had from the institution was to hide under the duvet. . . . It was quite a difficult service to work in.” (Laura: Scotland).

Jacky (Scotland) spoke of the effects of inadequate staffing levels on Luke. “He shared with other people who had quite high needs, complex needs as well, and if he didn’t get attention he would walk out of the building.” Brenda (Melbourne) also commented on the detrimental effect of having to work to a rigid time table:

“We just had to talk with him softly and all that. It calmed him down. I think we needed time with that – it took time and in the morning we have to rush and get them ready to go to work. Some go to [a day centre] and it’s a bit rushed. We can’t spend any more time with the client you know.”

7.5.2 Limits relating to the service user

Where the legality of a solution is not an issue, a service user’s past experience of reaction to his sexual behaviour can have a great impact on limiting the efficacy of an in-house solution. In Luke’s example staff considered masturbation as a possible answer to ending his need to do the chicken dance. This was prior to health professionals suggesting the same thing. Jacky (Scotland) explained his behaviour in the bath and the way he wears his pyjamas back to front – a legacy of his years in an institution, but further that:

“The friction [of doing the dance] must give him a feeling of pain but I think there’s a confusion between pleasure and pain. And this guy now is nearly 40.”

It may be the case that with some service users the ways people have reacted to their sexual behaviour in the past – unacceptable or otherwise – has made it difficult for them to be open and honest about the subject today. Grace (Melbourne) voiced uncertainty on how to proceed with Frank since they need him to confirm or deny certain behaviours they think he may be involved in but his answers keep changing:

“We’re unsure, but we’ve asked questions but we’re not getting any answers with regard to ‘How do you know that man? Do you give him money?’ – ‘No’ [he replies], and then the answers will change.”

A similar case of service user denial affected Luke forming sexual relationships which Jacky (Scotland) believed might have helped him give up his more unusual expressions of sexuality:

“The problem is . . . he’s got a type he goes for . . . and as I say . . . anybody he has a like for was definitely not interested in him. I’ve seen him. There’s two girls at his sports club that are very similar, and one’s quite eager to talk to him and yet that’s not the person he’s interested in. It’s the one that’s not interested in him. He can get quite annoyed if people aren’t interested in him.”

The service user’s condition or level of understanding may also serve to limit how effective any treatment, including those that are in-house, might be. Jean (Melbourne) said that Trev’s condition, autism, meant that, “they like to be by themselves a lot – don’t like mixing with other people.” However he was showing that he was sexually attracted to members of staff which indicated that he could also be attracted to females with whom he could have a legal relationship. Beth (Melbourne) also indicated how poor or non-existent communication skills, such as is the case with Trev, prevent service users from getting suitable solutions put in place. She asked “How do you differentiate where when he’s non-verbal how to get to the bottom of where his anxiety comes from?” Luke’s condition also prevented more satisfactory outcomes from his consultations with health professionals so that eventually they felt that calming medication was the only solution they could offer.

Having decided how to proceed in addressing service user’s unacceptable sexual behaviour, workers can then be left wondering if they’ve done the right thing. It may be the case that, as referred to above, that the workers are actually feeding in to a situation when their intention is to change it. When asked if it was just a matter of giving a service user space to talk about his issues Louise (Scotland) replied:

“ I don’t know because the particular chap I’m talking about – although we wanted to speak to a counsellor [no-one suitably trained was available] he wasn’t willing to give it up.”

Beth (Melbourne) had a similar doubt about Trev:

“Yea I think there’s times he needs to be ‘yes we can talk about it’ and go through the processes but not make too big a drama out of it. . . . Maybe that’s just my opinion . . . But, yes, there’s times when – he’s quite manipulative – he can drag people into it.”

7.6 Sum up

Health professionals cannot be held responsible for all these situations but nevertheless they are left to SCWs to cope with. As McKenzie *et al* (2011) have acknowledged, support staff are having to work with service user behaviours such as sexual assault and rape which are otherwise assigned to health staff in secure units. Given that they are based in the community the ensuing responsibility these workers shoulder is enormous in terms of the safety of the service user, and potentially other service users, and the public at large.

Again, the worker's 'proximity' to the service user informs the nature and extent of their involvement in his support. Knowing the individual means being able to pre-empt the service user's reactions and behaviours in certain situations, even when they may involve assault. Thus Team Leaders and Key Workers devise strategies which they share with other workers in order to keep the service user and others, safe. Although this may at times amount to ensuring the service user does not offend through simply being co-present at all times, workers still have to prevent unacceptable sexual behaviour whilst adhering to strict rules around the use of restrictive practices and whilst simultaneously conforming to the ethos of maintaining the service user's 'community presence'. At other times workers are required to invent strategies which they base on knowledge of the service user in order to distract him from his unacceptable sexual behaviour or to protect him from negative reaction from others. The embodied practices required amount to more than the 'residue' of work that those acknowledged as professionals leave behind to which Hugman refers. Rather, these are situations that professionals *cannot* address. No other type of worker inhabits this 'field'. Nor have the skills this requires been generally acknowledged.

Once more there are limits to SCWs working with the service user to modify his unacceptable sexual behaviour, those that relate to the service user himself, which would prove difficult to overcome. Nevertheless, the worker's 'proximity', it may still be argued, means that they have the best chance of overcoming these obstacles. For example, these workers will be aware of situations in which the service user's

level of verbal communication belies a deeper level of learning disability. When this is the case, the worker can modify her style of communication to allow for this, so has a better chance of helping the individual to understand any advice or information. Workers also indicated that they needed training, specifically in counselling, but also around aspects of the law that does and may apply to the sexual behaviour of this service user group. Further, management need to acknowledge the nature of the support that some service users require and ensure that the staff have the time to carry it out effectively.

In this and previous chapters I have referred to the ‘proximity’ or nature of the relationship between SCWs and their service users. Whether choosing or not to address the behaviour in-house or have input from a Health Professionals, the nature of the behaviour, especially when sexual, gives rise to a wide range of emotions in the worker. How these inform their attitudes and motivations will be addressed in the following chapter.

Chapter 8

Feelings

8.1 Introduction

In the last chapter I suggested that the number of situations in which health professionals' input is sought but not possible constitutes an emerging 'field' and one that is of necessity the jurisdiction of the SCW. In this 'field' staff roles have been shown to relate to the SCW/service user 'proximity'. Utilisation of this relationship, I have further suggested, improves the chances of successful interventions into unacceptable sexual and other challenging behaviours. As with any close relationship, working or otherwise, emotions come into play, particularly in difficult circumstances.

Working relationships involve coming into contact with colleagues as well as service users, their parents and health professionals. A wide gamut of emotions can surface as we attempt to do our job. This can be particularly true when supporting individuals who have a learning disability and whose behaviour is problematic, such as when their sexual behaviour is unacceptable. Positive feelings such as affection for the service user can accompany negative feelings such as shock or disgust at the nature of their unacceptable sexual behaviour. The purpose of social care work for people who have learning disabilities has changed dramatically over the last twenty years. Not only does this involve consideration of service users as individuals who are to be supported in a person-centred way to be integrated into their local and greater community, but also that when their behaviours challenge, the blanket response of reaching into the medicine cabinet is considered to be unnecessary, unethical and unlikely to be effective. Rather than suppressing individuals' behaviours with drugs, it is now the case that people are supported to try to work through the causes of their behaviour in a way which is aimed to be effective to them in their particular condition and context. This is not such an easy path to take since each case has to be considered and strategies devised without the certainty that it will

make a difference, but also without the effect of making the service user too passive to continue the problematic behaviour. It is also to take a long-term approach rather than the quick fix administration of medication which is now usually only used as a last resort. As a result SCWs to one extent or another are much more involved with individuals in their attempts to modify their challenging behaviour. When this is sexual in nature it places an extra element of concern for those involved given the cultural rules on what is and what is not sexually acceptable, especially where people who have learning disabilities are concerned. Sadly attitudes from the past in which any sexual activity on their part is viewed with disapproval and disgust still exist to some extent. Support staff like any other individual will have a range of values and attitudes they bring to their job. In this study these attitudes were probably reflected in a biased way by the nature of those who volunteered to be interviewed for this research and who take on service users' issues around unacceptable sexual behaviour; a task which can evoke a variety of emotional responses as well as roles.

Experiences represented here include many aspects of unacceptable sexual behaviour - service users trying to look up women's skirts, women prostituting themselves for money or goods, men who are sexually attracted to children and those who may or may not be raping other service users. Workers have also spoken about unusual sexual behaviours for which they have no strategy apart from containment in one form or another³³. Roles they have been involved in as part of their duty of care for service users have included a wide spectrum of tasks. They have been detectives in pursuit of establishing the cause of the behaviour. They have been teachers of sex education and relationships. They have been protectors of the public but mostly also the offending individual himself. These and many other roles they have accepted and taken on which others may have ignored and avoided. Research undertaken by Dagnan (in Mee, 2010) into healthcare workers' willingness to help their charges was found to correlate with their understanding of these individual's circumstances. When workers involved in this research gave accounts of their feelings about the work they do, they too demonstrated a high level of understanding of their service

³³ The nature of acceptable restrictive practices that support organisations can use in both Scotland and Melbourne, are very precisely set down.

user's circumstances, as well as other related emotions. However, negative feelings relating to other aspects of their job were also expressed.

8.2 Positive feelings

8.2.1 Understanding

Support workers felt that they understood the causes and consequences of service users' unacceptable sexual behaviour. Arguably such understanding underpins their willingness to take on the task of its modification. Given the circumstances of some service user's upbringing in which, for instance, they were given no sex education or had their natural sexual behaviours suppressed by anxious parents, there is a plethora of reasons that could explain why their sexual behaviour is now unacceptable.

Respondents identified a lack of sex education as a factor in displays of unacceptable sexual behaviour in this service user group. This may not only be because past carers have judged their level of disability to be too profound to understand that they also have sexual needs. As Maggie (Melbourne) sums up:

“The people that I work with are quite extreme on the scale I guess compared to somebody without disabilities and really don't have these skills at all. Yet they have these desires that they don't necessarily understand”.

Other workers made similar assessments of their service users at the moderate and mild level of learning disability. Workers offered explanations for this thus for instance comments were made regarding the failure of institutions to provide such education. Jacky's (Scotland) remarks on Luke indicate the attitude towards sexual behaviour that service users could experience whilst in an institution:

“He still wears his pyjamas round the wrong way. He's got that definitely you can't touch. But we say that that's alright you can do that in your room, but he'll not touch it. Even when he's in the bath he's got it shoved underneath him. He won't touch it, so he's definitely got the idea that it's bad”.

Arguably past attitudes to Luke's sexual behaviour may explain the way it is currently manifest.

Previous support organisations may have denied service users their sexuality.

Opportunities to form sexual relationships were also denied. Referring to a previous

support service Laura (Scotland) explains of Clive that they “never gave him the opportunity that he missed before because he’s always been in an institution”.

Similarly Grace (Melbourne) explained that in Frank’s case:

“Where he used to live – it used to house I think 22 residents in one house – from what I can gather he used to come out of his room at night and go to another person’s room. . . . Management got wind of this and they put an alarm on his door”.

Interestingly, the two men involved have maintained their relationship even though they are now in different services and are no longer denied it.

Respondents also understood the influence of parents’ over-protective approach to their children’s subsequent sexual behaviour:

“I could understand the situation. He had these thoughts and because he’s got his disability as well, obviously he would be finding it harder to understand why he’s thinking like that. And just because of his religious background – his family. As I say, his religious background. He’d been taught from an early age that to have these feelings is wrong – taboo.” (John: Scotland)

Workers also understood that parent’s fears for their children’s vulnerability informed the way they brought them up ignorant of sexual matters. Laura’s (Scotland) account is typical of this:

“I remember her [service user] telling me a story. Quite sad actually. She was sitting in front of the fire with her mother. She really liked this boy and her mother told her, ‘don’t ever talk about going out with people. It’s not part of your life. It’s not for you, just for your sisters’”.

Worker’s also understood the effects of abuse on the abuser’s own sexual behaviour.

Referring to Dale, Charles (Scotland) commented that:

“Some of the places he went to school there’d be kids who had been through similar [sexual abuse] and were themselves abusers. So he was living in an abuse culture at that time and it’s no wonder that he grew up with the sort of behaviours he had”.

Whether the service user’s behaviour is more or less serious, workers were aware of their motivation. Referring to a woman who prostitutes herself Louise (Scotland) noted that:

“We have a service user here at the moment. We were talking about using sex as currency, and she does use it for what she wants from various people. And this has

been her background for many years. We've only supported her for the last year or so."

Also referring to a female service user but one who is promiscuous, Wendy (Melbourne) explained her motivation, "She likes to have somebody and whether she felt 100% comfortable with it or not, she wasn't going to say 'no', I don't think".

Not all behaviours are consciously driven however. As Maggie (Victoria) pointed out:

"These people I work with are quite extreme on the scale I guess. . . . [and] really don't have these skills at all yet they have these desires that they don't necessarily understand."

Whatever the motivation it is nevertheless important to understand the service user's needs:

"We've got a couple of clients here that are partners. They're having oral sex and this and that. . . We encourage them that when they want to do that they do it in private." (Dawn (Victoria)).

Similarly Maggie (Victoria) spoke of:

"a couple who go down to the bottom room down there and take themselves away for however long they need then come back up."

It is not only a matter of understanding that service users need space and time in order to fulfil their sexual needs appropriately. Rose (Scotland), referring to Ray when he was between health professional services, brought up the subject of sex education, "I think as far as sex education's concerned we really need to do a lot more work." Understanding can also include knowing when to disengage from the service user, as when Beth (Melbourne) spoke of Trev's propensity to talk frequently about his sexual behaviour and also Louise (Scotland) when she had similar misgivings about her service user and she observed that he was often "dwelling on it".

How the health professional understands the service user's condition also has impact on their treatment of the behaviour. Laura (Scotland) noted that in Clive's case health professionals assumed that his behaviour could never improve:

“The gentleman in question came to us with a reputation of being very aggressive and very abusive and that he should always be supported by 2 members of staff, and these 2 people should always be male. I think there was an unsaid, unwritten rule . . . The CPN had known him from way back and could kind of control him so I always thought they were going by his reputation and were trying to suppress him. They never gave him the opportunities that he missed before because he's always been in an institution.”

Here it would seem, the health professionals involved were looking to his past to explain his present excessive sexual behaviour, even though as Laura further pointed out it was causing him pain and distress.

Yet health professionals' understanding of the service user and his circumstances makes for more successful outcomes, as in Dale's case whose previous encounters with health services had been negative and unproductive. Charles (Scotland) noted:

“He's [now] got a really nice psychologist who really was the first one who was really quite nice to him – was pleasant and seemed caring and giving him some respect and didn't see him as a perpetrator and maybe saw him as a victim.”

As Jean (Melbourne) suggests above, Trev, “doesn't have an outlet”. This statement is as true for service users whose sexual behaviour is not problematic. Jacky (Scotland) also commented on this matter with regard to Luke: “A lot of people say he wants a girlfriend but as I say, it's very difficult because I don't see a way to facilitate that”. Charles (Scotland) had more to say on this theme when he observed:

“Yes, a huge amount of people with learning difficulties end up with someone with learning disabilities but if there's a label as an abuser you're denied that – you're limited. If somebody's got a learning disability their chances of getting a partner are severely limited, if not nil, because if he strikes up a relationship with anybody else that's seen as vulnerable, that's going to be curtailed”.

This in spite of Luke's progress made through his support team and the positive relationship he has with his current psychologist, for as Charles went on to say, “What options does that leave him? It doesn't really leave him any options”.

Where consent or privacy is not an issue, SCWs understanding and subsequent support of the behaviour can have results that have positive effects on the service user. In the case of Bill, Rose (Scotland) noted that:

“It’s unfortunate he used a key to let us know but he was telling us ‘I like this but I want a bigger one (sex toy)’. It was great he was able to do that. And everything’s been great for him for a long time now and he’s happy with it”.

Where challenging behaviour may be linked to sexual frustration then acknowledgement and accommodation is better for all concerned. As Maggie (Maggie) asserts:

“I think if people need five or ten minutes of private time – if that means that no-one’s going to get assaulted or they’re going to have a bad day because of it – go for it!”

Because sex has been a subject off limits to many service users in the past, workers understood their responses when the subject of sex was broached and allowed for this. Aware of their need for knowledge, at appropriate junctures Grace (Melbourne) asks service users if they want to talk about sex but will get the following response. “They might go, ‘Oh no! I don’t want to talk about that’. But I say well when you’re ready, ask me a question”. Similarly, she said that in Frank’s case when she tries to talk to him about sex, “He just flutters me away and doesn’t want to talk about it.” John (Scotland) also remarked on the need to give service users time to get over their reticence to talk about sexual matters. Referring to Ray, he said:

“We sat him down and explained to him that everybody has those sorts of feelings, it’s not that they’re bad but how appropriate it is in where you’re doing it. So we kind of got that fear away from him that it’s OK to speak about it.”

8.2.2 Compassion

Social Care Workers can feel compassion for service users in many circumstances including where unacceptable sexual behaviour is concerned. When Rose (Scotland) had to respond to Tom’s situation she did so with his feelings in mind:

“At that point I took over as Team Leader and thought ‘Ok, we need to do something about this immediately. I can’t take the lady right out of his service because it would be too harmful to him.’”

Similarly Jacky (Scotland) commented on teaching methods that have recently been developed for children who are diagnosed with Fragile X which were not available to Luke who is now in his 40s:

“They teach them in certain ways where it seems to be through experience. And that can be difficult because how do you let somebody be arrested?”

Wendy (Melbourne) also spoke with compassion for Chloe:

“Well I think she would like a relationship and as far as Chloe’s concerned she likes the sexual side of the relationship as well. And that’s fine . . . but I think the casual sex . . . it’s not really what she wants. It’s just she doesn’t know how to control that side of it, but she would like a full relationship with somebody of her own. We would all like to have somebody of our own.”

8.2.3 Affection

Working with a service user every working day or at least on a regular basis, leads to a relationship building up between those concerned. This relationship may come with feelings of worry and occasional exasperation when workers feel that they are getting nowhere with a problem, but it can also come with feelings of affection for the service user. Although the sexual behaviour may be the most challenging aspect of the service user that members of staff encounter it is through their understanding that workers maintained very positive attitudes and relationships with service users whose sexual behaviour is unacceptable. Referring to Ray Rose (Scotland) said:

“He really is a great guy- a nice guy, and like I say, he doesn’t like this about himself – doesn’t want to be like this. . . . He’s a person and this is only part of him”.

Similarly, John (Scotland) described Tom thus: “The person is a big happy-go-lucky person. You have to see the whole person.” Yet as John explained to Tom the possible outcome of him continuing his unacceptable behaviour:

“You could be kept in hospital and you wouldn’t like it because the people [support staff] know you and like you. I could tell them [hospital staff] how much fun you are but these people are strangers and wouldn’t know the good side of you. You’d just be someone who attacked somebody and could do it again.”

8.2.4 Confidence

Maggie (Melbourne) commented on the way her confidence has grown with experience to the point that she is confident enough to use her initiative when problems arise:

“I’m very lucky to have worked in the field for quite a long time and I think it’s also my personality. I’m a bit pushy like that so if I think there’s something wrong I will support the family or support the [service user’s] house to find a resource and I suppose I go on getting better at having resources in my head as well.”

John (Scotland) remarked on the confidence he got from having a good working relationship with Ray made it easier to talk to him about sexuality and relationships. He added that Ray was also at ease because of this: “And the bonding we had together – he was quite comfortable.” Charles (Scotland) described what gave him confidence to address Dale’s issues:

“We had very little turn over and we’ve got a really strong team that feels comfortable with making decisions. We’ve got parameters and we work within that but they [staff] basically know where we’re going and how we’re going to get there, you know.”

Louise (Scotland) also drew confidence from her organisation’s well drawn-up policy on Sexuality and Relationships and from her management:

“If I ever found myself in an unfamiliar situation I would refer to the policy and procedures manual, otherwise I would seek help. . . . The organisations I’ve worked for, if they haven’t been prepared [for a situation] then they’ve put things in place so it is.”

Confidence was also expressed through workers’ acceptance of the work they do. In supporting a man whose challenging behaviour was kept to a minimum through allowing him time each day to masturbate, Dawn (Melbourne) remarked: “I didn’t feel there was any problem because I feel it was part of my job.” John (Scotland) expressed a similar sentiment when he explained:

“You’re working with people with disabilities, and they might not all be physical disabilities you can see. So it’s just part and parcel of the job. You just get on with it.”

8.2.5 Service user's respect

Workers also felt they had the respect of those they support. Status as well as familiarity was given as the reason for this:

“I’ve worked in the field for quite a long time and people [service users] I work with – they trust me. Sometimes they seek me out [because] something’s wrong. So it’s probably like they respect me as well.” (Maggie, Melbourne: Day Centre Manager).

