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**“In our house we’re not terribly sexual”:  
Exploring the Barriers to Supporting Intellectually Disabled  
People in the Area of Sexuality and Intimacy**

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## ***Abstract***

How support workers enable, regulate or constrain the sexual expression of intellectually disabled people who live in service agency group homes is the subject of this thesis. A general literature search of what intellectually disabled people currently experience in their lives, including their experiences in the area of sexuality and intimacy, begins this investigation. Secondly, an extensive literature review of the support role, incorporating an appraisal of past and current issues related to the support position in general and to the area of sexuality support in particular, was completed. What intellectually disabled people themselves would like in relation to sexuality and intimacy support was included in this section. Thirdly, a review of research studies focussing on the operation of the support position within service agency systems was undertaken.

These explorations revealed a high degree of reluctance on the part of workers to provide assistance in the sexuality area, despite a proven necessity for support to be made available to the intellectually disabled people they worked with. Review research studies suggested a variety of causal factors in explanation of this reluctance. These suggestions link to two meta-reason positions. Failure to provide support either stemmed from individual worker's inactions due to ignorance and/or incompetence, or from wider systemic failures on the part of agency services to positively value and support this key service role in this area. However, little if any analysis of the possible influence of the broader social, emotional and cultural contexts, in which the concepts 'sexuality' and '(intellectual) disability' are located, could be found in the studies reviewed.

Eleven in-depth interviews were conducted with front-line support workers about their sexuality support practice. Preliminary readings of the interview texts revealed a similar reluctance on the part of the workers concerned to assist those they worked with in this area. Interview texts were then subjected to a post-modernist inspired, interpretive discursive analysis. This analysis uncovered and tracked how key power/knowledge effects inherent in the terms '(intellectual) disability', 'sexuality',

‘gender’ and ‘desire’ inhering in the concept of an ‘ideal (sexual) couple’ interweave to shape the ‘no support necessary’ practice responses held in worker’s interview talk.

From this exploration it is suggested that research studies of workers’ practices as an aspect of the promotion of change in support outcomes in the sexuality support area need to go beyond the parameters of recommendations that stem from considerations of either individual or systemic limitation alone. It remains a convincing point to suggest that poorly performing workers need retraining in this area and the overall value of the support role within service organizations needs reshaping. However, future research recommendations also need to engage more directly and effectively with the effects of the wider social and emotional “ideal (sexual) couple” ambiguities that also influence worker’s lack of assistance in this complex and sensitive support area. The use of a post-modern perspective as a helpful conceptual tool in unpacking the power these ambiguities hold within the support position is offered as a productive way forward for future research and practice development.

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## *Prologue*

I began this thesis to explore what the barriers to supporting intellectually disabled people to participate in the paid workforce were and how these barriers could be overcome. Near the end of my first literature sweep I read an article by Janet Holmes and Rose Fillary (2000). The comment in this article, that intellectually disabled people are not dismissed from their jobs because they lack cognitive skill but largely because of their "inability to interact effectively with other people" (Greenspan & Shoultz, cited in Holmes & Fillary, 2000, p. 274) was intriguing. I was particularly drawn to this comment as it distinguished between that which related to community-based support initiatives from that which pertained to whatever these other interactional matters might consist of. This distinction made me think that such a division might be masking something important. Further, this something might show how these other matters might not only be central to the success of not only any formal supported employment initiative, but also of any inclusion-orientated initiative undertaken. This idea motivated the change in topic I subsequently made.

Another central influence on my change of topic was my change in employment. I became a learning and development adviser in a human service agency providing services and support to intellectually disabled people. Much of my time was spent facilitating training workshops with new and experienced support workers. These sessions included 'delivering', as the agency put it, standardised, pre-packaged information to workshop participants. Because I delivered so many workshops using the same format these sessions became an opportunity to gauge worker agreement or resistance to the material over time, and in different locations around New Zealand.

As a result I became concerned about the mismatch between the frameworks shaping how the information I was using was compiled and delivered and the difficulties that seemed to constrain worker's practices. These models of practice, or what Koppers calls the "common sense logics that fix people into their relative positions and into clear narratives" (2002, p. 2), often seemed to present more of a hindrance than a help



in aiding worker's understanding of the complexities included in the term sexuality support and what these complexities meant in relation to workers job descriptions.

I also became concerned about what might be happening to workers while they were on the job. Although a very experienced teacher of adult students, I was vastly under-prepared for some of the stories and emotions that came up in these sessions. Some workers challenged aspects of the workshop material with passion. Others appeared completely disinterested in the information being presented. Many came to the workshops looking tired and stressed. At one point during a long session, one person fell asleep. Some sessions were very tense while others seemed to allow workers to relax and take stock of what they were trying to achieve. These effects were most noticeable when it came to information and discussion about matters pertaining to support for social and intimate relationships among the people these workers supported. I began another literature search this time in the area of sexuality and intimacy.

I am responsible for the information in these chapters but I could not have completed the thesis without the contributions of the people who agreed to be interviewed for this project. The reality is that employment in any low-paying position in the service sector in New Zealand means working within the operation of certain social inequalities. Taking part in interviews that might reveal questionable organisational policies or practices can result in adverse material outcomes for service workers in New Zealand. Often workers are unable to challenge these outcomes effectively. The courage shown by the interviewees is hereby acknowledged.

Throughout this thesis, I refer to the group of people supported by workers as "intellectually disabled people". This term, rather than "learning-disabled", "developmentally disabled" or "mentally retarded" is used by the National Advisory Committee on Health and Disability (NACHD 2003), in its influential report to the Ministers of Health and Disability Issues. Thus it is a term recognised as having particular currency at policy and practice level. However, while the report uses the phrasing, "people with intellectual disability", I have referred to members of this group as intellectually disabled people.

# Chapter 1

## *Background, Research Question, Rationale and Context*

This chapter is divided into three parts. The first part summarises research findings about the current quality of life for intellectually disabled people in key life domain areas. This review provides the background for the research question. The second part of the chapter states the research question and includes a rationale for sexuality support as the primary subject of consideration. This consideration underpins the prioritisation of direct support workers and what they do as the object of enquiry. The third part locates the support position within the context of beliefs about intellectual disability and sexuality held in the wider community. This section includes a broader context for the examination of sexuality support as a powerful social dynamic, worthy of research attention. The chapter ends with an initial definition of sexuality.

### *Introduction*

It is estimated that between 11,500 and 15,000 adults in New Zealand currently require assistance due to an intellectually disabling condition. Support required by people in this group is life-long and spans significant health, communication, mobility, literacy and social interaction needs. Levels of support vary widely from person to person. Numbers of people who require support are provisional, due to the lack of more explicit demographic information (NACHD, 2003, p. 46). More men than women can be found in this group, representing the higher rate of some genetically based conditions in males thus the greater vulnerability to differential developmental outcomes experienced in general by boys (Bray, 2003a).

Within this larger group, three adult cohort groups can be identified. These include:

- i)* adults who have spent much of their lives in institutional care or parental homes

- ii) adults who have experienced degrees of segregation from community life and who continue to use the services of agency service providers established since the 1970s
- iii) younger adults, who are more fully integrated into the life of their local community.

This research project focuses on the support offered to cohort group two, those who currently use group home and day services, supplied by community-based service agency providers (Beadle-Brown, Mansell, MacDonald & Ashman, 2003). Many of the people now in group two have been represented in group one in the past. While the age range of people who use agency support services in New Zealand is diverse, this population is getting older. The average age of those who comprised group two in 2002 was 50 years (Donald Beasley Institute, 2002, p. 44).

### ***Intellectual Disability***

There is no generally accepted definition of ‘intellectual disability’ in New Zealand (Bray, 2003). Medicalised explanations of the term in 1992 include the American Association of Mental Retardation (AAMR) definition and the World Health Organisation (WHO) definition (Bray, 2003, pp. 9-17). The recent National Health Advisory Committee definition, used for this research undertaking, includes the following three criteria:

- i) a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)
- ii) a reduced ability to cope independently (impaired social functioning)
- iii) these characteristics precede adulthood and have a lasting effect on subsequent development (lifelong impairment).

It is also noted that the current definition of ‘intellectual disability’ has undergone a shift in focus over the last five decades. This change reflects a gradual development in thinking from the idea of intellectual disability as a trait intrinsic to the individual towards a broader understanding of the term as descriptive of how individuals “perform” the relationship between themselves and the cognitive and adaptive skills

requested by surrounding environments. References that match both aspects of this definition feature in this research.

### *History*

Post-family support for intellectually disabled adults in the last 50 years in New Zealand has consisted of three broad strands of provision (NACHD, 2003). These include care in traditional institutional settings, the provision of community-based service initiatives and more recently, the emergence of a variety of independent community-living support options. All forms of provision have been available. However, changing attitudes towards support provision have resulted in a substantial shift in focus and personnel within each of these options. The most substantive shift in service provision in New Zealand has involved the large-scale movement from funding and support within institutional settings to community based service options (Hunt, 2000). The last long-term institution for intellectually disabled people in New Zealand closed in 2006.

Community-based services for intellectually disabled people were initiated in response to extensive critiques of the negative effects of institutional living (MacArthur, 2003). These critiques also emphasised the social and economic advantages of providing services to enhance a positive quality of life for members of this group. In New Zealand these notions paralleled similar trends in North America (Lakin, Prouty, Polister & Coucouvanis, 2001) and Western European countries (Marquis & Jackson, 2000), where these ideas also linked notions of quality of life to inclusion in community settings and access to community-based support services (Bray & Gates, 2003). Since the 1970s, service provision for intellectually disabled people has concentrated on developing skills to enable full participation in the life of their local community.

Section One outlines literature findings related to intellectually disabled people and their daily life in community settings. As so few New Zealand-based studies have been undertaken, this section relies heavily on the results of international findings, thus on the assumption that these findings will also describe what is happening in a New Zealand context.

## **Section 1:**

### ***Intellectually Disabled People and Quality of Life***

Most intellectually disabled people who leave the family home enter a group home. These are usually a service facility staffed by an agency provider set within a local community setting (Beadle-Brown et al., 2003). Currently these homes consist of ordinary housing units, either owned or leased by not-for-profit service agencies. These agencies are themselves largely government funded. In New Zealand many intellectually disabled people live in accommodation originally built as nuclear family-style homes (Hamilton, 2006). Support within these homes is extremely flexible, ranging from houses with flexible part-time staffing arrangements to homes that are intensively staffed and where people receive day as well as evening and night support (Simmonds & Watson, 1999). In New Zealand as in other countries, positive evidence of overall improvement in individual quality of life as a result of agency service placement can be found (O'Brien, 1990).

#### ***Quality of Life in Domestic Environments***

Positive evidence of lifestyle improvement can be found across a variety of indicators in relation to quality of life for intellectually disabled people in domestic environments (Spreat & Conroy, 2001). These indicators include more advantageous material standards of living, increases in developmental progress and more sustained engagements in daily living activities (Agar, Myers, Kerr, Myles & Green, 2001; Jones, Perry, Lowe, Felce, Toogood, Dunstan, Allen & Pagler, 1999). Residents living in serviced homes have been found to exercise some independence in their daily lives particularly in relation to choices in the areas of meals, leisure activities and clothing. However, it has also been suggested that opportunities for people to make meaningful choices in all areas of their lives within these environments often remains severely restricted.

### ***Difficulties with Service Systems***

The service agency is legally recognised as the owner of the house in the majority of agency service homes, thus security of tenure for residents is not guaranteed (O'Brien, 1994). Those living in the homes are rarely consulted in decisions involving selecting new residents, deciding when an existing resident should leave, dealing with household safety hazards or hiring or firing house workers (Heller, Miller & Factor, 1999). Residence in agency homes can also depend on conforming to the requirements set by the support team who are employed to follow agency support policies. Use of the space within the house is regulated by these policies to the extent that some houses have areas that remain off-limits to those who live in them (O'Brien, 1994).

People who live in the homes report having little idea about how the service agency they are attached to works and have only a vague knowledge of the service personnel working beyond their immediate residential environment (Goble, 1999). An acceptance of external power remains characteristic for members of this group, even when major decisions affecting their lives are being discussed (Marquis & Jackson, 2000). It has also been found that intellectually disabled people from ethnic minority groups remain at the margins of both service and funding support in this setting (Simmonds & Watson, 1999).

### ***Quality of Life in Community Settings***

Research findings indicating positive evidence of improvements in quality of life for intellectually disabled people in wider community settings can also be found (Spreat & Conroy, 2001). These indicators include more frequent contact with family members and a greater measure of involvement in the activities of local communities (Agar et al., 2001). Yet while overall gains have been achieved, the gains individual intellectually disabled people have experienced can vary considerably (Felce, Lowe & Jones, 2002). In particular, improvement indicators for people with lower adaptive behaviours (i.e. those in most need of assistance) have been less favourable (Simmonds & Watson, 1999). The extent of this variation is not always acknowledged in literature findings (see Donald Beasley, 2002, p. 4, for an example), despite a small number of studies reporting no significant gains having been made

over time between living in an institution and living in community-based settings for some intellectually disabled people (Felce et al., 2002).

### ***Job Participation***

Intellectually disabled people are now able to take up vocational services or supported employment programmes designed to place people in mainstream work settings (Bennie, 1996). However, how successful these initiatives have been in assisting people to find and keep jobs remains questionable. Most intellectually disabled people who are in work either work part time or in a voluntary capacity. Not enough funded supported employment services to meet the needs of all who want to take up this option are available. Job change for a significant number of people within the first two years of their employment has been noted, as has the number of people who still need ongoing support after an extended period of time (Bray, 2003b). In these cases the support individuals require has not transferred to the workplace but remains contingent on the presence of outside assistance.

### ***Income***

Intellectually disabled adults in New Zealand have low levels of personal income, with many dependent “exclusively on earning replacement benefits throughout their lives” (Mirfin-Veitch, 2003a, p. 3). People in this group rarely have control of their finances and often have to ask others for their money (Goble, 1999). This dependency continues despite a significant amount of money being paid out on behalf of intellectually disabled people for goods and services that “they will not end up owning themselves” (Mirfin-Veitch, 2003a, p. 3).

### ***Participation in Community Life***

Participation in community life involves being able to access a range of citizenship roles such as tenant, volunteer, employee and parent (Broderick, 1996, cited in Bray & Gates, 2003, p. 6). As intellectually disabled people engage in few of these functions they are rarely recognised as being actively involved in their community. Women are more likely than men to be seen as a group rather than individuals in

community settings. They are also perceived as needing more social and emotional care and support from others, and are also more likely to be excluded from aspects of life in the public arena (Kjellberg, 2002). In addition older intellectually disabled people are more likely to be accommodated in larger supported facilities that offer less potential for social development (Agar et al., 2001; Beadle-Brown et al., 2003). Research findings also suggest that providers place greater emphasis on social activities and community integration for younger service users. Thus, as Agar et al. (2001) note, presence in the community may only be an illusion for older intellectually disabled people.

In addition, undertaking activities in community settings is not always pleasurable for intellectually disabled people. Some people in this group have reported feeling vulnerable, socially anonymous, disaffiliated and rejected by local community members (White & Dodder, 2000). Women without intellectual disability have been found to respond more positively towards the inclusion and participation of intellectually disabled people than non-intellectually disabled men (Krajewski, Hyde & O'Keeffe, 2002).

### ***Socio/Emotional Conditions***

A pattern of low-level violence and bullying remains common in the lives of many intellectually disabled people. This finding has been replicated both internationally (see, for example, Jenkins & Davies, 2006) and in New Zealand (Donald Beasley Institute, 2002). Both women and men in this group are more than four times as likely to be assaulted as other adults (Jenkins & Davies, 2006). The degree of psychological trauma and anxiety these assaults have created remains largely unknown, pointing not only to a dearth of research on this important area but also to a lack of highly trained counsellors who can provide long-term counselling and rehabilitation strategies to people in this group (Sinason, 1992). What is also reported is that women are markedly more stressed than men (Simmonds & Watson, 1999).

In addition, the rate of psychiatric disorder and depression within this community is three to four times the rate of the general population (Davis, Judd & Herman, 1997), with women exhibiting more symptoms than intellectually disabled men (Lunsky,



2003). Psycho-social factors precipitating psychiatric disorders include limited communication skills and a lack of good coping strategies. These factors may make people more susceptible to psycho-social stressors. Discrimination, labelling, rejection, ridicule and stigma together with a variety of interpersonal and social losses are also found to trigger or maintain depressive episodes (Sinason, 1992). However, the interface between the provision of mental health and intellectual disability services continues to pose problems for both consumers and providers working in each service area (Simmons & Russell, 2003).

### ***How Intellectually Disabled People View their Lives***

Ramcharan & Grant (2001) recently reviewed a range of international studies concerning how intellectually disabled people feel about their lives and their participation in the local community. Factors associated with increased levels of satisfaction by people in this group centre primarily on satisfaction with immediate surroundings. These factors include: satisfaction with participation in domestic tasks, access to privacy and pleasant surroundings, being able to be with friends, having friendly staff and not being with aggressive and noisy co-residents. However, people in this group also reported feeling less satisfied with the quality of their friendships, their ability to take risks and the quality of assistance they receive. Intellectually disabled people also report a lack of enduring relationships with others, a presence but not full participation in their community, economic deprivation, the ongoing use of segregated settings and insufficient social support to meet their needs and expectations (Ramcharan & Grant, 2001). Further reports include additional negative satisfaction ratings caused by: lack of money, isolation, harassment by people in the local community, poor food quality (Gregory, Robertson, Kessissoglou, Emerson & Hatton, 2001), and a continuation of institutional-type constraints on preferred lifestyles (Frawley, 2003).

### ***The Supported Independent Living Option***

Supported Independent Living (SIL) options have been mooted as a recent response to the idea that there is an “urgent need to ‘deinstitutionalise’ community-based service structures” in New Zealand (Seborn & Bennie, cited in Sullivan, 2005, p. 210) and

elsewhere. Supported independent living frameworks have been associated with the provision of a greater flexibility of choice in support accommodation, support worker assistance and agency provision of the kinds of support required. Yet for some, living independently of group home support has meant living in marginal housing and being at high risk of poverty due to limited education, limited social skills and a lack of work opportunities (Lunsky, 2003). To date very few studies related to SILs have been undertaken and even fewer have compared the benefits and drawbacks of these two types of services. What has been suggested is that the overall quality of these services too can be very variable (Simmonds & Russell, 1999).

### *Discussion*

As Spreat & Conroy (2001) note, deinstitutionalisation addressed some of the lifestyle advantages that institutional settings could not supply. However, moving people from large institutional facilities to group homes does not seem to have resulted in the widespread cessation of the feelings of alienation and isolation experienced by intellectually disabled people. Research reveals little evidence of enduring economic, social and community relationships between intellectually disabled people living in group homes and their peers in the wider community (Bennie, 1996; Tannous, Lehman-Monk, Magoffin, Jackson & Llewellyn, 1999; Todd, 2000; NHACD, 2003). While implementing desirable service outcomes for people in this group has been acknowledged as “becoming more complex” (NACHD, 2003; p. 19), many intellectually disabled people continue to live in settings that, as one researcher suggests, represent cultural prisons of social and economic control (Armstrong, 2002). Further many continue to live in environments that appear to be controlled by or for the convenience of others (Treese, Gregory, Ayres & Mendis, 1999).

It has been suggested that the deinstitutionalisation movement only achieved the idea of presence and opportunity rather than the reality of genuine participation for members of this group. (Agar et al., 2001). Meanwhile the continuing separation of people in this group from life in their local communities remains characteristic (Bray & Gates, 2003). At present what seems to be provided for the majority of intellectually disabled people is an illusion of inclusion, underpinned by a change in

locale, in turn assisted by a rhetoric of 'lifestyle improvement', while isolation and alienation remain the essential realities of the lives of people in this group.

### ***Sexuality and Quality of Life***

In view of the research papers summarised above, it is unsurprising that one of the greatest difficulties currently facing people in this group involves taking part either independently or with support in social and intimate relationships (Felce, 1998; Jones et al., 1999). Literature studies suggest that few intellectually disabled people have meaningful relationships with other people, apart from family members and paid assistants (Jameson, 1998). Research continues to uncover the discriminatory attitudes and significant disadvantages faced by many in their desire to explore and maintain sexual and intimate relationships in particular (Milligan & Neufeldt, 2001). It has been suggested that masturbation may be the only form of sexual outlet for many intellectually disabled people (Szollos & McCabe, 1995, p. 218).

Intellectually disabled people themselves have expressed a clear desire for a close, long-term relationship with someone (Goodley, 2003a). However, few opportunities seem available for people in this group to establish relationships beyond the 'serviced' world of agency-based support (Mattison & Pistrang, 2000). Understanding how these two findings might influence support worker performance is the driving force behind the research question I pose in the second part of this chapter.

### ***The Problem of Material Environments***

Literature studies suggest that within the service world of intellectual disability support, environments that are constructed on behalf of intellectually disabled people rather than by them is a key factor in the difficulty experienced by members of this group in the sexuality area. People who live in agency homes are rarely left alone and spend large amounts of time within sight or sound of others. Some service providers have been found to directly prohibit sexual activity. However, it is more common for sexual expression to be implicitly discouraged, principally "by not providing privacy

for people to engage in sexual and intimate behaviour” (Sundram & Stavis, 1994, p. 256).

Bedrooms are often small and rarely have double beds in them while “accommodation for couples is almost non-existent” (Brown, Croft-White, Wilson & Stein, 2000, p. 66). The lack of material space can make it “almost impossible” (Mattison & Pistrang, 2000, p. 24) for individuals to create opportunities for intimacy with others. This lack may also contribute to the difficulties experienced by members of this group developing and maintaining close emotional relationships (Szollos & McCabe, 1995). The absence of the space to discuss thoughts and feelings about sex, sexual experiences and needs, may also be send negative messages to intellectually disabled people about the importance of their own sexuality (Szollos & McCabe, 1995). As an example, where people in this group have had a sexual experience, many have been either sexually victimised or punished for “inappropriate” sexual behaviour (Hingsberger & Tough, 2002).

### ***The Problem of Inadequate Knowledge***

High levels of confusion and a lack of adequate sexual knowledge remain characteristic of members of this group over time (Frawley, 2003), with men found to be less knowledgeable in this area than women (Hall, Morris & Barker, 1973; Szollos & McCabe, 1995). Many of the ideas people in this group hold are inaccurate, inconsistent and contain many misconceptions. At least some of these misunderstandings relate to the misinformation people have been given about both disability and sexuality. Sex therapists report cases where people have been told about unreal dangers in order to make them fear sexual encounters or expressions of their own sexuality (Hingsberger & Tough, 2002; Sinason, 1992).

People in this group have also been found to possess little understanding of more the complex notions related to sexual pleasure and desire (Aunos & Feldman, 2002). This may be the result of having received too little reflective education about this aspect of sexuality (see, for example, the work of Hamre-Nietupski & Ford, 1981, for a case in point) or in the case of women in particular, having generalised a single unwanted sexual experience that has been less than pleasurable (Timmers, DuCharme & Jacob,

1981; Brown, Hunt & Stein, 1994; McCarthy, 1998). Social skills training often become the solution to how to address the relationship problems intellectually disabled people experience. However, such training may be of little use if people do not have concrete opportunities to establish relationships with others. It has also been suggested that it is relationship skills training rather than sexuality training that should be prioritised for people in this group (Hingsberger & Tough 2002).

### ***Problems for Intellectually Disabled Women***

Deinstitutionalisation brought only limited opportunities for heterosexual sexual encounters for some intellectually disabled women while all women continue to face a number of difficulties in this support area. Studies suggest that attitudes towards sexuality and women in this group have not significantly altered in the last fifty years (Williams & Nind, 1999). Intellectually disabled women are more likely than men to be excluded from the sexual scenes of their choice (Stone, 1995). It has also been noted that wanting to have sex is frequently labelled negatively for women by agency providers yet is seen as appropriate behaviour for men (Williams & Nind, 1999). In addition intellectually disabled women have to deal with negative images about non-normative appearance (Christian, Stinson & Dotson, 2001), with the “hierarchy of attractiveness” (Sinason, 1992, p. 279) non-normative appearance creates leaving many in this group in despair of being physically attractive to any potential partner. Finally, women in this group have little access to reproductive education, health care and limited choices in relation to reproductive issues (Long & Holmes, 2001), while support for women who are lesbian or bisexual is virtually non-existent (McCarthy, 1999; Abbott, Howarth & Glyde, 2005).

Women who are sexually active have been found to experience predominantly penetrative sex, with a significant lack of sexual pleasure reported by many. Many women also experience ongoing sexual violence perpetrated by spouses, dates, or casual sexual partners (Jenkins & Davies, 2006), and speak of the disillusionment they experience when they feel they are “used for sex” (Johnson & Traustadottir, 2005, p. 154). It is unsurprising that only a small minority report being positive about their sexual lives, while the majority feel that they continue to lack control over

decisions about what they want to do, with whom, when and how in this area of their lives (McCarthy, 1999).

Some commentators have described women in this group as having been rendered invisible in the two human rights struggles in which they should have a place – the women's movement and the disability movement (McCarthy, 1999). It is difficult to see where they might gain the support they need. Yet while these issues remain ignored the status quo, seen as a system that promotes the interests of intellectually disabled, white, heterosexual, able-bodied men, will continue to place lesser value on intellectually disabled women and the support they need (Clements, Clare & Ezelle, 1995).

One of the few ways in which women have been acknowledged as having different experience to their intellectually disabled male counterparts is in the level of sexual abuse they experience. Intellectually disabled women continue to experience a wide variety of unwanted sexual behaviours, including fondling, oral sex and sexual intercourse, with many experiencing repeated assaults over time (Jenkins & Davies, 2006). Yet changes in practice occurring when these problems come to light are enacted in relation to solutions rather than approaches to this problem. In the past, intellectually disabled women were institutionalised so they would not be sexually abused. Currently if the matter is given attention, the perpetrators are the ones who are likely to be locked up. Within this difference intellectually disabled women are more likely to be recognised in the role of victim rather than as active sexual beings with at least some degree of control over their own sexuality (Williams & Nind, 1999).