“Yes, sometimes I think having this title [Team Leader] and it’s the same when staff report back to me – ‘Oh, I’ve been trying to get someone to do this for ages’ [Team Leader succeeds where SCW does not] . . . and I think it’s down to the designation that some of the people we support relate to.” (Laura (Scotland) Team Leader).

“I think in my own experience . . . I’ve always been treated a bit differently by service users because I was viewed as management,” (Louise (Scotland) Team Leader).

Key Workers and other front-line staff also felt that they had the trust and respect of service users.

8.2.6 Feeling supported

Feeling they had support from colleagues also made for a more positive experience of their work with these service user under these difficult circumstances. John (Scotland) commented that in the case of Ray:

“We’ve got good strategies in place and a good team. We just try to keep his mind active so he doesn’t have these thoughts.”

Rose echoes John’s sentiments when she said, “They’re such a good team.” Support from management at any level is also appreciated and makes for workers feeling more positive about their role in supporting service users:

“I think [management] have been very supportive of me . . . We have a range of issues here both good and bad and when it’s bad [management] are pretty supportive of ideas I come up with and how I use my time.” (Maggie (Melbourne) Day Centre Manager).

In Appendix i I refer to past situations in which front-line staff acted in defiance of their management to support service users with their issues around sexuality. Fortunately for all concerned management’s selective definition of ‘duty of care’ is less common now and workers and service users both benefit from management’s understanding of and commitment to the latter’s human rights. In one organisation

represented here, a large national agency of many years standing, they have their own trainers in sexuality. In light of the very individual nature of service user's level and means of understanding sex education can be tailored for staff around the service user's particular issue and level of understanding. Not many organisations have this resource and Tom's support staff appreciated its input and support:

“I spoke to the trainers and asked them if they could design the course specifically around this chap for his whole team – if they could modify it, because there was such a need” (Rose: Scotland).

A further element of management support was dealing with unspoken misgivings about working with a service user. Rose, with reference to Tom, who, had punched a worker and broken his ribs, recalled:

“You've got a bunch of guys [staff] who are all trying to be dead macho and act as if they're not a wee bit fearful. But [training] worked out really well I think because it instilled a bit of confidence in the guys”.

Management also showed understanding of staff by taking their feelings into account when allocating staff to certain service users. Again, Rose (Scotland) talking of Ray explained:

“There are people [staff] who felt ‘I've got children that age – a child or partner's child played in that playground’. So there was a lot of issues surrounding that so we had to work through a lot of things”.

Those further up in the organisation's hierarchy also rely on the support of their line managers. Maggie (Melbourne) who reports having had to deal with some extreme situations over the years has full confidence in having management's backing:

“As long as I keep them in the loop, and make sure that when the shit hits the fan, so to speak, they're prepared for it as well. And they've been very good”.

Openly facilitating communication channels also provides support for workers allowing them to voice concerns and exchange and share ideas around a service user's support. In the case of Tom, Rose:

“made sure that there was adequate time for supervision; that there were team meetings. We had really good discussions about it. ‘How are you feeling about this? How are you coping?’”

8.3 Characteristics of professionalism

At this juncture it is important to comment on the nature of those workers who made these positive comments in which they express their understanding, compassion and affection for the service users concerned. McVilly (2010) points out that: “The support needs of people with disability can be very complex” and insists that: “it is rocket science”, and that it is thus “a *professional* undertaking.”

(McVilly accessed 14/06/11). McVilly then defines what he describes as professionalism in front-line support staff as having:

“Meticulous adherence to undeviating courtesy, honesty, and responsibility in one’s dealing with customers [sic] and associates plus a level of excellence that goes over and above the commercial considerations and legal requirements”.

Davies (1998) also identifies professionalism in care work as going beyond the text book towards the added quality of a close and sustained relationship with the individual who is cared for. The positive comments expressed by workers above confirm that they do rather more than tick the boxes that constitute merely doing one’s job. Rather, they display behaviours and attitudes that have been associated with high levels of commitment to supporting service users in the most difficult circumstances (see Willner & Smith, 2008), Lambrechts *et al*, 2008). These genuine feelings which spring naturally from affection also relate more closely to those of the migrant nannies who look after other people’s children to whom Hochschild refers in *Global Women*, than to those managed emotions she writes of in *The Managed Heart*. As Grandey (2000) comments, these require effort.

Unfortunately no workers came forward for interview who owned to being unwilling to be involved in interventions into service users’ unacceptable sexual behaviour although those who were willing made reference to having such colleagues. Reference was made to their lack of confidence because of a lack of training and some wished not to be involved in particular cases for personal reasons, which in both cases implies that these staff members would not discount the possibility of ever being involved in interventions into unacceptable sexual behaviour. Reference was also made to members of staff who were in effect in denial about service user’s sexuality. Thompson (2000) offers an explanation of this including the worker’s

embarrassment or disgust at the service user's behaviour. Where the latter is the case, it may be as Grieve *et al* (2006) have found that these workers' negative attitudes can have a negative impact in any therapeutic programme that has been put in place. They may also try to impose their views on the service user.

There can be no doubt that some service users display extreme and distressing behaviours, in some cases the nature of which has compelled loving parents to seek alternative support to their own. They may have been looking for ways in which their relative's behaviour could be contained, or they may have been hoping for positive input from a professional service that would provide support for the individual to abandon his unacceptable sexual behaviour. Whatever the parent's motive, it remains the remit of support organisations to assist service users to live an integrated life in the community. Support workers with a more positive helping attitude towards his sexual behaviour have best chance of achieving this. However, this is not to imply that they too do not also experience negative feelings about their part in this process.

8.4 Negative feelings

8.4.1 Surprise/shock

Given the situation they face it may not be surprising that workers also have negative feelings with regard to the roles they play. Where these workers are concerned this negativity is a reflection of the situation rather than of the individual service users concerned.

Workers may be surprised or shocked into immediate action when they realise a service user's behaviour threatens the safety of themselves or others. They may feel that they need support and information from others when first encountering a situation such as was Edward's experience when he was galvanised into action when he heard reports of Ray's behaviour. In this instance the organisation had set the procedure out clearly for him to refer upwards to his line manager, Ray's Care Manager and also bring in the services of the Community Learning Disability team.

He was also in the fortunate position of having an in-house expert to call on; a very rare situation.

A sense of urgency also arises from situations involving actual physical violence that can be traumatising for those members of staff involved. Referring to Tom's attack on one of her team, Rose (Scotland) exclaimed, ". . . he came home from work on a Friday [and assaulted a worker] – which is etched in my brain forever." Similarly Brenda (Melbourne) was "shocked" when a service user tried to embrace her.

8.4.2 Fear

Workers were themselves the subject of the unacceptable sexual behaviour, some, like Louise, who knew the service user well, felt in control of the situation and so was not afraid. However, familiarity does not always result in a lack of fear when made the object of unwanted sexual attention:

"He's very nice – a very nice person. But sometimes he comes and holds you [demonstrates holding someone by the shoulders from behind] – and massages you, and it's scary."

When managers are involved it is sometimes the fear of others that they need to address. In Ray's case Edward (Scotland) said that:

"People at the time were very very good. Very understanding and very valuing. I think there was a couple of people that had a bit of concern and needed some support in having it explained to them but there was definitely a period of a couple of weeks where nobody knew how [the behaviour] would manifest itself."

8.4.3 Frustration

Frustration may be felt when workers are prevented from supporting their service users in ways they feel to be appropriate. This may be because they feel that they are not getting the support they themselves need. Laura felt that health professionals were not taking Clive's sexual issues seriously but moreover, that some of her then colleagues were also unhelpful. Talking of a general silence she has encountered at team meetings when referring to service users' sexual behaviour she commented:

"We should all be sitting there saying 'how can we help these people?'"

Although having only a mild learning disability Dale required 24/7 support to modify his unacceptable sexual behaviour. Yet Charles felt frustrated with the nature of training his organisation provided for him and his team to support Dale. He explained:

“The service that I work for has been running for nearly 7 years and we started training – if that’s what you call it. It was like being spoken to for . . . a couple of hours, listening to some very very basic information . . . stuff we’ve been doing right from the start.”

As Maggie (Melbourne) pointed out, it is also frustrating having to wait some time before getting an appointment with a health professional, but even more so when they lack knowledge and experience of working with the learning disability user group. Maggie in fact finds the whole experience of working with generically trained health professionals frustrating, not only because she has to tell them of the services they can refer her service users on to but also because of the fact that they do not know how to approach working with people who have a learning disability, for example by addressing her instead of the co-present service user.

Nevertheless, as stated, service users may accept advice or instruction from a health professional that they have ignored when it was given by a support worker. Although a service user may not have had contact with a particular individual from the health professions there may be an understanding or awareness of their role as figures of authority from their experiences in institutions, without necessarily having a grasp of the concept of ‘professional’. Louise (Scotland) offered the following reason for this:

“Most of the people I’ve supported over the years have come from a hospital. You know, they’ve spent 20 – 30 years in hospital and there’s a recognition for nurses. Although the uniform’s gone they’ve still got that recognition”.

8.4.4 Intimidation

Fear of others may not always involve service users directly. With multi-agency work this fear may be unfounded; more a sense of one’s own lack of experience and/or comparative lack of status. Maggie (Melbourne) described a situation in which she, as a younger worker, had cause to attend a meeting about a service user:

“I remember going to a meeting with a Social Worker, Speech Therapist, Dietician, GP – there was like 15 people around this table and I remember thinking to myself, ‘Oh my God’.”

When asked if she felt intimidated, Maggie, now an extremely confident Day Centre Manager, replied, “Yes, very very intimidated.” However, one worker was left in no doubt about his standing in the eyes of the Care Manager and Health Professionals involved in Dale’s case:

“Basically the tone towards the team is shocking at times. I mean, the last time [the Care Manager] was saying, ‘I’m not going to blame the team but . . .’, and he said that 6 times during the meeting, and what does somebody say when they say [that]? . . . They then criticise the team.”

Charles also commented on his treatment at the hands of the CPN: “Och, she’s terrible and all. The amount of times she’s been rude to me”

Workers have also found that their organisations funding bodies - usually local authorities – have been particularly fearful when it comes to the balance between level of risk which is sometimes an element in the development of acceptable sexual behaviour, and the human right to be free to take risks. Charles’ support of Dale brings up all sorts of issues, not least of which involves risk as he and his team attempt to support Dale to live as normal a life as possible. Charles spoke of local authorities fear whilst also demonstrating an understanding of their predicament:

“Nobody wants to take risks. We live in a blame culture. And Social Work – I look at the baby P situation and how it’s going to reverberate. Another overhaul of Social Work. Another sort of blame culture being instigated . . . and it’s just trickling down to us.”

Rose (Scotland) was also in a situation in which a service user’s human rights were almost denied because of the funding body’s fear of public castigation. When he was insistent that his aged parents were not to be informed of his wish to buy a sex toy, which is not illegal behaviour, Rose said that they responded:

“No, we can’t take responsibility for that. We need to inform his parents because what if they find out? We’ll all end up on the front of The Sun!”

8.4.5 Worry

Related to fear is worry. Because workers have to take a long-term view of the service user's behaviour and the process of modification, and add to this the unknown prospect of its efficacy, they fear what might happen in the future. This may be the consequences the behaviour has had for the service user. Grace (Melbourne) has fears for Frank because of the nature of his behaviour and the fact that it takes place outside of his home. Thus he is exposed to public discovery and its consequences should he continue to take sexual gratification from cars. Jacky (Scotland) describes Luke as looking like "just an ordinary guy in the street" whose learning disability is not apparent until you get into conversation with him. Thus she also has worries about the consequences for Luke because of his behaviour:

"I've seen people threaten to kick his head in because he's gone to [a club] and clocked a female, or you're out in a café and he's clocked a female, and he'll stare at them and the boyfriend [will say] 'I'm having you!'"

For Grace (Melbourne) there is also the worry about what else Frank may be getting involved when he goes into town independently, "He's also been known to stand at the market and wave money around . . . and we're worried. Is he doing that to get sex?" Apart from the risk of contracting a sexually transmitted disease, Frank also faces the possibility of being physically assaulted. Thus Grace also worries about Frank's safety, "We're waiting for the day when he may come back with a black eye – a phone call from the hospital."

Since service users have the same human rights as anyone else, restrictive practices are not usually thought appropriate and need to be officially sanctioned. Therefore workers cannot solve worrying situations in this way. Luke whom Jacky supports gets sexually aroused by loud noises such as is made by children laughing and chattering but as she points out, "We discourage but we can't stop him from going on the bus. . . [at] times that the children are on the bus." Workers as well as health professionals are also unable to state that a behaviour has been modified by treatment or has simply been abandoned by the service user. Thus workers may worry about a behaviour recurring. Wendy (Melbourne) remarked of Chloe that, "At the moment as I say, she's been pretty good. I just hope it stays like that."

8.4.6 Uneasy

Workers can also feel that they are working against their nature; having to be cruel to be kind, if you will. Rose (Scotland) spoke of the female member of staff who was the object of Tom's attentions and who has to be very firm with him when she meets him³⁴ in case he gets the idea that she's encouraging the relationship he imagines they have:

“It's been quite a learning curve for her because it's the whole thing. You work with somebody with a learning disability and you want everything to be nice. You don't want to be direct with somebody. You don't want to hurt their feelings.”

8.4.7 Burn out

A further feeling described by workers was that of burn-out such as that experienced by Laura (Scotland) in a previous work place where she supported Clive. Lacking support from health professionals she said:

“We were all up for getting this man some help but we were up against a brick wall. I think that's why I left the service.”

Although there are a variety of negative emotions listed here, none of them are judgmental of the service user or his behaviour. Rather, they relate to ways that prevent these workers providing service users with more effective support, or matters which have to be taken into consideration in order to provide better support.

8.5 Sum up

These SCWs demonstrated that they understood the reasons for their service user's behaviour which included, ways that the latter's behaviour was rooted in their past experiences either as being themselves victims of abuse or of having been denied sex education. Workers understood that over-protective parenting was one reason for their lack of suitable education and over-protective care from either parents or support workers meant that they had never had the opportunity to develop and experience healthy sexual activity and relationships. Understanding was also demonstrated of the consequences for the service user should their behaviour go

³⁴ They live in a small Scottish town where the chances of meeting with someone you know are high.

unaddressed, as well as the negative impact on the service user's chances of forming healthy sexual relationships once his behaviour has been modified. In short, the latter situation equates with the dog that gets the bad name i.e. they will be stuck with this label – indefinitely.

Based on such understanding, workers also showed compassion for their service user's situation, which arguably, informs their willingness to become involved in supporting the individual to act appropriately and overcome the extra disadvantages they face should their sexual behaviour be inappropriate. These workers also showed real affection for these service users and realised that there was a need to acknowledge their good points which far outnumbered the 'bad', to truly, 'see the whole person'. SCWs also expressed their feelings of confidence which grew with experience but relied from the outset on support from their management team as well as colleagues who shared the support of their service user. Furthermore, in terms of McVilly's definition of what it is to be professional, a term he advocates should be applied to Social Care Work involving care of individuals with complex needs, these workers may be regarded as belonging to a profession.

However SCWs also expressed negative feelings about their work with service users whose sexual behaviour is unacceptable. Without the information they required to support the service user effectively they felt shocked when they then became the target of the behaviour. The fact that one worker can be startled by something that others in the organisation knew about seems incomprehensible, yet it is not uncommon in care work where staff are not treated as true professionals.

Comments were also made concerning the fear workers felt faced with potentially violent situations in the work place. However, the understanding and support of line managers, along with well considered management plans of which all were made aware, served to allay these fears. Yet the service user also has the potential to become the victim of violence from passers-by should their behaviour manifest in public. Thus SCWs also worry that sooner or later the individual will suffer for their behaviour whether or not the worker is co-present, such can be the public's animosity towards service users whose sexual behaviour is unacceptable.

SCWs also expressed their perceptions of being inferior to other workers – “I’m only a support worker” (Laura: Scotland), a sentiment also expressed by Maggie, now an experienced and extremely confident Day Centre Manager, when she was starting out in care work and found herself a lone voice in a meeting with a selection of health professionals. When dealing with particularly difficult situations, the extent to which SCWs depend on support from both their management and the health professionals they choose to consult, is demonstrated in the level of frustration and even burn-out that was expressed when none is forthcoming.

Taken together their expressions of both positive and negative emotions indicate these workers’ will to support their service users to modify their unacceptable behaviours and a wish for an appropriate level of support in order to do this more effectively. Such commitment in these circumstances - circumstances that some other workers refuse to engage with – amounts, I would suggest, to what McVilly defines above as ‘professional’ in what is acknowledge as a profession in countries such as Denmark, a country which has different social and political values (Boddy *et al*, 2006). Here, they write, these workers are well qualified and paid, and by implication enjoy greater status than their counterparts in Scotland and Melbourne.

Chapter 9

Discussion

9.1 Social care work as a profession

It is hard to equate the high quality of care with which SCWs such as John in Scotland and Wendy in Melbourne provide their service users with that seen recently on BBC's programme, *Panorama*. This concerned the care home Winterbourne View in Bristol where residents were systematically physically abused and humiliated. Within the context of learning disability services McVilly (2010) asks two questions:

“What are we going to do to safeguard the interests of people with disability in receipt of . . . support services?”

And:

“What are we going to do to safeguard the reputation of practitioners and to position the support of people with disability among the occupations that are respected and aspired to in our community . . . ?”

One answer McVilly suggests is the professionalisation of Social Care Work.

Schinkel and Noordegraaf (2010) describe the traditional notion of professionalism as involving “a service ethic, some form of association and a secure technical knowledge base” (p85). Noordegraaf and Schinkel (2011) refer to emerging or new professions, e.g. journalism, social work, teaching etc. and note that these cannot really be compared to ‘classic’ professions such as that of the GP or lawyer. Nevertheless, they add, these new professions may try to establish a technical base, service ethics and jurisdictions in order to appear and act as professionals in the classic sense. These authors argue against the functionalist perspective of ‘professional’ under which these aspiring groups cannot be considered in any ‘pure’ sense. Rather, they state that professionalism is socially constructed, underpinned by a value system which determines what is deemed a ‘profession’ and what is not. This essentially Bourdieusian stance further infers that the value system at play acts

in the interests of those most powerful in society. Such classification, Bourdieu argues, is actually culturally arbitrary and historical (Schubert, 2012). As Schinkel and Noordegraaf explain:

“What is at stake is the ability to give symbolic weight to certain educational resources, codes of conduct and to institutional guarantees of occupational exclusivity, that is, the ability to make a difference” (2011: p88).

Within a patriarchal society women and the forms of labour and ‘soft’ skills with they are associated thus find themselves on the negative arm of the Grand Dichotomy, and their ‘inherent’ skills represented in vocational rather than academic education where both these terms are ascribed lower and higher values respectively.³⁵ However, to reiterate the work of McVilly (2010) who is himself a health professional, in order to assure the reputation of SCWs and safeguard the interests of people who have a learning disability, Social Care Work must be professionalised. This would mean that the characteristics – occupational exclusivity, a service ethic, a form of association, and a secure technical knowledge base – as suggested by Schinkel & Noordegraaf - would apply. Having a secure ‘technical knowledge base’ is usually associated with traditional male occupations such as engineering and other forms of work that require knowledge of equipment or systems. However, if the nature of the SCW/service user relationship is central to the possibility of successfully addressing unacceptable sexual and other challenging behaviours, as has been suggested above, then the personal attributes of the support worker expressed through having a good working relationship, it may be argued, is their ‘secure technical knowledge’.

9.2 Exclusivity: professionalism and the ‘field’

If we accept Noordegraaf and Shinkel’s characteristics of ‘professional’ then Social Care Work has to meet these, the first of which is ‘exclusivity’ which refers to workers having a unique ‘field’. As data shows, in both Scotland and Melbourne, working without the in-put of a health professional is not always a matter of choice

³⁵ The vocational/academic educational split ensures the regulation of scarcity of the latter which also accommodates professional autonomy (Schinkel and Noordegraaf, 2011).

for support staff even when these workers regard the service user's behaviour as 'serious'. Much as they might require and value the services of health professionals in these circumstances, a number of reasons why this is not always possible became apparent. The health professional's workload was mentioned as was the scarcity of those specially trained to work with people who have a learning disability. What this reflects, it may be argued, is the under-funding of health services and perhaps also the fact that specialising in this field is not an attractive proposition for many who are, or wish to be, medically trained (Owen & Standen, 2007)³⁶. As these writers assert this is because Learning Disability nursing has been looked on within the medical profession as lower status compared to other specialised nursing areas.

Additionally in some cases, health professionals who were consulted by staff could not offer effective treatment. This too has been the subject of research in which miss-diagnosis involves the attribution of behaviours to the individual's learning disability rather than some other cause. When this happens no treatment is offered and because of the faith people put in health professionals, this is not usually questioned and further pursued. Nor can health professionals be present when the behaviour occurs and requires instant response.

Cases were also cited in which parents refused to have health professionals involved in their son's care. Staff in support organisations did not feel that they could insist on consulting health professionals if the service user's parents did not want them to be involved. Although they are their son's guardian and have certain powers where their dependent relative is concerned, these parents could be challenged in court as being criminally liable and further, being in breach of the service user's human rights³⁷. Yet clearly, support organisations were reluctant to do this. This may be due

³⁶ This raises questions about how valued people with learning disabilities actually are, even when there are laws about 'equality'.

³⁷ "British jurisprudence regarding parental treatment refusal on religious grounds remains unchallenged: parents who fail to obtain medical treatment for their children, are subject to criminal liability even if their refusal is religiously based. . . . Australian courts adopt a similar view: the child's welfare is paramount. Every Australian jurisdiction has legislation permitting certain medical treatments, including blood transfusions, without parental consent." (S Woolley, (2005) accessed

to their lack of legal knowledge, a reluctance to upset parents who they feel have already suffered through having a child with a disability, or because they do not have the confidence or finances to take the matter to court. They might also fear public derision should they decide to challenge parents on the subject of their child's rights to sexual activity. It is also the case that service users refused to, or cannot interact with the health professional as was the case with Dale. Whatever the reason, SCWs have to use their skills to deal with situations that would otherwise be the work of a health professional. This, I would argue, should be taken into account when considering SCWs and the professional status of the work they do.

Data also shows that in both Scotland and Melbourne, there are times when a decision is made to deal with unacceptable sexual behaviour in-house. These involve behaviours which could bring the service user into contact with the criminal justice system. To reiterate Mackenzie et al's (2011) findings, SCWs are working with the same behaviours as health workers in secure houses. If it is accepted that the word 'professional' applies to individuals who provide a unique service – occupational exclusivity or a specific 'field' - then those workers cited above can claim this status because although some aspects of the service may also be provided by health professionals in secure settings, their place of work is in the community where a greater level of risk applies. This calls for a different, more advanced level of risk management which it may be argued, further supports the argument for the professional status of SCWs.

9.3 Ethics and social care work

Characteristics of a 'profession' include that it has a code of ethics that informs its practice. National and state policies regarding the support of individuals who have a learning disability take the Declaration of Human Rights as their point of departure. Promoting and maintaining these individuals' community presence is also a central aim. Embracing these principals means that previous practice, which amounted to incarceration and isolation of people who have a learning disability, is rejected. For

16/12/12). Additionally, whether or not an adult, the off-spring still has a right to medical treatment under Article 25 of the Declaration of Human Rights, even when it is not for life-threatening reasons.

SCWs these considerations form the ethical basis of their duty of care. With regard to the human rights of individuals who have a learning disability, upholding their right to confidentiality and also the right to take risks informs respect for their personhood and also their aspirations - their right to be and their right to live as full a life as possible. Thus support organisation's policies are ultimately based on these principles which includes those on Sexuality and Relationships.

9.3.1 Ethics, human rights and confidentiality

Keeping a client's or patient's personal information confidential is regarded as fundamental to the ethics of 'pure' professions such as the solicitor or doctor. Guidelines for Social Care Workers in Scotland and Melbourne also advise on the need to respect and treat service users' information as confidential. However, it is accepted within the 'pure' professions that confidential information regarding the client or patient is required in order for all those involved in representing or treating the individual. This is required as fundamental to best practice whilst simultaneously setting the limits of access to the information. However, human rights guidelines include circumstances under which the right to confidentiality may be waived and that is when the safety of others or the person himself is concerned³⁸. This waiver applies to SCWs as much as to doctors or solicitors.

9.3.2 Ethics and human rights and risk

Legislation in both Scotland and the State of Victoria is based on promoting the human rights of their service user and makes it clear that their aim is that individuals who have a learning disability should be accepted and included in their local communities, and that this is central to support workers' duty of care. Duty of care in both localities refers to protecting the vulnerable from harm, but it is also concerned with protecting the vulnerable from doing harm, either to themselves or others. Where this is the case provision is made through the *Mental Health (Treatment and Care) (Scotland) Act 2003*, and in Victoria the *Disability Act 2003*, over which the

³⁸ The service user must first be asked if his confidential information may be shared. If he refuses, the worker may still share his information but has to explain to him why they regard this as being necessary.

appointed Medical Officer and the Senior Practitioner respectively preside on the matter of use of restraint. Thus it is within their jurisdiction to decide whether a service user's behaviour will be dealt with in a locked ward or out in the community. Where the latter is the case then workers face ethical decisions regarding the service user's right to take risks within the context of maintaining his community presence.

None of those interviewed made mention of either the Medical Officer or Senior Practitioner being involved although behaviours such as Rays posed the potential of harm to children. However, the matter of consulting these officials is not compulsory since guidelines in both locations also acknowledge the need for workers to manage the risk without compulsion to consult these experts. Taking for instance Victorian guidelines, *Personal relationships, sexuality and sexual health policy and guidelines* (2006), which, as mentioned above, contains advice to front-line workers on procedures to follow including situations where service users display abusive sexual behaviour. This makes it clear that managing such risk is an accepted aspect of duty of care within support organisations and by their support workers. However, this is not to say that workers and their organisations do not look for input from health professionals in order to benefit from their expertise in order to manage the risk the service user's behaviour represents. This may mean a curb on his right to take risks through taking steps to discourage and prevent his unacceptable sexual behaviour. For example, in Melbourne Grace's preferred line of action is to find Frank activities for his 'free' days which will restrict his access to cars but maintain his community presence in a dignified and independent way. This is opposed to Frank's parent's preferred strategy which involves finding Frank 24/7 support. . Similarly Ray's dignity and independence is maintained through the strategy whereby he has been advised on ways he can avoid being in the company of children and at time of interview this was working well, as Rose explained. Other situations are dealt with as they arise. For instance, since his behaviour was discovered he has been on a beach holiday. In order to make this possible staff arranged for him to go to a couples- only resort. In short, staff are ever vigilant and ever mindful in their support of Ray's life in the community. In so doing, they meet the criteria of using the least possible restraint whilst also being mindful of the children's safety.

Murray (2009), quotes Sercombe and writes that being professional indicates “an ethical commitment to a client and to a field of action” (14), and gives as example the doctor who commits herself to the patient and to the practice of healing. Hewitt & Larson (2007) also acknowledged that care workers do more than simply ‘care taking’. Writing from the American perspective they concur that the job of care worker is complex and requires specialised knowledge, skills and attitude. Moreover, they argue, these workers make ethical judgments on a daily basis. Situations in which they find themselves having to do this can, as data shows, have serious consequences for the service user, any potential victim, and indeed the worker herself. Decision making at this level is also arguably a mark of what constitutes ‘professional’.

9.4 ‘Technical skills’

A further mark of the ‘professional’ is the nature of skill involved. Hewitt & Larsson (2007) suggest that in social care work skills include:

“supporting a disabled individual to integrate with family, friends and communities, SCWs require skills in relationship building, resource networking, conflict resolution, bridge building and many others” (179).

In addition, evidence gathered from the above data lists counselling, strategies, investigation and communication as just some of the skills SCWs require. However, it is the manner in which workers embody their practice which is, according to Reinders (2010), of central importance. As Schuengel et al (2010) remind us, clients with disabilities are especially vulnerable in terms of communicating their emotional responses and needs which implies that those who have their care are significant figures in their lives. They conclude, “Direct-care staff are in the position to bring out the best or the worst in their clients with intellectual disabilities” (39).

McVilly (2010) regards professionalism in care work as something that goes beyond commercial considerations and legal requirements. Certainly, data from both Scotland and Melbourne shows that ability to understand and also empathise with the

service user, are attributes in providing a better service. Schuengel et al (2010) have also identified that:

“Extraordinary sensitivity and interest in the client as an individual are required for care givers to be able to perceive often very subtle clues, connect them to the context and interpret these cues correctly” (ibid).

There are dividends from this for the SCW as John’s relationships with Ray and Tom shows. Only through the quality of their working relationship did John have their trust, in Ray’s case to be open and honest about his behaviour, and in Tom’s to take advice to go to hospital voluntarily which at first he was unwilling to do.

Unfortunately general perceptions persist that SCWs are merely continuing the ‘unskilled’ unpaid work still associated with women in the home. However, Virkki (2008) in her research into ways SCWs deal with violent or threatening service users found that the emotional skills they used to defuse such situations derived, not from their experience of bringing up children but from their occupational education and work experiences. She concludes, “Thus emotional competences are considered professional resources and assets of an occupational group . . .” (p79). I would further suggest that to imply that such emotional ‘management’ is simply transposed from the worker’s domestic situation does not generally allow for the nature of the behaviour being ‘handled’, nor can the relationship with the service user be compared with that an individual has with her own children. To suggest as much is highly contentious. There is also the assumption that people who have ‘emotional intelligence’, and who work in care, want or have children. Virkki also points out that the service provider/service user relationship described by Hochschild between flight attendant and customer cannot apply to SCWs. Citing Mann she writes that:

“Many employees in the caring profession manage their emotions in accordance with the moral disposition to care and see managing this as an important part of their professionalism and not as an act of obeying the explicit demands of their employers. Rather than exploitative, the emotional aspect of their work seems to be a source of satisfaction for them” (p75, my italics).

Furthermore, Sadhu et al (2012) in their research which sought to determine which unqualified health care assistants could be trained in therapeutic treatment of sex offenders who have a learning disability and found that “therapeutic ability [is

a]personal characteristic rather than experience” and that “those with greater ‘emotional intelligence’ [are] most therapeutically minded” (316).

9.5 Role, status and proximity.

Data suggests that where interventions into unacceptable sexual behaviour are dealt with in-house, the nature of roles taken on by staff reflects workers’ ‘proximity’ to the service user and also the related level of ‘emotional intelligence’ these roles involve.

9.5.1 Managers

Though both managers were involved in initial investigation into service users’ behaviour it is interesting to note the differences in the level of their involvement. Edward investigated Ray’s behaviour following information from front-line staff on his comments about children. Following this Edward’s role in treatment amounted to liaising between Social Services and Health Professionals. This is not to underestimate the work that managers do in these and other situations where their experience and skills provides guidance not only for the staff, but also for their organisation. Nevertheless, Maggie who manages a Day Service is involved in each stage of treatment along with her staff. This includes making decisions that a service user’s behaviour requires investigation. Unfortunately, no Day Centre managers from Scotland were interviewed for this thesis which means there was no-one with whom to compare Maggie’s experiences so no comment may be made on this point.

A further role which fell to management before health professionals could be consulted was to expedite appointments. Edward explained that securing an appointment would normally take eight to twelve weeks but his involvement as a manager indicated the serious nature of the situation and the need for the service user to be prioritised on the waiting list. Both Edward and Maggie reported that they had successfully secured timely appointments for service users. This may be taken as indicative of health professionals’ recognition of their status as managers in both locations.

9.5.2 Team leaders and key workers

Team Leaders' and Key Workers' involvement in treatment also reflects their 'proximity' to the service user. When the decision has been made to modify a behaviour in-house tasks they undertake include giving advice, counselling, working on and implementing strategies as well as investigating and interpreting service users' actions. This appears to be the case in both Scotland and Melbourne. For example, Grace's level of involvement in Frank's support is comparable with the of John or Rose in their support of Ray. Carrying out these roles calls for direct contact and on occasion, spontaneous reaction on the part of these workers. They also rely on having a level of knowledge of the service users' style of communication and existing behaviours which can only come about through knowing them well. Key Workers because of their daily proximity to the service user are also perfectly placed for those 'teachable moments' in which they can impart knowledge and advice. Knowing the service user well also informs decisions when coming up with strategies for dealing with the behaviour or protecting them from the repercussions of their behaviour. Having the trust of the service user also means that Key Workers are in a situation to counsel them on the advisability of actions which they would otherwise refuse to do. Of importance here is the fact that when Edward (Manager) discovered Ray's behaviour with binoculars, it was John the Key Worker who was then immediately called in to help get Ray to talk about what had been doing and why. John's role was further, to reassure Ray that he would be given help with this rather than be punished. This trust between Key Worker and service user also gives the latter confidence in the former to help them rather than judge or punish them for behaviours which are unacceptable. It may be suggested then that superior knowledge of the service user is an important aspect of the Key Worker's 'field'.

9.5.3 Other front-line staff

As demonstrated above in the case of the casual and the probationary worker, they may not even have been told that there is an issue around the service user's sexual behaviour, as was the case with Vera who became aware of the behaviour when she was subjected to it. Nevertheless these workers still have the direct support of the

service user whose sexual behaviour is unacceptable. Sometimes, as in Vera's case, they will be their sole support when the behaviour is manifest³⁹.

The worker may not even be sure what the strategy is, for example, when Brenda said 'I think he's on tablets or something, I don't know.' The fact that workers coming under these categories know less about those they support than their manager who has little or no direct contact with the service user, I would argue, is not conducive to providing service users with the best service possible.

As demonstrated, these roles reflect the worker's status within the organisations. To some extent those in management already acknowledge status-wise. Yet the skills required to manage are different in situations and with different 'proximity' to service users, which like Edward, is usually the case. These skills, moreover, do not demand the same level of emotional intelligence even though the manager may clearly have this attribute.

9.5.4 Roles in the emerging 'field'

As in situations where SCWs choose to deal with service user's issues in house, those in which they have no choice but to do this follow a similar relation to worker status and 'proximity'. For instance the manager's role to expedite appointments with health professionals may be regarded as the direct relationship between his position in the organisation and the authority with which this is underwritten. Similarly, the roles of Team Leaders and Key Workers relate more closely to their relationship with the service user. Thus strategies are drawn up which are directly influenced by the individual service user and the worker's level of knowledge of them. For example, Wendy's relationship with Chloe informs not only her awareness of situations in which her unacceptable sexual behaviour is more likely to manifest, but also insights into why Chloe behaves this way in the first place. That is to say, Wendy recognises Chloe's need to have a close personal relationship and the fact that she thinks her promiscuous behaviour is a means towards achieving this. Since

³⁹ One female worker I interviewed for my MSc was a casual worker who eventually found out by accident that the person she had been supporting had been charged and found guilty of sexually abusing children. Management knew about this but did not tell her. Meanwhile she had been supporting the man to go to shopping malls and parks and other places frequented by children.

Wendy is aware that this is the case, she encourages and supports Chloe to keep in contact with a former boyfriend of whom she is very fond. Part-time, probationary, casual and agency workers, according to data, are less likely to be involved in devising strategies though they usually implement these as advised by Team Leaders or Key Workers. This situation applies to workers in both Scotland and Melbourne.

9.6 Challenges to Social Care Work and the claim to professional status

As explained throughout this thesis, Social Care Work continues to be perceived as simply an extension of unpaid work women do in the home and so has little status. This is in spite of the fact that in both Scotland and Melbourne it is possible for workers to gain degrees in this subject. Admittedly few workers have such qualifications and those who do will be streamed into management positions where their direct contact with service users will often be limited. Front-line workers can find themselves involved in supporting individuals who have various manifestations of challenging behaviour to live freely in their community yet this unique service or 'field' is not considered a 'profession'. Similarly, the fact that they work to a code of ethics and require specific skills goes unrecognised as detailed below.

9.6.1 Problems with policies

In the past organisations' failure to provide Sexuality and Relationship guidance led to criticism and concern that this resulted in staff ignoring situations, including rape⁴⁰ which did nothing to forward the industry's claim to professionalism. This, according to my data, appears to be changing since all organisations represented have such a policy. However, as also found, not all offer guidance on situations involving service users' unacceptable sexual behaviour. In spite of this workers interviewed used their experience and common sense to manage these situations. However for

⁴⁰ However, as a number of my respondents were keen to point out, in the past when they reported their concerns about a service user's sexual behaviour to their management, their concerns and the situation got ignored (see appendix i for these workers' accounts).

those workers who lack this level of confidence and ability failure of organisations to provide guidance further undermines claims to professionalism.

L. Brown (1998) commented that where policies did offer guidance on addressing service user's unacceptable sexual behaviour, these focused on short rather than long-term approaches to reducing the behaviour. However, I would suggest that whilst behaviours that are more likely to respond positively to short-term approaches may be similar, such as for inappropriate touching, those requiring longer-term solutions are more complex and need to be contextualised by the service user's individual circumstances. For example, Anna responded quickly to Louise's request to stop touching her, whilst Frank's sexual obsession with cars will be a more complex process requiring investigation into what can be done about his behaviour and also how this can be applied within his context as an individual. Thus it would not be possible for a policy to cover all the situations and service users' circumstances when a long-term solution is called for. As Brown & Stein (1997) note, policies provide a starting point from which to begin addressing these service user's support needs but need to be translated into individual service level contracts. Acknowledgment of the level of complexity SCWs deal with in such cases as Frank's is also required in defining Social Care Work as a 'profession'.

9.6.2 Problems with ethics: confidentiality

Data collected suggests that a support organisation can take contradictory and conflicting stances where service user confidentiality is involved. This also undermines Social Care Work in claims to professional status. Unless a front-line worker is the first to be subject to the inappropriate sexual behaviour or to observe it, she is dependent on others for this information from the outset of the service user's support, as indeed is the service user. Situations in which organisations have no control over the amount of information they receive about a service user's sexual behaviour include where it comes from their parents, or when a criminal charge has

been dropped for want of ‘reliable’ witnesses⁴¹. Whilst it would be difficult to hold parents to account, or to establish fact where the judiciary has failed, the situation is different where previous support organisations are concerned. It seems then that organisations’ approach to sharing information is different to that of other lines of work defined as ‘professional’ such as doctors or lawyers. It also appears to be subject specific, i.e. sexual behaviour. This begs the question, when it comes to confidentiality, why has a line been drawn under the service user’s sexuality, when for example previous support organisations have provided information about bowel movements or sleeping patterns? Laura (Scotland) made an important point when she spoke of the nature of information given by managers of a service user’s previous service compared to its front-line staff. It may be the case that the managers to whom she referred restricted the nature of the information they passed on because of their understanding of ‘confidentiality’ and their own perceptions of the professional status of SCWs. Knowledge of all aspects of a service user’s life is needed in order to begin to give effective support. Furthermore, if those in support work do not treat each other as professional then without the required information unprofessional practice will ensue which will further undermine claims to this status.

Data also shows that organisations not only withhold information about a service user from on-coming services. Contemporaneous services may also withhold information on a shared service user. This may also be because those who are in possession of the knowledge are limited in their understanding of confidentiality and human rights. This demonstrates a misunderstanding of the law and also the concept of ‘harm’. Withholding information from fellow services may also indicate a failure within the industry to identify itself as professional. Communication is a two-way process and when members of staff receive information that one of their service users has been involved in an incident in another support service without getting further details, they could ask. Yet in the name of confidentiality there seems to be an acceptance of what happens in a different service stays in a different service; a kind of etiquette or culture within support services that you do not get told and you do not

⁴¹ Witnesses who have a learning disability are often assumed to be unreliable. For this reason cases of serious assault or rape may not even make it beyond police investigation, or indeed, their own support provider (Guardian, accessed 23/08/11).

ask. Thus in situations such as Frank's in which he may or may not be getting abused by a sexual partner, as Grace acknowledges, there is a need for both support organisations to sit down and discuss their strategy for discovering what is happening and then what they intend to do about it. Sharing information in these situations has the same relevance for care workers as it does for health workers. That is to say, it is not a matter of spreading salacious gossip, but of having the information you need to do your job; to have access to your 'field'. What is being questioned here is the integrity of SCWs and by implication their status as 'professional'.

Whilst advocating the necessity of organisations having information on the service users they are about to engage with, Churchill & Livingstone (1997) also advise that managers need to consider how much information can and should be shared with the rest of the team. Here it is not only a question of the service users' human rights to confidentiality but also about the professional status of the SCW. They note that for the manager this is a fine balancing act between safety and confidentiality. Willner & Smith (2008) also note that for managers, care of the service user can sometimes involve having to decide between safety and confidentiality. Yet as far as human rights are concerned, it is clearly stated that where the safety of the potential victim or culprit is an issue, then this can be waived. As argued, all unacceptable sexual behaviours have the potential to be harmful, be it the harm caused to the victim who has been sexually assaulted, or the harm done to the service user because he is arrested for exposure. Nevertheless, organisations which may now take a human rights approach to service users' sexuality may also retain a negative attitude towards sharing information with all members of an individual's support staff. It is even the case, as research suggests, that occasionally managers who do not have their direct care withhold important information about service users from those who do as was the case with Vera mentioned above (see also Sangster, 2007). While it may be understood that Team Leaders and Key Workers have greater knowledge and involvement in a particular service user's treatment, it would be expected that other workers who also have care of that individual would have commensurate knowledge since they are also involved in their care. They should certainly have knowledge of the service user's management plan which ought to include strategies for managing

all behaviours which are problematic. To do otherwise, I would argue, defies logical explanation, not to mention Scotland's national and State directives that apply in Melbourne, since as demonstrated those most likely to have relevant information withheld from them can be left with the sole support of that person in the course of a shift, even when there is the potential for the service user to commit an offence including sexual violence. Failure to share such information amongst all staff that have the individual's care indicates that those who work in this 'field' – the decision comes from successive generations of management – accept society's perception of the lowly status of support work and the misrecognition of the importance of the work they do.