### ***Problems for Intellectually Disabled Men***

The sexuality of intellectually disabled men, outside of a focus on abusive sex, also remains largely invisible (Cambridge & Mellan, 2000). Although they are able to describe the sexual things they do many men experience a significant lack of sexual understanding related to their behaviour. Many are not able to relate what is right and wrong about sexual behaviours. Guilt about sexuality and the absence of opportunities to talk about feelings and emotions are reinforced by a stereotypically assumed reluctance on the part of men in general to admit to emotions and feelings as part of

their sexual experiences with women or other men (Cambridge & Mellan, 2000). Intellectually disabled men are also most likely to receive sex education within a heterosexual context, despite the frequency of homosexual behaviour between members of this group.

The term 'challenging behaviour' is often used to characterise the unconventional sexual behaviour of men in this group, with cross-dressing in particular generating considerable professional and management concern (Cambridge & Mellan, 2000). Intellectually disabled men can also display sexual behaviours that are socially difficult or physically harmful (Thompson, Claire & Brown, 1997). Why this happens is considered by the men concerned to relate to the absence of a regular sexual partner. However, agency workers and professionals only consider this idea causal after other factors including poor interpersonal relations, inability to talk about sex, absence of sexual knowledge, poor sexual performance and dysfunction, are eliminated (Trudel & Desjardins, 1992).

### ***What Intellectually Disabled People Think***

Very little information is available about what intellectually disabled people themselves think about this area of their lives. However, research studies reveal that in general, attitudes held by this group largely reflect wider community attitudes toward sexual issues (Timmers et al., 1981; Frawley, 2003). In addition, some have been found to hold more conservative attitudes towards masturbation, nudity, talking about sex and homosexuality than other groups. Intellectually disabled women are more likely to reject outright the idea of having a sexual relationship than their male counterparts (Heyman & Huckle, 1995).

Prohibition by authority figures is the reason most often given by people in this group to explain why sexual relationships are 'wrong' or why they are not able to have a sexual relationship when one is desired (Frawley, 2003; Heyman & Huckle, 1995). Authority figures can include direct support workers and family members (Frawley, 2003). However, intellectually disabled women have named support workers as being the people they would talk to first about difficulties with sexual matters. For men, friends and support workers and members of the medical professions are equally seen

as people to talk to when they are “worried about sex or having trouble with it” (Timmers et al., 1981, p. 37). Yet these issues are not the ones people in this group most want to talk about. When asked about what they needed to help them meet their needs in the area of relationships and sexuality, most wanted to know how to meet other people and how to talk to the people they are interested in (Chivers & Mathieson, 2000). While a recent study notes that some positive changes to sexuality support have occurred over time, it is also acknowledged that practices have “not changed to the extent that relationships are actually facilitated and developed” (Lesseliers & Van Hove, 2002; p. 148).

Queries about the validity of research undertaken with intellectually disabled people, who have been found to experience problems making sense of the specialist language researchers use, have been raised (Heshusius, 1982). Some people have difficulty answering sexuality related questions and find talking about the issue extremely difficult. However, what is acknowledged is that intellectually disabled people know more about the topic than is evident from their responses (Edmonson, McCombs & Wish, 1976; Sinason, 1992).

### ***Gay, Lesbian and Bisexual Issues***

Problems experienced by gay, lesbian and bisexual intellectually disabled people have only recently begun to be explored. A contemporary study suggests that people identifying within these orientations report being frightened about what might be said if they make same-gender feelings known (Abbott et al., 2005). Gay and bi-sexual intellectually disabled people are concerned that they might be told to leave where they are living if their orientation is found out, and that they might not be able to continue to use services if agency workers realise they are gay. Research also reveals that gay intellectually disabled people have been bullied because of their sexual orientation. In contrast to non-gay intellectually disabled interviewees, most intellectually disabled gay people who have had same-gender sex said that they enjoyed it (Abbott et al., 2005)



## ***Section 2: The Research Question***

The focal point for the research topic evolved out of my practical experience as an agency services learning and development adviser and my reading of the research literature during the review process for this thesis. The interface between these practical and theoretical points of reference became the following research question:

**What influences how support workers enable, regulate or constrain the sexual expression of the intellectually disabled people they support?**

In posing this question I sought to provide an understanding of how current sexuality support processes are handled in New Zealand, what these processes contain and how they relate to the wider context in which intellectual disability, sexuality and support work is located.

### ***Why the Support Position?***

I wanted to explore the support position rather than concentrating on the position of intellectually disabled people themselves because, by definition, intellectually disabled people are recognised as a social group who require significant, lifelong assistance that can span all life-domain areas. In particular the support position and how it operates is critical to how successfully people in this group are able to form friendships and intimate relationships. Workers are the key to people being able to access and maintain a range of social experiences. Workers maintain and enhance skills through creating activities to enable people to develop social competencies (Mansell & Elliot, 2001). It is workers who carry out the management plans developed on behalf of the individual they work with (Cambridge & Carnaby, 2005), and it is workers who decide the extent and substance of community access on a daily basis for those they support (Treese et al., 1999).

A number of recent initiatives in the disability field have enhanced opportunities for physically disabled people to find outlets for the development of sexual expression. These include the disability rights movement, disability-related work environments, support from other disabled people, “avant-garde artistic communities” (Shuttleworth,

2002, p. 116) and Internet communities such as chat rooms. While these environments have made access to sexual life far more possible for physically disabled people, they have only limited potential for access for intellectually disabled people without some form of assistance.

These comments sit alongside research papers that indicate that the difficulty intellectually disabled people have in this area results as much from their restricted social environments as from any cognitive impairment (Heyman & Huckle, 1995). Both insights indicate that support is absolutely crucial for intellectually disabled people to be able to develop and facilitate enduring friendships and satisfying intimate connections. This point has also been taken up by further researchers, who suggest that assistance for intellectually disabled people may need to include facilitating sexual activity, as well as sex education, counselling, and protection from exploitation (Hingsberger, 1997; Craft & Brown, 1994). Further it is noted that the typology of indicators of quality of life for members of this group be widened to include a more overt assessment of the factors that affect the relationship between those who are supported and those who support them (Felce, 1998). Finally, it has been suggested that these explorations need to cover the prevailing attitudes and beliefs support workers hold and the cultural composition of the supportive environments they work in (Williams & Nind, 1999). Thus examining the support position is to address the suggestions these researchers have made within a New Zealand context.

In choosing to explore this role, I was also influenced by contemporary understandings about disability, recently come to be known as social model principles (Oliver, 1990; 2004). A focus on the term 'disability' as a descriptor of the negative relationships experienced by impaired people in relation to the economic and social spaces they inhabit is central to these understandings. Within this view, social processes rather than bodily impairments are foregrounded as the major source of disabling conditions. Exploring the support position rather than the position of the impaired person is a way of beginning to work within the parameters of this changed understanding.

Through this focus on positions rather than individuals, I had become interested in the research process itself, particularly the contribution of research findings to pinpointing the difficulties workers face and how they could be ameliorated. Lennox, Taylor, Rey-Conde, Bain, Purdie & Boyle (2005) recently comment on a tradition within the service agency sector of holding unhelpful views of the research process and its recommendations. Human service agencies consider research as something conducted by outsiders who have little knowledge of what is ‘really going on’ within service organisations and whose negative evaluations could subsequently lead to involvement in litigation. These researchers suggest that such views may inhibit the role research recommendations play in initiating positive changes within agency provision and support practice. I was interested in finding out what it was about the research process that might create these views, what these influences contain and what could be done to lessen the impact of this vision of research within agency systems.

### ***Why Sexuality Support?***

As research studies show, any freedom intellectually disabled people might have to develop skills and expertise in the area of sexuality and intimacy remains “severely curtailed” (Hingsberger & Tough, 2002, p. 9). This compromises the capacity for intellectually disabled people to take their place within the community as “full citizens with rights” (Frawley, Johnson, Hilier & Harrison, 2004, p. 6). Within contemporary euro/western thought, individuals are encouraged to think of sexuality as something intrinsic, inner and concerned with deeply private emotional investments. However, contemporary ideas increasingly link sexuality and sexual expression to notions of social identity and selfhood. Thus sexuality not only involves notions of private and personal desire but is also a marker of social status. In this view a claim to the right to sexual expression also includes a claim “for a full constitution of self” (Shuttleworth, 2002, p. 122). In euro/western culture, it is suggested, non-disabled adults take these steps towards selfhood themselves (Heyman & Huckle, 1995). However, the support needed aspect of intellectual disability ensures that many intellectually disabled people cannot access this pathway to selfhood on their own. While they remain in a sexual limbo they are unable to successfully activate the other

societal privileges adulthood confers. Addressing the issue of sexuality support is also to address this difficulty and what might be causing it.

Yet while I was concerned that a lack of freedom to access the sex act might place further limits on an already severely compromised group of people, the thought that members of this group might also lack entry to the range of emotional expressions that precede any positive sexual experience, e.g. tenderness, affection, warmth, friendship and love, also motivated this quest. As Heshusius (1982) remarks if freedom to pursue avenues towards sexual expression is repressed, a question mark can also be placed against how intellectually disabled people's access to the entire range of sensual and affectionate experiences is handled.

However, at this stage I note other findings that signal the need for caution in relation to difficulties inherent in examining this support area. Such research requires unravelling some very complex physical, social and emotional issues. The words sexuality and disability can evoke deeply held emotions, values and beliefs that vary in relation to a wide range of contexts. This degree of variation can polarise and inhibit open discussion of the topic (Stinson et al., 2002).

### ***Sexuality and the Theoretical Context***

I undertook this topic to promote a deeper level of understanding of how support processes in the sexuality area are currently constituted in New Zealand. However, I was also drawn to this exploration because it provided a chance to examine how well served intellectually disabled people might be by current theoretical models linking disability to notions of full involvement in community. As Shuttleworth (2002) comments, inclusionist frameworks have assisted in establishing the right for intellectually disabled people to be in community settings. However, it is not as easy to include the key interpersonal interchanges through which the concept of community is shaped, and in which dating, romance and sexual intimacy take place, within these conceptual frameworks. Inclusionist models continue to have difficulty crossing the division between the constraints and freedoms that mark the boundaries between public and private spaces in which 'community involvement' as a concept is

defined. It is suggested that these models may only make the personal prejudices and negative attitudes towards intellectually disabled people occurring in the private domain more difficult to prove and to legislate against (Jameson, 1988). As sexuality is as much a private-domain activity as it is a public-domain entity, orientating the topic towards this support area enabled me to uncover and explore the problems dominant theoretical frameworks themselves might pose in relation to the notion of full community inclusion.

Thirdly, I was drawn to this topic in recognition that ‘full constitution of self’ within euro/western society held within the right of any individual to sexual and intimate expression, is not just an issue for intellectually disabled people alone (Shuttleworth, 2002, p. 122). I take Barnett’s point that, if the lack of a sexual and intimate life is what happens to members of this group, then this omission “poses fundamental questions for the rest of us. Revision of social ways of doing is needed” (1999, p. 65). At the broadest level, issues that arise for all disabled people offer “an excellent window” on life, when life is defined in terms of, “being socially accepted as a discrete and unique individual” (Yeatman, 2000, p.184). Thus sexuality is not just about the operation of individual thoughts, feelings and actions, but also constitutes a focal point for the operation of a wide-ranging series of social phenomena that all community members have a stake in. If sexuality can be seen as a point at which cultural elements empower individual members and if these elements can be shown to differentiate between different social groupings, what is happening to intellectually disabled people in this area is an issue that affects us all. As Sinason astutely remarks “Who amongst any of us has access to full sexual rights at all times?” (Sinason, 1999, p. 278).

Finally I chose this research topic as a way of trying to link what is happening for intellectually disabled people to the wider cultural, social and political dynamics that shapes the sexual behaviour of disabled and non-disabled people alike. In asking the question: where does individual responsibility begin and end in the context of sexuality support, I seek to explore what creates the points of division that influence the sexual wellbeing of all society’s members.

### ***Section 3: Support in the Wider Context***

Because workers are drawn from their local community, how the community views the concepts sexuality and disability will significantly influence the development of pro-active support practice. The last section of this chapter outlines literature review studies relating to how wider community members view these two concepts and how these views influence possibilities for intellectually disabled people in this area. As this section relies heavily on international research, I assume these findings also apply to wider community beliefs in New Zealand.

#### ***Three Social Beliefs***

Ideas about intellectual disability and sexuality held in the wider community have been found to be largely negative. While some progress has been made in reducing stereotypical and prejudicial views, research papers suggest that community members continue to be disturbed by the idea of intellectually disabled people expressing their sexuality, experiencing intimate relationships, making love and possibly having children (Hingsberger, 1997). These attitudes have been found to mirror stereotypical ideas about the sexual status of disabled people, which remain resistant to social change (Milligan & Newfeldt, 2001). In particular the idea that a "relationship with someone with a disability, particularly one in which sexuality is physically expressed, is disgusting, repulsive and somehow perverse" remains widespread (Finger, 1994; p. 53).

Three beliefs about intellectually disabled people and sexuality have been isolated within the wider community. They include:

1. Intellectually disabled people do not have sexual drives therefore they are non-sexual (Milligan & Neufeldt, 2001).
2. Being intellectually disabled renders people in this group unable to (biologically) function in the sexual area of their lives (Williams & Nind, 1999).

3. Intellectually disabled people lack the necessary appropriate judgement to be responsible for their sexual behaviour (Katz, Shemesh & Bizman, 2000).

These beliefs are said to echo more deeply held, psycho-social attitudes. The first belief, that “mentally handicapped” people are “sexless” (Williams & Nind, 1999), covers a widespread societal concern about sexuality and material bodies. When intellectually disabled people take on sex roles they also take on sexual identities. In doing so an underlying “aesthetic anxiety” is activated (Milligan & Neufeldt, 2001, p. 94). These feelings sanction the idea that such identities are inappropriate for those whose body shapes and appearances fall outside current societal prescriptions of physical attractiveness (Garland–Thomas, 2003). Further, viewing intellectually disabled people as lacking a sexual identity reinforces the social barrier against sexual relationships with people in this group, a barrier that “almost amounts to a taboo which few are willing to defy” (Milligan & Neufeldt, 2001, p. 96).

The second belief, that disabled people are unable to function sexually, serves to obscure a deeper set of community attitudes that link disability to eugenic concerns. These concerns centre on to how to prevent intellectually disabled people from procreating thus diminishing the intellectual and economic potential of members of the euro/western population (Williams & Nind, 1999).

The third belief, which includes the notion of ‘appropriate judgement’, underpins ideas originating from religious/theological traditions. These beliefs are now set within more contemporary notions of the responsible, civic minded citizen. If people can are seen as unable to give meaningful consent to a marriage contract, within a convention that decrees that sex is tied to marriage, being barred from marriage can be equated to being barred from having sex (Heshusius, 1982).

For Sinason et al. (1992), these values are held so deeply they rarely surface as points of overt consideration for wider community members. In the context of intellectual disability, sexuality becomes one of the three secrets that include: “the impairment itself, sexuality and death” (Sinason et al., 1992, p. 156). Sinason et al. further suggest that this information is kept hidden because of the unresolved anger and fear societal

members hold towards these three elements, despite their centrality to the experience of the human condition. In turn these emotions veil the deep-seated senses of shame produced when ideas about, “malformed babies link up with unconscious memories of childhood fantasy about how babies are made and unmade”. Further these anxieties are associated with wider concepts of good and bad sexuality, through which damaged babies become “stark evidence of an unhealthy sexual lifestyle” (Sinason et al., 1992, p. 257).

However, while keeping the secret about intellectual impairment and sexuality can reduce individual feelings of shame and guilt, this process obscures the possibility of being able to establish links between intellectual disability and social and economic deprivation at community level. Thus it effectively obscures a societal preference for victim blaming rather than acknowledging that some individuals can become part of a destructive social process over which they have limited to no control (Lamb, 1996). Keeping the secret, that socio-material deprivation encourages intellectually disabling conditions, also inhibits possibilities of identifying and intervening in cycles of systemic abuse and deprivation that can lead to individual impairment and disabling environments (Sinason et al., 1992).

All three beliefs work in tandem to create a broader view that regards the term ‘sexuality’ as so antithetical to ‘disability’ that there is no need to raise discussion about possibilities in this area for any disabled person (Timm, 2002). As Timm (2002) further notes, while this consideration makes it difficult to examine issues of sexual expression in relation to the wider disabled population, it becomes even more difficult to consider sexual expression and intellectual disability together. However, this view can be set alongside an opposing belief held about intellectually disabled people, as “predatory creatures with animalistic sexual appetites” (Keywood, 2001, p. 192). In this perspective these ideas link to wider community views of members of this group as a menace to society, a consideration based on societies fear of the unknown (Wolfensberger, 1972).



### *Community Attitudes*

It is very difficult to assess the influence of these attitudes on how intellectually disabled people themselves view their sexual lives. In the past sexuality-related issues provided a key justification for intellectually disabled people being placed in institutional settings as protection from the sexual abuse and exploitation of other community members. Institutionalisation was also used as a means of protection for community members against the possible threat intellectually disabled people could pose to non-intellectually impaired others (Craft & Brown, 1994).

Intellectually disabled people have also been sterilised to suppress aspects of their sexuality (McCarthy, 1999). While debate about sterilisation and young women has now become a more public issue (see, for example, Keywood, 2001), very little has been said about the physical or chemical sterilisation of young intellectually disabled men (Carlson, Taylor & Wilson, 2000). Yet both groups remain at risk of exposure to these procedures. It would be impossible for intellectually disabled people to have avoided internalising the deep-seated beliefs that substantiate these social practices. These practices may have influenced the decision by at least some people in this group to withdraw from any idea of intimacy of any description (Lesseliers & Van Hove, 2002). They may also have helped to perpetuate the idea that within this group there is a personal preference for a non-sexual lifestyle (Milligan & Neufeldt, 2001).

How far these attitudes have influenced those who work in the support environment is a question not fully addressed within the literature. It has been suggested that the lack of appropriate judgement belief (Katz et al., 2000) underscores the concern many support workers have about the potential difficulty some intellectually disabled people have in differentiating between consenting and non-consenting sexual partnerships (Wolfe, 1997). However, these difficulties are noted as of less concern to intellectually disabled people than they are to those who support them (Thompson, Bryson & De Castell, 2001).

## ***Further Discussion***

To consolidate the research question I wanted to find a working definition of sexuality that provided a framework through which certain behaviours in the support area could be viewed. Finding a suitable definition was difficult. As Sedgwick (2005) notes, the complicated mix of values, norms and interactions that constitute human life make it unlikely that the term ‘sexuality’ could be contained within a single definition. As she points out, our sexualities are constructed from the complex sets of possibilities and actions that comprise human experience. Thus it is a term “whose usage relations and analytical relations are almost irremediably slippery” (Sedgwick, 2005, p. 83).

Two of Sedgwick’s (2005) assumptions are used to provide an initial context for the use of the term ‘sexuality’ within this thesis. The first links sex, seen as a certain group of biological differentiations between members of the human species who have XX or XY chromosomes, to chromosomal sex. The second assumption views sexuality as an identifying point for the “arrays of acts, explorations, pleasures, identity formations and knowledges” (Sedgwick, 2005, pp. 83-85) that constitute the spectrum of positions between the most intimate and the most social acts in euro/western society. However, although these suggestions initially ‘fix’ sexuality in relation to the information contained in this thesis, it is also left open for further interpretation. Further understandings about the term and how it works are incorporated into the theory and analysis sections.

## ***Addressing Sexuality and Research Difficulties***

In foregrounding support for the development of intimate relationships I focus on a social area that some have found difficult to include in their research work. I hope that this initiative might encourage other researchers to begin to explore this complex and sensitive area. I also hope this study will add a further dimension to the existing body of knowledge about this topic.

The second chapter turns the focus of enquiry to the support position. It explores how this position is defined and how it currently operates in an agency service setting. This line of enquiry is based on an extensive search of the intellectual disability support

literature. Comments about how existing research findings conceptualise and structure the support position are included in this chapter.

## **Chapter 2**

### ***Profiling the Support Position***

#### ***Introduction***

This chapter outlines the profile of a support worker and investigates how the support position currently operates. This investigation builds up a picture of the key elements of the role based on international research studies conducted over the last twenty years. These studies have largely been carried out in response to discrepancies found between the vision of full community participation for intellectually disabled people who have left institutional settings and the difficulties experience by members of this group in attaining this goal.

These studies initially concentrate on three tangible issues related to support practice and the context in which it operates. These include: studies investigating how workers currently perform on the job, studies linking worker actions to problems inherent in the position itself and studies isolating problems inherent in service agency organisation structures. Then a small number of more recent findings suggesting the presence of more intangible support matters are summarised. How these intangible factors might affect workers' actions in respect of those they support is then detailed. As an aspect of this part of the chapter, research literature relating to how workers are viewed by intellectually disabled people is included.

#### ***Definition of a Support Worker***

Support workers are defined as employees of human service agencies whose primary responsibilities are to provide training, supervision, support and personal assistance in the home and in the community to intellectually disabled people (Ford & Honnor, 2000). Workers are hired from their local communities and may or may not have prior qualifications and experience in the nursing, education or disability fields. The majority of workers are women and many come from ethnic minority groups (Mattison & Pistrang, 2000). A first-line manager ordinarily links direct support

workers to management systems within an agency service (Brown et al., 1994). Workers usually know this person and are generally in regular contact. Support workers have a more distant relationship with managers higher up in the system, where “direct interaction does not occur often” (Whitaker, Archer & Hicks, 2003, p. 42).

### ***Support in New Zealand***

In the past in New Zealand, forms of support for intellectually disabled people, other than the kinds of support and care offered within family settings, largely consisted of day-to-day care in institutional settings. Nurses and nurse aides supplied this assistance under the supervision of a nurse matron or medical superintendent. What these workers did depended on the system each institution had in place to enable the day-to-day running of the facility (Hunt, 2000). In practice, the outcomes of care in these settings relied for the most part on the actions of individual workers, as Hunt notes.

*The majority of staff was excellent and dedicated to their job. Some “minders” were a bit harsh and lacking in compassion. A great change occurred in later years with the introduction of women in the male wards* (Hunt, 2000, p. 90).

Changes from institutional to community-based living in New Zealand and elsewhere have impacted on the nature, emphasis and quality of support provision (Test, Flowers, Hewett & Solow, 2003; Ford & Honnor, 2000). In turn this change has influenced the nature and function of the support role. Support work been reorganised to include provision for a quality of life in the following key areas. These include enhancement of choices, relationship development, client satisfaction, personal safety and community participation (Agar et al., 2001; McArthur, 2003). Yet as research indicates, this reorganisation has not resulted in either more comprehensive or effective support for the development of meaningful interpersonal relationships or valid community participation for intellectually disabled people.

A recent study undertaken in New Zealand defines the current profile of the support worker as an “unskilled and low-income female worker in her 40s and 50s who is

likely to have family commitments, including children at home” (Chai, 2004a, p. 82). This survey also reveals that the minimum standard required for support workers for service providers is:

- i)* good spoken communication, stated as a minimum by 92% of service providers surveyed.
- ii)* good written communication, as stated by 71% of providers surveyed.

Criteria for good oral and written communication also applied to the roles of coordinator/first line manager (Chai, 2004b). However, 74% of service providers surveyed in this study were found to have no minimum criteria for their workers, although relevant life experience and previous experience as a caregiver/support worker was deemed important.

### ***Individual Worker Performance on the Job***

This part of the chapter describes studies that detail how workers perform on the job. Although it remains unstated, it is suggested that these studies have been undertaken in the belief that workers have not promoted sustained and effective skill development, social and emotional growth and community inclusion for the people they support.

### ***Isolating a Discrepancy***

A few research studies note that many workers find their work intrinsically interesting (for example, Henry, Keys, Balcazar & Jopp, 1996). Workers express values that reflect respect for intellectually disabled people and an appreciation of them as individuals (Ford & Honnor, 2000). Workers have also been found to hold moderately favourable attitudes towards a number of aspects of their positions including: interactions with the people they work with, relationships with their co-workers and the nature of the work itself. However, other studies find that workers continue to distance themselves from those they support, providing “little in the way of facilitative assistance to support engagements in meaningful activities” (Cambridge &

Carnaby, 2005). As an example, workers in one survey were observed to average only 19.6% of their time in person-to-person interaction, which was less than time spent on personal pursuits at work (20.7%) and other matters “unrelated to their job descriptions” (Hile & Walbran 1991, p. 38).

Other findings note that few differences have been found between worker engagement in activities with residents living in custodial institutions and engagement with intellectually disabled people who are in community living service agencies. As an example, one study found that each person received attention 10% of the time on average in institutional settings and 12% of the time in the community setting (Felce, 1998). It has also been suggested that intellectually disabled people are able to exercise more choice in their daily lives when support workers are absent for periods of time (Simmonds & Russell, 1999).

In cases when worker’s attention level is high, actual provision of assistance and the substance of it remains low. Workers reinforce passivity and inactivity through how they engage with the people they support, thus lessening the potential of those they support for interactive behaviour through the reinforcement their own behaviour provides (Mansel & Elliot, 2001). The spoken and unspoken feedback workers give to those they support is highly influential in these interactions (Murray & Minnes 1994; McConkey & Ryan, 2001). More severely disabled people are less likely to be engaged in social conversation with workers than those who are more able to communicate (Hile & Walbran, 1991).

The functional level of the intellectually disabled person also strongly influences the amount and quality of interaction initiated (Hile & Walbran, 1991; Jones et al., 1999). Workers have been observed to be more likely to give attention to intellectually disabled people who are behaviourally more able (Felce, 1998). People with perceived lower levels of adaptive behaviour and cognitive competence also receive less training or stimulation and more routine custodial care than those who are more able (Jones et al., 1999). Other studies indicate that support performance can be influenced by the physical characteristics of the people they support (Hile & Walbran, 1991), with appearance setting the scene for workers to approach or avoid particular individuals (Bromley & Emerson, 1995). When psychiatric problems as well as

intellectual disability are present, workers are more likely to give assistance to people with mild intellectual disability rather than to people with more severe impairment conditions (Edelstein & Glenwick, 2001).