What is more problematic from the point of view of this research is whether an individual's rights to confidentiality can be set aside when safety is not seen to be an issue. An example of this would be the service user who masturbates in public areas of a shared house when no one else is present and who will go and do this in a private space when asked. Again I would suggest that just as the nurse, who as well as the consultant, has the care of a patient, for example, in need of a hip replacement, has full access to their information, then an argument can be made for all who work with a service user whose sexual behaviour is unacceptable to have the same access to this information as their management. The fact that part-time, casual and agency support workers may not be given full possession of a service user's details is further proof, it can also be argued, which reflects the lack of professional status that has dogged care work⁴². The fact that a probationer nurse has the same access to the same level of information as fully trained staff, not to mention doctors and consultants, is a mark of the importance that staff are treated as being professional and have full information in order to provide best service. Additionally, as Sadhu et al found even where workers feel positively about working with this service user group they can suffer emotional stress. Workers should never be surprised and shocked by behaviour that is already known about in the organisation. If they are to

⁴² Full time workers can also find themselves without information on the service user if they are filling an extra shift to cover staff absences or holiday cover. In this instance it is often the case that they are forced to read the person's notes whilst the individual sits nearby waiting to be supported. This has been my own experience on more than one occasion.

work with an individual, they should have all the information they need to support them effectively including ‘the bad stuff’ whatever their working relationship. Keeping important information from those who give front-line support can even result in life-threatening situations (Sangster, 2007).

As explained above, the status of the nurse is informed by its female caring aspect but also by that of the masculine skilled technician. It is this latter aspect which defines its higher status. The fact that managers of a support service can withhold information from their staff, it may also be argued, shows that this lack of status has been internalised, even by some of those who have risen through the ranks and gained qualifications on the way. This is a clear example of what Bourdieu refers to as ‘doxa’. Perhaps this is because of the power/knowledge status associated with what continues to be considered the traditional caring female role.

9.6.3 Problems with ethics: risk

Although SCWs recognise and manage the service user’s human right to take risks they are not always trusted or allowed to do so, no matter that this is a legitimate aspect of their remit. This is a challenge to the ethics which inform national and state policies on which the law, guidelines and their own organisations’ policies are based and which SCWs are entrusted to implement. As such it is also a challenge to claims to professional status. Although these challenges in Scotland and Melbourne did not come from the same sector this is not to suggest that this is always the case. In Melbourne both Frank and Fraser’s parents sought solutions to their sons’ unacceptable sexual behaviour insisting on 24/7 support. Whilst this may still have been thought appropriate by Fraser’s support workers, in Frank’s case Grace preferred to seek alternative activities for him, which involve a reduction to the element of risk but also maintains a degree of independent, more dignified community presence.

In Scotland two instances were cited where the bodies funding the support services in question were wary of respecting their service users’ right to take risks. Laura mentioned tensions arising between the organisation and the body that provides its

funding over a service user's sexual behaviour, even though the support organisation's strategy was carefully constructed to keep within the law. Similarly, when Rose was given to understand that Bill wanted a sex toy – which is also not illegal – the body that provides their funding objected, voicing concerns that the local press would vilify them.

These situations seem extraordinary given that no laws were to be broken. It may be hazarded that the hysteria and fear of public outcry is evidence that old attitudes towards the sexual activity of people who have a learning disability has not changed. Yet these decisions were taken following discussion and much deliberation and as part of support organisations' ethical obligation to service users. This is further challenge to the SCWs claim to professional status.

9.6.4 Problem: misrecognition of SCW's 'technical knowledge'

The fact that the ability to form good working relationships with service users is not generally recognised as a professional skill is apparent in the SCWs' lack of status and wage levels. More importantly, as data shows, health professionals are failing to acknowledge the value of this relationship when working with people who have a learning disability. Although they may acknowledge the status of SCW managers and Team Leaders and also ascribe important roles to the latter, Key Workers who play a pivotal role in attempts to modify behaviour may not be so closely involved when health professionals are called in such as was the case where John was not consulted about the possible use of a relaxation tape to help Tom keep calm.

Permanent staff whether Key Workers or full or part-time, may have little involvement apart from implementing strategies which involves giving medication, giving simple instruction, or containing the behaviour by ensuring that the service user is never by himself in situations that might trigger the behaviour. Although no agency workers were interviewed, when required, they will also have direct contact with the service user and have these roles to perform (Sangster, 2007). Given the Key Workers' superior knowledge of the individual service user, failure to acknowledge this can only be counter-productive to the process of behaviour modification. Moreover it is a failure on the part of the health professional to

acknowledge this aspect of the Key Worker's 'field'. Workers also spoke of feeling frustrated over the problems that can be met when trying to engage with health professionals, such as waiting to get an appointment or the fact that the health professional is not specially trained. Difficulties also arise due to the difference in status between SCWs and 'professionals' which can make it more difficult for them to challenge the latter's decisions. Maggie had this experience when she first started work and found herself the only dissenting voice in a room full of health professionals⁴³. Similarly, Charles and his team experienced what can only be referred to as bullying when they attended meetings with other professionals. Of course health professionals can also back up support staff as was the case with Rose when Bill made it clear he wanted a sex toy but did not want his parents told about this. In society in general, which would include members of the health professions, support staff are perceived as being of less status in relation to health professionals. This, no matter that the subject under consideration – the service user – is the SCWs' area of expertise – their 'field' – and that the possibility of successful interventions into the behaviour is dependent on the unique knowledge and relationship they have built up.

Hewitt & Larsson (2007) found that in England, Denmark and Germany the personal attributes of staff were highlighted and in England particularly, personal qualities were seen "as a real source of strength for this group of care workers" (p181). They conclude that these attributes cannot be taught. Nor could life experience which they also found was rated as being important to the quality of service. Nevertheless, to date, these qualities have no value in terms of status and reward.

Boddy et al (2006) also comment that in Denmark and Germany personal qualities and having life experience make best use of the intellectual foundation of the degree courses they run. As one Danish manager commented:

⁴³ Maggie's recommendation which was dismissed by these professionals was duly upheld by the judge when she took the matter to court.

“to be able to maintain the job – personally, professionally, and administratively – it is necessary to develop intuition and a sense of the situation – the most important element in the work, plus theoretical knowledge” (101).

Reinders agrees when he insists that:

“Professional expertise is necessarily embodied knowledge therefore in this sense that without cultivating its personal dimension, the professional will be less capable of making adequate judgments.” (2010: p32).

To put it another way, it's the singer, not the song!

9.6.5 Problem: quality assurance

Hewitt & Larsson (2007) comment that SCWs lack status and are poorly paid. Additionally research into SCW work undertaken by Manthorpe *et al* (2010) in King's College London has found support work has been generally understood not to require professional accreditation. Indeed, within the field of learning disabilities their review of other studies indicated that about 75% of staff did not hold qualifications. Interestingly the authors go on to say that a lack of qualifications (and here a lack of status may also be understood) is in fact an advantage. They cite a Merseyside housing support study by Hennessy & Grant in which it was found that the overly 'professional' worker was seen as a disadvantage because of authoritarian associations. This raises two interesting points. First, those who can claim to be 'professional' and the demeanour with which this is associated may be alienating to the service user which is a barrier rather than an access to their 'field'. Secondly, the question arises over why the inability to interact successfully with a service user group can be a characteristic of the 'professional', whilst having the ability to interact successfully is not. This may be taken as evidence that traditional technical skills continue to be valued whilst 'soft' skills are not. However, this is to deny the symbiotic nature of these distinct but equally necessary skill sets of the subject expert and the 'relationship expert'. Thus the logic which underpins the existing power relation that separates the two is flawed and unhelpful.

In Australia, Murray (2009) found the standard of Social Care Work variable. He adds, almost half of all disability support workers are semi-literate. This may be

because of the high incidence of immigrant workers who take up social care work. Nevertheless they have the same level of responsibility as their more highly qualified colleagues. Murray reminds us of the nature of this responsibility: “. . . they must be overtly familiar with legislation, government and organisational policy, technical and therapeutic guidelines and behaviour management plans” (p9). He does not suggest that it is the semi-literate workers who are providing the poorer quality care, and to some extent may be regarded, albeit by default, as confirming the findings of Kings College London with regard to skills SCWs require. Regardless of the skills required, organisations need to evaluate their workforce in the name of quality assurance. Yet if we have to adhere to the value of academic achievement, and good practice is to be defined mostly or in part by the good SCW/service user relationship, what counts as suitable training has to be revisited.

9.7 What should a degree in Social Care look like?

If it is accepted that subjects already identified as academic are not of most use to those who aspire to Social Care Work what then should a degree in Social Care look like? Within Scotland and Australia moves have been afoot to formalise SCW training through educational courses, but as shown, most workers have not had access to these, perhaps because their employers see no need for them, especially when they have to pay for it. Yet in Denmark, SCWs are not only provided with higher education and qualifications, but they are also well regarded in society, enjoying acknowledgement of their skills through status and wages.

Writing within the context primarily of residential care of children, Boddy et al (2006), note that in countries such as Denmark, Germany and France, educational training is based on the concept of ‘pedagogy’ rather than ‘care’. These writers explain the former term enjoys a wider meaning than here in the UK and Australia. Their version translates as ‘upbringing’ rather than education, as we would understand it. With regard to learning disabilities and other vulnerable groups, ‘social pedagogy’ may apply. Courses include modules in philosophy, psychology, politics and economics as well as creative and practical subjects such as art, sport, and gardening. Degree level courses based on pedagogy, they add, enhance the

student's 'tacit knowledge' (emotional intelligence) which alone, they maintain, is not sufficient qualification to effectively support service users.

These degrees are generally taken prior to seeking employment and so not a financial consideration for employers. Yet to insist on such qualifications could debar those with highly developed 'emotional intelligence' who do not feel themselves to be academic or who could not afford to attend university. Furthermore, priority is given to the individual's educational attainment rather than their personal attributes. Additionally, as explained, in the UK and Australia, individuals holding this qualification would be forced down the managerial road when they sought promotion.

9.8 Without academic qualifications, how is the worker with the 'right stuff' recognised?

If we accept that the workers' attributes are just as, if not more important than qualifications, then the problem of how these may be recognised needs to be addressed. Although Schuengelet al (2010) recognise the positive impact of the support worker's personal characteristics they argue that academic qualifications are more important. Yet Reinders gives priority to personal characteristics. He thus takes issue with the fact that in measuring the quality of service a support organisation gives, standardisation means that "Quality must be accounted for in terms that are independent from the one who is providing the service" (29). By this he refers to the fact that for organisations and those who oversee them it is enough just to tick the boxes - the service user has choices in his environment, his food, and has a variety of chosen activities - without taking into account his relationship with the worker who supports him with these. Reinders refers to expertise in such a relationship as 'tacit knowledge' and says that this calls for "a renewed reflection on the nature of professionalism and quality of care" (p38). He borrows the term from Polanyi whose conception of this is contained in statements that are personally indexed e.g. I have a feeling that . . . something tells me that . . . etc. Reinders also quotes Polanyi who states that 'tacit knowledge', ". . . is constituted by the fact of the relationship of the knower to what is known" (31). Thus Reinders suggests a

reconsideration of what constitutes professionalisation within the care industry to include the quality of carer/cared-for relationship. Given the level of trust, understanding of both the service user's context as well as level of communication etc., I would suggest that those with greatest 'proximity' who were interviewed for this research demonstrated a high level of tacit knowledge as defined by Polanyi, and may therefore be considered to possess skills that further define the 'field' that indicates their profession. Nevertheless, as Schuengel et al (2010) point out, given the organisations' priorities:

“professionals may experience little positive feedback from their organisational context if they invest a lot in attachment [. . .] Their client may show appreciation but clients usually do not have a say in personnel evaluation and promotion” (44).

9.9 Sum up

If we accept Noordegraaf and Shinkel's (2011) characteristics of professionalism, then Social Care Work can make a claim to this status. Their 'field' is defined by the unique setting in which they work – the community. Their support of the service user takes place here even when the seriousness of the individual's behaviour is such that it would otherwise take place in a locked ward. SCWs also provide support in the community when the necessary input of health professionals is not available to them. Since it does take place in the community, even those sexual behaviours thought not to be serious could have serious consequences for the service user. Thus SCWs work with a greater level of risk to the service user and any potential victim.

Social Care Work also meets the criteria of the 'professional' in that it has a code of ethics based on the service user's human rights to confidentiality and to take risks within the context of his community presence. As Larsson (2007) reminds us, these workers make ethical decisions on a daily basis, whatever the situation. The right to take risks must also be considered given National (Scotland) and State (Victoria) directives that workers must aim to empower service users as opposed to 'babying' them, and do this with a mind to their community presence. Empowerment has also to be balanced with the workers' duty of care, often making ethical decisions the result of much deliberation.

With regard to their ‘technical skills, as cited above, a plethora of researchers have commented on the importance of what is variously referred to as ‘emotional intelligence’ or ‘tacit knowledge’ in front-line SCWs. Certainly, evidence from data indicates that the working relationship between the worker to the service user also relates to the roles they take on as part of modification of the latter’s unacceptable behaviour. These good working relationships exist particularly within the context of the worker/service user ‘proximity’ which usually involves Key Workers or Team Leaders who work in situ.

Claims to these attributes are not however unproblematic. The ‘field’ of the front-line worker is not acknowledged in society. Witness the lack of status and poor wages. More specifically data shows that the skills of front-line SCWs may be ignored by health professionals, which is to the detriment of the service user. The matter of work ethics may also be denied through self-misrecognition. This is apparent in the confused way in which the matter of service user confidentiality is shared with fellow workers. Worker’s legibility to make ethical decisions regarding risk has also been called to question as in situations cited above involving those who fund support services.

It may be argued that all the above challenges to the professional status of support work are based on the low status of the skills involved which are associated with women’s work in the home. Without denigrating these skills which workers still often use, there is a need to raise awareness of what else is involved in support work, the level of responsibility it entails, and the personal qualities required to ensure best practice. Thus there is the need and challenge within the support industry to evaluate the support worker’s personal qualities rather than simply tick boxes regarding activities and choices, etc. To return to McVitty’s quotations that open this chapter, we need to respect and safeguard the interests of people who have disabilities. Where possible this would include counting their opinion of their support workers along with standard measures of evaluation. As to safeguarding the reputation of Social Care Work and promoting it as something to which people aspire, as Mc Villy goes on to

suggest, this requires acknowledgement of its professional status. Characteristics defined above, I would argue, legitimise claim to this.

Chapter 10

Recommendations and conclusions

10.1 Recommendations

Following on from the above discussion, this chapter continues by making recommendations based on findings which would serve to counteract those ‘patchy responses’ with which service users’ unacceptable sexual behaviour has previously been met in both Scotland and Melbourne. Within the workplace context what is included here concerns procedural, educational and environmental considerations, as well as the recognition of the roles and responsibilities SCWs face when supporting service users whose sexual behaviour is unacceptable. What then follows is a review of research methods followed by recommendations for further research. The thesis then ends with my reflections on this research experience before drawing to a conclusion.

No matter how willing and confident staff feel about taking on service users’ unacceptable sexual behaviour certain elements may still serve to limit workers in their efforts to support the service user to modify his unacceptable sexual behaviour. These may relate to the context of the service user, the support service, or the working relationship between the SCW and the health professional. Organisations and their workers can have a greater or lesser amount of control over these limiting factors, and arguably, given the present state of knowledge about learning disability in its many manifestations, those over which workers have least control relate to the context of the service user himself. Included here is their level of understanding of the consequences of their behaviour; behaviour not readily recognisable as sexual; behaviour that seems to have become ingrained, and the service user’s reluctance to discuss their sexuality. Yet better sex education and a more open attitude towards sexuality in society will mean that in the future for the on-coming generation of people who have a learning disability, some of these limits will be removed. What follows then are recommendations which affect those barriers related to service provision and to working with health professionals, which affect the worker’s

practice and ultimately the service provided to the service user. Ultimately these recommendations are made as measures towards establishing Social Care Work as a profession. To this end recommendation is also made regarding the identification of workers who have the necessary 'emotional intelligence' or 'tacit knowledge' which includes service users' opinion of their working relationship.

10.1.1 Policies

Given that unacceptable sexual behaviour can be such a stigmatising factor in the lives of people who have a learning disability, the importance of organisations addressing such matters cannot be over-emphasised. Previous researchers have noted that response to service users' unacceptable sexual behaviour has been patchy. In order to put an end to this, organisations should initially ensure that the worker understands from the outset of their employment that this could become part of their responsibilities and that they will be expected to be supportive of the service user in all aspects of his life. A clear statement to this effect should be included in their job description as well as the fact that they will only be excused this duty in extreme circumstances. Further reinforcement of the worker's responsibilities should be made at their induction. There is also the need for organisations to provide policies on Sexuality and Relationships. Whilst some workers willingly and confidently work without reference to their policy, not all workers have this level of confidence even when the behaviour is considered to be 'less serious'. The content of these policies should include guidance on initial responses to discovery of a service user's unacceptable sexual behaviour and how to best support the service user in question. As argued above, whilst inclusion of suggestions for dealing with more common behaviours such as masturbation in inappropriate places is feasible, it is not possible for the organisation to provide strategies for more complex situations and behaviours. However in both situations workers should have guidance on how to proceed to address the situation. This said, workers also need to have direct access to the policy, either in hard copy or in electronic form, rather than have it kept at head office.

To sum up:

- Job descriptions for SCWs should make it clear that apart from where there are exceptional circumstances workers will be required to address service users' unacceptable sexual behaviour.
- All support organisations should have a Sexuality and Relationships Policy which includes procedure in the event of the discovery of a service user's unacceptable sexual behaviour.
- Workers should have direct access to this policy, either electronically or in hard copy.

10.1.2 Information

Additionally, workers need to have information about the service user which enables them to provide effective support. Where this involves previous or contemporaneous support services workers indicated that this is not always forthcoming which indicates the organisations' failure to comply with guidelines set out by governments and from the organisations themselves regarding keeping proper records. Such records should include details of any of the service user's issues and how the organisation has gone about its modification.

Where confidentiality is an issue, behaviour that results in harm can be disclosed to on coming services because the service user's human right to confidentiality is forfeit when harm to them or a victim is a possibility. However, 'harm' can also result from behaviour considered 'less serious' such as masturbation or exhibitionism, in that they can result in criminal charges and so I would argue that right to confidentiality in these circumstances should also be forfeit for the sake of the service user's continuing well being. Misunderstanding of confidentiality and the way it relates to the service user's human rights can also prevent contemporaneous support organisations sharing information on a shared service user. Workers need full information in order to support the service user effectively and when they feel this is being withheld they should feel able to request information and also confer with other services.

Whilst policies where they exist are available to all staff, (though not always readily so), it is a different matter when it comes to information that is meted out by management on what they regard is a 'need to know' basis. This is based on the worker's status within the organisation rather than whether they work with the individual in question. Yet even agency staff can have sole support of a service user so I would argue that they, along with part-time, casual and probationary staff 'need to know' in order to provide the support the service user needs.

To sum up:

- Service users' unacceptable sexual behaviour should be recorded in a clear manner using unambiguous language, and a management plan similarly written up and placed in the service user's records.
- This information should be provided to on-coming support services.
- When incidents of a sexual nature occur contemporaneous support services should confer to discuss and share their concerns and strategies.
- All front-line staff who work with the service user in question, whatever their work status, should have full information about his behaviour and his management plan.

10.1.3 Training

A positive step towards overcoming 'patchy' responses concerns staff training. Whilst some colleagues such as those to whom Grace referred were reluctant to get involved in working with a service user's behaviour because they had not been trained, others like Louise took on a role, in this case as counsellor, even though she had not been trained to do so. The reluctance of the former and the uncertainty of the latter suggest that there is more need for organisations to provide staff with suitable training in order that they will be able to improve the service to the service user, and simultaneously allay workers' fears of getting involved as well as what they should do.

A basic training course which should be compulsory for all members of staff would emphasise the need to respond to all unacceptable sexual behaviour in a prescribed manner set down by their organisation. This would include how to write an accurate record of the behaviour and subsequent developments expressed in clear language that future members of staff will be able to understand (Sangster: 2007). General training would have to include the legal aspects of service users' sexuality and relationships; what is and what is not a sexual offence, and also the matter of confidentiality. This is not just about which related Acts exist but how these may be understood. A case in point is that concerning human rights and limits to this. Evidence shows that even those who hold influential positions in relation to the service user's life, such as Care Managers, are unaware of conditions under which confidentiality may be waived or kept, as was the case with Bill who did not want his parents told about his use of sex toys. Thus it should not be surprising that members of front-line staff are also unaware of legislation affecting the lives of those they support.