### ***Review***

These results sketch an image of the support worker as an under-performer who displays very little interest in or regard for the material and social development of many of the people they support. From the underperformer point of view, ideas about why workers fail to engage reflect an underlying assumption of deficiency on the part of the individuals concerned. It is suggested that workers lack either knowledge about how to encourage people to actively make choices (Heller et al., 1999), or the strategies or the skills to make these choices happen (Balcazar, MacKay-Murphy, Keys, Henry & Bryant, 1998). Other ideas include that workers do not understand, or believe in the philosophy behind community inclusion (Bray & Gates, 2003). This suggestion also reinforces the wider question mark these studies place against worker's abilities to perform in the job. In support of these studies, researchers further note that agency hiring systems may fail to adequately screen out those who are unsuitable for the position (Hall & Hall, 2002). In addition it has been found that at least some new workers are uncomfortable working with disabled people (Test et al., 2003).

Recommendations to improve worker performance from these research results cluster round the under-performer image. It is suggested that workers need to be encouraged to begin the reflective process necessary to change their attitudes and practices (Craft & Brown, 1994). These reflective processes would assist workers to begin to re-vision their role as models, teachers and counsellors for those they support. In addition these processes would help workers to develop the competency they need to assume a teaching and a liaison position in their role where necessary. These studies also recommend that workers begin to view themselves as protectors, interveners, advocates and empowerers for those they support, and as needing to acknowledging that they have a key responsibility towards the personal integrity and safety of those they work with (Craft & Brown, 1994).



### ***Problems in the Worker Position***

The findings described above provide compelling reasons why many intellectually disabled people lack a sustained quality of life in community settings. However, while these findings isolate the presence of an under-performing worker, through either ignorance or design, other studies suggest a number of different causal factors can affect worker's performance. These factors lie beyond the direct control of the individuals themselves. This research strand provides a different insight into why workers might do what they do through isolating material and social factors lying within the discrepancy between the acknowledgement of workers as the most valuable resource of agencies supporting intellectually disabled people (McVilly, 1997; Hall & Hall, 2002; Test et al., 2003) and the reality of the low occupational status of the direct support position within the helping profession (Weiss, 2003). Two points of concern, stress and retention, dominate research interest in this strand.

### ***The Retention Problem***

Because of the chronic difficulties service organisations experience retaining staff, the length of time a worker spends in the position has been the subject of close research attention (Rice & Rosen, 1991; Beadle-Brown et al., 2003; Test et al., 2003). Some agency administrators regularly deal with what have been called “unacceptably low” (Hall & Hall, 2002, p. 201) rates of worker retention. Mean support staff tenure within agency services is typically close to three years, yet approximately 40% of employees hold their position for less than one (Razza, 1995). Workers can average only 10 months on the job, hardly long enough it has been suggested to develop meaningful relationships with those they support (Hall & Hall, 2002).

Service industry rates of turnover vary. In the United States annual turnover rates of between 50 and 75% have been reported, with these rates described as one of the most “critical challenges facing the field of developmental disabilities” (Test et al., 2003, p. 15). In the United Kingdom turnover rates are more likely to range from between 10 and 30% (Mattison & Pistrang, 2000). Causal factors explaining the difference between these two figures have yet to be explored, however retention problems continue in both countries. Turnover rates can cause significant difficulties for service provision. These include having a negative impact on the continuity and consistency

of service delivery to individual intellectually disabled people as well as a negative impact on the development of realistic organisation budget planning (Burtnek, Thallas & Burdett, 1996).

Other factors affecting worker retention includes the high rate of shift work (Chai, 2004a). Much support work includes varying hours meaning that many work part-time. Yet these hours can often be long and irregular. Poor remuneration is also influential. For example, when travel costs are incurred, it has been found that workers can end up earning less than the minimum wage (Chai, 2004b). Some workers take a second job to pay their bills (Test et al., 2003; Chai, 2004b), while qualified individuals may decline the job because of the low status and pay (Test et al., 2003).

### ***The Stress Problem***

Research surveys pinpoint tensions leading to worker burnout as a significant factor in issues of performance and retention. Support work has been found to be a highly stressful position that affects worker engagement with those they support (Ito, Kurita & Shiiya 1999; Hatton, Emerson, Rivers, Mason, Swarbrick, Kiernan, Reeves & Alborz, 2001). Stress factors related to the dimensions of the job itself have been extensively explored. Research in this area reveals that this work consists of a large variety of tasks, with one study identifying up to 155 different job titles for the position (Test et al., 2003). These include assisting a group of people who can have complicated patterns of behavioural and verbal communication, yet workers are often hired with very limited areas of professional expertise (Chai, 2004a). This problem in particular is becoming more acute, as “the needs of people with intellectual disability become more complex” (Chai, 2004b, p. 50). As well as managing the needs of those they support, workers also have to manage the conflict that can arise between themselves, family members and needs assessment agency personnel in relation to the sometimes unrealistic expectations placed on them and those they support (Chai, 2004b). This too can be an extremely stressful task.

### ***Solutions to these Problems***

These studies uphold the image of a lowly paid, undervalued, stressed and low-skilled individual. From this perspective researchers have made a series of wide-ranging suggestions about how these problems might be ameliorated. They include greater remuneration, the establishment of career paths and the delivery of training programmes as key factors in improving stressful conditions. Guaranteed work hours and reductions in staff workloads have also been noted as useful ways forward (Ford & Honnor, 2000). One important recommendation involves encouraging a culture of learning so workers can understand the “value of learning and education to the successful development of their role” (Chai, 2004b, p. 54). However, while these initiatives may encourage more worker engagement with the requirements of their role, further research has queried how these suggestions are to be translated into workable change in workers’ daily practice.

### ***Problems in the Organisational Structure***

A third strand of studies examining how support work itself is structured within service agencies suggests that there may be no simple long-term solution to the difficulties outlined above. This section provides a more contextual picture of how wider organisational structures can influence worker performance, thus shaping the responses worker’s make in respect of those they support.

### ***Difficulties for New Workers***

Recent studies suggest that new support workers can be exposed to a high risk of failure to perform (Cambridge, 1999). New appointments can be placed in difficult work situations at a time when they lack the necessary competencies to perform the essential tasks of their role well. In these circumstances more experienced workers can challenge new worker’s abilities, and these challenges can undermine support innovations initiated by new recruits. Cambridge (1999) notes that without clear and competent guidance, inadequate and damaging support responses can become routine within new workers assistive practices. Such interactions then become established ways of doing within the wider practices of the agency itself, resulting in a culture of worker exploitation and abuse that is difficult to eradicate.

### ***Differing Consequences for Workers***

Co-workers and line managers are the most important influences on how workers perform in respect of those they support (Mansell & Elliot, 2001). However, both groups differ significantly in the areas of practice they influence. Co-workers generally are involved in either positive or negative consequences relating the ongoing experiences of people who use the service. Line-managers tend to deal with consequences related to the administrative issues involved in the support process (Mansell & Elliot, 2001). Even so researchers note that a large number of workers do not report any strong or certain consequences, either good or bad, relating to any outcomes of their work. In reality most support workers seem to work in environments where very few people notice whether they are doing a good job or not. As Ito et al. (1999) remark, regular supervision, team meetings and informal opportunities for discussion are crucial to the maintenance of a healthy work environment. These researchers further suggest that these events do not take place often enough in agency service organisations.

### ***Communication with Managers***

The relationship between workers, line-manager and higher managers is central to how well individuals perform on the job. For example one study has recorded burnout scores for workers that are significantly lower when they are able to consult with supervisors (Ito et al., 1999). Workers themselves highly value organisational cultures orientated towards their wellbeing, yet many experience the culture of the agency they work for as being orientated in the opposite direction (Hatton et al., 1999). In particular, good communication pathways between workers and their managers remains the exception rather than the rule within the support sector (Chai, 2004b). Communication difficulty between workers and managers reflects the traditional management practices many service agencies continue to use. The one way communication system inherent in traditional management systems can lead workers to experience difficulty conveying their viewpoints to either first-line managers or to those higher up the organisational chain. Workers end up overstating a difficulty in an effort to get their viewpoints heard or allowing a support issue to develop to crisis

point in order for notice to be taken (Whitaker et al., 2003). Whitaker et al. (2003) further note that line managers often have supervisory as well as administrative roles in relation to their workers. Workers can become reluctant to seek advice from this quarter if it means they are exposing what might be regarded as weaknesses to someone who has power over promotions or contracts.

### ***Differing Audiences and the Support Role***

While workers form the centre of the network of expectations held by all interest groups in relation to those they support, each group may differ in relation to how support practice is actioned (Cambridge, 1999). In addition to supervisors and managers, other groups such as relatives and specialist professionals can influence worker's long-term behaviour. Poor performance can be attributed to the outcome of individual workers experiencing inconsistent expectations from these different audiences, expectations that also encourage priority being attached to tasks other than those of providing support to the people they are working with. However, in-depth analyses of the barriers these differing audiences might create and maintain have yet to be undertaken.

### ***Summary***

These studies suggest that the low levels of interaction said to characterise support performance may consist of more than just examples of individual inaction due to ignorance and/or incompetence. Worker's actions can be attributed to a systemic failure to recognise either the financial or social value of the role, a failure that amounts to an overwhelming "neglect of staff's needs" (Mattison & Pistrang, 2000). Worker's actions can also be attributed to the breakdown of organisational systems of management that fails to deliver meaningful and ongoing guidance for individual workers or effective supervision for the complexity of the tasks they undertake (Askheim, 2003). In this scenario a lack of strong, certain consequences enacted by managers for examples of negative practices by individual workers will also compromise chances for a meaningful life for intellectually disabled people who use agency services (Mansell & Elliot, 2001).

### ***Intangible Factors in the Support Position***

While the first set of studies isolates an under-performer figure, the second set of surveys presents a different image. These studies reveal a series of isolated, disconnected individuals who are stretched beyond their means to do anything about their conditions of work and whose only recourse in the face of overwhelming difficulties is to quit. Thus rather than poor performance being blamed on worker actions, poor performance can also be ascribed to the system in which the worker operates. Recommendations to alleviate the problems depend on which view predominates within the research design. However, these two positions do not capture every facet of the direct support role.

### ***Factoring in the Emotional Aspect of the Role***

As Hatton et al. note, multi-layered examinations of the complexity of the emotional relationship between those who support and those who are supported is an aspect of research that continues to be “greatly under-developed” (2001, p. 258). A few contemporary studies have begun to explore the idea that a strong emotional interplay may exist between workers and the intellectually disabled people they support. These studies suggest that an examination of what lies within this as yet untapped dimension of research interest might be highly influential to the development of more engaged and effective support practice.

Traditionally the performance of support work has been bound up in the idea that intellectually disabled people do not have the capacity to form strong emotional bonds and intimate relationships (Mattison & Pistrang, 2000). The research process itself may have been influenced by this idea, meaning that researchers have continued to concentrate primarily on examining and commenting on aspects of physical caring and practical skill development in relation to as one researcher has put it, “the interplay between staff attention and resident behaviour” (Felce, 1998, p. 291). Thus as the idea that intellectually disabled people are as capable of forming strong emotional ties as non-disabled people is established, studying the emotional dynamics involved in the support process has become a more acceptable line of investigation.

### ***A Positive View***

Some studies exploring the more emotional aspect of the support position reveal a more positive view of workers and their relationship with those they support. Some workers have been found to take on roles that transcend the more traditional, detached ‘care’ position that guided how the support process operated within institutional systems. In these studies, workers see themselves as social guides and friends in relation to the people they support. They understand their role as including the creation of a safe, trusting atmosphere in which the person supported can feel comfortable enough to accept guidance and feedback (Mattison & Pistrang 2000, Bambara et al., 2001). Workers also report that effective support can be wholly dependent on establishing and maintaining feelings of liking, caring and trust between themselves and those they support (Mattison & Pistrang, 2000). In addition, some workers have been found to establish relationships with those they support that go beyond “professional duty” (Krass & Erickson, 1988, p. 197). A study of non-intellectually disabled community members involved with people in this group notes that most community members who maintain ongoing involvement with intellectually disabled people are either former support workers or their friends (Newton, Olson & Horner, 1995).

This literature set substantiates the profile of the support work position as inhabited by a caring and emotionally engaged figure that exhibits an active interest in facilitating full and ongoing community membership for intellectually disabled people. Studies such as these highlight the importance of support people as both future friends and co-facilitators of community-based friendships in the lives of people who live in residential settings in particular (Jameson, 1988). As Bambara et al. (2001) indicate these latter findings stand in sharp contrast to more traditional ways of thinking about the support relationship within the intellectual disability sector. These findings de-emphasise the continuation of emotional distance between workers and those they support in favour of seeing workers as the key to facilitating intellectually disabled people to form ‘real’ friendships in the community. Thus they also question assumptions about what best practice in the support relationship might look like (Maidment, 2006). Yet while some workers have affirming emotional

relationships with the people they support, negative emotional interplays are also common outcomes of the interactions between workers and the people they work with (Jenkins & Davies, 2006).

### ***Worker Reticence***

Worker reticence has made it difficult to examine the emotional aspect of their position. Workers are reported acknowledging that personal factors that they are reluctant to reveal have significantly impacted on the implementation of support practice, at least in some areas (Howard & Hegarty, 2003; Chai, 2004b). As Bromley & Emerson suggest, support workers have been “understandably unwilling to report one’s own feelings” (1995, p. 351) about their support practices in some key areas. Yet these researchers do not explain why they consider this lack of communication to be understandable. Lezzoni et al. (2005) note that current social customs may keep workers from verbalising any critical views or negative feelings they might have about the people they support. However, this reticence may also stem from other aspects of their work and be associated with a wider variety and complexity of positive and negative feelings inherent in the positions that workers take up in respect of those they work with. For example, Todd’s (2000) landmark study describes the dual position workers can adopt when supporting intellectually disabled people in community settings. Some workers will adopt the role of cultural broker while supporting in public settings, acting as a social intermediary between those they support and other community members. Other workers can take up the role of benevolent conspirators when assisting in community settings, adopting strategies that prioritise the non-disclosure of the disabled identity of the person they support for the comfort of members of the non-disabled community.

For Todd (2000), these two roles play an instrumental part in both validating and invalidating the social presence of intellectually disabled people as members of the community without question or comment, and are undertaken by workers for the perceived benefit of the community. While this researcher queries how taking up these positions might either facilitate or obstruct the social participation of intellectually disabled people, this finding also suggests the presence of a deeper,



more complicated set of connection that characterises the relationship between members of these two groups.

In respect of these sets of connections Buckingham (2003) suggests that such negative interplays may be inherent in the position itself. As he notes, any positive relationship between workers and those they support will remain difficult to sustain as long as only one partner in the interaction is deemed the decision-maker, that is when it is only the worker who can take up the position of saying 'you choose'. As he also suggests, locating a duty of care aspect of support within the role can introduce a degree of surveillance of the intellectually disabled person on the part of the worker. This surveillance aspect can present barriers to the development of positive and affirming interactions between workers and those they support.

### ***Emotion in the Support Position***

The following studies explore aspects of the more negative emotional complexities that characterise the support position. These examples come from research studies that have begun to link the issues support work raises and the responses workers make to them to the emotional aspect of the role. Very few studies have been undertaken in this area, thus many gaps in research understanding in this area remain.

These surveys suggest that workers can become drawn in by the perceived needs of those they support, and as a result can feel overwhelmed by the responsibility the emotional aspect of their work generates (Mattison & Pistrang, 2000). Workers have difficulty with some of the emotionally painful disability related issues intellectually disabled people deal with on a daily basis. In some cases they feel that the people they assist are frustrated with their inability to provide those they support with what they want. In other cases they report feeling responsible for the problems their client's lack of quality of life can create (Sinason et al., 1992). Yet while they can become discomforted when those they support appear to become dependent on them, workers themselves tend to minimise the emotionally ambivalent aspects of their work.

Researchers have queried whether the 'we prefer not to know' attitude workers can take up is a stance adopted because "it is easier simply to attend to the more physical

and practical aspects of their care” (Mattison & Pistrang, 2000, p. 7) than to deal with the complexity of the emotional issues their work raises. Yet these researchers also ask “how can we ignore such critical aspects of people’s lives as their emotional experiences?” (Mattison & Pistrang, 2000, p. 7) pointing to the presence of a reality that indicates that being able to ignore the emotional aspects of intellectually disabled people’s lives may simply not be possible, despite worker’s efforts to distance themselves from those they support. These researchers also note that many workers downplay the emotional support area of their work with the people they work with. Choosing to end the relationship by moving on becomes a final coping strategy to deal with these complex emotional connections.

It has also been suggested that it may be difficult for workers to “think about the meaning of their client’s difficult responses because of the ‘unbearable feelings’ underlying such behaviours” (Mattison & Pistrang, 2000, p. 155). Yet workers themselves report few opportunities to discuss the emotional aspects of their work with more experienced colleagues or managers, suggesting that they too lack the emotional support they need to do their jobs well (Cambridge, 1999). As an example, Cambridge’s (1999) study isolates instances of support workers reporting cases where they witnessed abuse perpetrated by other workers on intellectually disabled people. Having reported the allegation of abuse, the worker was then asked to work alongside the person they had made allegations about. In these circumstances, inadequate briefing and updating on the progress of individual worker’s complaints also creates anxiety about reporting such incidents in the future.

### ***Emotional Ambivalence***

While the findings above indicate the emotional issues involved in the support role, the influence of emotional ambivalence on worker’s behaviour has yet to be thoroughly examined at academic level. The following examples are taken from studies that have not directly considered this aspect of the role, but indicate the presence of a particular set of ambivalent positions as a consequence of the issues under consideration. Each example suggests a series of complexities that may constrain workers “assisting behaviours” (Maidment, 2006, p. 119).

### ***Example 1***

A recent study isolating the reasons for intentional and unintentional injuries in intellectually disabled people includes the following observation from the researcher concerned. This researcher “observed an adult with intellectual disability fall heavily” (Donald Beasley Institute, 2002, p. 51). The only [sic] action of the worker who was present was to say to the injured client “Oh, have a nice trip” (Donald Beasley Institute, 2002, p. 51). This remark was noted as indicative. More than that the apparent lack of concern on the part of the worker observed prompted a great deal of concern on the part of the researcher concerned. At best this remark seems an odd thing to say. At worst this behaviour indicates a deliberately uncaring attitude. However, this interaction could also hint at a series of more complicated emotional ambivalences that led to the recording of this scenario with its seeming (in)action and lack of care on the part of the worker observed.

For Marks, the value accorded to carers/assistants within service agencies “seems to mirror the value accorded to the people they work with” (1999, pp. 107-8). She suggests that those who work most closely with disabled people experience related forms of the social and cultural difficulties the people they support experience. These include similar feelings of isolation and denigration felt by intellectually disabled people, leading workers to feel like they too are treated as if they are stupid. These feelings she suggests leads some workers to pass this devaluation and stress back to the people they support. In addition, Marks (1999) notes that some workers may be drawn to working with vulnerable groups of people with whom they believe they share an affinity. In particular workers who are unable to deal with their own sense of vulnerability or shame may identify these characteristics in their support of others in emotional ways that adversely impact on the relationship between themselves and those they work with.

### ***Example 2***

In this example, a researcher records being drawn into the position of “member of staff” (Tregasis, 2004, p. 61) due to the amount of time she spent in fieldwork in an area that included a number of physically and intellectually disabled people. Identifying as physically impaired herself this researcher reported feeling

uncomfortable about being ascribed the ‘staff’ position, a comment indicating the emotional ambivalence this position held for her as a disabled person. This ambivalence stemmed from a number of allied positions, which she commented on at length.

This role allowed this researcher to be privy to comments made by other workers that probably would not have been shared if she had continued to be seen as ‘outsider’. She was also able to witness behaviours that she would probably not have been privy to if she had not been accorded ‘insider’ status. For example, she was able to note down examples of staff members using tones of voice and judgemental language with an intellectually disabled woman that correlated with reports of this technique being used to exercise social control over intellectually disabled people. Yet, being ‘staff’ made it difficult for her to, “challenge immediately and in a public way these cases of discriminatory practice” (Tregasis 2004, p. 61), lest this lead to the fieldwork for her project being terminated.

Her position became even more problematic as she became aware that it was the ‘staff’ position that contributed to her inability to comment unfavourably on the practices witnessed. Being unable to comment, she felt that her lack of action effectively sanctioned the practices she disapproved of. Equally disturbing was the idea that, as an outsider within the service environment, she could expect her comments to be listened to and acted on. However, being viewed as ‘staff’ meant that managers would be far less ready to act on suggestions about the inadequate support practices witnessed.

### ***Example 3***

Researchers have begun to explore aspects of the emotional ambivalence that operate in environments in which behaviour modification techniques are regularly used. These techniques known in New Zealand as behaviour support, have been used in many service organisations settings (Hunt 2000). Controversy about the use of these techniques has featured in academic discussion for a number of years (Biham, Sigelman & Westbrook 1997; Wagner, 2002). However, until recently this debate has concentrated on ethical considerations and therapeutic effects of the techniques

involved, rather than detailing the impact on the social and emotional contexts in which such interventions have taken place (Wagner, 2002, p. 274).

More recently however, the social and emotional impact of these techniques has received closer research attention. This consideration has focussed on how intellectually disabled people might be viewed by “the perceivers” (Biham et al., 1997, p. 568) that is by workers, as a product of the use of these techniques. It has also focussed on how this perception might affect the social image of the intellectually disabled person in the mind of the workers concerned. However, what this consideration leaves out is any reflection on any other unintended effects that might equally influence worker’s responses to the person concerned.

To this end it is now acknowledged that rather than negative (or challenging) behaviour on the part of an intellectually disabled person being viewed as an intrinsic action, the behaviour of intellectually disabled people and the support workers who assist them “are intertwined” (Mitchell & Hastings, 1998, p. 142). Central to this premise is the largely negative emotional responses of the support worker to the presence of challenging behaviour. Mitchell & Hastings (1998) conclude that worker’s responses fall into two categories that include feelings of depression/anger or feelings of fear/anxiety. Both sets of emotions have been found to strongly influence how subsequent interactions are negotiated between workers and the intellectually disabled person concerned.

These researchers challenge future research carried out in this area to focus on the part emotions play in staff responses as a means of understanding the nature and function of assistive practice. They view this challenge as an important step, as it has been found that although a non-blaming stance in respect of difficult or violent behaviour on the part of the intellectually disabled person de-stigmatises these incidents, such behaviours continue. As Brown & Scott (2005) note these behaviours include frequent assaults on other intellectually disabled people as well as on workers themselves. Whether the adoption of a non-blaming stance has affected the worker position is impossible to accurately gauge. Thus it is also difficult to judge whether this change

of attitude has made it harder or not for workers to work through the emotional aspects of experiencing incidences of physical abuse directed against them.

### *Summary*

Research studies substantiating aspects of an emotional relationship between workers and those they support reiterate that the support role holds considerable power (Henry et al., 1996). Yet it can also be a powerless position containing, as Cambridge (1999) remarks, dangerous ambivalences for both parties. These few studies offer a tantalising image of a worker caught between a number of different physical, social and emotional locations that sometimes enables and sometimes constrains their support responses. Yet, how might these positions influence what becomes possible for workers to achieve within the context of their work? Research studies also reveal that much of the emotional ambiguity the worker position contains is not factored into either study design or into recommendations for change studies suggest.

What these examples do is raise the idea that support work involves workers experiencing the effects of a number of ambiguous emotional positions. However, they do not reveal how workers might be equipped or how they might equip themselves to negotiate the parameters of these emotional locations. What becomes exposed is the lack of research focus on how individual workers emotional responses might be influential to their support practice and a gap in recommendations that detail how practice shortfalls in relation to these interactions can be supported and improved within service organisations.

For example the researcher involved in the events outlined in the two examples noted above - Donald Beasley Institute (2002) and Tregasis (2004) - did not record the actions taken at the time to address the issues the researchers became involved in. Direct action on behalf of the intellectually disabled person involved was compromised due in part to emotional discomfort relating to the ambivalence of the researcher's own position. Whether their subsequent behaviour was justified, they too became as if 'under-performing workers' at that moment. They subsequently wrote about their experiences. Perhaps this was the only way these researchers saw of being

able to somehow address the emotional difficulties they had become caught up in. Yet when workers are caught in such a dilemma, what avenues are open to them?

Recently Fullagar, Owler & Hugill (2001) suggest an approach to support practice that prioritises the idea of support as a dynamic process of interactions that are responsive to the ongoing needs of each intellectually disabled individual. Re-visioning support in this way would allow workers to draw on a range of interpersonal approaches that would cover not only “what staff do to support individuals, but also ‘how’ they engage with that person’s own experience and aspirations in an ongoing and meaningful way” (Fullagar et al., 2001, p. 15). However, for this approach to become an all-encompassing step forward, fundamental questions about the operation and expectations of the role also need be asked. While the emotional ambivalences surrounding the role are not addressed, it is doubtful how far these recommendations can translate into behavioural change at a practice level.

### ***Connecting Workers to Those They Support***

The examples noted above indicate that the emotional complexities held within the worker position are inextricably linked to the presence of those who are supported. Yet too few research studies have explored how intellectually disabled people view those who support them. Further little has been recorded about the feelings of intellectually disabled people in general, or how their feelings are communicated to and received by others (Mattison & Pistrang, 2000).

### ***Workers and “Being Known”***

Research undertaken reveals that intellectually disabled people are deeply engaged with the relationship they have with their workers and hold a number of different attitudes toward the role of worker and the individuals who hold the position (Goble, 1999; Mattison & Pistrang, 2000; Frawley, 2003). Personal involvement with their worker is positively regarded by intellectually disabled people, with consistency of support highly valued, particularly when intimate personal care is required (Marquis & Jackson, 2000). Physical support is seen as always being there and positively associated with access to meaningful and enjoyable activities. In addition people who

are primarily non-verbal value communication through worker touch. Workers in key-worker relationships are viewed by intellectually disabled people as people they can rely on, as someone who has a long-term perspective of their needs and as a person who is a constant in their lives. There is also a sense of “being known” by this worker, a quality that they highly value (Mattison & Pistrang, 2002, pp. 146-8).

However, researchers also note the presence of a significant divide between workers and intellectually disabled people, a gap that may leave the people who are supported in emotionally vulnerable positions. Intellectually disabled people possess little to no knowledge of the structures that define the role of their worker and have no organisational power within the service system to be able to negotiate what that role could look like (Treese et al., 1999). People in this group see themselves as subordinate to and almost completely reliant on workers for their physical and emotional wellbeing, blaming themselves when a support person leaves the job (Sinason et al., 1992; Test et al., 2003). Perhaps because of this many people in this group interpret their relationships with support workers as a friendship, which can cause great distress and loss when a worker moves away (Firth & Rapley, 1990, cited in Mattison & Pistrang, 2000). Yet while researchers have noted a general eagerness to highlight familiarity and contact with their workers, some comments made by intellectually disabled people have ranged from wariness and dislike of individual workers to comments hinting at powerful attraction, feelings that can sometimes be overtly sexual (Goble, 1999).

### ***Emotional Blandness***

Some research studies suggest that intellectually disabled people downplay their emotional responses in respect of the support they receive in at least some areas. Goble (1999) isolates a blandness that seems to characterise many responses made by intellectually disabled people when questioned at interview. He notes the persistent use of the expression ‘all right’ to describe participant’s feelings about particular experiences. As he queries, are the lived experiences of this group really all right? Or does this phrase indicate the presence of an already-established tendency for people in this group to be reticent in their expression of strong emotion? Does this expression say something more about the “communicative conventions of the participant’s



world” (Goble, 1999, p. 453) that research, as yet, has not been able to access? As Sinason et al. (1992) point out, it may be difficult for people to express their feelings because of their fear of angering or offending the people on whom they depend.

Crotty also alludes to this issue, when discussing the difficulty researchers experience in enabling “many students [i.e. intellectually disabled people] tell stories at all that included feeling and emotion” (2002, p. 10). As he finds, service plan related achievement stories told by intellectually disabled people tend to recount the doings of people and things in their lives far more often than they express feelings and emotions related to these experiences. While he does not fully explore the reasons why the feelings dimension might be left out, Crotty does speculate that perhaps this is a convention used by those who have little belief in their own effectiveness and who “attribute outcomes of things which they have “no influence over to such things as luck, fate or powerful others” (Crotty 2002, p. 19). However, emotional reticence may also be an outcome of living within supportive environments that downplay both the positive and negative emotional aspects of interrelationship.

### ***Further Discussion***

These findings reveal that high expectations are held of those who take on the position of support worker (Weiss, 2003). These expectations include that these individuals will be able to work autonomously and for little remuneration in sometimes very stressful positions that require high levels of personal and professional judgement, often made on a daily basis. Yet these expectations are held of a group of people who can feel they are neither respected nor empowered by those around them. These findings also reveal that the emotional ambiguity inherent in the role rarely features as the subject of consideration in either analysis of worker’s actions or as an aspect of commentary on a part of their role that they may need assistance with.

Studies touching on issues of emotional ambivalence pinpoint a number of intriguing questions about the worker position. If it is the “communicative conventions of the participant’s [intellectually disabled person’s] world” (Goble, 1999, p. 453) that feelings and emotions are not discussed, how does this convention affect workers and their role? To what extent might what has been seen as unhelpful actions on the part

of individual workers actually reflect the negative emotional environments in which workers operate? To what extent might these responses reflect the need for workers to conform to surrounding expectations? Could these actions also mirror an uncertainty about how workers are to respond effectively in situations where strong emotions are evoked, yet are simultaneously kept hidden? How far might it be possible for workers themselves to be supported in the emotional areas of their work, if it also the communicative convention of their working world as well as the world of those they support is not to dwell on emotional issues?

These findings also raise a number of intriguing questions about research undertaken in relation to the worker position. What greater complexities have research studies yet to capture about the worker's role? How might the emotional complications that inhere in the worker position affect the process of research itself? Why have so few studies about beneficial support practices been undertaken? What complexities underpin the allure of the "bad stories" (Weis & Fine, 2000, p. 46) about workers, stories that dominate current research interests in the direct-support area?

The following chapter consists of an extensive literature search, detailing research findings about worker performance in the sexuality support area. These findings are placed within the context of the broader issues covered in this chapter.

## Chapter 3

### *Human Service Agencies, Workers and Sexuality Support*

#### *Introduction*

Chapter One isolated research findings related to how the group of people defined as needing ongoing support to live ‘an ordinary life’ (NACHD, 2003) currently fare in relation to the acquisition of valid life choices and life chances. Chapter Two utilised findings of key elements contained in the support location from an extensive review of research literature. This review exposed a gap between the assistance people require and the circumstances they currently inhabit. In doing so it built a broad picture of the tensions inherent in this role. This chapter adds a further dimension to this picture, concentrating on factors involved in worker performance in the sexuality support area, the focal point of the thesis.

Part One of this chapter outlines research survey results detailing sexuality and worker support factors compiled over the last twenty-five years. The majority of studies undertaken have been included as the research field in this area is very small. These surveys cover worker’s attitudes and behaviours in relation to issues of sexuality and intellectually disabled people living in institutional or agency service settings. These findings reveal an ongoing ambivalence on the part of workers to engage fully with this aspect of their role. Some rationale for this hesitation is included.

Part Two of the chapter summarises research information compiled through reviewing the few contemporary studies that broaden the parameters of this investigative field and connect sexuality support practice to the service framework in which it is sited. This part of the chapter is divided into two sections. The first covers formal organisational responses designed to improve levels of practice in relation to the problems worker’s face. The second section documents key elements that operate in the gap between the structure of organisational systems and difficulties workers experience. These issues have yet to become formally recognised by agencies as issues that need addressing, although problems the agency management role might

contain are briefly outlined. These studies suggest that worker ambivalence can also be seen as an expression of the problems service agencies themselves experience. These problems cohere around negotiating how a duty of care/dignity of risk tension created by the intellectually disabled aspect of those they support is managed in the sexuality area.

### ***Part 1: Documenting Sexuality And Worker Support Practice***

Until 1983 very few formal studies examining the role of the support worker in relation to issues of sexuality and intellectually disabled people were undertaken. Such findings as were published document a fostering of sexual ignorance among intellectually disabled people, with many institutional settings designated as single gender only (in Lutzer, 1983). In places where men and women lived in the same institution, an absence of rooms that allowed for intimacy, work overload experienced by institutional staff, care systems based on discipline and authority, over protection of residents and extremely restrictive social practices comprised the reality of the sexual life of many intellectually disabled people (in Trudel & Desjardins, 1992). Gender segregation in these settings to prevent sexual activity was also common (in McCarthy, 1999), while practices of therapeutic sterilisation remained widespread (in Lutzer, 1983).

### ***Consequences of Sexual Behaviour***

While it has been found that sexual ignorance was encouraged, early research studies also confirm that sexual activity between intellectually disabled people was a feature of the life of those who lived in institutions. In these locations in general, sexualised behaviours acted out in private were deemed more acceptable than those exhibited in public. Unacceptable behaviours in these cases could consist of “public masturbation, public long kissing and public homosexual behaviours” (Kempton & Kahn, 1991, pp. 96-7). However, the consequences of in-private sexualised behaviour being discovered were inconsistent, sometimes resulting in very unpleasant outcomes for those concerned. In some mixed institutions all heterosexual behaviour was punished, at times through the use of solitary confinement and shaven heads (McCarthy, 1999).

In some single gender institutions workers were found to focus on repressing and punishing homosexual behaviour until female residents were included “whereupon it switched to repressing any expression of heterosexuality” (Gordon, 1979, cited in Szollos & McCabe 1995, p. 251).

Reports of this time vary greatly in respect of how sexualised behaviours were addressed by managers and administrators. However, it was workers who were primarily instrumental in how these behaviours were dealt with in practice (Saunders, 1979). One study reported that when sexual behaviour was discovered 91% of the discoveries were made by workers, who often reacted either in anger or in denial of what they had found (Trudel & Desjardins, 1992). This study also revealed that the attitudes held by workers to sexualised behaviours were largely negative. Yet within this generalised discomfort a wide range in extremes of outlook could also be found. Some workers denied that intellectually disabled people had a sexual life, others adopted an attitude that sexual behaviour of any kind was inappropriate, while others were tolerant of limited expression of sexuality such as holding hands and kissing (Murray & Minnes, 1994).

### ***Variations in Worker Response***

Other research studies undertaken reveal that the sexuality support aspect of their work was not discomforting to all workers. Some observations of worker/resident interaction at this time show that some settings were highly permissive, with workers neither encouraging nor discouraging of any form of sexualised behaviour to any great extent (Felce, 1998). In addition some workers reported being conscious of the resident’s sexual needs (Trudel & Desjardins, 1992). Other workers reported counseling those they supported about sexuality issues and as expressing significant interest in assisting them with their sexual wellbeing (Saunders, 1979). However, other reports suggest that workers were fired for not adhering to the traditions of conservatism in this area they were supposed to maintain (Gordon, cited in Sweyn-Harvey, 1984).

### ***1983–1994***

During this period research studies reveal support workers holding a higher degree of tolerance for the major aspects of the sexuality of those they worked with than had previously been documented (Sweyn-Harvey, 1984). Worker attitudes were found to be dependent on a number of factors, including occupational level, being able to talk about sex, number of children, education and age (Brantlinger, 1983). In relation to worker practices people who were supported experienced barriers largely from a minority of workers when they attempted to get their needs for intimacy met. This minority could include older support workers and those with fundamental religious values (Johnson & Davies, 1987). Support workers in general expressed more conservative attitudes in this area than disability professionals, suggesting that levels of educational difference between the two groups could be influential (Murray & Minnes, 1994). Workers were also reported to have isolated a growing need for attitude change education to be made available to a range of support personnel in this area (Brantlinger, 1983).

### ***Research Studies from 1994***

Since 1994 the volume and scope of research in this area has grown markedly. This broadening of interest has been seen to parallel the more open attitude in society towards the sexuality of all individuals (Loftgren-Martenson, 2004). Aspects of research undertaken since 1994 follow earlier attempts to isolate support worker characteristics and attitudes, with this information now being sought for the additional reason that workers found to be supportive of sexuality issues might be able to develop and implement sex education programmes “for their clients” (Murray & Minnes, 1994, p. 121). Concerns continue to be raised about the possible impact on intellectually disabled people of the effect of the more conservative attitudes of support workers over 50 (Murray & Minnes, 1994). In addition research surveys note that while workers may hold more tolerant attitudes than they did in the past, some workers continue to think that it is not part of their job descriptions to ask those they support what they need in the area of sexuality and intimacy (Frawley, 2003). Most will wait for a person to ask before with sexuality education or sexuality support is offered (Abbot et al., 2005).

Other studies have concentrated more closely on worker attitudes and their influence on support practices. Findings in this area reveal that practices continue to be compromised by seemingly irreconcilable conflicts between individual personal values and the concepts of choice and dignity of risk in relation to the people workers support. Where conflict occurs, the values workers hold, as well as defining their own roles, tend to define and shape the attitudes and practices of those they support (Murray & Minnes, 1994). As an example, although many workers know that agency policies in this area exist they tend not to be motivated to change their practice because of policy guidelines (Christian et al., 2001).

Workers themselves are reported as noting more training as significant in respect of increasing their confidence in this area (46%), followed by clear policy guidelines (42%) and then opportunities to discuss issues with colleagues (23%). However, when asked about their level of confidence in handling future incidents, only prior successful handling is reported by members of this group as being helpful in increasing levels of confidence (Christian et al., 2001). As Wolfe (1997) comments, more specific and concrete rather than general policies are needed to assist workers to address this policy/practice disparity. Christian et al. (2001) further suggest that more research is needed to determine how well workers might be handling the incidents they encounter, as only a limited number report seeking advice from a manager about these issues.

In respect of worker practice, the assumption that the more intellectually disabled the person the less sexual that person is, makes it less probable that workers will undertake support in this area for those with high and complex needs (Wolfe, 1997). However, other findings query why, given that they are often already in the position of being “responsible for supervising any risky but beneficial non-sexual behaviours” (Kaesler, 1996; p. 318), workers should continue to view support in this area as different to other practices related to personal and intimate care. In response a more contemporary finding notes that because the majority of support workers are female, the kinds of sexual norms that might comprise the personal views of workers that guide their practice may represent a restrictive set of rules and regulations about possibilities for personal behaviour (Lofgren-Martenson, 2004). Abbot et al. (2005)

also suggest that workers remain concerned about whether they know enough to be able to support intellectually disabled people with high needs well, whether their managers will support them in this role and what parental attitudes and behaviours towards their support work in this area will be.

### ***Isolating Troubling Sexual Behaviour***

As the idea that at least some intellectually disabled people live sexual lives in service agency settings has become more acceptable, research undertaken from 1994 has probed what these behaviours might consist of. Two thirds of workers report encountering “an incident of a sexual nature” (McConkey & Ryan, 2001, p 85). What workers report finding difficult cover a range of different activities. These include: non-consenting sexual behaviour among those workers support, behaviour where consent is questionable, concerns about masturbation, behaviour which although not abusive is difficult because support workers had to witness it, people they support’s frustration about unmet sexual desires, conflicting sexual values between support workers, families and the people they support, and personal experiences of being sexually abused (Thompson et al., 1997, p. 577). It is not clear precisely what might influence why these behaviours are deemed problematic, although they may be seen as difficult because of worker’s ambivalence about what to do when it comes to dealing with sexual behaviour and people in this group.

### ***Gender and Support Practice***

Another area of research interest since 1994 has included an exploration of links between gender and sexuality. Although small in number, these studies suggest that workers are gender specific in at least some aspects of their practice. In particular while workers have been found to agree that intellectually disabled women have the same sexual desires as other women, many continue to fail to recognise intellectually disabled women as sexual beings (Christian et al., 2001). In addition, significant percentages (44.2%) have been found to consider that there are more important issues to focus on when providing assistance to the women they support. On the other hand female workers are found to focus primarily on male sexual behaviours in order to protect the women they support (Lofgren-Martenson, 2004). This research finding



suggests that downplaying the importance of sexuality for the women workers support may hide yet another area of worker ambivalence. It is further suggested that this hesitation might be based on the fear that an emphasis on sexuality within support work will result in the possibility that “someone will become pregnant, or will be sexually abused, or will lose control of their sexuality” (Lofgren-Martenson, 2004, p. 201). In addition the majority of support workers think that the intellectually disabled people are heterosexual, and do not expect those they support to be gay or lesbian (Abbot et al., 2005).

### *Summary*

All findings reviewed in this section reveal that although a wide spectrum of attitudes in relation to this aspect of their work can be found, in practice support in this area is characterised by a greater or lesser degrees of ambivalence and difficulty on the part of individual workers. These difficulties are clearly evident when workers manage the variety of sexualised behaviours already occurring in service settings. On the one hand these review findings outline the presence of an ambivalent, confused figure, unable to navigate the discrepancy between the idea of sexuality support and its relationship to their daily practice. On the other this figure is portrayed as decisive and orderly, guided in their usually lack of practice through the purposeful use of their personal skills and experiences.

What is noticeable about this set of research data is that it contains nothing concrete to indicate what the best practice criteria might be that workers are said to be either in confusion about or ignoring their responsibilities in relation to. Neither does the research undertaken seek to define sexuality. By default, the term becomes a descriptor for an unstated list of behaviours that are usually unacceptable to workers but not always to those they support.

What is also noticeable is that some quality of life assessment surveys completely bypass any consideration of any sexuality aspect of support provision, irrespective of how it is defined. For example, one study of worker practices from this period evaluated instances of ‘community participation’, defined as participation in activities in other than institutional environments, as an indication of whether or not an holistic

quality of life for study participants could be said to be supported. Quality of life particulars used included the number of times intellectually disabled people “have been shopping, been to a café, to a pub, to a hairdresser, to their bank, to a social club... [and] ... on a bus” (Agar et al., 2001, p. 395) as key support indices. While this study noted that 17% of people “did not even go shopping” (Agar et al., 2001, p. 395) as an indication of the extremity of the lack of support for community participation, participation in any sexual and/or intimate relationship was not included as an assessment factor.

### ***Human Service Agencies and Sexuality Support***

The second part of the chapter concentrates on literature findings in the sexuality area that relate to organisational constraints found to be influential in respect of worker performance. As Chapter Two indicates, contemporary studies in the support area in general have moved away from an emphasis on the problems individual workers pose as an overall explanation for the difficulties intellectually disabled people experience achieving a quality of life. In the sexuality support area, research commentators now suggest that the effects of structural controls over intellectually disabled people can also severely compromise the development of healthy sexual identities and satisfying intimate relationships for members of this group (Hingsberger & Tough, 2002). In addition, while how workers assist those they support has consistently remained a significant aspect of research concern, it has also been noted that research needs to “take note of the wider political and social issues which are inherent to the context of residential care” (Mattison & Pistrang, 2000, p. 17). Without significant change in these areas it is mooted, growth in the emotional and sexual lives of intellectually disabled people will continue to remain compromised (Hingesberger & Tough, 2002). However, very few in-depth research inquiries into the effects of the ‘wider political and social issues’ that influence how sexuality related issues are managed at agency service level have been undertaken. Thus this part of the chapter provides a very sketchy outline of an area of research interest that is in pressing need of more in-depth attention.

### ***The Dual Obligation Conflict***

Contemporary literature findings reveal two dual obligation conflict positions related to service provision for sexuality support influential to how workers respond to those they support in this area. The first position involves service providers being funded to provide support to develop and promote the abilities of those who use their service while also being funded to protect those they support from harm in the context of their behaviour (Sundram & Stavis, 1994). The second position relates to the provision of appropriate support, where providers are funded to provide suitable support to the people who use the service while equally being obliged to provide a safe and supportive work environment for employees who work in their service settings (Christian et al., 2001). Thus far service systems seem unable to effectively reconcile these conflicting obligations within the sexuality support area. The following discussion examines research studies related to how agencies services currently manage these at-odds dualities.

### ***Promoting Ability/Protecting From Harm***

Service agency responses to providing support to develop and promote the abilities of those who use their service while protecting those they support from harm in the context of their behaviour has been found to consist of an across the board downplaying of the issue within agency planning mechanisms. Contemporary findings suggest that organisations continue to deprioritise the need for privacy and expressions of intimate behaviours in all guidelines for programme planning and implementation processes (see Frawley 2003, as an example). Strategic planning mechanisms continue to treat intellectually disabled people as if “they don’t have a desire for intimacy”, underpinned by an assumption that “so long as no-one discusses sex and sexuality, hopefully the individuals with DD/MR will not be inclined to focus on it” (Allen, 2003, p. 127).

For Burns (2000) this lack of planning also signals the presence of a pervasive lack of attention to issues of gender at the wider agency level. This lack of awareness conceals any necessity for agency personnel to find out about intellectually disabled people’s sexual experiences (Hamilton, 2002), even though this information is essential so to orientate support to meet requests for assistance in this area (Frawley,

2003). Downplaying or ignoring the role of gender in the lives of intellectually disabled people provides service personnel with the means to circumscribe what might be possible for intellectually disabled individuals in this area of their lives. However, the complications this lack of gender prioritisation and its outcome creates are central to the difficulties individual workers and intellectually disabled people experience in this support area.

### ***The Impact of Gender Neutrality on Service Provision***

Gender issues in service provision describe the variety of areas in which the views, experiences and needs of women and men who use services substantively differ. They include how these differentials are treated in relation to the level and kind of support offered to individual men and women. At wider service agency level, the intellectually disabled label continues to act as the primary identity for support purposes (Burns, 2000). Thus very often women and men in this group are talked about “without reference to gender” (Williams & Nind, 1999, p. 559). As a result, as Cambridge & Mellan suggest, “informal codes relating to particular sexual behaviour or the sexual norms within particular cultures or communities” (2000, p. 295) related to gender, that usually provide the guidelines for the creation of sexual possibilities, are not influential within agency service settings. These researchers further note that such an absence increases the probability of sexualised behaviour being re-labelled as challenging “or pathological” (Cambridge & Mellan, 2000, p. 295).

Whether service providers operate this way out of religious conviction, parental pressure, staff philosophy or greater or lesser measures of all three factors is a question that remains open. However, it has been suggested that while sexuality support is an aspect of service planning that continues to be neglected, this lack affects the overall development of organisational energies and resources to assist workers to support those who use the service to develop, maintain and sustain intimate relationships (Burtnik et al., 1996). The overall silencing of the role of gender in service provision also underpins the difficulties agencies can experience when trying to deal with the ongoing problem of how to protect groups of individuals who use services from one another (McCarthy & Thompson, 1996).

Yet, while service agencies largely deprioritise sexuality-related issues at the meta-level, research studies have also found that services do provide some promotion of ability support avenues in this area. However, protection from harm rather than the promotion of ability aspect of support provision invariably typifies the focus of initiatives undertaken. In respect of some of the sexualised behaviour documented protection from harm strategies may be necessary. One survey undertaken revealed two agency service cases where an intellectually disabled person had sex for cigarettes, one case of sex for money, a further case where a person was used by a third party for prostitution and another incident where emotional exploitation of the person concerned was considered to be taking place (Brown, 2002).

### ***Sexual Abuse and Gender Neutrality***

Research findings suggest a clear association between intellectual disability and high levels of sexual abuse experienced by members of this group (McCarthy & Thompson, 1996; McCarthy & Thompson, 1997; MacArthur, 2003; Taylor, Keddie & Lee, 2003). Incidence and prevalence figures in this area differ widely, however calculations of 61% of women and 25% of men with intellectual disability having experienced at least one instance of sexual abuse provide useful percentage guidelines (McCarthy & Thompson, 1996). Yet these figures do not take into consideration the difficulty some intellectually disabled people have in disclosing information about what has happened to them (McCarthy & Thompson, 1997; Sinason, 1992).

Research studies have also found that sexual abuse is most likely to occur in positions where the abuser is known to the intellectually disabled person concerned. People who abuse can include other intellectually disabled people and close and extended family members including other adults known to the family, such as support workers and volunteers (McCarthy, 1999). However, the most significant group of abusers of intellectually disabled people are intellectually disabled men and the most frequently abused group are the intellectually disabled women they live with (Thompson, Claire & Brown, 1997).

Causal factors in explanation of why this form of unwanted activity continues remain inconclusive. It is noted that sexual and other forms of abuse become acute when

people live with others of the opposite gender that they are not related to, and that they may not have chosen to live with (Thompson et al., 1997). Studies also indicate that a gendered hierarchy of elitism can exist between those in the intellectually disabled community, which may also be influential (Thompson et al., 1997). The influence of this hierarchy is particularly significant where people live with others with very marked differences in level of cognitive ability.

### ***Service Agency Provision in Mitigation of Abuse***

When sexual behaviour occurs in service settings it is often labelled ‘inappropriate’ by service personnel (Hamilton, 2002). Possibly as an outcome of abuse incidence figures this label is frequently used in the context of sexuality and intellectually disabled men. However, while this practice constitutes a service commitment to protection from harm in the context of individual men’s behaviour, limiting behavioural strategies to the level of the individual and deeming them ‘inappropriate’ ignores other rationales for why certain behaviours might be taking place. Thus this strategy may be problematic as a long-term solution to assist the resolution of the abuse aspect of the behaviour. In particular, it becomes difficult to examine the idea that certain behaviours may have much to do with the gender neutering aspect of service provision as the unsuitable nature of the actions exhibited (Clements et al., 1995). For intellectually disabled men, their behaviour may be more due to the consequence of a desire to assert a masculine identity and to be seen as male, rather than due to an individual lack of awareness of what is appropriate and what is not.

A limited number of sexuality support options for some intellectually disabled men and women have been initiated by a few agency providers, largely due to specific incidences of abuse within their services (McCarthy & Thompson, 1997). Yet it is noted that the quality of agency responses to these instances continues to be mediated by a number of adverse factors (MHF Briefing No 12, 2003). These factors include unclear definitions about what constitutes abusive sexual behaviour, inconsistent perceptions of risk within certain service areas, poor service co-ordination, a lack of specific care planning, failure to agree to suitable supervisory measures and a lack of clarity within and between agencies (MHF Briefing No 12, 2003). Guidelines for sexual abuse have been isolated as recent helpful feature of service provision. Yet

these are not always clear enough to be helpful to individual workers or those they support. Nor do guidelines and indicators always address the complex ethical and advocacy issues these incidents can raise (Thompson et al., 1997).

### ***Sexuality Education and People who use Services***

Sexuality education for those who use agency services is used as a means of promoting ability in this area. This option is now more readily available to some intellectually disabled people. However, promotion of this initiative within service agencies is not often wholeheartedly endorsed or well thought through by the providers concerned (Cambridge & Mellan, 2000). Reviews of educational programmes uncover the presence of 'normative' views of sexuality that reinforce traditional and stereotypic notions of sexual behaviour, where the physical act of sex is treated as functionally separate from any emotion dimension (Chivers & Mathieson, 2000). Within this view, sex education becomes a series of 'specialist' training programmes that emphasise bodily distinctions between women and men, STD's and mechanistic aspects of heterosexual intercourse (see Hamre-Netupski & Ford, 1981, for an example).

Sexuality sessions are often placed within the context of the dangers involved in acts of sexual expression. For women, pregnancy threat or menstruation worry underpins access to information and education in this area. Yet difficulties can be created for women in this group when sexuality is defined in terms of sexual penetration, thus presented within a context of male sexual performance alone. Such stereotypic notions can preclude the possibility of intellectually disabled women being seen as desiring and as capable of initiating sexual contact on their own terms. Sexuality for men is presented as biological in nature and function and as operating without them being able to make choices about what they do. Thus men are offering little flexibility in how they might express aspects of their feelings and emotions. These notions also inhibit the development of alternative sexuality education sessions that go beyond specific information about hetero-normative behaviour (Chivers & Mathieson, 2000).