Some of those front-line workers who were interviewed have regarded the behaviours they have dealt with in-house as 'less serious' meaning that they believe that nobody including the individual was physically harmed. Yet as stated above, 'harm' encompasses being exposed to the possibility of a criminal charge which *all* these behaviours have the potential to do. Failure to understand the implications of 'less serious' behaviour is also the failure of the worker to recognise the high level of her responsibility and the importance of the job she does. Providing training for all staff on how to proceed when they suspect or have confirmation that a service user is behaving in a sexually unacceptable manner, and the law, would improve the service available to this service user group. Since specialised training is a form of social capital this would arguably improve the status of SCWs.

To sum up:

- All staff should be given basic training on Sexuality and Relationships which includes the organisation's procedure when a service user's unacceptable sexual behaviour becomes apparent. This should be compulsory.
- Basic training should also include how to write up accurate records of the behaviour, expressing it clearly and using unambiguous language.
- Training should include those laws concerning sexuality and service users who have a learning disability and additionally, laws on what constitutes criminal sexual behaviour. The law as it relates to confidentiality and human rights should also be taught.

10.1.4 Who should get specialised training?

Given the range of unacceptable sexual behaviours that SCWs may encounter and the different working relationships with the service user within an organisation, it would not be possible or practicable to give every worker the same level of training in sexuality. Recommended above is training for all staff which is intended to help workers support the service user effectively whilst also giving them the confidence to do so. However, examples of behaviour cited above clearly indicate that some staff will require extra training. Although it would be impossible to train workers to meet every eventuality an advanced level training programme would boost these workers' confidence as well as their ability to deal with more complex behaviours.

Staff involvement in supporting service users to modify unacceptable behaviour follows the pattern as set out in Figure 1 where the working relationship to the service user correlates with the worker's status in the organisation. Here, the manager who works off-site has a different jurisdiction or 'field' from that of the front-line worker, even though they have themselves at one time been likely to have worked there. Their area of jurisdiction has thus moved from a particular service user to that of the organisation, informed by the experience they have gained on the way. As managers, whether they work on or off site, they enjoy a status recognised both within and outwith the organisation so their involvement in any case indicates

its serious and/or complex nature. However, following their initial involvement focus shifts from the managerial 'field' to that of the front-line worker. Both are necessary, but the status of the latter, whose 'field' is deeper knowledge of the service user, is less, yet equally if not more important to the service user's chances of modifying their behaviour.

Key Workers and, where they have a history of working with the service user, Team Leaders can lay most claims to this 'field'. This is especially true when these individuals display characteristics Mee has identified as belonging to those most willing to be helpful and who Sidhu *et al* describe as being 'emotionally intelligent'. These Key Worker and Team Leader's accounts of their feelings about working with this service user group certainly indicate a high level of rapport and understanding of the reasons for their behaviour. Additionally, feelings of empathy and affection were expressed by male as well as female workers who know the service user and see that they cannot be defined solely by their sexual behaviour. Workers were also aware of reasons that explain their behaviour thus they approach these issues willingly rather than ignore them.

Other workers who may be full or part-time, casual, have a lesser role to play, and will to a lesser extent occupy the same 'field'. This is understandable given that their familiarity with the service user and his circumstances will not be so developed since they will spend less time with him, or they will have others for whom they are more responsible. However, given that none of my volunteers for interview included those unwilling to become involved in interventions into service users' unacceptable sexual behaviour, it may be surmised that some of these would have included Team Leaders and Key Workers. These individual, it would be hoped, would benefit from basic training. That said, there is a need for support organisations to identify staff suitable for advanced training, and where possible and where there is the likelihood of a good rapport being build up between the two, match them with those service users who would most benefit from their support.

To sum up:

- There is a need for support organisations to identify members of staff who can claim ‘emotional intelligence’ since evidence above suggests that they would most benefit from advanced training. As mentioned above, psychologists managed to identify successfully health support workers who would most benefit most from training in counselling patients. Their methods of identification might be considered.
- Where it does not already exist but management feel confident that a good rapport would build up between the two, these staff members should be allocated to the service user in question and given advanced training.

10.1.5 What would be included in specialised training?

In many different contexts and to different degrees, workers, and especially Key Workers already perform counselling services for their service users. However, like Louise, mentioned above have not been trained to do so. Norman (1998) like McConkey (2005) argues that the behavioural therapeutic aspect of nursing work could be taken on by SCWs and as argued above, knowing and being known by the service user would be beneficial to this. Walsh-Mooney (2009) with reference to psychotherapists writes of the importance of rapport in therapeutic relationships and goes on to argue that this is also essential to Social Workers’ practice. She cites Autinov & Blum when they argue that the type of therapy used is immaterial since it is the quality of the relationship between therapist and client that is the defining factor in its success. Walsh-Mooney further cites Jorgenson who describes rapport as being ‘truly relational’. Thus it is not something that can be worked on but rather as Tugenberg & Dickey (also cited in Walsh-Mooney) describe as:

“meaningful interaction – to share a joke, to share a hot drink, to share something of yourself, to share similarities, to talk freely, to be spoken to with respect, to be treated as an individual, to be valued, to be known, to express empathy, to be available and to be flexible.” (24)

The fact that they have already established rapport with the service user (their particular ‘field’) suggests that with training, these workers could be especially

effective. Such training would of course extend the skill habitus of SCWs to include the legitimate ability to provide this therapeutic service, which is currently the preferred approach to service users' behavioural issues, sexual and otherwise. Since this has trickled down from 'higher' grade workers, it should improve perceptions of SCWs' status as workers and support work as a profession.

To sum up:

- Training in behavioural therapy should be taught to those workers assessed to be most likely to benefit and be of benefit as a result.

10.1.6 Working environment

Even though willing and having been suitably trained, the worker's practice will suffer if her workload means she cannot give each service user the attention and support that they need. This should be borne in mind when choosing service users to share a house and when deciding on staffing levels. In view of this organisations need to be very sure that those who are being asked to share a home can live together stress-free but additionally they ought to recognise the difficulty and importance of the work their staff do in the modification of unacceptable and other challenging behaviours. Management must also ensure that staff working in difficult conditions have the opportunity to express their feelings and concerns and where possible of course, allayed as far as is possible.

Where a situation is particularly complex or unusual, workers may need look to others for their expertise. I came across one organization in Scotland which has sexuality trainers who support workers in this way. Unfortunately not all organisations have this facility. However it is important that workers have information on services that are available to them. In Victoria, the State Government in conjunction with Monash University has a department which deals with, amongst other things, service users' sexual behaviour⁴⁴. Yet as Maggie pointed out, GPs are

⁴⁴ Centre for Developmental Disability Health Victoria's Sexuality and Disability Services. The Centre charges a fee for these services.

not usually aware of this facility to which they can make referrals, and further, not all SCWs know of its existence thus it is important that workers to have this knowledge.

To sum up:

- As far as possible, support organisations need to consider the work load each household of service users represents to the front-line worker, and ensure that this will not lead to staff burn out. This may also have implications for appropriate staff/service user ratio.
- Regular supervision for members of staff who support service user to modify their unacceptable sexual behaviour should be provided. Furthermore an open-door policy should be in place for access to management when front-line staff feel the need to discuss their feelings and anxieties about the role they play.
- Support organisations should draw up and provide each unit in their service with a comprehensive list of local and national and on-line resources they can draw upon when supporting service users whose sexual behaviour is unacceptable.

10.1.7 Working with health professionals

Mention was made of the ineptitude of generically trained health professionals when working with people who have a learning disability. In relation to the training of CLDNs in England, Mee (2010) encouraged students to go and listen to members of this service user group talking about their experiences of care/support. This, he writes was an illuminating, if not cathartic experience for these students who, through their choice of this specialised profession, had already shown an interest in people who have a learning disability. Mee quotes one student thus,

“The experience led me to reflect on my practice and helped me to conceptualise my role. As a consequence, on future placements I began to take a more proactive approach and challenge oppressive practice which compromised the rights and dignity of the people I was supporting.” (39)

I would suggest that Mee's approach to training these nurses might also be of benefit to generically- trained medical staff and ultimately, the learning disability population they serve.

In addition to extra training for health professionals in communicating with service users , since they will still not have the opportunity to get to know each individual service user well, the presence of a Key Worker or Team Leader in consultations, would, I contend, benefit all concerned, where the service user agrees. In these situations, health professionals might benefit from talking with workers in close 'proximity' to the individual since they are in a better position to advise on what is new and different about a service user's behaviour as well as keeping medics fully informed on any developments.

To sum up:

- In order to improve health professionals' consultations involving people who have a learning disability, meetings and discussions with this service user group could afford them insights into providing a more positive experience for both parties.
- Where the service user agrees, health professionals should include the Key Worker or Team Leader in consultations with the service user thus utilising their specialist knowledge of the individual and his circumstances.

10.1.8 The status of SCWs

As McVilly has stated above, the support needs of people who have a learning disability can be extremely complex. Even if they are not, or are not always, the level of responsibility SCWs carry is high. On occasion this can also include responsibility for input that trained health professionals are unable, for one reason or another, to provide. Yet these workers' level of responsibility and their skills go largely unacknowledged. As Hewitt and Larsson insist, "The profession (sic) of direct support must be recognised as a primary labour market that requires highly skilled workers who are adequately compensated with a living wage. This requires

substantial improvements in the public's understanding, awareness, and appreciation of the important roles [they] play" (2007: p183). Professionalisation of Social Care Work could serve as acknowledgement of the responsibility and skills of these workers as well as deterring less committed individuals from working with this vulnerable group.

To sum up:

- Social Care Work should be recognised as a profession. In addition to having prescribed qualifications and its own ethic code, professionalisation could include annual re-accreditation and a licensing process similar to that of Social Workers.
- So specialised are these skills that I would argue that front-line and their management are in fact two distinct professions. Presently workers' only promotional path within care work is via managerial positions. Whilst first-hand knowledge of front-line work should be mandatory for service managers this should be only one of two choices for those who seek promotion and acknowledgement of their abilities. This would simultaneously act to enhance the status of SCW since it would render SCW per se something to aspire to.
- Quality assurance should involve consultation with service users who should be invited to comment on their relationship with those SCWs who work most closely with them. Where this is not possible because of the service user's ability to communicate verbally, Work Place Assessors should be trained to evaluate the SCW/service user relationship from other indicators.

10.2 Review of method

Such literature as presently exists on the role of the support worker in the modification of unacceptable sexual behaviour in people who have a learning disability has been of a quantitative nature and not concerned with these workers lived experiences, which this work has as its basis. Similarly such literature as presently exists on the working relationships between health professionals and Social

Care Workers, actually concerns Social Workers (see Hugman, 1991; Doran, 2001; Keene & Li, 2005). Thus findings from this research extend the scope of this subject to include SCWs' involvement in the multi-agency approach. Having said this, a review of the method used here is necessary for clearer assessment of its findings and conclusions.

As stated in the Method section, this had to change when it became apparent that Grounded Theory would be unworkable due to a lack of interviews. Although numbers are not such a pressing requirement for qualitative research as for that which is quantitative, questions remain over the validity of truth claims. Whilst it is true that further examples of situations, staff roles, and their limits may have arisen, this work never set out to provide a comprehensive list of each as its aim, but rather, since the subject was under-researched, to open it up for consideration, and make a case for the important but under-acknowledged nature of the work support workers do.

Phenomenological hermeneutics seemed like a workable alternative given that in prioritizing the need for the insider researcher, it acknowledges but also values the subjective nature of qualitative research, and additionally, insists on the value of lived experience, which in interviewing these workers, I aimed to do. Analysis did not follow the prescribed manner of PH since my interviews were already completed and the numbers so few that I could not pursue themes. This, in any case, would have been about my agenda rather than that of the workers since I would have selected those which were obvious to me and pursued them with further related questions. Rather, and with greater difficulty, I gathered themes from the information they had given me which were of course directed by my initial questions but these were more general and so allowed them wider scope. However, as Heidegger has explained 'truths', or to use the methodological term, validity, involves construction by the triad; the one who is the insider researcher, the one who is the subject of research, and the one who reads the outcome of the research. Thus it is now left to the reader of this work to decide the truthfulness or validity of what is written here; to decide if in Robson's words this work has 'street credibility'. If the reader is

already familiar with the subject of people who have a learning disability what is written here may hold resonance for them and if not, they may seek confirmation through further enquiry.

As to this work's reliability, as explained above, interviewees may respond differently to different interviewers, but are results less reliable as a result of this? The gender of the interviewer has been shown to affect what is said at interview, as has the level of rapport established in the process of interviewing. For example, and as explained further in the section on Reflexivity, women I interviewed gave more detailed accounts of the same incidents than did the men who were also involved. This said, their accounts matched at the basic level of telling the story of the incidents involved. It may be conjectured then that if I was a male researcher the men would have given the greater detail.

In the course of interviewing it was felt that one question in particular was causing negative emotions in those I initially interviewed. This was the question on awareness of their organization's policy on Sexuality and Relationships, which was included with the aim of gauging ways in which this influenced the worker's practice. When it became apparent that this question was embarrassing the interviewees who thought I was testing them on their knowledge, I decided to drop it. Instead I decided to alter the focus of research into these workers' policies to that of gauging the extent to which they advise workers on ways to approach service user's unacceptable sexual behaviour as L. Brown's study had done in the 1990s.

An important element of this research concerns work-place hierarchies and the 'field' the individual service user represents. Analysis includes the nature of the work in which SCWs are involved and the level of information they have about those they support. Some interviews may have been considered to be of poor quality since they were short and did not provide much detail. However, this situation served to reinforce my arguments concerning the lack of information and involvement some front-line workers have on the sexual behaviour of individuals whose daily support they provide. Compared to those at higher management level these workers may not

have all the necessary details, yet the service users' direct, and occasionally sole, care. Furthermore, it is in the spirit of phenomenological hermeneutics to let these workers with less involvement in the situation, speak for themselves.

10.2.1 On being an 'Insider'.

In Hiedegger's terms the ideal research scenario involves the lived experiences of subjects and additionally, the 'insider' status of the researcher. In relation to objective quantitative research this is about as far away as one can get. Although this thesis identifies with Hiedegger's directives, there is a need to reflect whether indeed I have been standing too close to my subject area and these workers to produce findings which are credible and useful. My findings reflect my closeness to, and sympathy for, fellow support workers in that they include instances of practices that are resourceful, effective and worthy of recognition, such as that done by Maggie who manages a Day Centre in Melbourne, and Rose whose level of understanding of Bill's communication style means that he feels free and able to make his wishes known. However, this is not to suggest that the roles these workers currently take on and those which they might be trained to do are without limit. For example, it took a psychiatrist who has undergone seven years of specific training to diagnose Luke's schizophrenia which is at the root of his unacceptable sexual behaviour.

As explained above, an essential element of treating unacceptable sexual behaviour is knowledge of its motivation. Although factors such as lack of sex education ('counterfeit deviance') are given as reason, research undertaken by Lindsay (2005) found that those subjects who have a learning disability and whose sexual behaviour is unacceptable have greater sexual knowledge than those who do not. Similarly, Lindsay finds that evidence of the effect of having social difficulties, e.g. being stigmatised because of the disability, inconclusive. Lindsay also questions the explanation of poor impulse control in this service user group, noting that in many cases evidence of, albeit simple, grooming strategies are present. Furthermore, Keeling et al (2009) report that several studies into victim empathy and cognitive distortion show numerous similarities between those with and without a learning disability, although these have been particularly singled out in relation to the former.

Sondenaa et al (http://www.medscape.com/viewarticle/581737_6, accessed 20/06/2013), also list behavioural learning as a reason why people with learning disabilities might develop unacceptable sexual behaviour, i.e. the abused becoming an abuser. Currently, however, single factor explanations are rejected in favour of Integrated Theory which as the name suggests refers to a combination of any of these single factors (Keeling et al, *ibid*). Recognition of such complex reasons for unacceptable sexual behaviours demands years of training in order to gain the necessary knowledge. As has been argued throughout this thesis, it is the individual service user who constitutes the SCW's 'field' of expertise, not the aetiology of unacceptable sexual behaviour. As I have further suggested, it is the joint efforts of workers who have these two separate areas of knowledge that makes for more successful outcomes for the service user.

10.2.2 Generalisability

It is recognised that using qualitative methods in research poses problems regarding the extent to which findings may be generalised. This is due to the smaller number of respondents involved compared to those necessarily garnered when using quantitative methods. Although this research involved a purposive sample this is no guarantee that those interviewed were representative of these workers as a whole. Given the sensitive nature of the research subject and also the vulnerability of the service user group, convincing organisations to allow access to their workforce proved even more difficult than was anticipated. Denying access is likely to have been for more reasons than were given and on which we can only speculate. It may thus be surmised that the organisations prepared to get involved in this research felt more assured about their circumstances, practices and also in the integrity of their staff⁴⁵. Thus they may not be representative of the support sector as a whole.

Staff interviewed fitted the description of the purposive sample in that they had experience of working with service users whose sexual behaviour was unacceptable. Their responses at interview also demonstrated, I would argue, their integrity. Yet

⁴⁵ **Charles's account of his practice was positive although the one he gave of his organisation was not**

there must have been others who also have fitted this description but were not able to be interviewed, perhaps because of the time factor; and other who simply did not want to be interviewed for whatever reason as well as those who were not given the opportunity by their employers. Thus the data presented here comes from the staff of organisations which at time of research felt comfortable in taking part in research and who were available and also willing to be interviewed. In terms of the integrity of this research, findings and conclusions cannot be assumed to apply in all other circumstances. That said, this work did not set out to provide a definitive account of workers' experiences but to open the subject to further research.

I believe that the method used for this research was appropriate for the above mentioned reasons. The greatest problem I faced and from which all other problems stemmed concerned the small number of interviews I was able to arrange.

10.3 Ethics: reflections

People who have a learning disability may certainly be numbered among those considered vulnerable. Furthermore, the subject of sexual behaviour is a sensitive one. In gauging the level of ethics involved in this research I believed that because I would be interviewing support workers rather than those they support, that Level 1 as set out by the University of Edinburgh's School of Social and Political Science would be fitting since it concerns maintaining subjects' confidentiality which I felt able to do. However, on reflection, there were other matters to consider. At Ethics Level 2 researchers are cautioned on the need for the higher level of scrutiny which is required where illegal practices may be involved. Some of the sexual behaviours mentioned at interview were indeed illegal in terms of their nature or where and how they took place, but support workers and their organisations were aware of this and were supporting service users as part of their legitimate remit.

More problematic were situations in which the effectiveness and level of risk involved was open to question. In the course of interviewing a situation was mentioned which involved staff taking a potentially high level of risk regarding the behaviour of a service user and also the safety of others. I had not anticipated such a

situation when I applied to the university's Ethics Committee, nor had I provided for it in the confidentiality agreement I required my interviewees to read and sign prior to interview.

When Level 2 of the ethics standards applies researchers are further advised to keep records of ways in which they are addressing the ethical issues as the research proceeds. Although at time of the interview in question I felt concern over the risk involved, simultaneously my perceptions of the interviewee and her organisation was that she and they were exemplary in their practice and further, that they had decided their approach to this particular service user's management plan in consultation with, and with recommendation of, a specialist health professional and under the guidance of the service user's Care Manager. I therefore feel vindicated in taking the matter no further although I should have given account of my reasons. If there had been no management plan or if I thought it ill-considered then I would be required, under the School's research ethics procedures, to report matters to the Police, Social Work or other appropriate authority.

With regards to research participants it is as Brown & Thompson (1997) remind us, that they have to give informed consent to interview which means making them aware of the ethical implications of anything they may say. The School's research ethics procedure concurs with this and advises that a warning to this effect must be included in Information and Consent Forms. Appendix ii is the version of the consent form I used amended to include a section dealing with ethical concerns over disclosure of questionable practice.

10.4 Further research

Since the numbers interviewed for this research were smaller than could have been wished for, a further study could serve as a triangulation exercise in which these findings could be corroborated. Research involving participant observation might be useful here although the difficulties faced in gathering subjects for interview might be even greater in light of organisation's perception of the disruption the participant observer might cause to their daily routine.

With regard to the situation in Scotland where the future of the CLDN post seems tenuous⁴⁶ an evaluation of situations in which SCWs work with and without their input in the modification of service user's unacceptable sexual behaviour and other challenging behaviours could be compared, the results of which could inform any decisions regarding the CLDN future and also SCW training.