Sexuality sessions target primarily those who are physically able and who have mild levels of intellectual impairment, substantiating ideas that they are designed to cater

only to those who can most easily approximate a normative lifestyle (McCarthy, 1999). Educational opportunities also continue to be conducted largely in groups despite suggestions that formal sex education classes for members of this group may be largely ineffective (Szollos & McCabe, 1995). In addition it has been noted that it is counter productive to provide individuals with educational opportunities without addressing, at the same time, the problem of a lack of material opportunities to put what has been learned into practice (Walsh, 2000).

Too few sexuality education programmes for people who use services have been formally evaluated (Szollos & McCabe, 1995). Follow up studies related to what information has been learned from training sessions, how much knowledge has been retained, what people have understood of what they have learned, and how their behaviour might have changed as a result of their participation in a training programme have yet to be completed. What has recently been suggested is that intellectually disabled people themselves can find these programmes “embarrassing and irrelevant” (Frawley, 2003, p. 4) to their specific needs and desires.

### *Agencies Concentrate on Socio-Material Change*

How to improve agency practice in the promotion of abilities of intellectually disabled people has sparked vigorous and spirited debate in both international and New Zealand contexts (in New Zealand see Brook, 1999; MacArthur, 2003; O’Brien & Sullivan, 2005). However, rather than addressing how to improve the current quality of life within a service setting in an holistic sense, including improvements in the area of sexuality support, many debates continue to prioritise the adoption of material rather than relational changes to current agency practices.

Within this prioritisation quality of service remains firmly linked to issues of optimal size of facilities, relative merits of residential versus independent living circumstances, live-in versus shift staffing options and how to create an optimal balance between structured programmes and unstructured leisure time (O’Brien, 1994). Some degree of shift in quality measurement criteria towards a more direct focus on the importance of supporting opportunities for quality in social interaction have been noted. However, researchers suggest that these methods continue to rely



almost exclusively on observed and/or reported engagements in activities provided (Wills & Chenoweth, 2005). These methods can be singularly unsuitable for many aspects of sexuality support practice.

Moves towards assisting those who use services to have a say in how they are supported represents a positive service response that could be influential to changes in the sexuality support area. Yet despite the presence of a self-advocacy movement, intellectually disabled people are still often denied an influential voice in key agency service decisions (Armstrong, 2002). Where attempts are made to include their voices it is uncertain whether these opinions are effective in supplying providers with information that results in significant alterations to service provision. It has been suggested that the stories intellectually disabled people tell may just be seen as individual anecdotes, helpful in finding out what individuals think of service delivery, rather than posing meaningful challenges to the philosophical notions underpinning the concept of service and support (Froese, Richardson, Romer & Swank, 1999). In addition in the sexuality support area, some intellectually disabled people who use service may be reluctant to share in public stories about experiences they consider private and personal.

### ***Summary***

Literature review studies complied indicate that the ambivalence found to characterise individual workers support behaviours is replicated at agency level. Agency planning mechanisms too seem to consider that there are more important issues to focus on than planning for the provision of assistance in this area. This consideration must affect the priority workers themselves place on this aspect of their role, although it is not clear to what extent their practice is affected.

However, this overt lack of recognition and prioritisation is offset by evidence of a certain level of engagement at agency level with dealing with the outcome of abusive sexualised behaviour in particular. This engagement largely consists of presenting sexuality-related information to intellectually disabled people on the basis of the idea that ignorance of what constitutes acceptable sexual practice motivates the actions of some people in this group. Guidance received from these sessions falls within a very

narrow focal range in respect of the “broad spectrum of positions” (Sedgewick, 2005, p.83) the term sexuality can encompass. This focus also prioritises the idea that sexuality is a difficult and dangerous undertaking. How this information might either help or hinder worker practice in relation to those they support remains unclear in literature findings at this point.

### ***Developing a Safe Work Environment***

The second dual obligation aspect of service agency provision uncovered through the literature review relates to the provision of suitable support. In this area providers are funded to provide support to those who use their services while also being contracted to provide a safe and supportive work environment for those who work in service settings (Christian et al., 2001). How to provide a safe and supportive work environment is now receiving a greater degree of service agency attention. Within this focus sexuality-related training opportunities represent the most significant assistive tool service providers offer service employees (Taylor et al., 2003). These opportunities are a welcome addition, as research suggests that very few workers received formal instruction in this area in the past (Saunders, 1979), although workers themselves have consistently expressed a need for such instructions over time (eg Sweyn-Harvey, 1984; Johnson & Davies, 1987; Trudel & Desjardins, 1992). However, more recent findings suggest that a number of difficulties affect the efficacy of this measure as a support tool designed to increase worker confidence and expertise.

### ***The Value of Training***

While research suggests that training can increase support worker awareness, contemporary findings note that universal sexuality training provision has yet to become a “firmly established feature of general service provision” (Chai, 2004a, pp. 83-84). It also remains unclear what degree of skills based training, or attitudinal based training, or how much of both might be the most effective option to assist the promotion of best practice in workplaces in this area. Workers themselves have reported wanting sessions that explore more ‘real’ instances of managing sexual

behaviours, plus training that would make agency guidelines more explicit (Taylor et al., 2003). For example, one survey has captured worker's frustration about the lack of access to clear guidelines in training sessions to address how to teach masturbation skills (Szollos & McCabe, 1995). Findings also suggest that many training sessions offered are too short, with very few follow up or evaluation sessions offered. In addition overall, it is women rather than men who pursue training about sexuality whereas men chose to access training about challenging behaviour or agency management (Craft & Brown, 1994).

While training is more available, it remains common for workers to continue to seek experts to address sexuality and relationship issues and to provide counseling and education to the people they support (Chivers & Mathieson, 2000). This form of support for workers is now more readily available (Taylor et al., 2003). However, Craft & Brown (1994) suggest that an 'expert model' approach can reinforce the idea that this area is to be treated as separate from other worker practices and as an area that is more difficult to work in because it requires specialist skills. The continued use of an 'expert model' can also inhibit workers themselves from working with those they support to identify and meet their sexual and intimacy desires.

### ***Support and Policy Initiatives***

In addition to training initiatives, formal agency service responses to providing a safe and supportive work environment for those they employ have consisted of constructing and implementing policy initiatives as a guide to successful sexuality support practices. These documents are said to be a key to successful service provision in that they outline the parameters of the entitlements those who use the service can expect. In doing so they also guide worker's behaviour by ensuring that they know what the expectations are that these entitlements hold (Frawley, 2003). However, while these documents can be seen as key conceptual tools, research suggests that in practice the construction, provision and use of policy documents in the area of sexuality and intimacy support varies widely. These suggestions place a question mark against about how useful these documents are as key assistive tools.

In some cases, sexuality related organisational policy documents have been found to be non-existent (Mirfin-Veitch, 2003b), while other findings question the quality of the documents currently in use. For example, Brown et al., reviewing “a number of policy statements” (2000, p. 78), find no examples of policies that advocate unequivocally for the rights and autonomy of people in sexual matters. Nor do any clearly state the expectations of support workers as facilitators of sexual acts between people and their chosen partners. In addition these researchers also indicate that only rarely do wider agency personnel use policy documents to help keep safe workers and the people who use the service in this area.

Craft & Brown (1994) propose that policy difficulties may also relate to how the documents themselves clarify, implement and manage the agendas set regarding sexual issues. In part this lack of coherence can be attributed to the “framework of liberalism” (Craft & Brown, 1994, p. 16) underpinning the content of much of the existing documentation. Within this framework human nature is deemed universal and unchanging, with sexuality positioned as a timeless and fixed essence ultimately equated to very narrow interpretations of heterosexual intercourse. In addition sexual equality in every area is uncritically assumed. Guidelines falling within these conceptual parameters may be divorced from the day-to-day reality of the lives of intellectually disabled people. Thus workers may be unable to reconcile the gap between the rhetoric contained in the guidelines with the material realities of day-to-day support practice.

### ***Summary***

While training sessions and policy guidelines are now more generally available, it is questionable how influential these initiatives can be in respect of the development of pro-active support processes. While they may be designed to support workers to increase feelings of competence and clarity about their role and their ability to perform in it, the presence of the problems outlined suggest that the influence of these initiatives may be being undercut. In respect of training initiatives, the idea of using outsider expertise potentially compromises worker’s ability to see themselves as competent support players. The use of liberal frameworks within policy documents may present workers with support guidelines that are unable to be implemented in

practice. This inability may stem from agency planning mechanisms continuing to concentrate on the development of skills for independent living rather than prioritizing how to develop skills for interpersonal and sexual intimacy (Clements et al., 1995).

## ***Part 2: The Gap between Organisational Systems and Worker Difficulties***

The research outlined above suggests that organisational initiatives that begin and end with extending workers theoretical knowledge and/or providing idealised practice guidelines do little to promote change within the context in which workers enact sexuality support. Organisational responses that more directly assist workers with practice difficulties in this area are urgently needed. Research studies that detail service responses to the problem of sexual abuse in relation to the workers position are briefly outlined. In the absence of research information about more general sexuality-related practice difficulties, these studies exemplify how far the service sector has yet to go in managing the provision of safe and supportive work environments for workers in any sexuality related area.

### ***Organisational Systems and Abuse Support***

In the area of sexual abuse, organisational systems rely on the presence of workers as frontline protection for the people who use the service, rather than relying on formal response system mechanisms to address the problems abusive behaviour causes. However, organizational support for the worker first-response position itself remains equivocal (Craft & Brown, 1994). While workers report being aware that sexual abuse is happening, they also tell of difficulties knowing what to do about their concerns about abusive practices because they could be making trouble for themselves if they push for their suspicions to be investigated (Cambridge, 1999). This comment links to other findings suggesting that at least some workers have become desensitised to practices of sexual and other abuse in their workplaces, considering these experiences

as normative and to be expected “when groups of people receive a service together” (McCarthy & Thompson, 1996).

### ***Support for Workers and the Interplay between Gender and Sexuality***

While research findings note the difficulty workers experience gaining support for working in environments where abuse can be a commonplace occurrence, the greatest difficulty for agency services isolated by contemporary research is the lack of organisational attention paid to how support practice is influenced by the differentials of power the interplay of gender and sexuality creates (Clements et al., 1995). Specifically, very little attention has been paid to the working conditions of women, who form a significant majority of support workers, in relation to the intellectually disabled men they support. A small number of research initiatives illustrate the importance of examining the operation of gender in relation to power differentials in support practice, as these influences are critical to the successful operation of assistance. These findings are scanty, representing another aspect of support practice that is in need of more detailed research attention.

### ***An Ethos of Female Care***

The frequent sexual harassment of women workers by some intellectually disabled men they support has become a contemporary research concern. A clear discrepancy between genders in the self-reporting of instances of harassment, expressed as a ratio of 18 to 1 for harassment directed at women workers, has been isolated (Thompson et al., 1997). Contributing to these statistics is the practices of some intellectually disabled men who use services. These practices reveal “an understanding of the ethos of female care” that is premised on an acceptance of “female inferiority and powerlessness” (Thompson et al., 1997, p. 574).

How this ethos might affect how workers respond is yet to be fully explored. However, it is noted that women workers have to make considerable allowances for what might ordinarily be seen as unacceptable or abusive behaviour because of the particular circumstances of their work. In doing so, some can feel they contribute to an “unusual relationship ... between staff and men with learning disabilities”

(Thompson et al., 1997, p. 548). For example some women workers have reported being asked if they have had sex with their boyfriends. They describe how they are not always clear why they are being asked such questions and how they should respond. One result of this circumstance could be that men who use services receive confusing messages about where the boundaries lie between themselves and those that support them, messages which women workers may be in no position to influence (Thompson et al., 1997).

This research finding also suggests that a breach of boundaries between women support workers and the men they support in intimate care is unavoidable (Thompson et al., 1997). Intimate care breaks usual social rules about how to behave so that this aspect of support can be attended to (Brown et al., 2000). Usual limits are overstepped, moving relationships between workers and those they support beyond ordinary employer/employee interactions. Setting and maintaining secure sexually and emotionally related boundaries in these circumstances can become extremely problematic for some women workers.

Women workers also face the challenge of how to fulfil intimate care responsibilities without compounding the risk of sexual harassment. Difficulties can arise when bathing men who become aroused, leading to recognitions that this response could be linked to the presence of the worker. In these circumstances it is also not always clear what motive might lie behind some of the actions of the men they support. The idea that they might be ‘leading him on’ or that they have become an aspect of a personal fantasy, become factors that influence how women negotiate where and when to action intimate care, and what kinds of responses they offer. In cases such as these women workers awareness of their own sexuality influences the decisions they make about how they position themselves in relation to the men they work with.

### ***Worker Distance***

By regarding the men they work with as asexual, “for example severely disabled men” (Thompson et al., 1997), women workers make a judgement about potential for sexualised behaviour. While this enables them to more easily accept the high degree of physical contact requested by their work, their responses are also a judgement call

about the meaning of the behaviour exhibited by some of the men they work with. Resolving this tension means that some women workers adopt a 'professional' role that includes routinely keeping a distance from the men they support, so to maintain a degree of objectivity. How these strategies might compromise what these workers can offer by way of sexuality support is yet to be fully explored.

It has also been found that young women workers in particular may be at risk in 'gender-neutral' services where there is little overt recognition of the difficulties that might arise through their involvement with the men they work with. This can have a dramatic effect on the way these workers perceive and respond to some behaviour of the men they support. While it is suggested that this should not mean that young women, or women in general, should not engage in certain kinds of work, how this engagement itself is managed within the service agency they work for needs to become a priority (McCarthy & Thompson, 1997).

### ***The Effects of a Group Staffed Home Model***

Residential support workers are employed to work in settings designed to mirror the emotional and physical environments of family households (NACHD, 2003). These settings conform to an 'explicit' model of service provision, seen as that of a supported home run under the informal principles of 'ordinary life' collective living. O'Brien & O'Brien (1991) suggests that this model may lead some workers to see their role as akin to that of a parent and the people who live in the home as like their children. However, this model may also lead to a different blurring of interpersonal boundaries in some support areas. This blurring may contribute to the development of levels of intimacy that could be potentially detrimental to the wellbeing of not only residents but workers as well.

It is suggested that the division of roles reproduced by traditional patterns of power and dominance within 'family home' style environments may set up a number of difficult dynamics (Clements et al., 1995). Women workers may unintentionally end up colluding in practices designed to contain intellectually disabled men's sexual behaviours within these domains. That this position might have a relationship with how women workers might seek to control aspects of the environment in which they



work has been undervalued if not outright ignored by both theoretical and practical research in the disability and sexuality support area. What needs to be more thoroughly investigated is the difficulty experienced by workers as well as those they support in respect of how these roles are negotiated. Women workers in particular may unwittingly be bringing their first family experiences into their workplaces.

### ***Summary***

The absence of formalised organisational responses to how women workers are positioned in respect of some of the men they support indicates that some workers will use their personal values as support guidelines. Research suggests that relying on workers own value systems compromises pro-active support in this area, yet this may not be the only reason why women support workers might be reluctant to provide assistance. How agency services can become more gender conscious, and what that might mean for the support role in the sexuality area, is not commented on in research recommendations. This lack of analysis remains a significant omission in the light of the findings outlined. These findings also raise the question about the role of agency personnel in the maintenance of these difficulties.

### ***The Manager Role***

Support work is largely organised as a hierarchy with a designated first line manager linking support workers to wider agency systems (Brown, 1994). Recent research findings note that this person plays a pivotal role in successful support provision (Chai, 2004a). Very little research data is available on the relationship between managers, workers and sexuality support, even though the complexities outlined in relation to service delivery in this area also impacts on the clarity of the roles, responsibilities and expectations of those in management positions (McCarthy & Thompson, 1996).

In general managers have been found to be more willing to work on issues of adult sexuality and protection in generic contexts rather than on the more complex questions of abuse, homosexuality and risk management at an individual level (Thompson et al., 1997). However, a more recent study reveals a wide degree of

tolerance variation to sexualised behaviours, similar to research findings related to support worker attitudes and practices, may also exist at management level. As part of a general survey of workers, one service user was noted as attending a day centre where the manager was found to leave women workers to cope on their own with verbal harassment and minor assaults. In contrast the manager of the respite service had decided the person's situation warranted employing only male support workers to see to all personal care and supervision needs (MHI Briefing No 12, 2003).

It is noted that variations found in support responses such as those outlined may stem from a lack of clarity about the extent and scope of the management role, again a finding similar to the lack of clarity experienced by workers. However, it has also been suggested that variations in responses to how sexualised issues are resolved may also reflect differing degrees of management competence (Cambridge & Mellan, 2000). Cambridge & Mellan (2000) also note that while some workers are becoming more interested in carrying out support work in this area, they remain unwilling to do so because of lack of management support or encouragement for their efforts. Where sexuality workshops are available, they tend to be attended by workers, who can become more knowledgeable about practice priorities than their managers. It is not clear from literature findings exactly why this happens, or what is currently being done about it.

### ***Support for Managers***

While surveys reveal that the position of support worker is under-supported within the wider service agency context, doubt has also been raised about whether the management role itself is adequately supported. As Rickford (2000) suggests, service agency managers are “first in line for blame ... but not always first in line for training” (in Henderson & Seden, 2003, p. 85) to assist them to manage the dilemmas, constraints and challenges of their work. This factor may compromise the capacity of individual managers to manage risk factors that fall outside of narrow and defensive sexuality support practices.

Managers are under pressure to deliver services according to standards and frameworks developed by governmental agencies. Yet many first line managers have

had no prior management or strategic operations training. Frontline managers often take the job for reasons of staff support and operational development but find themselves pulled into strategic commitments because they have “crucial local knowledge that is vital in strategic planning” (Henderson & Sedan, 2003, p. 90). This can make managers unavailable to deal with many of the day-to-day operational demands of their job. Many managers come from direct support backgrounds, yet expectations remains that they will be able to make the transition from worker to manager without any formal education. However, while lack of management training can make decision-making difficult, it has also been suggested that applying traditional management qualification techniques to social care settings may miss the complexity of management practice in this arena (Whitaker et al., 2003). Traditional management strategies may also be more suited to management within a public setting and may not translate well to management of people who work largely in the private domain.

How the issues raised by these few studies are resolved remain aspects of research yet to be undertaken. How the relationship between managers and workers is constituted and sustained on a daily basis is a topic that is in need of more in-depth research consideration. Of particular concern is the recent suggestion made that managers can experience social repercussions from workers when they fall out with those that work for them, and that managers may have to ignore certain worker behaviours in order to ensure that services continue to function (Cambridge, 1999). In addition, there have been few attempts by researchers to propose practical solutions to the problems they have found that might guide agency services towards better support practice in this area. Such guidelines are clearly necessary.

### ***Research and Practical Solutions to the Problems***

For Brown et al. (2000), the role of the worker within the concept of sexuality support is to assist the person to make their own decisions and to learn from their own mistakes. The discomfort workers experience in working in this area they believe originates from a systemic lack of clarity about the assistance they are to give, located in the failure on the part of agency providers to verify the tasks involved in sexual support as a legitimate part of the role (Brown et al., 2000, pp. 9-12). However, these

comments do not consider the ethos of care that may affect the performance of women workers in particular, neither do they suggest any practical way forward to rectify the clarity problem they isolate.

Comments included in another study suggest that the concept of positions can be used to reveal where workers might stand in relation to their day-to-day practice in the sexuality area. Brown (1997) isolates four differing categories of thought that support workers attitudes and values can be put into. These categories or belief systems could be used to uncover potential support 'types' recognisable by the key beliefs held. Within the typology Normalisation Advocates believe in human rights for the people they support. With training given, people would be able to participate in marriage and having children. The Supporters of Abstinence group believe that sex outside marriage is undesirable and people with intellectual disability are "incapable of successfully participating in marital relationships" (Brown, 1997, p. 13). Sex education should be given only so that people can be protected from possible abuse. The Responsibility and Control group support sexual activity but also support extensive birth control methods, including sterilisation, as a means of preventing pregnancy. This group also supports sexual education for this reason. Humanistic Stalwarts are seen as the strongest supporters of human rights for the people they support. Support workers in this group believe that individuals should be able to participate in sexual activities and marriage "with procreation" (Brown, 1997, p. 14) if they so desire.

It is suggested that it should be from the position of the Humanistic Stalwart that attempts to provide the needed support and education to the people workers support in the area of sexuality and intimacy should be made. Yet while this recommendation is a very sensible one, it is hard to see how this approach might usefully assist in changing women support workers practice in respect of the 'unusual relationship' between themselves and the intellectually disabled men they work with.

Exploring ideas about quality support, Brown et al. (2000) outline three agency positions that categorise the divergence of support worker practice in this area. In the Stop Position, service provision for expressions of sexuality is either forbidden or so

many barriers placed in the way that it is effectively not an option. In the Polite Position, individual support workers are supportive and encouraging, but in practice they either hold back from practical assistance or are constrained by their manager's reluctance for them to take on the role. In the Go-Ahead Position, unconditional commitment from support workers is obtained through an agency wide acknowledgement of the right to "sexual citizenship" (Brown et al., 2000, p. 13) of each individual. Perhaps the concepts outlined in this study are the most useful as service managers could use these positions as guidelines through which to begin to reflect on where their services are placed in relation to these categories. However, whether these reflections on their own would result in sustained changes in worker behaviour remains doubtful.

### ***Further Discussion***

Overall, this chapter reveals that research that explores worker's actions in the area of sexuality and intimacy support has had a very limited history. Studies completed over the last twenty years consistently reveal service problems that continue to stymie the adoption of sustained, effective and ongoing assistive practices. The information compiled for this chapter shows a clear need for a greater number of research studies to examine how intellectually disabled people and those who support them perceive their relationship in this area (Mattison & Pistrang, 2000). Research initiatives also need to explore how these perceptions affect both the person who is supported and the workers concerned. Yet in 2007 the field remains greatly under-developed in New Zealand and at international level. In some areas research remains non-existent, for example how men who are support workers might negotiate aspects of their position within a mixed gender group home, has yet to be the subject of research investigation. The depth and complexity of this area is alluded to in findings that report that when men become involved in the personal care of women who live in group houses this move can be open to misinterpretation as intrusive or sexualised responses by, at least, those who live in the house (Clements et al., 1995).

In addition, little research has been carried out tracing the influence of existing policy documents on behavioural change within wider agency services in this area (Felce et

al., 2002). This lack remains despite suggestions that rather than attempting to alter the values of individual workers alone, it may be more fruitful to encourage a productive organisational culture throughout the agency (Hatton et al., 1999). Such research needs to be undertaken. In respect of this finding it has also been suggested that it may be counter productive for agencies to continue to rely on the work of a group of people at the end farthest away from the generation of policy initiatives to deliver on the initiatives the documents outline (Parker & Clarke, 2002). Recently it has been proposed that service agencies themselves “need to be supported by education that focuses on values and attitudes, rights and safety” (Johnson & Traustadottir, 2005, p. 159), so to make support for sexual and intimate relationships an integral part of what service provide. However, what these sessions will contain is the key to the influence they will have. It remains questionable how far from the “framework of liberalism” (Craft & Brown, 1994, p. 16) these sessions might be able to go.

What international abuse statistics uncover is evidence that there may be a lack of honesty and reflection about what is happening to both people who use services and those that support them in the area of sexuality and intimacy within service settings. This lack of honesty, or reflection, or both, has meant that there cannot be any acknowledgement made that a number of women workers themselves may have been prior victims of sexual abuse thus who may need particular support from those they work for at certain times. This point is of particular significance when instances of sexual abuse are placed alongside wider issues of gender, class and ethnicity for women as a group (Sinason, 1992). In addition workers who represent more than one of these socio/cultural groups are more likely to be affected. Although this issue may affect how women deal with sexual issues subsequently in their workplaces this implication has yet to become worthy of formal acknowledgement. In fact it has been suggested that women support worker’s difficulties in this area continue to be dealt with unsympathetically by managers, even more so when these managers are men (Thompson & McCarthy, 1997; Burns 2000).

Research information about instances of successful sexual support practice in this area is extremely difficult to find. Recorded instances of outcomes of changes of worker

attitudes relate to improved practice are few. This finding upholds the idea that any changes in current attitudes on the part of individual workers may either be too difficult to implement or that the results of changes in attitudes and behaviours remain at an informal level within agency practice. Because of the difficulties experienced between researchers and service agencies, reports about these changes may be difficult to acquire, yet this information is important. How these difficulties are worked through remains a challenge to be taken up by researchers as well as in the human service sector.

As has been pointed out, raising support worker's awareness in the area of sexuality and intimacy support may provide a way forward from these difficulties. However, it may not be the complete solution to providing workers with the strategies to deal with the situations they encounter in their workplaces. It has been suggested that raising awareness can merely "paralyse support workers" while continuing to "disempower people who use the services" (Craft & Brown, 1994, p. 412), due to the narrow and rigid assumptions about sexuality and sexual expression these awareness strategies uphold (Cambridge & Mellan, 2000).

Research studies this chapter outlines suggest that the assumptions currently made about support worker practices in this area are equally narrow and may also only serve to further alienate particularly women workers who experience difficulties in their workplaces. The results of these surveys also question whether workers can rely on management guidance to help them. As is suggested, reported incidences of sexual abuse in particular seem to decrease "the further away from individuals with learning disabilities a researcher goes for information" (McCarthy & Thompson, 1996). This support is vital because of the baseline assumptions made not only within service provision, but within literature findings as well. These assumptions include that all workers have had an adequate sex education, that they are very comfortable with their own bodies (Hingsberger & Tough, 2002), and that recognition of the rights of the individual will be enough to change the minds of workers who might find the sexuality area challenging and difficult.

This chapter reveals that sexuality issues are not being adequately thought through in the context of agency provision. The literature review raise instances of the ambiguities workers deal with, including the emotional issues faced by women workers when dealing with a number of sexualised behaviours that can cause discomfort and anxiety. Such behaviours may leave some workers vulnerable in relation specifically to some intellectually disabled men they support. These accounts also include the negative effects of possible power dynamics created when workers work within a more private 'home environment' rather than in a more public 'job site'. How power dynamics are currently theorised within a disability and a disability support context form the substance of the next chapter.



## Chapter 4

### *Theoretical Perspectives and Support Provision*

*“Between the experience of living a normal life at this moment on the planet and the public narratives being offered to give sense to that life, the empty space, the gap, is enormous”*

*(from Berger, cited in Smith 2006, p.2)*

The specific actions of everyday life consist of many causal factors originating” within a complex web of personal, social and political variables” (Whitehead, 1992, p. 47). This chapter examines key ‘political variable’ causal factors influential to the actions constituting the practice of sexuality support. I examine three central theoretical frameworks currently underpinning support practice in the disability field. I outline how impairment, disability and support is currently conceptualised in each framework strand. I then appraise how the influence of each strand might enable and regulate possibilities for worker practice in the intellectual disability area in general and in the sexuality support area in particular. This chapter provides a significant point of explanation for the development of the post-modern perspective I then summarise in Chapter Five. It also underpins development of the rationale for the use of this perspective as the basis for the methodology I outline in Chapter Six.

### *Concept 1: The Individual/Medical Framework*

One aspect of the matrix of variables influential to support initiatives for intellectually disabled people includes ideas that originate from individualised/medicalised conceptual frameworks. These frameworks theorise the relationship between the material presences of a (biological) body and how this body works in relation to the physical and social locations in which it is found (Shakespeare 1996; Scully 2002). These frameworks prioritise the idea of this body as a working unit, constructed and maintained through a network of physiological processes. Objective ‘mappings’ of bodily difference through assessing and categorising as data the presence of physical,

behavioural, psychological, cognitive and sensory inadequacy, characterises how this approach influences material practices. Acquisition of this data fixes the notion of a working standard against which further objective mappings can then be undertaken. Bodies whose activities conform to certain expressions of these working standards are deemed 'normal' while bodies that deviate from these (already developed) standards become 'abnormal' bodies (Scully, 2002).

Individual/medical approaches are primarily concerned with managing the presence of long term to permanent bodily differences that deem certain bodies 'abnormal' bodies. After being designated abnormal certain support practices are then put into place. Therapeutic intervention is the key to the dimensions these approaches cover with support interventions undertaken in the first instance to be curative or restorative, and then to be adaptive. Thus initially, support consists of restoring complete function to the body to the fullest extent possible. Only then it is geared towards adapting the environment to diminish the remaining limitations imposed by conditions that cannot be restored or cured (Finkelstein, 2001). At this time support does not just alleviate 'problem' conditions but seeks to reduce allied social senses of difference or strangeness any at-variance condition might impose on a material body (Price & Sheldrick, 2002). However, alleviating 'problem' conditions remains the dominant, preferred support priority.

### ***Difficulties with an Individual/Medicalised Approach***

This model has provided a very successful basis for support practice in that has been hugely successful in alleviating functional limitations imposed by many body-related conditions. However, fundamental difficulties in addressing how this model can adequately unravel the matrix of social and political variables that comprise disabling conditions and their support have been isolated (Scully, 2005). In particular, it is suggested that the central idea of elimination of bodily difference, or cure, presumes there can be only one way that a human body can be known and that this knowing is only possible through reference to a very limited set of biologically based embodiments known as the healthy or normal body (Scully, 2002). Because of this central assumption medicalised/individualised strategies are unable to work with the idea that a 'normal' bodily shape is equally the basis from which a preferred status for

certain body types is interpreted “in accordance with cultural standards” (Scully, 2002, p. 48).

What the workings of this model hide is the idea that concepts of normality and abnormality do fit easily into a materially based conceptual format. In reality, the social and political contexts that construct key aspects of an individual’s daily life do not solely relate to ideas that originate from the concept of an essential body (Shuttleworth, 2002). While this reality remained obscured, the data collection mapping exercise that creates the initial ‘evidence’ for ‘the condition’ found within the individual body cannot be seen as a particularly rigid and powerful form of social control. While this point remained obscured, it becomes impossible to raise any questions about the value of defining an individual bodily state in such a way. Nor is it possible to begin to examine what the social and political implications might be of ‘being defined’ in this particular manner (Shakespeare, 1996).

### ***Cure Defines the Limits of the Support Role***

The goal of medicalised/individual support strategies is the future point at which biotechnology will have advanced to the degree where individual bodies can be cured of any abnormality, after which no support will be necessary (Cheu, 2002). In the interim however these approaches do not solve all body related problems. Thus certain abnormal bodies remain actively problematic and ‘in need of support’ within this framework. Because curative dimensions are prioritised over adaptive solutions support strategies developed from individual/medicalised explanations can do little about any material, emotional and cultural difficulties that attend bodies less able to recover from illness than bodies that can. Thus little effort is made towards widespread accommodation of a range of abilities within personal, social and political interpretations of what a body can do. Nor is it necessary for any effort to be made towards challenging the idea that issues of bodily ‘fitness’ might merely be a reflection of the attitudes and values of a data produced, statistical norm (Shuttleworth, 2002).

### ***Intellectual Disability and Individual/Medicalised Approaches***

Until recently the term intellectually disabled has been referenced through individual/medical ideas related to bodily management. A variety of terms including feeble-minded, subnormal, mentally deficient and moronic represented the data classifications that specified the grouping of individual bodies deemed unable to be cured. As cure was impossible in cases of 'intellectual disability' these classification categories were used to physically separate these "organically diseased variants" (McIntosh, 2002, p. 6) from other members of the general population as the preferred support option.

Moves away from the idea of a physically separate system of support as the starting point for the management of intellectually disabled people's requirements were based on systems of thought that encompassed the principles of Normalisation (Wolfensberger 1972; McIntosh 2002). Aspects of these principles prioritised adaptive/habilitative rather than curative aspects of this conceptual model. The habilitative aspects of individual/medical concepts in particular underpinned initial moves towards the reintegration of intellectually disabled people in local community settings (Brown & Smith, 1992; Whitehead, 1992; Williams & Nind, 1999; Fullger et al., 2001).

### ***Two Kinds of Support Principles***

Two different ways of looking at support for intellectually disabled people characterise Normalisation-inspired principles. The Scandinavian idea promotes a philosophy of support for living an ordinary life in circumstances most akin to the "ways of society" (Williams & Nind, 1999, p. 660). Within this framework notions of individuality and choice are promoted as key quality of life indicators for each intellectually disabled individual. Practical support is provided against the backdrop of the idea of the "least restrictive environment" service provision can create for each individual concerned (Whitehead, 1992, p. 57). In contrast the North American idea, termed Social Role Valourisation (SRV), emphasises an aspect of the principles that draw on already-established notions of what is culturally valued by society in general. Support is geared towards developing an empowering social status for intellectually

disabled people, on the assumption that improved social status will eliminate the difficulties members of this group experience (Williams & Nind, 1999).

Within this framework, socio-material aspects of the 'ways of society' provide the yardstick from which support is actioned. Key indicators of quality of life in this framework primarily relate to socio-material effects "such as housing, work and leisure activities" (McIntosh, 2002, p. 68) rather than support developed through the use of wider concepts of individuality and choice. These indicators are then used to measure the effectiveness of support enacted from these principles (O'Brien, 1994).

### ***The Value of Normalisation Principles***

As a conceptual tool normalisation principles were effectively able to decouple support from the notion of medicalised (passive bodily) care and reposition it within notions of (re)habilitative assistance. In doing so they promoted an understanding of the concept of intellectual disability that went beyond earlier considerations of the condition as a state lying beyond medical treatment, or more traditional teleologically based assumptions of the condition as an evil to be contained (Wolfensberger, 1972). Normalisation/SRV promoted what was heralded as a new era for intellectually disabled people through the promotion of access to support options that encouraged normalised rather than institutionalised styles of living. These principles took account the social as well as the physical contexts in which intellectually disabled people from institutional settings were living (Whitehead, 1992). They also provided a blueprint for support systems to concentrate on the individual rather than reiterating a total provision model characteristic of institutionalised support. However, while both sets of principles were underpinned by the (re)habilitative aspect of the individual/medicalised notion of disability, SRV became the guiding principle widely adopted as the foundation for the development of support practice in New Zealand (Hunt, 2000).

### ***Social Role Valourisation and the Role of 'The Other'***

Key difficulties have been found to underpin the concept of SRV as the basis for conceptualising support provision. Because SRV principles primarily link back to the existence of a material-only body, the processes of social inclusion through social

reevaluation these principles propose continue to uphold the idea that mixing with bodies deemed normal, thus socially valued, will result in the acquisition of a preferred status for those who are non-preferred. Thus although they draw attention to the role of the social context in the construction of intellectually disabled peoples lives, they do not disrupt the central assumption of individual/medicalised ways of thinking, that there are those that are deemed 'normal' and those that are 'abnormal/deviant'. Thus they do not challenge ways of thinking that take for granted the idea that individuals need to continue to be categorised as favoured or non-favoured, and that it is necessary to do so. As has been suggested, the processes of social marginalisation and devaluation contain far more complexity than just the result of the workings of unfortunate oversight (Brown & Smith, 1992). These difficulties call into question the effectiveness of using normalisation/SRV-based models as a methodological tool from which to undertake support practices.

### ***Social Role Valourisation and the Role of Support***

Because SRV ways of thinking cannot isolate or interrogate the role of wider social processes in the lack of social position already inhabited by intellectually disabled people (Valachou, 1997), the notion that abnormality is established through the presence of a valued social group continues to influence support processes associated with this principle. Yet in practice, those who are valued are not only valued at the expense of 'others' but those who are valued also become the "models of appropriate behaviour and the arbiters of what is valuable" (Brown & Smith, 1992, p.138) in relation to the devalued group. SRV ways of thinking obscure the idea that the forms of powerlessness created through the ascription of positive and negative valuations are themselves created by the presence of the socially valued group, who are also instrumental in the process of devaluing. Difficulties occur when judgement calls about worth and value at once position intellectually disabled people as inferior to more socially valued support personnel, while also positioning the same intellectually disabled people as gaining value through the actions of the group whose existence creates the position they are in. The support difficulties that arise when members of these two groups inhabit these contradictory spaces at the same time cannot be explored or reconciled within a SRV support methodology.

### ***Social Role Valourisation and Normalising the Social Body***

These conceptual difficulties mean that most intellectually disabled people will not be able to achieve full ‘normal’ status through SRV based support practices, as these ideas only provide a route to the acceptance of those who are most able to conform to specific normative categories (Valachou, 1997). From this point on it becomes more apparent that attempts to normalise intellectually disabled individuals inherent in SRV principles are not enacted purely for their benefit, but in order to “normalise the social body” (Keane, 2005, p. 91). Indeed being able to pass for normal only contributes to a further endorsement of the assumption that ‘abled is normal’. While this selection process further isolates people for whom normative status is not possible, it continues to underpin the continuation of the social credibility of those who comprise the normal population, i.e. the group who benefit from those who are able to ‘pass for normal’ (Williams & Nind, 1999).

Within SRV frameworks preferred social roles are assumed to be apolitical, thus SRV processes also cannot address the political tensions created when intellectually disabled people are given value by socially valued others, rather than respect being held as inalienable (Whitehead, 1992; Young & Quibell, 2000). After this, developing an encompassing analysis that might uncover more empowering ways of viewing intellectually disabled people that might benefit the members of both groups becomes as impossible as it is unnecessary. Being apolitical the principles also sidestep other social issues that may be influential to the social value of both groups, such as gender, class, ethnicity and age. This restriction creates yet more points of difficulty in that when the role of the valued group itself remains unexamined, it cannot be seen that any power held by the valued group is itself only conditional. In reality SRV principles do not allow those in the ‘socially preferred’ group to be in any way disabled. Thus they only offer “a route ... to the elite club of physically perfect people who conform” (Williams & Nind, 1999).

### ***Why the Pre-Eminence of Social Role Valourisation Principles?***

Why SRV principles were adopted over principles that would establish support frameworks within the broader outcomes of individual choice in relation to a least restrictive environment, remains speculative. For some researchers and disability

writers the practice of institutionalisation has been seen as one outcome of a prior failure of community members to integrate intellectually disabled people into the social, economic, cultural and interpersonal aspects of local community life (eg Katz et al., 2000). Did accessing a community environment that remained shaped by prior exclusionary practices make it necessary for service systems to put time, resources and energy into the SRV “reparation of the disability” (O’Brien, 1990) framework, rather than working with the ‘least restrictive environment’ (Agar et al., 2001) aspect of support? Did having to negotiate the pervasive social barriers that institutionalisation was the outcome of leave service providers with “little energy or incentive” (McIntosh, 2002, p. 69) to develop more long-term individualised support strategies that would work more effectively?

Or did adopting SRV models, rather than supporting intellectually disabled people’s development of choice and control, mean that service systems did not have to relinquish the aspects of social and economic control the principles themselves enabled (Davis, 1993)? Did service professionals, for their own ends, continue to opt for systems of support that related more easily and comfortably to funding measures designed to provide material support, rather than opting for the provision of ‘least restrictive’ service options for the intellectually disabled people they supported (O’Brien, 1990)? Answers to these questions remain open. Yet while they remain speculative the idea that the acceptance by service providers of the idea of stigmatised identities as culturally normative, critical to SRV principle philosophies, continues to obscure the idea that these principles themselves might be implicated in the maintenance of intellectually disabled people in a subordinate position.

### ***What Does Community Mean?***

The hope normalisation/SRV principles held out was that putting the principles into action would enable people from long stay institutions to be supported to enjoy life in the wider community. However, as Lysack (1998) queries, is there any one community into which intellectually disabled people can be normalised? What could be meant when the word community is used in the context of support for community participation within a SRV framework? Does the word refer to a physical locality or a concept of shared interests and values, the two most common meanings of



community? Does it refer to both? If there are other images associated with the word community for support purposes, what are they and how do they function within the idea of support for the full inclusion of people in this group? Within normalisation/SRV principle frameworks what the term community can only mean is a location other than an institution or a segregated setting designed for intellectually disabled people. Placing community within this parameter means that the global “issue of ‘community participation’ ” (Bray & Gates, 2003, p. 2) or more pragmatically, how intellectually disabled people might actively be supported to live any kind of a satisfying life, becomes a support problem that SRV principles cannot be fully address.

### ***Normalisation/Social Role Valourisation and Support in New Zealand***

Many strongly believed that putting normalisation-based principles into practice would create high quality lifestyles for intellectually disabled people in New Zealand. In other euro/western countries critiques of the principles were initially slow to gain momentum principally because of their strength as a powerful and all encompassing moral vision of how to action community-based service provision for intellectually disabled people. Support service training sessions introducing the principles to new workers encouraged unquestioning acceptance of their use as the basis for their work. Any doubts raised about aspects of the principles were firmly discouraged (see Brown & Smith, 1992). In some cases those who were sceptical of how the principles might be actioned were regarded as having “failed to acknowledge their own subconscious fears and unspoken negative values” (Chappell, 1997, p. 47) about those they supported, or their ability to grasp the essential elements contained in the concepts was called into question.

How these principles have been used and if they continue to be used in service and support practice in New Zealand is impossible to fully quantify. It is recorded that disability support providers even flew to Australia to engage in training sessions (Sullivan & Munford, 2005). It has also been suggested that normalisation/SRV principles “did have some success in improving service provision for intellectually disabled people” (Sullivan & Munford, 2005, p. 22) in New Zealand. Both points indicate a period of time where dissemination of these principles was active within

service delivery systems. However, it has also been noted by the same commentators that these principles did not address the reasons why the use of the principles were necessary in the first instance, pointing to a waning of enthusiasm at some stage for the efficacy of the ideas and their use as a support tool in this country.

Other comments suggest that SRV related principles in particular remain active within intellectual disability and support theorising and practice in New Zealand. The principles are also seen as a contemporary “antidote to social devaluation” (Kendrick & Hartnell, 2005, p. 40), and as ideas on which support performance ought to be built. SRV should continue to be used by service systems as “theories such as SRV can help a great deal to illuminate practical ways forward as well as raise consciousness of what is at issue” (Kendrick & Hartnell, 2005, p. 43). However, while the principles cannot take into account the effects of antecedent factors that necessitate their initial use, how far it might be possible for service systems to use these ideas to conceptualise what is currently ‘at issue’, so to be able to fully illuminate what lies ahead, remains very doubtful.

### ***Consequences of Normalisation for Intellectually Disabled People***

It is hard to quantify what the consequences of the adoption of normalisation/SRV-related principles have been for intellectually disabled people and for the development of relationships between themselves, support personnel and other community members. For members of this group who spent time in institutional settings, the principles assisted their relocation into local community settings under the dictum of simple humanity rather than as a result of fiscal considerations alone. However, what has been suggested is that when association with those who are socially valued underpins the social goal for those who are not, this practice tacitly endorses the assumption that relationships and friendships between intellectual disabled people themselves are somehow of less substance and value (Mattison & Pistrang, 2000). As a result as Apsis herself an intellectually disabled woman notes, intellectually disabled people can be left in the vulnerable position of doing “anything to be accepted by able-bodied people or people who are valued by society like service providers, social workers and professionals” (1997, p. 653).

### *Normalisation Principles and Support Practice*

Very little discussion has been recorded about the pros and cons impact of normalising principles in general and SRV principles in particular on implementation of support practice. However, what has been found is that by using the presence of a norm referenced group as the yardstick against which support provision is to be measured has meant, in practice, the adoption of a restrictive ‘professional’ normalcy that continues to leave people in this group living lives that can be more normal than the norm (Brown & Ringma, 1989; McIntosh, 2002). It has also been suggested that placing a “central emphasis on the prevention of service users being cast into socially damaging roles” (McIntosh, 2002, p. 68) continues to effectively undermine many efforts by workers and agency providers to assist those they support to effectively choose and control their own life pathways. A more difficult outcome of the use of the principles is that, in practice, the attitudes and practices of workers as representative of the normative group become examples of the desired behaviour to which those who use services are supposed to aspire. This may contribute to the development of unequal power relationships between members of the two groups that neither intellectually disabled people nor the people who support them may be fully able to address.

Yet as Simmonds & Watson (1999) have recently pointed out, while normalisation-style approaches played a prominent role in academic theorising relating to support provision, it is still far from clear that the principles were extensively adhered to in the implementation of service initiatives. They suggest that it is possible that support services may have been operating from a wider conceptual framework based on different assumptions and imperatives. In this respect Parker & Clark (2002) note that changes from institutionally based to community based services may have been driven as much by economic and fiscal pressures to make community integration look economically attractive to bureaucrats and politicians, as they were by actions that were underpinned by the humanitarian considerations normalisation principles endorsed.

### *Normalisation/Social Role Valourisation and Sexuality Support Practice*

What impact the use of Normalisation/SRV principles as the basis for support practice has had in the area of sexuality and intimacy for intellectually disabled people is very difficult to accurately pinpoint. One suggestion offered is that normalisation principles in particular opened up some opportunities for sexual expression, while they also “raised the profile of sex education” (Williams & Nind, 1999, p. 663) for people in this group. Yet expressions of sexuality and intimacy were recorded as taking place before normalisation principles were utilised. While these opportunities may have largely been unsatisfactory and abusive, reinscribing sexual opportunities within narrowly defined ideas about normality also gave extremely problematic messages to intellectually disabled people about themselves and their wants and desires in this area.

By placing a lesser value on friendship relationships between people in this group support options to develop intimate relationships between intellectually disabled people may also have been affected. In this regard, sexuality and disability professionals have noted that intellectually disabled people have understood the negative messages inherent in their lack of social value. Some may have learned not to seek friendship with intellectually disabled others as a result (Sinason, 1992). At least some intellectually disabled men have been found to prefer to have a relationship with a non-disabled woman as a strategy to be able to ‘pass’ for non-disabled (Hingsberger & Tough, 2002). What the consequences of such attitudes have been for intellectually disabled women has yet to be fully evaluated. However, it could be suggested that SRV principles may also have contributed to the problems of sexual abuse experienced as a result of the hierarchy of elitism noted in Chapter Three.

Yet perhaps the most difficult problem the principles endorse is that support practices that adhere to the prioritisation of the need for social value in the sexual area assume that heterosexual, penetrative sex is all that women and men in this group will want to experience (Long & Holmes, 2001). The difficulty this view can create is hinted at in early comments made about individual gains achieved through normalisation-led support practice interventions in this area, as this now oft quoted and much celebrated remark made by two influential sexuality commentators of the time reveals.

*There is a spring in his step, he looks up rather than down, his shoulders are erect: he is a man, and here is his woman to prove it (Craft & Craft, 1978, cited by Lunstrom-Roche 1982, in Williams & Nind, 1999, p. 663).*

It is also suggested that principles that place positive social value on specific groups in respect of specific ‘normalised’ attributes may have left some women and men workers in potentially sexually vulnerable positions relative to the people they support (Hamilton, 2002).

### ***Summary***

Within the habilitative perspective of individual/medicalised perspectives of disability, forms of support to address any difficulties conform to conceptual parameters consistent with the idea of alleviating problem conditions. As these conditions themselves are premised on already established systems of representation, these parameters can neither be reframed nor discarded. Thus the idea of inferiority and lack through comparison that underpins the operation of the support position also remains fixed. Habilitation, referenced through a normalisation/SRV conceptual framework can create a two-sided worker figure that includes the presence of a ‘good guy’/saviour as arbiter of all that is favoured, and a ‘bad guy’/oppressor by virtue of the non-disabled status the support position holds. The already established representations this duality draws on may offer some explanation why intellectually disabled people see themselves as subordinate to workers for their physical and emotional wellbeing. It may also suggest why at least some workers see themselves as having to exert forms of social control over those they support. The duality may also partly explain why workers seem to be in confusion about the extent of their role and how they engage in it.

### ***Concept 2: Social Model Principles Framework***

Normalisation/SRV principles were designed to assist the development of support systems that would counter the negative effects of the relationship between (material)

bodily difference and disabling contexts. In practice these systems encouraged the adoption of some practices that disempowered and disadvantaged many of those they were designed to assist (Marks, 1999; Ramaekers, 2005). In recent years developments in theoretical understandings about the nature and function of disability have challenged the notion of the dysfunctional body as the point of departure for considerations of disability and support processes. These different understandings focus on 'disability' as a descriptor of the negative economic and social relationships experienced by impaired people. Within this view, social processes rather than bodily impairments become the major source of disabling conditions (Riddell, Baron & Wilson, 1999). Understandings from this perspective have come to be known collectively as social model principles (Oliver, 1990; 2004). Since the mid 1990's, a number of differing epistemological positions have been explored in relation to the ideas these principles contain. Two distinctive lines of discussion are held within this framework. These connote the idea of disability as an outcome of material inequality and disability as a descriptor of the existence of unequal social relationships.

### ***Disability as a Lack of Resources***

This perspective takes as its starting point the notion of disability as a socio-material property rather than the term relating to a biological condition characteristic of an impaired individual (Price & Sheldrick, 2002; Armer, 2004). The essence of this approach reprioritises the notion of bodily impairment in relation to its surrounding context resulting in 'disability' becoming a descriptor of the disabling socio-material conditions experienced by impaired people. Disabling conditions arise as the direct result of a society that is "built on a competitive market foundation" and that "it is this social system which disables us" (Finkelstein, 2001, p. 4, see also Tregaskis, 2004; Armer 2004; and in New Zealand, Sullivan & Munford, 2005). Within this framework, for example, moving on wheels is only disadvantageous in a world full of stairs (Young, 2002).

Emancipation from disabling barriers is dependent on impaired people taking on a disabled identity and collectively isolating and confronting the effects of a disablist/materialist society (Oliver, 1990, pp. 30-42). By exerting influence on political structures in order to transform policies and practice and implementing social

model ways of thinking on order to expedite the appropriate allocation of resources, the need for impaired people to confront the effects of a disablist society would diminish. Impaired people would then be accorded the same rights as all non-disabled people without question (Ussher, in Sullivan, 2006, p. 124).

### ***Disability as Unequal Social Relationships***

The second perspective is based on an acknowledgement of the continuing presence of unequal social relationships between those with physical, sensory, cognitive and/or emotional bodily impairments and unimpaired people who approximate the norm. Unlike SRV principles this approach prioritises a social definition of disability, defined principally as “the effects of the human psyche in moderating social intercourse” (Armer, 2004). Thus ‘disability’ does not just connote a set of socio-material circumstances that excludes impaired people, but also signals the presence of an artificial and exclusionary social construction the outcome of which penalises impaired people who do not conform to mainstream expectations of appearance and behaviour (Shakespeare, 1994; Corker, 1999; Tregaskis, 2004). Unequal social relations occur as the result of able-bodied people continuing to view ‘the problem of disability’ in individual/medicalised terms, rather than attributing disability to the results of their own socialisation processes which, in turn, give rise to the subsequent attitudes and practices experienced by disabled people (Garland-Thomas, 2004). Challenging and changing the attitudes of the able-bodied people rather than prioritising socio/material change will result in the effects of disabling conditions diminishing over time.

### ***The Influence of Social Model Principles***

As has been suggested, the ‘disabling conditions’ aspect of the term ‘disability’ has been greatly under-theorised in the past (Rioux, 1997). Separating bodily impairment from disability allowed for the development of new conceptual understandings in relation to the term. These capture the distinction between individuals having impairment effects and experiencing disabling surrounding circumstances (Llewellyn & Hogan, 2000; Oliver 2004). This distinction enables challenges to be made to the terms of reference from which individual/medicalised models of thinking originate. It

also provides an epistemological means by which principally medicalised notions of disability can be rejected as being, of themselves, disabling barriers. In this view social model principles become an emancipatory concept through which disabled people have been able to reframe their experience of impairment in a way which explains that it is not “after all, ‘our own fault’ that we face discrimination and social exclusion” (Tregaskis, 2004, p. 343).

These principles also shift attention away from perspectives based on the ‘needs of these disabled people’ towards the concept of support based on notions of human rights and justice (Armstrong, 2002). This change has provided a framework for a wider examination of the perceptions and practices of those termed non-disabled and of social structures and practices that infer that it is the impaired individual who needs to be fixed (Oliver, 1990). The social dimensions of social model principles in particular describe some of the effects of political structures and social processes that construct some people as ‘normal’ and others as ‘deviant’, and then give socio-material advantage to the former. It then becomes possible to see how theoretical understandings about these structures and processes might not only provide information about how ‘disability’ is understood, but also begin to include how ‘normality’ might be constituted (Armstrong, 2002).