Similarly, since the Intellectual Disability Nurse is now a de-registered post in Melbourne and has been replaced by generically trained Community Nurses (Mott, 2007), research into their contribution to the health and well-being of people who have a learning disability could also be researched. Additionally the extent to which SCWs in the State of Victoria consult with generically trained nurses could be compared with that of SCWs in States such as New South Wales where IDNs are still registered. Although a significant amount of contextual factors would have to be taken into account, a comparison of findings would also be useful for deciding future service provision to this service user group in both Victoria and Scotland.

Research which would be relevant in both countries concerns the reasons why parents do not want health professionals involved in their adult child's treatment when staff in a support organisation thinks this would be appropriate. Results of this might be used to allay parents' concerns once it is established what these are.

A further area of enquiry relevant to both locations concerns the service user's chances of forming a healthy sexual relationship once they have been involved with forensic services. Charles (Scotland) brought up this extremely important point, which raises the fundamental question, why do we seek to modify service user's unacceptable sexual behaviour? Should we accept that treatment is solely about stopping the behaviour? Is it only to contain the behaviour, which would be, I would contend, mostly for the sake of others? Or is the purpose of treatment also to offer the man the prospect of eventually forming a healthy sexual relationship? Since this is more likely to be with another who has a learning disability, who is thus

⁴⁶ Scottish Government, accessed 24/06/10.

essentially regarded as being vulnerable, is it feasible to expect that others will accept that he has overcome his past behaviour especially if forensic services have been involved?

Another area of research inspired by a worker who was interviewed concerns men who have a learning disability and whose sexual behaviour is unacceptable, but nevertheless they have 'fallen between the gaps'. I would suggest that this involves men who have a mild learning disability and whose support needs have not been recognised by either the education system, the Social Work Department, or indeed, the judiciary. Given the numbers of men in jail who have a mild learning disability (for one crime or another, some of which are sexual), questions are raised as to how this has come about, and at what point might intervention have been made?

Finally, if it is accepted that there are workers whose 'emotional intelligence' is such that they could provide the best possible support to service users with more complex needs, then research is required into how they may be identified.

10. 5 Reflections on the research process

Four years engagement with a single project leaves a lot to look back and reflect upon. How has it affected me as a person? How has it affected those who have supported and guided me? How has it affected those who agreed to be interviewed and how will it affect those who are the subject of this research, service users who have a learning disability? Like most other PhD students I started out with a clear notion of what I wanted to do and how I was going to do it. Coming to terms with this level of self-deception was not so easy. Of course being awarded a PhD would be of benefit to me, but I also hoped and intended that the information I could provide would have a positive effect on the lives of service users who have a learning disability and that this would open gatekeepers doors so I could access workers to interview. Thus it was deeply frustrating and disappointing to find that so few of the former responded although I had the notion that it would not exactly be easy given the nature of the subject and the vulnerability of service users.

I was looking forward very much to holding interviews; my favourite stage of research made even more interesting for me since I also work as an SCW with people who have a learning disability. I now have some fond memories of these interviews in which those I spoke with were warm and engaging and so obviously dedicated to the work they do. Reinharz (1997), as mentioned above recognised that the researcher, rather than being a one dimensional being has a variety of ‘selves’ that they bring to interview. Thus I came to interview as, amongst other things, an academic, a woman, someone from a particular culture (Western), someone who works with people who have a learning disability, and simultaneously, a worker of low status, and also, I hope, a friendly, non-threatening human being.

As an academic, I felt that I had compromised those I interviewed when asking them about their knowledge of their company’s policy on Sexuality and Relationships, since I was not there to test them and my working self realised that they may not even have had the opportunity to read this document. Hence, as described above, I changed the focus of my research into these workers’ policies

I was fortunate enough to interview three workers from the same organisation all of whom referred to the same two situations. It was interesting to note the difference in the amount of detail of the behaviour and the language used by the two men compared to the woman. I can only conclude that she felt more comfortable telling me, another woman, these details, than did the men who were, I think, more embarrassed speaking to a woman researcher about sexual matters in such detail. Nevertheless these men’s contributions raised many interesting points including those on status and proximity. The situation in Melbourne was similar but in this instance it was women from non-western cultures who were more reticent to speak openly about sexual behaviours, preferring to leave gaps in their sentences but looking me in the eye to confirm that I understood - body language that means the same in both our cultures.

Reading back over the transcripts, particularly of one male worker’s account, I felt so touched by his attitude and level of commitment. His warmth, regard and concern

for his service users shone through his words as he recounted his experiences. It reminded me of when I first set out to work with this service user group. Having had no previous experience of this, I can remember wondering if I would like it. I had never had any interactions with a person who has a learning disability, as far as I was aware, and so was not sure that I would be able to 'connect' with them. What amazed me was the speed at which this connection formed, bringing with it a deeper commitment to these individual's well-being. I am not claiming to be as 'good' an SCW as John, but it helps me appreciate the high level of support he gives his service users

If John reminded me of the quality of work that SCWs perform, then as well as this Charles' account of his treatment from his 'superiors' reminded me of the low status of SCWs. Coming to interview as an insider probably gave me a head start in terms of empathy with those I interviewed. Still, it came as a surprise to find one individual so angry. As Charles related his experiences I could see why he would be so furious and cynical. Subjected to insult and ridicule, his was surely an extreme example of ways in which the responsibility and skills required for this job are misrecognised. However his experience was in keeping with utterances, quoted above in which the need for SCW training is derided and those who do this work dismissed as 'the great unwashed'. As one of these workers myself, I shared Charles' anger, and felt compelled to include the points he made.

One interview involved the dawning realization that the worker had misunderstood my brief. Rather than those who abuse she believed I was there to interview her about those who have been abused. Whilst she had experience of the latter she had none of the former. I felt that I was wasting my time and hers by letting her continue to relate her experience which would have been a really good interview had my research been into supporting the abused. However, she was so enthusiastic about the interview, and what she had to say was truly interesting that I could not bring my 'nice' self to bring it to a halt. Later, going home on the train I listened to the interview again but could not find anything that I could use. However, she did bring up a point for future research and that concerns men who have mild learning

disabilities whose sexual behaviour is problematic yet they have no support service. In short, this begs the question, since they may be known to the police, how have they managed to fall between the cracks?

In another interview, I finally established that the worker had no direct experience of working with the service users whose sexual behaviour is unacceptable, and said to her that I could not interview her because of this. She paid me no heed and sat waiting for my next question. I did not feel that I could ask her to leave the interview so instead began to ask her about the organization she worked for, which had a different structure to any I had come across before. Perhaps I should have been a bit more assertive in both these cases, yet when people put themselves forward to help you by agreeing to be interviewed then it is an awkward situation in which there is the possibility of coming across as rude and ungrateful. One further aspect of being 'nice' is the will to please. In Charles' case I got the impression, which may have been wrong, that he hoped I would be able to do something about his situation, and because this was not part of my remit as a researcher, I still feel that to some extent I let him down.

One further aspect of interviewing that arose concerned their quality, as defined by the amount of relevant detail they produced. All but four were of extremely high quality and of obvious use. However, given that questions of status, and 'proximity' were part of my project these scantily detailed interviews actually verified the pattern of knowledge of and involvement with service users' unacceptable sexual behaviour. This was evidenced by their silences. Or have I merely turned a problem to my advantage? Quite honestly I do not think that I have. It would not have been in the spirit of Phenomenological Hermeneutics to ask other workers about the knowledge and involvement of those who are part-time, casual or probationers. They had to give their own accounts in order for my conclusions to have any research value.

Regarding my interview schedule, the first question concerned the worker's awareness of their organisation's policy on Sexuality and Relationships. The first worker I interviewed was embarrassed when I asked her about this and said that she

should have read it before being interviewed. This was not what I intended them to do at all. I only wanted to know if they had had the opportunity to read it, not ask them detailed questions about it like in a class-room test, and I did not feel good about making them feel uncomfortable in this way. Subsequent workers were also put out by this question so I stopped asking it and changed the focus of my interest in these policies from ways in which they might influence the worker's practice to a review of their content regarding the support of service users whose sexual behaviour is unacceptable.

Although I did not get as many interviews as I wanted I visited several workplaces I had never been to before. All were modern, bright and well decorated except for one which put me in mind of one of the negative aspects of group homes that you occasionally come across. The décor was dingy and in need of a lick of paint. The furniture was miss-matched and shabby as if it had been bought from a charity shop. I remember thinking that I hoped the staffs' attitudes would not match the out-of-date surroundings. This was unfair of me and far from being the case. I was forced to remember that third sector service provision depends on the generosity of others and that organizations like the one I work for, which is part of a local government Social Work Department, are very fortunate in respect of our working environment.

As an insider I had experience of some of the situations to which interviewees referred and would, where I could, offer suggestions which might help although I knew that was not what I was there to do. For example, I suggested organisations that might be able to help. However, I felt that this also made for a good relationship between us since these experiences were something we shared and could both relate to. Workers certainly responded in an open and positive way. Some even remarked that they had enjoyed the interview experience. I also offered stories from my own experience, not, as Sennett (1996) suggests, in the hope of extracting a like-for-like story, but to clarify situations or confirm that what I understood by what they were saying was correct.

When it came to writing about my findings I also found this was affected by my lack of interviews. At the outset of the research there were a couple of aspects I was particularly keen to write about. One of these was the comparison of workers' experiences in Scotland and in Melbourne. The other was related to this and concerned the lack of an equivalent of CLDNS in the latter, and the effect of this on their SCWs. I stubbornly held on to my intent to include these in my thesis no matter how often my supervisors voiced concern over the wisdom of doing so. I think this was because of the extent to which my curiosity and wish to add something to current debate in Scotland around the future of CLDNs drove my commitment to my research. Eventually – finally – sense prevailed with the acceptance that I had interviewed too few workers to make a creditable contribution in this respect.

Padgett (1998) remarks that researchers involved in qualitative research into sensitive topics often experience what she terms an emotional 'backwash' once the interview process is complete. It is true that having formed this brief but positive relationship with those who were interviewed, and getting to know their stories, I cannot go back and ask how they are getting on. This would be to ask them to breach their confidentiality agreement and thus be much more than I am entitled to. Yet it leaves me from time to time wondering how things are going for them and their service user. In short, as a researcher I have parachuted into their lives, gathered their stories, and parachuted out again. My only hope and consolation is that this research goes some way to providing them with the training, support and the regard of society which I believe they have earned.

10.6 To conclude

In Denmark Social Care Work is regarded as a profession. In Scotland and in Melbourne this is far from being the case as perceptions persist about this jobs association with undervalued work that women traditionally have done in the home. Moreover, perceptions of these workers includes that they come from some imagined unintelligent underclass – 'the great unwashed'. Evidence gathered in this research confirms the scurrilous notion of such a statement. Even when they do not have a specific role to play in the modification of service user's unacceptable sexual

behaviour, SCWs carry a large weight of responsibility in terms of the consequences for their service users if they fail to do their job, even in those situations they regard as 'not serious'. In any line of work there will be individuals who go beyond their employment remit, and I would argue that those Key Workers and Team Leaders who were interviewed can be counted in their number. Further research, I would argue will find that this is a quality common to all such workers whom I would name as experts in their 'field'. Nevertheless, this expertise is not valued and acknowledged in this society. Nor do health professionals always recognise that bringing in their level of knowledge of the service user would make for improved consultations and potentially better outcomes for the service user.

A further point concerns the proportion of service users whose sexual behaviour is unacceptable who are being treated in the community. We have seen that in certain circumstances SCWs choose to work with the behaviour without the input of health professionals. There are also circumstances where they consider it appropriate to work with health professionals. There are also occasions when even when requested, the health professional's input is just not possible. In terms of the worker's status it is thus important to remember the point made by McKenzie *et al* that these workers are dealing with the same types of behaviour as may be found in a locked ward, for example, rape and sexual assault. The fact that SCWs have these individual's care out in the community must then be regarded as a great responsibility requiring a high level of competence from those who have their care.

The level of responsibility and competence thus associated with these roles, however, goes sometimes unacknowledged by the worker herself as well as by society in general, as Social Care Work is viewed as a low status job. Yet their required skill set is under review. Currently research is underway in Scotland which considers the best ways of teaching SCWs a range of clinical skills; currently the habitus of nurses. They are also being taught how to compose social stories; currently the habitus of psychologists (Ali & Frederickson, 2006). Moreover, the strength of their rapport with these service users, according to Sadhu *et al* cited above, means that they could also successfully provide counselling services. Given that our society fails to

attribute care work with professional status, developments such as the acquisition of clinical, psychological and counselling skills, could indeed, in Bourdieu's terms, extend the habitus and social capital of Social Care Workers. However, this would not be an end in itself. The whole point of care work is to add to the quality of life of others. As McVilly (2010) suggests,

“Professionalisation of the direct support workforce might offer a way forward in the interests of both people with disability and those who provide support”.

This is to say, the value a society puts on vulnerable individuals is directly related to the value we put on those who have their care. Recognition of this in relation to people who have a learning disability and those who support them is now, I would argue, long overdue.

Bibliography

- Ali, S. & Frederickson, N. (2006). 'Investigating the evidence base of Social Stories', *Educational Psychology in Practice* 22 (4): pp. 355–77.
- Adams, R. & Savran, D. (2002), '*The masculinity studies reader.*' Adams, R. & Savran, D. (eds.), Malden: Blackwell Publishers, pp1-8.
- Allam, J., Middleton, D. and Browne, K. (1997) Different clients, different needs? Practice issues in community-based treatment for sex offenders', *Criminal Behaviour and Mental Health*, 7, pp. 60 - 84.
- Allan, G. (1991) 'Qualitative research', in Allan, G. and Skinner, C. (eds.) *Handbook for research students in the social sciences*, London, Falconer Press.
- Almond, L. and Giles, S. (2008) 'Young people with harmful sexual behaviour: do those with learning disabilities form a sub-group?' *Journal of Sexual Aggression*, 14(3), pp. 227 - 239.
- Alveson, M. (2002) *Postmodernism and social research*. Buckingham, Open University Press.
- Anells, M. (2006) 'Triangulation of qualitative approaches: hermeneutic phenomenology and grounded theory.' *Journal of Advances Nursing*, 56(1), pp. 55-61.
- Asksey, H. & Knight, R. (1999) *Interviewing for social scientists*, London, Sage.
- Atkinson, P. (1997) 'Narrative turn or blind alley?' *Qualitative Health Research*, 7, pp. 325-344.
- Barber, C. (2011) 'Encountering Learning Disability in General Health Settings.' *British Journal of Health Care Assistants*, 15(7), pp. 342-344.
- Barr, O. (2006) 'The evolving role of community nurses for people with learning disabilities: changes over an 11-year period.', *Learning Disability and Mental Health*, 15, pp. 72 - 82.
- Baszenger, I. & Dodier, N. (1997) 'Ethnography: Relating the Part to the Whole'. Silverman, D. (ed), *Qualitative Research: Theory, Method and Practice*, London, Sage.
- Bazeley, P. (2008) *Qualitative data analysis with NVivo*, Los Angeles, Sage Publications.

- Bazzo, G., Nota, L., Sores, S., Ferrari, L. Minnes, P. (2007) 'Attitudes of social service providers toward the sexuality of individuals with intellectual disability.' *Journal of Applied Research in Intellectual Disabilities*, 20, pp. 110-115.
- Beebee, J. (2003) 'Improve and Care'. *Learning Disability Practice*, 6, pp. 10 - 15.
- Bell, D.M. & Espie, J. (2002) 'A preliminary investigation into staff satisfaction, and staff emotions and attitudes in a unit for men with learning disabilities and serious challenging behaviours', *British Journal of Learning Disabilities*, 30, pp. 19 - 27.
- Bergh, P.M.v.d. and Hoekman, J. (2006) 'Sexual offences in police reports and court dossiers: A case-file study.' *Journal of Applied Research in Intellectual Disabilities*, 29, pp. 374 - 382.
- Boddy, J., Cameron, C. & Moss, P. (eds.) (2006), *Care Work: Present and future*. London: Routledge.
- Bollard, M. (1997) 'Promoting the Health Care Needs of People with Learning Disabilities', *British Journal of Community Nursing*, 12(1), pp. 46-51.
- Bourdieu, P. (1977) 'Structures, Habitus, Power: Basis for a theory of symbolic power', *Outline of Theory of Practice*, Cambridge, Cambridge University Press.
- Bowen, G.A. (2009) 'Supporting a Grounded Theory with an audit trail: an illustration', *International Journal of Social Research Methodology*, 17(4), pp. 305-316.
- Brittle, R. (2009) 'We must not lose specialist skills in learning disabilities.' *Nursing Times*.
- Brown, H. (1994) "'An ordinary sexual life?' A review of the normalisation principle as it applies to the sexual options of people with learning disabilities.' *Disability and Society*, 9(2), pp. 123-144.
- Brown, H. (1996) 'Ordinary Women: Issues for women with learning disabilities', *British Journal of Learning Disabilities*, 24, pp. 47 - 51.
- Brown, H. and Barrett, S. (1996) 'Understanding and responding to difficult sexual behaviour.' in Craft, A. (ed), *Practical issues in sexuality and learning disabilities*, London, Routledge.
- Brown, H. and Stein, J. (1997) 'Sexual abuse perpetrated by men with intellectual disabilities: a comparative study.' *Journal of Intellectual Disability Research*, 41(3), pp. 215- 224.
- Brown, H., Stein, J. & Turk, V. (1995) 'The sexual abuse of adults with learning disabilities: Report of a second two-year incidence survey.' *British Journal of Learning Disabilities*, 8(1), pp. 3-24.

- Brown, J.F. (2005) 'Maintaining long-term therapeutic programmes: A qualitative case study.' *British Journal of Learning Disabilities*, 34, pp. 117 - 121.
- Brown, L. (1998) 'Challenging and inappropriate sexual behaviour in people with learning disabilities: A literature review.' in Office, T.S. (ed.), Edinburgh, The Scottish Office Central Research Unit.
- Bryman, A. (2004) *Social research methods*, Oxford, Oxford University Press.
- Buckley, C. & Waring, M. (2009) 'The evolving nature of grounded theory; experiential reflections on the potential of the method for analysing children's attitudes towards physical activity.' *International Journal of Social Research Methods*, 12(4), pp. 317-334.
- Cambridge, P. & Mellan, B. (2000) 'Reconstructing the sexuality of men with learning disabilities: Empirical evidence and theoretical interpretations of need.' *Disability and Society*, 15(2), pp. 293-311.
- Carter, S.M. & Little, M. (2007) 'Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research.' *Qualitative Health Research* (17), pp. 1316-1328.
- Chaplin, E. (2008) 'Mental Health Services for People with Intellectual Disability: Challenges to Care Delivery.' *British Journal of Learning Disabilities*, 37, pp. 157-164.
- Charmaz, K. (2007) *Constructing Grounded Theory*, Los Angeles, Sage Publications.
- Chivers, J. & Mathieson, S. (2000) 'Training in sexual relationships: An Australian Model' *Sexuality and Disability*, 18(1), pp. 73-80.
- Christian, L., Stinson, J., & Dotson L. A. (2001) 'Staff values regarding the sexual expression of women with developmental disabilities.' *Sexuality and Disability*, 19(4), pp. 283 - 291.
- Churchill, J. and Livingstone, J. (1997) 'Managing the service on a day to day basis.' In Churchill, J., Brown, H., Craft, A. and Horrocks, C. (eds), *There are no easy answers: The provision of continuing care and treatment of adults with learning disabilities who sexually abuse others.*, Chesterfield: Nottingham, ARC & NAPSAC. Pp 126-150.
- Clare, I & Carson, D. (1997), 'Practice: Wise and defensible decisions. In Churchill, J., Brown, H., Craft, A. and Horrocks, C. (eds), *There are no easy answers: The provision of continuing care and treatment of adults with learning disabilities who sexually abuse others.* Chesterfield: Nottingham, ARC & NAPSAC. Pp 69-88.