### ***Difficulties Relating to Social Model Principles***

For many disability activists, scholars and commentators, the importance of social model approaches to disability issues “cannot be downplayed” (Watson, 2004, p. 102). Critiques undertaken in relation to key aspects of the model remain testimony to the growing credibility and influence of the model itself. However, vigorous and sustained debate continues about the conceptual adequacy of the model as at once concept and a practice and a political tool for the continued emancipation of disabled people. It is beyond the scope of this chapter to record all that has been raised in discussion for and against aspects of the theoretical composition of particularly the social oppression aspect of the social model, and the positive or negative possibilities inherent in its use (see Gabel & Peters, 2004, for a useful contemporary summary). However, critiques of the socio/material aspects in particular come together in their appraisal of the underlying assumptive notion of a unified if physically impaired



individual on which these ideas are based (Corker, 1999). As the following discussion reveals, not all individuals who can be described as impaired are physically impaired. In addition, those who are impaired in this way can also inhabit other positions beyond the material ‘fact’ of their bodily condition. How disabled people as a group can fare in relation to the conceptual base of the principles, where intellectually disabled people can be seen as part of that group, are briefly outlined below.

### ***The Value of the Model when Impairment is Mind rather than Body***

Ideas about how social reproductions of disability can become social transformation have largely focused on how the concept of impairment can be used to support the social integration of disabled people (Watson, 2004). For some, making the distinction between the concepts ‘impairment’ and ‘disability’, where impairment is taken to refer to assumed biological characteristics of the body and mind can pose problems. For example, those who have a ‘mental illness’ or ‘intellectual impairment’ do not always consider their minds “impaired, damaged or sick” (Wilson & Beresford, 2002, p. 156). For people who take this approach, no unequal relationship exists in respect of any bodily impairment/disability division between themselves and other members of society. Rather than acknowledging that a disabled identity is an emancipatory move, mental health service users/survivors in particular but also some intellectually disabled people (Hingsberger, 2000), have been concerned about being associated with what is seen as an additional stigmatising label, that of ‘disabled people’ (Apsis, Beresford, Branfield, Chambers & Lanali, 2004).

### ***The Inclusion of Larger Social Issues***

There have also been concerns that the prioritisation of disability as form of ‘social oppression experienced within a socio-materialist world’ has ignored possibilities that other issues may be more pressing for many at significant times in their day-to-day lives. As has been suggested, the concept of collective action, necessary for the assumption of a disabled identity because “power at a community level is found in the action being taken together” (Van Houten & Jacobs, 2005, p. 643), does not adequately address the issue of the powerful effects of social difference.

For Begun (1992), the difficulty fitting the concept of social oppression at a collective level into the reality of diversity at an individual level contains more than just the occasionally problematic way in which disability rights claims are structured over the claims of other oppressive circumstances. Defining herself as an Asian woman, it is a strongly felt issue for her that some disabled people at different stages of their lives will identify with other than socio-materialist based oppressions. She notes that academic writers who promote social model ways of understanding may need to “show more tolerance” (Begun, cited in Campbell, 1997, p. 87) in case they do not become seen as the new oppressors of contemporary society (Lang, 1998). For others, while acknowledging that the emotional effects of exclusion are common to all disabled people, see as “an oversimplification” (Ghai, 2002, p. 98) the assumption that all impaired people will view their experience of impairment and oppression as equally oppressive.

As O’Toole (2004) notes, while being successful as a concept with which to challenge ‘problem-within-the-individual’ definitions, social model principles may be a less than useful tool for exploring intersections between disability and issues of advantage and disadvantage relating to ethnicity, gender, age, sexual orientation and ability. As she observes those who have benefited most from gains made within a disability movement committed to the use of these principles have largely been people whose expectations most parallel the needs of the “disabled (white) man” (O’Toole, 2004, p. 94). As an example, she notes the continuing reluctance among disability funder/providers to include diversity within community initiatives on the assumption that what is good for this image will be beneficial for all disabled people.

Uncovering conceptual difficulties such as these have left some commentators and researchers uncomfortable with the continuing relationship between social oppression model-based theorising and mainstream Marxist-based analyses. Within Marxist inspired epistemological understandings, a socio-material world is ‘already there’, already acting on the individual to reproduce the effects of disabling conditions and individual responses to them (see Abberley, 1997, pp. 25-44). This association reduces understandings of the complexity of socio-cultural interactions to more linear constructions that premise a socio-material “Marxian Utopia” (Armer, 2004, p. 50) as

their conceptual starting point. It is suggested that this association can narrow possibilities for examining the complexity of disabled issues involved at an individual level (Shakespeare, 1994).

### ***Social Model Perspectives and Intellectually Disabled People***

How influential social model inspired perspectives have been in improving the life chances of intellectually disabled people is difficult to isolate. As a set of principles they present a strong objection to the policies and practices based on the principles of normalisation/SRV. Social model perspectives have challenged assumptions made by these frameworks about what constitutes ‘normalcy’, through critiquing the experiences and social interests of those (able bodied people) who exercise power over disabled people (Armstrong, 2002; in New Zealand, Sullivan & Munford, 2005). It is suggested that social model perspectives can provide more constructive understandings about the social structures and processes that construct and underpin ‘intellectual disability’ as well as understandings about what constitutes ‘normality’ within a society. Further, social model perspectives enable these understandings to be seen as both historical and political questions.

However, the difficulties raised by researchers who question the capacity of the model to be completely inclusive, also raise issues about how well social model perspectives might be able to recognise and embrace the diversity and difference inherent “among the population of people with learning difficulties” (Armstrong, 2002, p. 340). What has been suggested is that when intellectually impaired people are taken into account within the more global ‘disabled people’ category, it is noticeable that social model based perspectives remain principally relevant for people within this group who fall within a narrow range of physical impairment conditions (Thompson et al., 2001).

### ***The Distinction between Ability and Advantage***

Social model ideas relating to distinctions between impairment and disability are based on the premise that while disability is socially constructed, the former is merely a neutral description of the (impaired) body. However, this focus excludes physically able, yet intellectually impaired people from many of the possible use of these ideas

as an emancipatory tool. This difficulty is further complicated by the continuing confusion within the model itself over what 'impairment' might mean in relation to intellectually disabled people. Intellectual difficulty, although a biological/brain 'dysfunction', is not a straightforward medical (bodily) construct (Dowse 2001). While some (bodily) factors can produce certain material effects (for example, epilepsy), the primary causal factor of intellectual disability is cognitive function. Socio/materialist explanations in particular obscure the way in which the term 'intellectual disability' itself is imbedded in wider cultural notions of 'ability' and 'competence', rather than socio/material notions of 'advantage' and 'disadvantage' (Armstrong, 2002).

In addition, while the unequal social relationships aspect of the model allows for disabling conditions to include oppression based on departures from normative expectations of individual behaviour, this analysis stops short of relating this behaviour to notions of 'abled' as related to cognition rather than biological functioning (Shakespeare, 1994; Corker, 1999; Tregaskis, 2004),

### ***Social Model Principles and Notions of Support***

Although discussions about the efficacy of the model as an emancipatory tool are well developed, policies enacted from within social model perspective frameworks have yet to result in the full inclusion of disabled people in the wider community (Young & Quibel, 2000). Nor have social model related positions had the envisaged "real impact on professional practice" (Oliver, 2004, p. 25) in the disability field. Speculation as to why this impact remains nominal in the support area in particular largely relates to conjecture about the questionable motives behind the interest disability professionals have shown in adopting social model principles "in their mission statements and the like" (Sullivan & Munford, 2005, p. 26).

However, as the working of SRV models of support have already shown, implementation difficulties can arise when trying to use a model for support practice that is based on the concept of dividing 'impaired/disabled' and 'able/non-disabled' into two distinct categories. Further, these two groups can become locked into antagonistic struggles for recognition and empowerment in which impaired/disabled people strive for their rights, while able/non-disabled people continue to refuse to

action the entitlements of those who fall outside of the boundaries of embodied norms (see Oliver, 2001). Within this either/or position complexities that characterise social interchanges are reduced to dynamics of the oppositional, in which ‘the disabled’ have very limited control while ‘the others’ are positioned as mobile and powerful. How this antagonism might affect support enacted from within social model ways of understanding can only be speculated on at this stage.

It is also suggested that continuing to focus solely on the disempowerment aspect of this dyad is to perpetuate an ‘impairment as deficit’ view (Van Houten & Jacobs, 2005), thus to contribute to the ongoing oppression of disabled people by upholding their representation as victims (Armstrong 2002). In reality the binary tensions inherent in the victim position may merely add to the difficulties already facing those who are trying to fit social model ideas into support practices (Price & Shildrick, 2002). In this regard, it been recently noted that some people, including “disability equality trainers have spent their time trying to make non-disabled people feel guilty that they were not disabled” (Oliver 2004, p. 24). While it is not clear whether the trainers concerned identified as disabled people or not, what the effects might be of the possible offering of a ‘guilty party’ fault or blame position to those who represent the non-disabled to work within is left to one side of this discussion. As yet social model principle theorising is unable to close the gaps created by these implementational “omissions and silences” (Apsis, 1999, cited in Armstrong, 2002, p. 342).

### ***Investigating the Flipside of the Coin***

It has been noted by some disability commentators that a social model frame of reference needs to encompass the necessity for an investigation of what is happening “on the other side of the (*disability*) coin” (Tregaskis, 2004, p. 344). As Tregaskis points out, this investigation is an important undertaking as it acknowledges the importance of non-disabled people in the maintenance of the exclusion of disabled people. However, this is only one aspect of the flip side of the coin that might be worth investigating. It can be suggested that that the assumptions the principles themselves make may obscure the difficulties inherent in a view that polarises groups of individuals in such a manner. As normalisation/SRV model theorising has shown

in respect of oppositional group positions, conceptual principles that do not allow those in the ‘socially preferred’ group to be in any way disabled, or disabled people to be in any way advantaged, negate the wider cultural systems of social oppression that comprise the substance on which both sides of this coin are engraved.

### ***Summary***

These ideas suggest that the support role holds a deeply ambiguous place within social model principle conceptual frameworks. Some lines of thought portray the strong image of an exacting oppressor figure whose attitudes and practices are imbued with disablist assumptions that are resistant to change. From this perspective, the complex interrelationship that links individuals to the larger issues of “vulnerability and power” (Price & Sheldrick, 2002, p. 66) that divide people into groups of those who support and those who are supported cannot be pinpointed or investigated. Thus how implementation of the principles might produce mindful and respectful personal interchanges, ethical social relations or democratic political relations among representatives of the two groups remains a difficulty that is yet to be fully addressed.

### ***Concept 3: Rights Based Frameworks***

While many social model principle inspired initiatives have concentrated on the analysis and removal of tangible barriers contributing to the social exclusion of those who are physically impaired, the concept of rights and social justice have become more influential in contemporary policy and practice development in the intellectually disability field (Armstrong, 2002; NACHD, 2003). These notions have been most significant in respect of reconceptualising the meaning of intellectually disabled support in terms of social justice and citizenship rather than in respect of either impairment effects or rehabilitative ‘need’ (Armstrong, 2002).

For intellectually disabled people, self-advocacy or “the demand to be heard, to make choices and to exercise civil rights” (Armstrong, 2002, p. 336) has become the means through which equal treatment claims can be asserted. Rights based initiatives to enhance support in the sexuality area hold out hopes that agency services and workers

will be able to develop a constructive way forward from current support practice impasses. However, while notions of human rights at first appear to be wholly positive, some query whether these approaches will create the circumstances necessary for the development of a more rounded quality of life for intellectually disabled people.

### ***Allowing the Right – How much does it enable?***

Rights based approaches recognise all intellectually disabled people as legal citizens and as equal to non-intellectually disabled people. From this perspective the social and material inequities intellectually disabled experience arise from a failure to “do justice” to members of this group (Young & Quibel, 2000, p. 747). Policy and practice frameworks designed within rights based parameters can be used to redress the legacy of inequality left by prior practices. Yet although rights based perspectives also pinpoint the existence of social inequalities, like SRV principles these perspectives can fall short of addressing “the misunderstandings from which the inequities originally stemmed” (Young & Quibel, 2000, p. 747).

Merydyth suggests that the difficulties inherent in rights based approaches arise from the historical development of the notion of rights themselves. Rights, rather than having been developed through informal and interpersonal processes of thoughtful arbitration, are “established by common law precedents” (Merydyth, 1997, p. 810). Within western legal systems these precedents have been developed and expressed through the civil obligations incumbent on the idea of the ‘reasonable man’ relative to examples of individual culpability. Within legal systems individual culpability and obligation is linked to the notion of redress, based on whether the moot “would a reasonable man do the same in similar circumstances?” (Warner, 1996, p. 100) draws a yes or no response.

Within frameworks that rely on the basis of precedent, explanations about why some groups of people experience social conditions that deprive them of the means to dignity, comfort, peace or security can only be considered within conceptual parameters that include notions of accidental oversight, ignorance or bad management on the part of one key individual or a key group of individuals. However, linking

deprived social conditions to these conceptual parameters is to infer that all that is necessary to redress social deprivation is to rectify the oversight, re-educate the ignorant, or correct bad management practices. Thus while legal rights themselves remain tied to the “dictates of virtue” (Keane, 2005, p. 93), assumptions that drive the ‘reasonableness’ of human nature inherent in the construction of the doings of the ‘reasonable man’ (Merydyth, 1997) detract from any examination of the goodwill-neutral complexities that sustain the matrix of conditions of power and powerlessness on which the complexity of social practice is based (Van Houten & Jacobs, 2005).

This realisation has lead some disability commentators to suggest that rights based policy positions may end up merely reflecting “attitudes of social paternalism” (Brown et al., 2000, p. 6) rather than providing solid pathways towards the provision of more inclusive forms of assistance to intellectually disabled people. At a more pragmatic level it has also been suggested that any benefits rights based legislation might accrue also depend on the ongoing goodwill of governments to continue to provide adequate funding for systems that protect the accessibility of rights based complaints, and to oversee the politics of court systems (Clear & Gleeson, 2001).

### ***Rights Based Principles and Sexuality Support***

Using rights based approaches to effect material change have had limited success in the promotion of social change for intellectually disabled people in relation to service delivery generally and in the area of sexuality support up until this point. Possible reasons for this are diverse. As not all intellectually disabled people are positioned similarly in relation to aspects of sexuality, intimacy and relationships, being able to develop a coherent rights-based agenda suitable for ‘the rights of all’ within a context that prioritises the right-to-action on an individual basis may be a difficult task.

In relation to sexual abuse, where the notion of individual rights arguments have encouraged changes to support practice, these changes become the successful conclusion to an individual problem rather than the start of ongoing efforts to tackle the multiple contextual causes and effects of the abusive behaviour found across service structures. As has been suggested, using rights based frameworks to fix the problem may only further polarise and fragment support options. Polarisation may



limit the extent to which individuals, managers and organisations might be prepared to actively support the rights of all intellectually disabled people to a full sexual life (Brown et al., 2000). In addition, within rights-to-entitlement frameworks, changes to organisational and personal practices become a management rather than a support problem. This orientation can lead to a concentration of resources on the re-organisation of different kinds of service provision while the underlying problems that relate to the “historical ways of doing things” (Van Houten & Jacob, 2005, p. 451) that infuse day-to-day support practice is left unchanged.

### ***Rights, Support and Wider Social Processes***

There have been suggestions that an emphasis on the rights of the autonomous individual only sharpens already existing distinctions between the more valued “public world of citizenship” (Bowden, 1997, p. 147) and the lesser-valued private world of interpersonal and domestic relationships. This distinction emphasises the social value accorded to “ideas of universalisability, impartiality, autonomy and rights” (Bowden, 1997, p. 151) rather than enhancing the social value of actions that enhance responsiveness to individual difference and maintenance of interpersonal relations of care and attachment. For Bowden full autonomy in the world of citizenship cannot be realised while notions of rights themselves are unable to fit comfortably into the world of interpersonal dependency. Although overtly undervalued, these dependencies nurture the climates of care and trust that ultimately construct and maintain the autonomous ‘public’ structures of society. As she suggests any social order that has difficulty valuing and enhancing informal practices of interpersonal activity diminishes future successful possibilities of enhancing any “public practices of justice, equality, freedom, responsibility, nurture and community” (Bowden, 1997, p. 151).

While rights based agendas remain epistemologically entangled with the social value of disabled people within the public sphere, actions to change what is going on within ‘private sphere’ locations in which the practices of sexual support are based, are unable to be fully implemented (Shuttleworth, 2002). Thus how existing pressure on the relationships and practices of care might influence possibilities for intellectually disabled people remains largely outside of the consideration of rights based initiatives.

Questions such as: How can support practitioners provide the support necessary in this area while protecting personal values? Or how can support be practiced without the exploitation of unpaid or lowly paid, mainly female caregivers? are unanswerable. Within rights based approaches such answers will be generated from the same social divisions that have created the initial need for the questions. Meanwhile, ongoing undervaluing of interdependence and interpersonal care remains “detrimental to both those who are cared for and those who do most of the caring” (Bowden, 1997, p. 159).

### ***Summary***

Rights based frameworks also reveal a powerful oppressive figure against which it is necessary to exercise “the demand to be heard, to make choices and to exercise civil rights” (Armstrong, 2002, p. 336) as a form of redress. As Bowden (1997) suggests this framework ignores the wider context in which the concept of support itself is placed, thus it misses the complexity of the interpersonal interchanges that create the divisions that rights based initiatives seek to overcome.

### ***Further Discussion***

This chapter explored the three dominant conceptual frameworks related to how disability and thus support is currently conceptualised. As these frameworks primarily focus on expanding the role and function of the category ‘(intellectually) disabled people’, how the support position is conceptualised remains a less well thought through, default consideration despite the ‘support needed’ aspect of disability being intrinsic to and contingent on the disabled position. As this chapter reveals the support aspect of disability remains caught up in a series of representations that refract through a core understanding of ‘disabled’ as a fixed position indicative of the presence of physical, behavioural, psychological, cognitive and sensory inadequacy/impairment in relation to a corresponding adequacy/abled position. Each framework investigated reproduces key aspects of this socially favoured/socially unfavoured divide which constructs and reproduces the social difficulties all three theoretical understandings seek to transcend.

This investigation raised the question of how to proceed from this point. Remaining locked into any one of the theoretical frameworks outlined as the lens through which to view the support role is to also encounter the problem of upholding the binary inherent in these frameworks. As the extensive use the normalisation/SRV model in service systems demonstrates, not taking into account the effects of this binary limits possibilities for pro-active support change. This analysis suggests that a more contextual view of disability and support is needed to address this issue.

The next chapter details how I begin engage with a new conceptual framework from which practice difficulties that affect workers and those they support in the sexuality area can be considered. I return to aspects of the literature review in order to start to reframe the support process as a series of inter-relationships that are imbedded within larger contextual points of reference. I unpack the difference between modern and post-modern ways of viewing and explore how a post-modern position might be able to re-site of notions of 'disability' and 'support' as a series of interlinked power dynamics that shape the actions of intellectually disabled people and those who support them.

## Chapter 5

### *Dissolving the Binary*

*'But that's exactly the problem', retorted Isabel. 'We are all stuck with the same tried and trusted ideas. If we refuse to entertain the possibility of something radically different, then we'd never make any progress – ever. We'd still be thinking that the sun revolved around the earth.'* Jamie affected surprise. *"Isabel, don't start challenging that idea now"*  
(McColl Smith, 2005, p 124)

Research studies outlined in the first three chapters endorse the proposition that sexuality support is carried out within a complicated matrix of social and material considerations. Within this matrix, tangible factors include the presence of individual impairment conditions and their effects, the support procedures required of workers, how management of workers and their performance is carried out and how arrangements made for support provision through formal agency regulation are resourced (Brown, 2002). Intangible factors, equally influential, include individual worker's values and attitudes, emotional factors contained in the support role and wider epistemologies that uphold particular material, social and emotional connections between the concept of support and the concept of (intellectual) disability.

Both sets of factors contribute to the pervasive and ongoing practice difficulties in the sexuality support area that seem to span the support environment at every level. The confusion workers express relating the duty of care aspect of their work to the dignity of risk necessary to enable intellectually disabled people to gain practical experiences of intimacy and sexuality remains a persistent difficulty. Workers continue to avoid acting on either the desires of the people they support for assistance or from any organisational policies relating to the right to receive pro-active support. Many report feelings of anxiety and discomfort about this aspect of their work, feelings that hinder rather than help the quality of their assistance. Such structural change as have been

implemented have done little to adequately deal with how emotions in such a sensitive area in particular, and the rationalisations they can produce, might compromise the interactions between workers and those they work with (Lenney, 2006). Meanwhile, many workers have yet to be provided with the safe and supportive work environments that would enable the implementation of more empowering support options.

This chapter details how I address a central query the literature review process raises. This query concerned the role the literature review process itself played in the continuation of the support difficulties the review process isolated. Although the studies outlined in previous chapters uncovered a number of problems relating to support and service practice, the results of these studies seemed to have had little effect on worker's day-to-day practices. Was this issue also likely to affect the usefulness of the research I was undertaking? In respect of the studies reviewed, the likely answer to this question was yes. This issue presented a challenge to how I was approaching this research study and changed how I ultimately worked with the information I gathered.

In this chapter I list a sample of recommendations that cover the range of practice suggestions made in respect of the literature review findings. I query the underlying epistemology of individual autonomy through which these suggestions are noted. I do this because I had begun to query how a positivist-inspired standpoint position might realistically tease out the complexities inherent in worker's practices, thus could pinpoint realistic solutions designed to address worker's current difficulties. I outline an alternative epistemological lens through which I propose to work with the interview data I collected.

### ***Research Recommendations***

Throughout the last two decades research commentators have made a number of suggestions about how the less than adequate support response circumstances research studies have isolated might be altered. These suggestions have been consistent over time. The substance of them is encapsulated in the following comments. Support workers "need to be made aware of the basic human and sexual needs and rights of

clients” (Brantlinger, 1983, p. 21) so to begin the process of change in assistive practices. Sex education for intellectually disabled people and training for support workers is needed to “give both a better understanding of their rights to protection and confidence to challenge unwanted sexual behaviour” (Brown & Smith, 1992, p. 412). Service agencies “must commit to formally examining their staff’s attitudes and to evaluating the effectiveness of their policies, procedures and training” (Christian et al., 2001, p. 290) so to improve overall support practice quality. Organisational managers “have a duty to ensure that all those involved are protected against sexual abuse and exploitation and that they are supported in the discussion and negotiation of supporting the sexual needs of disabled people” (Earle, 1999, p. 321). Policy guidelines are “required to enable staff to act positively, constructively and responsibly in response to the individual sexual needs of people with learning disabilities” (Craft & Brown, 1994, p. 21). It is hoped that new attitudes and practices eventuating from the implementation of these suggestions would enable “a new era of acceptance” (Hingsberger & Tough, 2002, p. 15) of proactive support to begin, one in which workers have “a clear and realistic idea about the nature (and limitations) of their work” (Mattison & Pistrang, 2000, p. 16).

### ***Recommendation Difficulties***

What is noticeable about these recommendations is that while they are consistent in respect of the antecedents they derive from, these very sensible ideas do not seem to have “filtered through” (Clements et al., 1995, p. 428) to sustained change at practice level. Fewer positive outcomes for intellectually disabled people in the sexuality area have eventuated than had been hoped for, raising suspicion that the new era of acceptance envisaged remains far from reality. In fact research data continues to reveal “a complex and rather distressing picture” (Chui, 2004a, p. 84) of current issues in this and all areas of worker practice. Meanwhile, many intellectually disabled people’s lack of practical access to a sexual and intimate life remains essentially unchanged since research was first undertaken.

What is also noticeable about the review is that recommendations made uphold the parameters of the disability/support divide. I suggest in Chapter 4 that this division ultimately fixes worker’s actions and how to change them to notions of individual

culpability by way of accidental oversight, ignorance or bad management on the part of one individual or key group of individuals. As has been noted, linking social deprivation of any kind to these conceptual parameters is to infer that rectifying the oversight, re-educating the ignorant, or correcting bad management practices is all that is necessary to redress the imbalance from which this difficulty has arisen.

Initially I had orientated this research process towards the outcome of finding factors influential to how workers enabled, regulated or constrained the sexual expression and sexual wellbeing of the people they supported. I had hoped that these findings would link to recommendations made about developing more sustainable pro-active options for assistance provision in this area. Worker's actions significantly contributed to how the day-to-day sexual expression of those they worked with were either enabled or constrained. Yet I had begun to see that remaining focused on the presence of culpability in one shape or another in respect of the actions of one individual or another posed the risk of this research undertaking ending up in a similar position to existing research outcomes. For example, even if individual workers were to be "made aware of the basic human and sexual needs and rights of clients" (Brantlinger, 1983, p. 21), the difficulties created by the idea that one individual might be able to effect consistent change within a multi-layered context do not go away. In practice, if individuals choose to change, they change within a context and as Lenney cautions; it is very hard to initiate change when "everyone else in your group may be against you" (2006, p. 188). Was I too going to end up making recommendations from my data in the knowledge that that they may be of little use to the people who had been most deeply affected by the support difficulties the review isolated?

In reality, support practice consists of a series of multi-layered tasks in which points of reference for supportive interventions constantly change depending on the physical, social and emotional locations of the individual and the surrounding environment (Koenig, 1995). Within this view the act of support consists of a breadth of interactions and intentions that draw on a number of complexities of thought and behaviour. Making recommendations about the quality or otherwise of supportive acts in this areas also requires drawing on a number of other shifting concepts that cohere around a set of 'best practice' criteria, a concept itself imbedded in the equally

complex notion of the ‘quality of life’ of the intellectually disabled individual who requires specific support for ‘daily living’ (Koenig, 1995).

Like Pilgrim and Rogers (1997), I had begun to think that the meanings made of the causes and effects, assumptions and conclusions about assistance in relation to support in the area of sexuality and relationships in the intellectual disability service field needed re-examination through a more flexible set of theoretical parameters. If existing disability-related epistemologies were unable to theorise the concept of disability support as reflective of this degree of physical, social and emotional complexity, using these standpoint positions to suggest how individual workers might more gainfully begin to initiate more enabling practices in their workplaces may not ultimately be a fruitful task.