- Courtney, J. & Rose, J. (2004) 'The effectiveness of treatment for male sex offenders with learning disabilities: A review of the literature.' *Journal of Sexual Aggression*, 19(2), pp. 215 - 236.
- Craft, A. & Brown, H. (1996) 'Personal relationships and sexuality: the staff role.' in Craft, A. (ed), *Practical issues in sexuality and learning disabilities*, London, Routledge.
- Craig, L. & Hutchinson, R.B. (2005) 'Sexual offenders with learning disabilities; risk recidivism and treatment.' *Journal of Sexual Aggression*, 11(3), pp. 289-304.
- Crotty, M. (1998) *The foundations of social research*, London, Sage Publications.
- Davies, C. (1998), 'Caregiving, carework and professional care.' In A. Brechin *et al* (eds.) *Care Matters: Concepts, practice and research in Health and Social Care*. Pp126-138.
- Day, K. (1993), Crime and mental retardation: A review. In Howells, K & Hollina, C.R. (eds.), *Clinical approaches to the mentally disordered offender*. Chichester, John Wiley & Sons, pp 111-114.
- de Santos, R. (2008) *Sub-Prime driven recession: Coming to a neighbourhood near you*. Edinburgh, Scottish Socialist Party.
- Deer, C. (2010) 'Doxa', in Grenfell, M. (ed.), *Pierre Bourdieu: Key Concepts*, Durham, Acumen Publishing Ltd. Pp 199-212
- DHS (2006), *Personal relationships, sexuality and sexual health policy and guidelines*. Melbourne, Victorian Government Department of Human Services.
- Dinsmore, A. & Higgins, L. (2011) 'Study of Patient's Experiences of Treatment by Hospital Staff.' , *Learning Disability Practice*, 14(5), pp. 18-22.
- Doran, T. (2001) 'Providing Seamless Community Health and Social Services', *British Journal of Community Nursing*, 6(8), pp. 387-393.
- Duncan, C., Cloutier, J.D. & Bailey, P.H. (2007) 'Concept analysis: the importance of differentiating the ontological focus.' *Journal of Advances Nursing*, 58, pp. 293-300.
- Edinburgh Evening News, 7th January, 2012: 28.
- Erenreich, B. & Hochschild, A. (Eds.) (2003), *Global Women: Nannies, Maids and Sex Workers in New Economy*, Metropolitan Books, New York
- Evans, J. (2002) 'Cautious caregivers; gender stereotypes and the sexualization of men nurses' touch.', *Journal of Advances Nursing*, 40(4), pp. 441-448.

- Fairbairn, G. (2002) 'Sex matters.', *Learning Disability Practice*, 5: pp20-24.
- Finch, J. (1984) "'It's Great to have Someone to Talk To": Ethics and Politics of Interviewing Women.', in Bell, C. & Roberts, H. (eds.), *Social Researching: Politics, Problems and Practice*, London, Routledge.
- Fyson, R. (2007) 'Young people with learning disabilities who sexually harm others: the role of criminal justice within a multi-agency response', *British Journal of Learning Disabilities*, 35, pp. 181 - 186.
- Garrett, P. M. (2007) 'Making Social Work more Bourdieusian: Why the social professions should critically engage with the work of Pierre Bourdieu.' *European Journal of Social Work*, (10),3: pp225-243.
- Gates, B. (2011) 'The Value People Project: Users' Views on Learning Disability Nursing.', *British Journal of Nursing*, 20(1), pp. 15-21.
- Grandey, A. A. (2000) 'Emotional regulation in the workplace: A new way to conceptualise emotional labor' *Journal of Occupational Health Psychology*, (5), 1: pp95-110.
- Graydon, C. (2006) 'Can Consent be Uninformed? Suggested Reform of Sexual Offences Against Persons with Intellectual Disability.', *Social Change in the 21st Century Conference*, Queensland University of Technology.
- Grieve, A., McLaren, S., Lindsay, W. & Culling, E. (2008) 'Staff attitudes towards the sexuality of people with learning disabilities; a comparison of different professional groups and residential facilities.' *British Journal of Learning Disabilities*, 37, pp. 76-84.
- Grieve, A., McLaren, S. & Lindsay, W. (2006) 'An evaluation of research and training resources for the sex education of people with moderate to severe learning disabilities.' *British Journal of Learning Disabilities*, 35, pp. 30- 37.
- Hames, A. & Carlson, T. (2006) 'Are primary health care staff aware of the role of community learning disability teams in relation to health promotion and health facilitation?' *British Journal of Learning Disabilities*, 34, pp. 6 - 10.
- Hayes, S. (1991) 'Sex offenders.' *Australian and New Zealand Journal of Developmental Disabilities*, 17(2), pp. 221 - 227.
- Hayes, S.-J., Murphy, G., Langdon, P.E., Rose, D. & Reed, T. (2007) 'Group treatment for men with intellectual disability and sexually abusive behaviour: Service user views.' *Journal of Intellectual and Developmental Disability*, 32(2), pp. 106-116.

- Heath, H. & Cowley, S. (2004) 'Developing a grounded theory approach: a comparison of Glaser and Strauss.' *International Journal of Nursing Studies*, 41, pp. 141-150.
- Hewitt, A. & Larson, S. (2007) 'The direct support workforce in community supports to individuals with developmental disabilities: Issues, implications, and promising practices.' *Mental Retardation and Developmental Disability Research Review*, 13:2, pp. 178-187.
- Hill, M. (1997) *Understanding Social Policy* (5th Ed.), Oxford, Blackwell Publishing
- Hill-Tout, J., Thomas, J. & Dunkerton, K. (1998) 'Managing the support of a sex offender with learning disabilities in the community: A team approach to intervention.' *Journal of Learning Disabilities for Nursing, Health and Social Care*, 2(3), pp. 163-167.
- Hochschild, A. R. (1983) *The Managed Heart: Commercialization of Human Feeling*, Berkley, University of California Press.
- Hugman, R. (1991) *Power in the Caring Professions*, London, Macmillan.
- Huppertz, K. (2009) 'Reworking Bourdieu's 'Capital'; Feminine and female capitals in the field of paid caring work.' *Sociology*, 43(45), pp. 45-66.
- Jones, A. (2006) 'Meeting the Cancer Information Needs of People with Learning Disabilities: Experiences of Paid Carers.' *British Journal of Learning Disabilities*, 35, pp. 12-18.
- Jones, M.C., McLafferty, E., Walley, R., Toland, J. & Melson, N. (2008) 'Inclusion in primary care for people with intellectual disabilities: gaining the perspective of service user and supporting social care staff.' *Journal of Intellectual Disabilities*, 12, pp. 93-109.
- Joyce, T.A. (2003) 'An audit of investigations into allegations of abuse involving adults with intellectual disability.' *Journal of Intellectual Disability Research*, 47(8), pp. 606 - 616.
- Jukes, M. (2004) 'Learning Disability Care: Is Valuing People Working?' *British Journal of Nursing*, 13(2), p.65.
- Jukes, M. & Bollard, M. (2003) *Contemporary learning disability practice*, Salisbury, Quay Books.
- Karellou, J. (2003) 'Development of the Greek Sexuality Attitudes Questionnaire - Learning Disabilities (GSAQ-LD).' *Sexuality and Disability*, 21(2), pp. 113 - 135.
- Karellou, J. (2004) 'Laypeople's attitudes towards the sexuality of people with learning disabilities in Greece.' *Sexuality and Disability*, 21(1), pp. 68-83.

Keeling, J.A. and Rose J L (2006) 'The adaptation of a cognitive-behavioural treatment programme for special needs sexual offenders', *British Journal of Learning Disabilities*, 34, pp. 110 - 116.

Keeling, J. *et al* (2009) 'Sexual Offending Theories and Offenders with Intellectual Disabilities.' *Journal of Applied Research in Intellectual Disabilities*, 22, pp468-476.

Keene, J. and Li, X. (2005) 'A Study of Total Social Services Care Population and its Interagency Shared Care.' *British Journal of Social Work*, 35, pp. 1145-1161.

Keywood, K. (2003) 'Supported to be Sexual? Developing Sexual Rights for People with Learning Disabilities.' *Tizard Learning Disability Review*, 8(3), pp. 30-36.

King, G., Kwohane, R.O. & Verba, S., (1994) *Designing social inquiry; Scientific inference in qualitative research*. Princeton, New Jersey, Princeton University Press.

Kirkintilloch Herald, *Tory mocks carers as the 'great unwashed'*. 6th October, 2010: p5.

Koch, T. (1994) 'Establishing rigour in qualitative research: the decision trail.' *Journal of Advanced Nursing*, 19, pp. 976-986.

Koch, T. (1995) 'Interpretative approaches in nursing research: the influence of Husserl and Heidegger.' *Journal of Advanced Nursing*, 21, pp. 827 - 836.

Koch, T. (1996) 'Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation.' *Journal of Advanced Nursing*, 24, pp. 174 - 184.

Lambrick, F. & Glaser W (2004) 'Sex offenders with an intellectual disability.' *Sexual Abuse: A Journal of Research and Treatment*, 16(4), pp. 381 - 392.

Langdon, P. and Maxted, H. (2007) 'An exploratory evaluation of the Ward and Hudson Offending Pathways model with sex offenders who have intellectual disability.' *Journal of Intellectual and Developmental Disability*, 32(2), pp. 94 - 105.

Lee, R.M. (1993), *Doing research on sensitive topics*. London, Sage.

Lillywhite, A. & Atwal, A. (2003) 'Occupational Therapists' Perceptions of the Role of Community Learning Disability Teams.' *British Journal of Learning Disabilities*, 31, pp. 130-135.

Lindsay, W. (2004) 'Sexual and non-sexual offenders with intellectual and learning disabilities.' *Journal of Interpersonal Violence*, 19(9), pp. 875 - 890.

Lindsay, W. & Taylor, S.J. (2005) 'Model underpinning treatment of sex offenders with mild intellectual disability.' *Mental Retardation*, 43:6, pp. 428-441.

- Lindsay, W., Mitchie, A. M., Whitefield, E., Martin, V., Grieve, A. & Carson, D. (2006) 'Response patterns of the questionnaire on attitudes consistent with sexual offending in groups of sex offenders with intellectual disabilities.' *Journal of Applied Research in Intellectual Disabilities*, 19, pp. 27 - 53.
- Lindsay, W.R., Smith, A., Quinn, K., Anderson, A., Smith, A., Allan, R. & Law, J. (2004) 'Women with intellectual disability who have offended: characteristics and outcomes.' *Journal of Intellectual Disability Research*, 48(5), pp. 580-590.
- Lockhart, K. (2009) 'Defining 'Sexualised Challenging Behaviour' in adults with intellectual Disabilities.' *Journal of Policy and Practice in Intellectual Disabilities*, 6(4), pp. 293-301.
- Lofgren-Martenson, L. (2004) 'May I?' About sexuality and love in the new generation with intellectual disabilities.' *Sexuality and Disability*, 32(3), pp. 197 - 207.
- Lopez, J. and Scott, J. (2000) *Concepts in the Social Sciences: Social structure*, Buckingham, Open University Press.
- Loretto, (2011), *Relationships and sexual wellbeing policy*, p4.
- Lyall, I., Holland A J & Collins S (1994) 'Offending by adults with learning disabilities and the attitudes of staff to offending behaviour: Implications for service development.' *Journal of Intellectual Disability Research*, 39(6), pp. 501 - 508.
- Macdonald, K.M. (1999) *The Sociology of the Professions*, London, Sage.
- Mackenzie, F. (2005) 'The roots of biomedical diagnosis.' in Grant, G. (ed.), *Learning disability: A life cycle approach to valuing people*. Maidenhead, O U Press.
- Malone, M., Berkowitz, N.H. & Klein, M.W. (1961) 'The Paradox of Nursing', *American Journal of Nursing*, 61, pp. 52-55.
- Mansell, J. (2005) 'Deinstitutionalisation and community living: An international perspective.' *Learning Disability Review*, 10(1), pp. 22 - 29.
- Manthorpe, J. *et al* (2010) 'Social Care Workers in Social Care in England: A scoping study.' *Health and Social Care in the Community*, 18: 3, pp. 316-324.
- Markoff, J. (1990) 'A comparative method: Reflections on Charles Ragin's innovations in comparative analysis.' *Historical Methods*, 23(4), pp. 177-181.
- Marshall, C. & Rossman G B (1995) *Designing qualitative research* (2nd Edition). Thousand Oaks: Sage.

- Maton, K. (2010) 'Habitus', in Grenfel, M. (ed.), *Pierre Bourdieu: Key Concepts*, Durham, Acumen Publishing Ltd. pp49-66.
- McBrien, J. & Murphy, G. (2006) 'Police and carers' views on reporting alleged offences by people with intellectual disabilities', *Psychology, Crime and Law*, 12(2), pp. 127 - 144.
- McCarthy, M. & Thompson, D. (2000) *Sex and Staff Training: Sexual Abuse and Safer Sex*, Brighton, Pavilion.
- McClimens, A. & Coombes H (2005) '(Almost) everything you wanted to know about sexuality and learning disability but were always too afraid to ask.' in Grant, G. (ed.), *Learning Disability: A life cycle approach to valuing people*, Maidenhead, O U Press.
- McConkey, R. (2005) 'Multi-agency Working in Support Services with Intellectual Disabilities.' *Journal of Intellectual Disability*, 19(3), pp. 193-207.
- McConkey, R., & McAuley, P., Simpson, L. and S, C. (2007) 'The Male Workforce in Intellectual Disability Services', *Journal of Policy and Practice in Intellectual Disabilities*, 4(3), pp. 186-193.
- McConkey, R. & Ryan D (2001) 'Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability.' *Journal of Intellectual Disability Research*, 45(1), pp. 83-87.
- McCormack, B., Kavanagh, D., Caffrey, S. & Power, A. (2005) 'Investigating sexual abuse: findings of a 15-year longitudinal study.' *Journal of Applied Research in Intellectual Disabilities*, 18, pp. 217-227.
- McCreddie, M. & Wiggins, S. (2009) 'Reconciling the good patient persona with problematic and non-problematic humour; A Grounded Theory.' *International Journal of Nursing Studies*(30).
- McKenzie, K., Matheson, E., McKaskie, K., Patrick, S., Paxton, D., Michie, A.M. & Murray, G.C. (2011) 'Health and social care staff responses to working with people with a learning disability who display sexual offending type behaviours.' *Journal of Sexual Aggression*, 7(1), pp. 56 - 66.
- McMillan, I. (2008) 'Time to tackle taboos over clients' sexual needs.', *Learning Disability Practice*, 11(6), p. 6.
- McMillan, I. (2009) 'A gem of a service.' *Learning Disability Today* (April 2009), pp. 15 - 17.
- Mee, S. (2010) 'You're not to dance with the girls: oral history, changing perception and practice.' *Journal of Intellectual Disabilities*, 14(33), pp. 33-42.

- Michie, A.M., Lindsay, W.R., Martin, V. & Grieve, A. (2006) 'A test of counterfeit deviance: A comparison of sexual knowledge in groups of sex offenders with intellectual disability and controls.' *Sex Abuse*, (18), 3: pp271-278.
- Miller, J. & Glassner B (1997) 'The 'Inside' and the 'Outside': Finding realities in interviews.', in Silverman, D. (ed.), *Qualitative research: Theory, method and practice*. London, Sage Publications.
- Milligan, M.S. & Neufeldt, A.H. (2001) 'The myth of asexuality: A survey of social and empirical evidence.', *Sexuality and Disability*, 19(2), pp. 91-109.
- Mills, J., Bonner, A. & Francis, K. (2006) 'The development of constructivist grounded theory.' *International journal of Qualitative Methods*, 5(1), pp. 1-10.
- Moore, R. (2010) 'Capital', in Grenfell, M. (ed.), *Pierre Bourdieu: Key Concepts*, Durham, Acuman Publishing Ltd. pp101-118.
- Moses, J.W. & Knutson, T.L. (2007) *Ways of Knowing: Competing Methodologies in Social and Political Research*. Houndsmill, Macmillan.
- Mott, S., Chau, A. & Chan, J. (2007) 'Meeting the health needs of people with disability living in the community', *Journal of Intellectual Disability*, 32(1), pp. 51 - 53.
- Muir, W. & Gibbs, S. (2006) 'Research in the psychiatry of learning disability.' in Freeman, C. and Tyrer, P. (eds.), *Research Methods in Psychiatry*, London, Gaskell (Royal College of Psychiatry).
- Munro, A., Holly, L., Rainbird, H. & Leisten, R. (2004) 'Power at Work: Reflections on the Research Process.' *International Journal of Social Research Methodology*, 7, pp. 289-304.
- Murray, S. (2009) *Assessment of the impact of compulsory registration and accreditation systems of support staff on disability service provision: England, Scotland, Norway, USA and Canada*, Churchill Fellowship Report, The William Churchill Memorial Trust of Australia.
- Noone, S.J. and Hastings, R.P. (2009) 'Building psychological resilience in support staff caring for people with intellectual disabilities.' *Journal of Intellectual Disabilities*, 13(43), pp. 43-53.
- Noordegraaf, M. & Schinkel, W. (2011), 'Professional capital contested: A Bourdieusian analysis of conflicts between professionals and managers.' *Comparative Sociology*, (10): pp 97-125.
- Norman, I.J. (1998) 'The changing emphasis of mental health and learning disability nurse education in the UK and ideal models of its future development.' *Journal of Psychiatric and Mental Health Nursing*, 5, pp. 41-51.

- Norman, I.J. (1998) 'Priorities for mental health and learning disability nurse education in the UK: a case study.' *Journal of Clinical Nursing*, 7, pp. 433-441.
- O'Sullivan, T., Hartley, J., Saunders, D., Montgomery, M. & Fiske, J. (1996), *Key concepts in communication and cultural studies*. London, Routledge.
- Owen, S. & Standen, P. (2007) 'Attracting and retaining learning disability student nurses.' *British Journal of Learning Disabilities*, 35, pp. 261-268.
- Padgett, D.K. (1998) *Qualitative methods in Social Work research: Challenges and rewards*, Thousand Oaks, Sage Publications.
- Parkes, N. & Jukes, M. (2008) 'Professional boundaries in a Person-Centred Paradigm.' *British Journal of Nursing*, 117(21), pp. 1358-1364.
- Perera, C., Simpson, N., Douds, F. & Campbell, M. (2009) 'A survey of learning disability inpatient services in Scotland in 2007.' *Journal of Intellectual Disabilities*, 13, pp. 161-171.
- Plummer, K. (2001) 'The Moral and Human Face of Life Stories: Reflexivity, Power and Ethics', in Plummer, K. (ed.), *Documents of Life - 2*, London, Sage.
- Pollard, K.C. & Meirs, M.E. (2008) 'From students to professionals: Results of a longitudinal study of attitudes to pre-qualifying collaborative learning and working in health and social care in the United Kingdom.' *Journal of Interprofessional Care*, 22(4), pp. 399-416.
- Poole, M. & Isaacs, D. (1997) 'Caring: A gendered concept', *Women's Studies International Forum*, 20(4), pp. 529-536.
- Prior, L. (1997) 'Following in Foucault's footsteps: text and context in qualitative research.' in Silverman, D. (ed.), *Qualitative Research: Theory, method and practice.*, London, Sage Publications.
- Rabinow, P. (ed.) (1991) *The Foucault Reader: An Introduction to Foucault's Thoughts*, London, Penguin Books.
- Race, D. (1996) *Stockport work training project*, North Western Regional Health Authority, Training & Development Team.
- Ragin, C.C. (1981) 'Comparative sociology and the comparative method.' *International Journal of Comparative Sociology*, 22, pp. 102-120.
- Reinders, H. (2010) 'The importance of tacit knowledge in practise of care.' *Journal of Intellectual Disability Research*, 54:1, pp. 28-37.
- Reinharz, S. (1997) 'Who am I? The Need for a Variety of Selves in the Field.', in Herz, R. (ed.), *Reflexivity and Voice.*, London, Sage.

- Richardson, S. & Asthana, S. (2006), 'Inter-agency Information Sharing in Health and Social Care.' *British Journal of Social Work*, 36: 657-669.
- Riddell, S. & Watson, N. (2003) *Disability, culture and identity*, Harlow: Pearson/Prentice Hall
- Riessman, C.K. & Quinney L (2005) 'Narrative in Social Work: A critical review.' *Qualitative Social Work*, 4, pp. 391- 412.
- Robertson, J. & Clegg, J. (2002) 'Dilemmas in the community risk management of sexually offensive behaviour.' *British Journal of Learning Disabilities*, 30, pp. 171-175.
- Robson, C. (2006) *Real world research*. Malden, Blackwell Publishing.
- Sajith, S.G., Morgan C & Clarke D (2008) 'Pharmacological management of inappropriate sexual behaviours: A review of its evidence, rationale and scope in relation to men with intellectual disabilities.' *Journal of Intellectual Disability Research*, 52(12), pp. 1078 - 1090.
- Sandhu, D.K., Rose, J., Rostill-Brookes, H.J. & Thrift, S. (2012) 'It's intense, to an extent': A Qualitative Study of the Emotional Challenges Faced by Staff Working on a Treatment Programme for Intellectually Disabled Sex Offenders.' *Journal of Applied Research in Intellectual Disabilities*, 25, pp. 308-318.
- Sangster, M. (2007) 'How do support workers of people with learning disabilities negotiate the tension between their protection and empowerment as sexual beings?' MSc. Dissertation, Edinburgh, University of Edinburgh.
- Schinkel, W. & Noordegraaf, M. (2011), 'Professionalism as symbolic capital: Materials for a Bourdieusian theory of professionalism.' *Comparative Sociology*, (10): pp67-96.
- Schuengel, C. *et al* (2010) 'People who need people: Attachment and professional caregiving.' *Journal of Intellectual Disability Research*, 54:1, pp. 38-47.
- Scottish Executive, (2005), *National Care Standards: Care Homes for People with Learning Disabilities*. Edinburgh, Scottish Executive.
- Sennett, R. (1996) *The Uses of Disorder: Personal Identity and City Life*. London, faber & faber.
- Sheeran, F.K. & McConkey, R. (2008) 'Frontline care in Irish intellectual disability services: the contribution of nurses and non-nurse care staff.' *Journal of Intellectual Disability*, 12, pp. 127-140.

- Simpson, A., Lafferty A. & McConkey, R. (2006) 'Out of the shadows: "our voices aren't going to go quietly into the dark anymore" (Self-advocate)', Belfast, University of Ulster.
- Slaughter, S., Dean Y, Knight H, Krieg B., Mor P., Nour V., Polegate E., Senaviraine C., Shenfield G. & Sherwood E. (2007) 'The inevitable pull of the river's current; Interpretations derived from a single text using multiple research traditions.' *Qualitative Health Research*, 17, pp. 548 - 561.
- Slevin, E. (2004) 'Learning disabilities: a survey of community nurses for people with a prevalence of challenging behaviour and contact demands.' *Journal of Clinical Nursing* (13), pp. 571-579.
- Slevin, E. & Sines, D. (2005) 'The role of community nurses for people with learning disabilities; working with people who challenge.' *International Journal of Nursing Studies*, 42, pp. 415 - 427.
- Smith, M.J. (1998) *Social Science in Question*. London, Sage Publications.
- Smith, P. & Gray, B. (2001) 'Reassessing the concept of emotional labour in the student nurse education: role of link lecturers and mentors in a time of change.' *Nurse Education Today*, 21, pp. 230- 237.
- Stark, H. & Brown Trinidad, S. (2007) 'Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory.' *Qualitative Health Research*, 17, pp. 1372 - 1380.
- Strauss, A. and Corbin, J. (1990) *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, Sage Publications.
- Sturdy, A., Knights D. & Willmott H. (1992) *Skill & Consent: Contemporary Studies in the Labour Process*. London, Routledge.
- Swengo-Wilson, A. (2008) 'Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities.' *Sexuality and Disability*, 26, pp. 167 - 174.
- Tarnai, B. (2006) 'Review of effective interventions for socially inappropriate masturbation in persons with cognitive disabilities.' *Sexuality and Disability*, 24, pp. 151-168.
- Thompson, D. (2009) 'Ethical and legal issues regarding restrictive responses to men with learning disabilities who sexually abuse.' in OLM-pavilion (ed.), *Sexual Lives*, Glasgow, Pavilion.
- Thompson, D., Clare I. & Brown H. (1997) 'Not such an 'ordinary relationship': The role of women support staff in relation to men with learning disabilities who have difficult sexual behaviour.' *Disability and Society*, 12 (4573 - 592).

- Thompson, D.J. (2000) 'Vulnerability, dangerousness and risk: the case of men with learning disabilities who sexually abuse.' *Health, Risk, and Society*, 2(1), pp. 33-46.
- Thomson, P. (2010) 'Field', in Grenfell, R. (ed.), *Pierre Bourdieu: Key Concepts*, Durham, Acumen Publishing Ltd. pp67-84.
- Tudway, J.A. & Darmoody M (2005) 'Clinical assessment of adult sexual offenders with learning disabilities.' *Journal of Sexual Aggression*, 11(3), pp. 277 - 288.
- Vaughn, P.J. (2003) 'Secure care and treatment needs of individuals with learning disability and sever challenging behaviour.' *British Journal of Learning Disabilities*, 31, pp. 113-117.
- Virkki, T. (2008) 'The art of pacifying an aggressive client; 'Feminine' skills and preventing violence in caring work.' *Gender, Work and Organisation*, 15(1), pp. 72 - 87.
- Walker, D. & Myrick, F. (2006) 'Grounded Theory: an exploration of process and procedure.' *Qualitative Health Research*, 16, pp. 547-559.
- Walmsley, J. (2004) 'Inclusive Learning Disability research: the (non-disabled) researcher's role.' *British Journal of Learning Disabilities*, 32(2), pp. 65 - 71.
- Walsh, A. (2000) 'IMPROVE and CARE: Responding to Inappropriate Masturbation in People with Severe Intellectual Disabilities.' *Sexuality and Disability*, 18 (1).
- Walsh-Mooney, H.A. (2009) 'The Value of Rapport in Rangetahi Maori Mental Health: A Maori Social Work Perspective.' Masters dissertation: Palmerston North, Massey University.
- Walters, A.J. (1994) 'The comforting role in critical care nursing practice: a phenomenological interpretation.' *International Journal of Nursing Studies*, 31(6), pp. 607-616.
- Walters, A.J. (1995) 'The phenomenological movement: implications for nursing research.' *Journal of Advances Nursing*, 22, pp. 791-799.
- Ward, K.M., Trigler J.S. & Pfeiffer, K.T. (2001) 'Community service issues.' *Mental Retardation* (39), pp. 11-19.
- Webb, K. (1995), *An introduction to problems in social science*, Bloomsbury, Pinter.
- Weeks, J. (1995) *Invented moralities: sexual values in an age of uncertainty*. New York, Columbia University Press.
- Weeks, J. (2000) *Making Sexual History*, Cambridge, Polity Press.

- Wheeler, P. & Jenkins, R. (2004) 'The management of challenging sexual behaviour.' *Learning Disability Practice*, 7(5), pp. 28-35.
- Wilcox, D.T. (2004) 'Treatment of intellectually disabled individuals who have committed sexual offences: A review of the literature.' *Journal of Sexual Aggression*, 10(185-100).
- Wilcox, E., Finlay, W.M. & Edmonds, J. (2006) 'His brain is totally different': An analysis of care-staff explanations of aggressive challenging behaviour and the impact of gendered discourses.' *British Journal of Social Psychology*(45), pp. 197-216.
- Wilkins, R. (1993) 'Taking it Personally: A Note on Emotions and Autobiography.' *Sociology*, 27, pp. 93-100.
- Willner, P. & Smith, M. (2008) 'Can attribution theory explain carers' propensity to help men with intellectual disabilities who display inappropriate sexual behaviour?' *Journal of Intellectual Disability Research*, 52(1), pp. 79 - 88.
- Wilson, N. (2009), '*Conditionally sexual*'. *Constructing the sexual health needs of men and teenage boys with a moderate to profound intellectual disability*. Unpublished doctoral thesis, Faculty of Medicine, University of Sydney
- Yacoub, E. and Hall I (2008) 'The sexual lives of men with mild learning disability: A qualitative study.' *British Journal of Learning Disabilities*, 37, pp. 5 - 11.
- Yates, S.J. (2004) *Doing social science research*. London, Sage Publications.

Websites

- Australian Government, (<http://www.comlaw.gov.au/comlaw/management.nsf/lookupindexpagesbyid/IP20041406?OpenDocument>, accessed 5/7/2010).
- Australian Government, (<http://www.hreoc.gov.au/about/legislation/index.html#ahrc> accessed 5/7/2010)
- BBC (<http://www.bbc.co.uk/news/uk-13548222>, accessed 4/12/12)
- Brooks, <http://www.qub.ac.uk/methics/BrooksK.pdf>, accessed 11/08/12
- City of Edinburgh Council, (2004), *Making Choices, Keeping Safe*. http://www.mcks.scot.nhs.uk/resources/Making_Choices_April_2004.pdf, accessed, 15/05/2007.
- Disability Forensic Assessment and Treatment Service, <http://www.dhs.vic.gov.au/home>, accessed 15/10/09.

DHS (2010) (<http://intranet3.csv.au/disability/residential>, accessed 18/06/2010).

ESRC

http://www.esrc.ac.uk/images/PFG_Non_DTC_Version_August_2012_tcm8-19338.pdf accessed 12/09/2008.

Guardian, (<http://www.guardian.co.uk/society/2011/jun/20/police-failing-learning-disabilities-study>, accessed 23/08/11).

HMSO (2007), Adult Support and Protection Act (2007)

<http://www.legislation.gov.uk/asp/2007/10/contents> (accessed, 20/10/09)

HMSO (2009) 'Adults with Incapacity (Scotland) Act (2000)',

<http://www.hmso.gov.uk/legislation/scotland/acts2000/20000004.htm>, accessed 15/10/09

HMSO (2009) 'Mental Health (Treatment and Care) (Scotland) Act.',

<http://www.hmso.gov.uk/legislation/scotland/acts2003/20030013.htm>, accessed 1/10/09.

HMSO (2009) 'Sexual Offences Act',

<http://www.legislation.gov.uk/asp/2009/9/contents>, accessed 3/10/09.

Hershberger, E.(2010), <http://www.ncbi.nlm.nih.gov/pubmed/20095765>, accessed 06/06/12.

McVilly (2010) 'Professionalism and Professional Accreditation: International Context, National Developments and Local Implications.

(<http://www.nds.org.au/presentation/article/17>, accessed 16/12/12).

Mental Welfare Commission, (2009), <http://www.mwscot.org.uk/>, accessed 25/09/09.

Mental Welfare Commission, (2009), 'Rights and Risks.'

<http://www.mwscot.org.uk/search/?keyword=Right%2C+risks>, accessed 25/09/09.

Mental Welfare Commission (2009), 'Rights of Carers.'

<http://www.mwscot.org.uk/search/?keyword=Rights+of+Carers>, accessed 27/09/09.

OPA (2009) *Independent Third Person Program* run by Victoria's Office of the Public Advocate (OPA). <http://www.publicadvocate.vic.gov.au/services/108/>, accessed 05/05/10.

Open University (Giddens, A.)

(http://www.open.ac.uk/socialsciences/identities/pdf/modernity_and_selfidentity_revisited.pdf, (accessed 9/01/2012).

Panorama, <http://www.bbc.co.uk/news/uk-13548222>, accessed 4/12/12)
Respond, <http://www.respond.org.uk/what-we-do/children-and-young-people-sservices/>, accessed 12/05/09).

Scottish Government (<http://www.scotland.gov.uk/Topics/health/care/adult-care-and-support/learning-disability>): accessed 26/8/2009.

Scottish Government (<http://www.legislation.gov.uk/asp/2002/5/contents>, accessed 01/09/10.

Scottish Government,

<http://www.scotland.gov.uk/Resource/Doc/181958/0051706.pdf>, accessed 24/06/10.

Scottish Government , Mental Health (Treatment and Care) (Scotland) Act 2003,
<http://www.scotland.gov.uk/Publications/2005/08/29100428/04289>,

Scottish Government, <http://www.scotland.gov.uk/Publications/2007/07/16091605/0>

Scottish Social Services Council (2005) *Codes of Practice for Social Service Workers and Employers*. <http://www.sssc.uk.com/>, accessed, 24/10/09.

Sondenna *et al* (http://www.medscape.com/viewarticle/581737_6), accessed 20/06/13.

State of Victoria,

(http://www.dhs.vic.gov.au/disability/improving_supports/quality_framework ,
accessed/05/07/10

State of Victoria, *State Disability Plan 2002 – 2012* ,

http://www.field.org.au/legislation/responsibilities/state_plan.html, accessed 30/09/09.

State of Victoria (2008) Family Violence Protection Act 2008,
[http://www.legislation.vic.gov.au/domino/Web_Notes/LDMS/LTOObject_Store/LTObjSt6.nsf/DDE300B846EED9C7CA257616000A3571/356F2A5EEEF039B4CA257981000F4E7F/\\$FILE/08-52aa013%20authorised.pdf](http://www.legislation.vic.gov.au/domino/Web_Notes/LDMS/LTOObject_Store/LTObjSt6.nsf/DDE300B846EED9C7CA257616000A3571/356F2A5EEEF039B4CA257981000F4E7F/$FILE/08-52aa013%20authorised.pdf), accessed 27/09/09.

S Woolley (2005) <http://adc.bmj.com/content/90/7/715.full>, accessed 16/12/12.

Appendix i

The 'Old' Days

Although my semi-structured interview schedule did not include questions about the past, several interviewees including those who were younger as well as those who were older, thought it important to explain how things were in the past with regard to interventions in service users' unacceptable sexual behaviour. Since this thesis is about their experiences, and it is in the spirit of qualitative research, I have included them here. Not only do they serve to give extra information regarding the context of their accounts of the present, but they also confirm and, importantly, add to existing findings on the subject.

Worker's past experiences

"I do think it's important to highlight how things are dealt with now compared with twenty odd years ago." (Louise: Scotland)

Accounts of the past referred to by the SCWs who were interviewed confirm the findings of literature on the attitudes of support organisations as well as those of some of their then colleagues. Reactions included ignoring the situation completely, moving either victim or culprit to another residence without addressing the behaviour, and subjecting service users to lock-downs. In fact one account comes from only four years ago and I would argue that this is further reason to include this appendix since it may be conjectured that there are to this day organisations that are failing to address their service users' issues around sexual behaviour.

As far as research is concerned, of greater importance however is the fact that workers also spoke of situations which have not been previously dealt with in existing literature. These involve front-line workers who went on to deal with their service user's unacceptable sexual behaviour in spite and in defiance of, their management's reluctance to do so. As such, these workers pre-empted policy change which brought to the fore the acknowledgement of the human rights of service users

who have a learning disability, and I would argue that their motivation to do so was based on their close working relationship with, and greater knowledge of, the service user, which informed the care they gave. This level of care – engendered by ‘proximity’ to the service user, I would further argue - transcended and transcends the prevailing lower organisational status of the front-line worker.

Louise’s quote which opens this section referred to her experiences of working as a nurse in a learning disability hospital where the standard practice in behaviour modification, be it sexual or otherwise, was to administer drugs (Lambrick & Glaser: 2004). Louise who is a qualified nurse has also worked on and off as an SCW over many years. She presently works as an SCW. Explaining conditions in the 1980s she said:

“You know the difference between the eighties and now in dealing with inappropriate sexual behaviour is phenomenal . . . Years ago in hospital it was drugs that was used. There was never – you know – a female patient could make an allegation of sexual assault by a male patient and there was never any police involved. Basically it was ignored” (Louise: Scotland).

She did however go on to explain that today, in certain circumstances drugs are the only appropriate treatment though she added that now: “there was even more stringent controls than there was back in the eighties because they used to be given willy-nilly if there was any problem” (ibid). This is due not least in part to the fact that, as mentioned above, little research has been done into the efficacy of drug treatment and also the fact that the side effects can be extreme (Sajith *et al*: 2008).

Writing in 1994 Brown & Barrett comment on organisations’ propensity to ignore service users’ unacceptable sexual behaviour even when it involved rape. They go on to offer practical advice on ways management and staff can go about addressing these issues. In spite of this, Carson & Clare writing in 1997 felt the need to ask “... should the interests of victims, for example, in seeing their attacker persecuted, be ignored?” (54). Unfortunately it was not only unacceptable sexual behaviour that continued to be ignored but any sexual behaviour that organisations and their staff found problematic (Hollomotz: 2008). As one interviewee commented: “I started

working over 17 years ago . . . and there was all sorts of unusual attitudes {in organisations} to perfectly normal things like masturbation.” (Edward: Scotland)
Another worker who had provided private space for service users to go to in their Day Centre when they felt the need to masturbate remarked:

“I do remember years ago getting into a debate with another staff member who worked for a different organisation and (she) thought it was inappropriate for people with disabilities to masturbate or touch themselves in any way.”
(Maggie: Melbourne).

Management’s approach – do nothing

Sexual behaviour that may or may not have been criminal could also be ignored as this interviewee’s account illustrates. Seven years ago, having entered a service user’s room because she had heard noises that led her to believe that the occupant was in distress, she came upon the man in the process of having sex with another male resident. She said: “I went to the office and I spoke to them about it . . . you know I told them about it and it was like it never happened.” (Grace: Melbourne).
Was sex practiced safely? Was it consensual? These matters were ignored completely at management level.

Of added concern is the fact that organisations ignored situations in which the victim of the abusive behaviour was also a service user within the same organisation. This, according to Brown and Stein (1997) was a particular problem in the UK, which, not surprisingly, leads to repeat offending including occasionally the abuse of even more service users. Yet, in the past, when staff reported service user’s unacceptable sexual behaviour to their management, they did not always receive the response they were expecting. Edward spoke about his experience of being a SCW to men who were openly masturbating. He and other sympathetic workers set about supporting and educating the men to act appropriately. Yet he added:

“saying that as well, there was an awful lot of staff and even management at that time [who would have nothing to do with the situation] that I think I was instrumental in being part of a group of staff members who educated them that it was perfectly reasonable and it was none of our business – not to get upset about it or overly concerned about it” (Edward: Scotland).

Similarly, and with reference to a female service user another interviewee related how she and fellow SCWs had eventually managed to educate her about appropriate masturbation; that it is acceptable when done in private. She remarked of the service for which she worked: “We definitely have changed. At that time some of the people who were directors of the organisation wouldn’t have listened – didn’t want to hear any of that” (Liz: Scotland). In Melbourne the same attitude could be found at management level. Looking for guidance regarding a service user’s sexual behaviour the worker stated that:

“People just don’t want to deal with it. That was the big bosses. That was the CEO. That was the managers – everyone – just nothing. So that was my first encounter with it [USB] but since then things have changed” (Grace: Melbourne).

Management’s approach – move the victim

One management response to receiving and accepting knowledge of a service user’s unacceptable sexual behaviour involved blaming the victim, or at least taking action against them rather than the culprit. One interviewee recalled how: “There was one particular [case of abuse in her place of work] and the vulnerable person was moved to a different residence so – separated” (Beth: Melbourne).

Management’s approach – move the culprit

On the other hand management’s response has been to move the culprit without actually making attempts or recommendations regarding modification of the behaviour in question. This amounts to containment; in effect, stasis. Gary’s story illustrates this. He recalled an incident in which a mother had witnessed a service user making inappropriate gestures to her son. He said:

“The boy’s father was notified at work and he came over and he wanted to really get into [beat up] this client, not understanding that the person’s got a disability. So within seconds through notifying all the parties they [management] had to act very quickly and remove the client from the house and the police got involved and everything and it got resolved but the client had been moved now from one house into another” (Gary: Melbourne).

Management's approach – lock down

Grace recalled in instance where a victim of abuse was advised by management to lock his door at night even though his preference was to sleep with it open. The abuser, however, then sought other victims and this time management's response was to put an alarm on the culprit's door which was activated at night so sleep-over staff would be aware of his movements. This did not address the man's behaviour and additionally, made him scared to leave his room to go to the toilet for fear of setting off the alarm. Inevitably this led to the individual urinating in his room. (Grace: Melbourne).

Research exists on the negative attitudes of support staff towards the sexual behaviour ('good' as well as 'bad') of service users. Research also exists on the failure of organisations to address service users' sexual behaviour ('good' as well as 'bad'). What has not yet been researched are those instances where staff were willing to support service users with their issues around their sexual behaviour but had to defy the management of their organisation in order to do so.

Appendix ii

Anonymity and Confidentiality

Research Participant Informed Consent and Confidentiality Statement

I very much appreciate your involvement in this study. As explained more fully in your Information Sheet, the aim of this study is to gain accounts of support workers' experiences of supporting service users who have learning disabilities and who display unacceptable sexual behaviour.

I would like to reassure you that the information you share will be handled and presented in a way which safeguards confidentiality. The one exception to this is where a matter is disclosed at interview which gives rise to concern about actual or potential criminal activity occurring. Where this is the case I am obliged under Level 2 of the University of Edinburgh's School of Social and Political Science Ethics, to make a report to the Police, Social Work Department, or other appropriate authority.

I agree to participate in the project entitled:

The role of the Social Care Worker in intervention into unacceptable sexual behaviour in people who have a Learning Disability

I confirm that (please initial each statement):

I have read and understood the research participant information sheet. -----

I consent to take part in the interview and that the interview will be recorded. -----

I consent to being questioned. -----

I agree to give consent for the anonymous data to be used in the research reports and subsequent thesis, subject to the conditions made explicit in the research participation information sheet. -----

I understand that:

My participation is entirely voluntary. -----

I am free to refuse to answer a question. -----

I can withdraw from the study at any time without prejudice. -----

I will receive a copy of the transcript with the purpose of withdrawing or adding to statements I have made in the course of the interview. -----

I will return the transcript within a fortnight of receiving it or accept that it will be used as it stands. -----

The research is being done toward the award of a PhD. -----

Please sign below to confirm you have read and understood the contents of this form; read the Research Participation Information Sheet and agree to participate in the research.

Signed: (Research Participant)

Print Name:

Date:

I confirm that I have explained the nature of this study to the Research Participant.

Signed: (Researcher)

Print Name: -----

Date: -----

If you have any concerns or complains relating to this research please contact:

Susan Hunter
Programme Director MSc Adult Protection
Social Work Dept
School of Social and Political Studies
University of Edinburgh
2:25 Chrystal Macmillan Building
15a George Square
Edinburgh
UK
EH8 9LD
susan.hunter@ed.ac.uk +44 (0) 131 651 1461