### *Changing the Focus*

Rather than providing pathways towards emancipatory change, all a large proportion of the research undertaken in relation to worker difficulty seemed to have achieved was a reiteration of propositions and recommendations that had come to rely on a largely unstated and unexamined set of assumptive beliefs. Bringing these studies together revealed the presence of a largely unstated “underlying model of what ought to be the actions of an ‘ideal’ staff member” (Scully, 2002, p. 428), evidenced largely by support practices that had, thus far, notably failed to live up to the mark. Further, the inference sustaining the substance of these findings has been that if support practitioners were to act in accordance with research recommendations not a lot would go wrong.

When I undertook the literature search for the first chapters of this project I found virtually no examples of research in the intellectual disability, support, sexuality and relationships area structured with more divergent theoretical frameworks in mind. In part this lack could be attributed to the very small amount of research studies when compared to research undertaken in, for example, the area of supported employment. However, it could also represent an orthodoxy from which the support position continued to be viewed in academic circles. From this perspective, finding a framework that tried to go beyond the established standpoint position relating to



disability support was to venture outside of some very well established academic parameters. However, as Llewellyn & Hogan (2000) perceptively note, any theoretical model of human life used to explain the human condition will always have its limitations. So, my difficulty was not so much about how using a different framework might challenge ‘acceptable’ academic boundaries, but the problem became more of a dilemma about how to work effectively outside of established theoretical viewpoints, while continuing to work within the academic parameters of the field, while also maintaining the “ethical order grounded in experience and available for inspection” (Frosh, 1997, p. 71) vital to the successful completion of this research process.

### ***Challenging the Notion of (Worker) Autonomy***

Explanations for how intellectually disabled people are to be supported in the sexuality and intimacy area have been set within either individualist (the person is the problem) or social realist (other people and the environmental circumstances they create are the problem) conceptual frameworks. These oppositional ways of understanding are underpinned by beliefs that assume that there is a world out there that exists independently of human perceptions of it and that accurate mapping of this ultimately knowable world is possible (Scott-Hill, 2002). As Scott-Hill (2002) suggests, these notions prioritise a linear vision of social relations in which uni-causal social connections operate as a consequence of the considered actions of rational and autonomous individuals.

Such functionalist views of individuals and their actions contain a number of fixed and interlocking belief systems about people and the society in which they live (Townley, 1993). These views are centred through five conceptual points of reference: individual autonomy, essentialism, reductionism, hierarchical dualism and linear causality. These concepts are captured in the following definitions.

**Individual autonomy** – humanity is conceptualised as intrinsically independent, competitive and freedom loving.

**Essentialism** – human beings are seen to possess an essential nature that comprises ideal characteristics that are shared by humanity as a whole.

**Reductionism** – humans understand their world as composed of separate elements in which social problems are best solved by processes of specialisation and abstraction that remain particular to each distinctive element.

**Hierarchical Dualism** – the world is understood as comprising sets of binary opposites or dualisms, where one side of the dualism accrues more value than the other through the operation of interconnecting sets of social beliefs that prioritise concepts of reason, power and control.

**Linear Causality** – consequences and impacts of material actions are linked to specific causes through sequences of linear relationships held within a framework. These suggest that such relationships hold the capacity for being predicted and controlled within the confines of a known universe.

As Scott-Hill (2002) further comments, such notions cannot easily contain the idea that social relations might be multi-causal, complex processes that happen between individuals who are interconnected in many ways. In addition these interconnections are not always amenable to the process of rational choice or to the imposition of individual control.

For Giroux, functionalist beliefs which describe “theory and practice have always been strongly wedded to the language and assumptions of modernism” (1996, p. 7). Thus any social process structured and driven by notions of human culpability and obligation will also derive “from the modernist view of the individual” (Giroux, 1996, p. 7). For Giroux, ways of ordering human social and material practices that take notions of human culpability/obligation as their starting point of reference contain the

following core beliefs. These include the capacity of individuals to think rationally, to exercise social responsibility and to act within an ultimately knowable world in the interest of reason and freedom. These beliefs interlocked with a core further assumption, of a moral obligation on the part of all individuals to conform to these referential dimensions.

Giroux's (1996) insight suggests that epistemological frameworks relying on the abstraction of individual behaviour and the quality of it from the context in which it is found, inhibit consideration of other ethical, political, social and theoretical processes that locate human behaviour as inter-dependent and mediated with/in surrounding emotional, social and material systems. Thus, these ways of thinking cannot challenge the idea that individual behaviours are not always predictable, controllable or ultimately knowable to either self or others. In addition these processes can inhibit the development of more rounded investigations of human behaviour that start from the premise that people are complicated and composite biological, social and emotional in-relation beings, whose actions are not always under the control of reasoned thought.

### ***De-Centering the Individual***

The second part of this chapter interrogates the notion of the autonomous, rational individual in order to find out how this conceptual starting point might influence what happens in the support location. To do so, I de-centre how this image is currently substantiated in the disability support field. I believe that the power this 'ideal' figure holds has obscured the need for conceptualising alternative ways of exploring disability support practice, thus has obscured the need to seek out a deeper explanation of what might influence how workers do what they do. This part of the chapter prioritises the idea that although certain fundamentals related to how the support process ought to operate may be readily familiar, they are in no way 'natural' or 'ideal'. Rather, these assumptions not represent already-established ways of ordering how support work is enacted. I contend that they also limit the development of more productive analyses of present support practice.

However, de-centering this image of autonomy also decentres the idea that workers will know “more than the other about the other” (Scully, 2002, p. 57) in relation to the people they support. Yet troubling this aspect of the autonomous individual in this location is important, as the power workers are said to hold in the support relationship is founded on this ‘naturalised’ notion. Further, the ‘knowing more’ attribution also provides the means through which research recommendations have been able to suggest that workers will be able to influence aspects of the existing social order, so to provide access to the good (sexual) life for those they support.

### ***Re-Visioning Disability Support***

During the literature review process I had isolated a series of underlying figures on which research studies reviewing the lack of adequacy of current sexuality support practice were based. I began to think how the production of these figures as ‘in opposition’ to impaired/disabled people might hinder possibilities of developing more pro-active assistive practices. In particular I was mindful of how the image of the trenchant, oppressor person image of social realist related perspectives seemed to limit possibilities for the development of more mindful personal interchanges and ethical social relations between those in the support position and those in the support-needed position. At this point, Davis’s definition of disability, as an explanation that offered a meaning of the term as something more “than about the person” (2002, p. 50), drew my attention. This way of viewing disability was instrumental in being able to begin to work with the binary these two positions created, thus to begin to interrupt the ‘abled/disabled’ fixed location this dualism created.

For Davis, ‘disability’ signals the presence of “a disruption in the sensory field of the observer” (2002, p. 50). Here the idea of a ‘sensory field’ encapsulates the complexity of the material, social, emotional and spiritual domains that make up the ‘that which a person would usually expect to encounter when looking’ position his definition includes. What interested me about this starting point was that it stood as much outside of, as it was located by, both the observer and a ‘that which is observed’ position. Thus, while the ‘usually-expected’ aspect involved both observer and observed positions, a third point was intrinsic to the location of both parties. Moreover this third position enabled the two categories (disabled/non-disabled) to be highlighted a

way that did necessarily distinguish either as being of greater or lesser value relative to the other. I noted that Davis' observer had no label other than that of observer thus anybody could be an observer, including an impaired/disabled person. In not labelling, this definition suggested that neither the positions of 'abled' or of 'impaired' needed to be fixed in different (oppositional/binary) locations, and perhaps it was more useful to be able to think of these two positions in this way.

I went back to social model definitions of disability/impairment covered in Chapter Four. I realised that even the 'artificial and exclusionary social construction that penalised impaired people' view contained in the unequal social relations definition did not allow disabled people to be in any way viewers themselves. Nor did it allow the 'those who viewed position' to also being subject to what 'the view' might contain. However, if it were the case that it was ultimately a result of able-bodied peoples socialisation processes that produced negative attitudes and practices (Garland-Thomas, 2004) yet if Davis had a point, that these negative attitudes could also be held by disabled/impaired people, then these socialisation processes could be said to contain a 'sensory field' commonality of experience in which every(body) is equally and actively located and involved.

Reflecting on what this overriding 'point through which the viewing took place' might contain left me thinking what contextual, intermediary elements it might locate, and how these elements might define and shape the abled/disabled binary connection and how it operated. Exploring this third element/location might prove to be a helpful way forward towards finding out why workers acted the way they did and why it might be so difficult for them to factor a more flexible approach into their support performance. I was also drawn to Van Houten & Jacobs idea about notions underpinning support for disabled/impaired people. They suggest that the overlying idea of the "independent and productive citizen who does not require care" (2005, p. 450) centres the construction of 'the disabled', in that it represents the more favoured support location against which judgements of who is 'in need of care' are made.

In the next part of the chapter I probe how the effects of this third point and what it contains might influence possibilities for support work performance when the 'in need

of care' position cannot be fixed but remains a permeable space in relation to its oppositional 'does not require care' category. I develop an epistemological context that will enable access to the idea of binary permeability and how the notion of category fluidity in relation to support performance can be investigated. I explore how this flexibility might operate in the support position. I introduce the idea of language as the medium that enables material actions to become at once fixed, negotiated, refixed and re-negotiated within the disability/support nexus. I then use these underlying ideas to re-frame notions of disability/support and sexuality through a post-modernist understanding of human action as derived from powerful already-established, yet constantly shifting socio-cultural understandings.

### ***Developing a Post-Modern Context***

While social realist epistemologies have proven effective as a powerful advocacy tool for impaired people (Sullivan & Munford, 2005), a number of exciting ideas following post-modern understandings about how the world operates have emerged within contemporary disability literature. These ideas theorise notions of impairment and disabling conditions from wider social and cultural spaces. These ideas foreground aspects of the interdependency that shapes the division made between the idea of impairment conditions and the idea of support needed. In doing so they address some of the pitfalls inherent in 'idealised' concepts from which current disability support initiatives are created (Scott-Hill 2002).

### ***Disability and the Notion of Cartesian Dualism***

For Ussher (1997) the concept 'disability', rather than being located within a disabled/non-disabled binary is set on a material-discursive continuum. Those who align themselves on the material end of the continuum focus on disability as the physical aspect of the impaired individual's experiences and on the literal implementation of institutional control on the material, social and economic environment (see Oliver, 1990). Those at the discursive end look at 'disability' from within social and linguistic domains, noting the symbols and signs of ideology, culture and power that are inherent in the word (see Peter, 2000). Ussher's view is

that epistemological discussion needs to move away from notions of binary divisions to allow for recognition and foregrounding of the processes of interaction and interrelationship within these two locations (Ussher, 1997, p. 2).

Iwakuma (2002) further suggests that both individual and social realist theoretical analyses of disability issues currently follow traditional euro-western, Cartesian dualisms of mutual exclusiveness – that if something is A it cannot be B at the same time – with perhaps detrimental material outcomes. For example, normality represents a standpoint position which assumes that all able-bodied people will have access to all rights in equal capacity at all times. Disability becomes it's (excluded) opposite. An inability to see the fluidity of both positions at the same time will produce implementation difficulties for any material practice. Any idea set with such a binary framework will produce limited outcome possibilities for disabled people and those who support them, particularly when these outcomes are sought within a social system that prioritises one aspect of this binary over the other.

### ***Disability as a Material Reality of Inter-Relationship***

For Price & Shildrick (2002) the reality of the 'disabled position' is that it cannot be fixed, but is productive of the breakdown of certainty experienced by 'the abled' in the company of a disabled person. Each encounter between abled and disabled people becomes as much a complex mix of emotion and sensation as it is a professional or clinical connection. However, what is disrupted is only the illusion of bodily and psychic wholeness that the notion of normalcy/abled implies. Price & Shildrick (2002) use the role of touch to illustrate this process of interactive encounter. In touching we 'become the other', with the interactive sensation produced through the moment of touching seen as indivisible from the sensation of being touched. Locations of power and powerlessness become diffuse through touch, as it becomes impossible to distinguish clearly between active and passive positions. What also becomes diffused is the idea that binary notions of subject/object are valid frameworks for analysis of the relationship between disabled/abled bodies.

### ***Disability as a Cultural Orientation***

For Cheu (2002) 'disability' describes a culturally based orientation to the social world rather than either a set of theoretical, binary related notions, or a mutable position on a continuum. Disability becomes part of a "representational system" (Cheu, 2002, p. 199) that signals more than either a bodily impairment or a curable, treatable or socially accomodatable condition, or even a socially created phenomenon. Rather the concept includes larger systems of representation that are culturally perpetuated. Within this perception, even the notion of (medical) cure is socially constructed. Thus 'disability' becomes "how society has defined *what a body can do* as much as what, in actuality, a body can do" (Cheu, 2002, p. 107). Within this 'what a body can do' field of perception, material bodies only look, move and respond in ways that an individual believes bodies will look, move and respond. This view raises the question: What/Who has control of the constructions of 'disabled/abled' reality? Is it what is believed rather than what is known?

### ***The Standpoint Position for the Data Analysis***

The premise, that 'disability' can be viewed as an aspect of a series of culturally perpetuated, larger systems of representations underpin the change in framework through which the data gathered for this thesis is explored. Adopting the idea of a culturally signifying representational process as the theoretical basis is to include a number of allied ideas in validation of key aspects of this position. These ideas include the insight that there is no ultimate truth (Giroux, 1996) to be found within the configurations of people, places, things and ideas that become the cultural signifying representations of 'disability/ability' referred to by Cheu (2002). However, these configurations assume, through negotiation, certain binary logics (eg Ussher 1997; Iwakuma 2002). These logics can be seen as derived from modernist inspired assumptions about key facets of the euro/western world. Implicit in and through the creation of these binary positions is the premise of favoured and non-favoured power effects. These effects are productive of the discord created when the social, material and emotional networks that uphold the concepts 'disability/ability' are constantly held in tension (Foucault, 1978).



In this scenario, power is the element that binds together the socio-cultural and socio-material conditions created by the combination of people, places, things and ideas that describe disabling conditions. However, power is not fixed for all time within any binary location but inter-relates productively (Foucault, 1975) rather than objectively or subjectively between and through individuals who may or may not be impaired or abled (Price & Shildrick 2002). Bodies of knowledge held as language, are central to the deployment and redeployment of the material, social and emotional effects of these inter-located productions (Foucault, 1975). Thus, ‘disability’ is not just something that is either invested in, through or by any individual but is seen as a series of redeployed multi-layered disbursements of power through which disabled/non-disabled identities and relationships are equally shaped. Adopting this conceptual position means being able to consider the support-needed aspect of disability as more than just something one material body ‘does’ to another within specific temporal spaces. It becomes a continual and reciprocal set of prior-formed interactions that are themselves embedded in processes that reproduce what lies within broader socio-cultural locations (Marks, 2002).

### ***Disability and Support Interconnections***

A number of postmodernist-related strands of enquiry are outlined in the next section of the chapter. This enquiry details the lines of thought I follow to come to understand the interrelationship that characterises operation of the disabled/support binary. These ideas highlight “a particular trajectory of a collusion with modernism” (Potter, 2005, p. 113) in so far as I see the ideas I work with from this point on as going beyond the parameters of individualist/social realist standpoint frameworks. Yet I also acknowledge an in-collusion position with the functionalist beliefs outlined earlier in the chapter, as they continue to actively engage the disability and disability support area.

### ***Developing a Post-Modern Position***

Modernist thought is based on the concept of a rational, independent, autonomous individual that connects the ontological aspect of human beings to existing epistemologies about the nature of humankind. This interface is said to provide an

accurate description of how aspects of the human condition have come to be (Giroux, 1996). These notions analyse the autonomous individual as in a symbiotic relationship with certain assumptive principles. These principles broadly include the “unity of humanity, the individual as a creative force in society and history, the superiority of the West, the idea that science is truth and the belief in social progress” (Corker & Shakespeare, 2002, p. 2). Within these frameworks, the hope is that society will become fully inclusive of all individual differences when everyone adheres to these foundational principles.

Post-modern thought holds back from placing the idea of the rational individual as the core element from which to explain, contain or change how social worlds work (Scully, 2002). A post-modern position maintains that knowledge about the world and actions that arise there-from do not necessarily derive from these core elemental principles, but are seen as social effects that assume power from an assembly of multiple social and cultural logics that derive from multiple locations (Thomas & Corker, 2002). This assertion decentralises the dominant role of the individual as the starting point from which explanations of why things are as they are, or why things are not as they should be, are created and developed.

Individuals are not the autonomous creators of themselves and adapters of their social words in a multiple-location view. Rather they are intrinsic in complex webs of social relations that determine who can appear where and in what capacity within constantly shifting social spaces. Within postmodernism the hope that society will become fully inclusive through means of full adherence to a set of fixed, assumptive principles is tempered by a questioning stance in relation to how these principles might be constructed and what pitfalls these constructions might contain.

### ***Ontology: The Material Body***

Re-locating meaning outside the confines of essentialist concepts of ‘the body’ has enabled post-modern thinkers to deprioritise the role of the physical body in favour of recognising the existence of bodies-in-construction, through which variable meanings are located, constructed and negotiated within and through the medium of existing social conditions. As such, a post-modern position questions functionalist ideas that

locate the individual as a corporeal identity (Price & Shildrick, 2002), viewing material bodies as much a product of social construction and interpretation through language as they represent essential realities. The pre-eminence of biological authority that underpins the centrality of the autonomous body within modernism is replaced with the possibility of a diversity of bodily positions and locations. From this point, the idea of bodily identity becomes a map rather than an essence (Kuppers, 2002), where only “through text and practice” (Price & Shildrick, 2002, p. 65) does any corporeal body become material. Material bodies take on a variety of iconic shapes, including the medical body, the fantasised body, the erotic body, the developing body, the supportive body or “the body in pain” (Scully, 2002, p. 54).

### ***Epistemology: The Body of Knowledge***

To set ideas within a post-modern context is to move beyond the notion that knowledge is that which is acquired by individuals through the application of pre-set epistemologies and methodologies. Within post-modernism, what counts as “knowledge and knowing” is developed through “the constant flux of cultural movements” (Michalko, 2002, p. 175), thus ‘knowing’ contains more than that which can be substantiated empirically and objectively verified as fact (Michalko, 2002). Within postmodernist thought, theories and facts are no longer stand-alone items but become interdependent and relational terms. “Facts are only facts within some theoretical frameworks” (Bevan & Bevan, 1999, p. 16) and ‘knowledge’ becomes no more than the construction of certain ways of saying and doing over time (Baker, 2005). What counts as knowing constantly shifts in time and space while issues of authority or who knows what, and legitimacy or how they know it, become deeply questionable issues. Such queries as: who is the knower in this context and what counts as knowledge at this time, become critical starting point questions in respect of any process of investigation into how “social and cultural history” (McKenzie, 2005, p. 456) shape the material practice of assistance.

The value of a post-modern belief as an epistemological position is that these notions uphold the idea that the support-needed aspect of disability is more than just an issue of (able-bodied) support for the impaired/disabled. How the non-disabled/able-bodied binary aspect of this interrelationship is constructed and the influence it holds can be

foregrounded as an equally important consideration. This consideration is necessary not just because it helps the disabled (see Tregasis, 2004), but also because a post-modern perspective views these relationships as mutually constituting each other (Price & Shildrick, 2002, p. 65).

### ***Positions of Power and Support Frameworks***

This section of the chapter brings together a postmodernist derived matrix of ideas about power, knowledge, normative assumptions and the role of language in constituting the support inter-relationship. These ideas shape the reconsideration of (sexuality) assistance as a network of social complexities through which real-time choices and limitations workers and those they support experience are constituted and upheld.

### ***Reworking Power Dynamics***

What the literature review reveals is that power dynamics are central to the process of (disability) support, yet the complex interrelationships these dynamics suggest are rarely uncovered or resolved within the studies undertaken. When power dynamics are commented on there seems little way forward from the insights gained towards lasting changes in support practice. Thus while research findings might assist the instigation of some individual change in some material practices, the outcomes of these changes only amount to reforming support structures into slightly different material locations while the wider power dynamics, of which these changes remain a part, continue to operate unchecked.

Traditional and fixed models of power that affirm power as held exclusively by dominant individuals, groups and structures in society, dominate key facets of modernist thought. For example, for traditional Marxists, power can only be exercised by ruling classes, through their link to the ownership of the means of production. In the material found for the review section, Buckingham's (2003) 'you choose' example outlined in Chapter 2 presents a perception of power dynamics most clearly in

keeping with this idea. For Buckingham, only workers are able to exercise the power vested in 'you choose' while the power to give power away provides the evidential proof that continues to validate this investiture. In emphasising a traditional appraisal of the role of power dynamics within this interaction, 'you choose' obscures the idea that it may, in reality, be impossible to fix notions of power and control with such degrees of certainty.

### ***Foucault and Power Dynamics***

While postmodernism provides the epistemological basis from which support processes are conceptualised and reviewed from this point, aspects of the work of Michel Foucault provide the basis from which the power dynamics that structure the 'flux of cultural movements' that shape disability support systems are uncovered and addressed (Foucault 1975). The strength of a Foucauldian view that makes it so useful is that it transcends traditional notions of power and influence. Foucault's work suggests that it is unrealistic to start from the proposition that power is fixed in imbalance, in that it will be completely or largely possessed by certain individuals and groups and not held at any meaningful level by others. The dominators remain in control only in theory while the position of those who are dominated also extend and advance the means through which alternative 'micro-physics of power' are expressed. In this view, 'you choose' becomes a signal that flags the presence of localized, flexible and linked sites of power negotiations that are contingent on a variety of social, emotional and material elements. In addition, these elements are potentially accessible to both disabled people and those they support.

### ***Three Aspects of Power***

For Foucault, power is "a multiform instrumentation", deploying through "the overall effects of its strategic positions" (Foucault, 1975, pp. 26 - 27). Power is everywhere because it comes from everywhere. As such it can never be acquired for once and for all by any single entity/person or organisational structure, nor can it be entirely overthrown, only exercised from within multiply shifting points of location (Logan, 1997). From this broad position three aspects of power are seen as relevant to the development of a method for analysing sexuality support work.

- 1) Power cannot be possessed by any one single individual. As an effect, power is manifested and sometimes extended as much by the position of “those who are dominated as those who are dominate” (Foucault, 1975, p. 27). Yet, power is also not simply transferred to and utilised by those who don’t have it, but it “invests them, is transmitted by them and through them” (Foucault, 1975, p. 27) exerting pressure even as those who are dominant actively seek to resist these power incursions.
- 2) Power cannot be manifested centrally “or monolithically” (Logan, 1997, p. 511), as it is located in and of a complex network of social strategies operative at every material and social level. Thus power cannot be identified as being wielded by any one organisation or state as each is merely a composition of ‘macro-power’ effects in which power is variously habited.
- 3) Power effects do not have to be viewed as negative phenomena. Power also holds empowering possibilities as well as exercising the excluding, masking or coercive outcomes these effects generate. Thus, where systems of power are viewed as being exercised negatively, these deployments are never “simply negative” (Foucault, 1975, p. 24) but are linked constantly in binary tension to positions where useful power effect outcomes are also being supported.

### ***Linking Power/Knowledge***

Another key Foucauldian understanding of the workings of power is the idea that concepts of power and knowledge are linked, so much so that there can be no power position that does not have a correlated constitution within a body of knowledge domain (1). Conversely there is no position where knowledge can be acquired outside of the “injunctions, demands and interests of power” (Foucault, 1975, p. 27). Thus there is no body of knowledge that does not presume and constitute, at the same time, power relations (Logan, 1997). Power/knowledge is a reciprocal and ongoing relationship, where each term grows with and through the other while it “sustains each

other's authority" (Allen, B, 2005, p. 95). Reconfiguration power and its effects not only has significant implications for how relationships between individuals might be theorised, but also disrupts how 'the individual' is constructed and identified (2).

Within modernism, models of power are premised on stable and clear-cut ideas of a core individual identity, in keeping with the notion of the autonomous individual. Within the post-modern, power is not grounded in such a definitive way. Rather the effects of power-knowledge systems and their antecedent power/knowledge "effects of domination" (Foucault, 1975, p. 26) "constitute subjects" (Walker, 1997, p. 744). In turn, subject positions cohere within certain power/knowledge effects for indeterminate lengths of time. Yet as power differentials are in constant flux, these subject positions also constantly alter. Thus, in circumstances when power cannot be fixed in one individual or a set of individuals, social or material actions can no longer be fixed to specific social roles.

## ***The Influence of the Normative***

### ***Normative Codes***

Within modernism, maintenance of the autonomous/'ideal figure' is confirmed through a continuous process of measuring and evaluating individuals. Measurements and evaluations are conducted in relation to already-established "prevailing codes of conduct that either prescribe or proscribe behaviours that members of the group can enact" (Lapinsky & Rimal, 2005, p. 128). Because these codes isolate what is ideal in respect of any behavioural event, they become convenient ways of promoting understandings about what the ideal is in relation to the production of specific behaviours within social systems. Normative codes also assist in decision-making processes in that they relieve individuals of having to think critically about the consequences of the assessments they make about specific events before acting on them.

Within the post-modern, the act of measuring and evaluating material actions is viewed as the product of a series of encoded "consequentials" (Shildrick, 2005, p. 3) of power/knowledge effect calculations. Rather than being tied to the premise of the

existence of knowable facts, such calculations are seen as relative to systems of moral judgements that derive from a central notion/figure, that of a “transcendent self as moral agent” (Shildrick, 2005, p. 3). In this position, transcendence refers to modernist beliefs that locate in the idea of a higher-order rational thinking self who exercise social responsibility and acts within the material world in the interest of reason and freedom. Power/knowledge effects of these calculation consequentials operate through binary measures of comparison and differentiation that, over time, become actualised positions through the repetition of degrees of conformation to this ‘transcendent self’. In turn, normatively constructed ideal positions (re)-construct social and material practice starting points congruent with these beliefs. Within the post-modern, it is assumed that no individual or group can stand clear of the effects of the operation of normative judgements which will contain, at the same time, both socially favoured and socially non-favoured qualities.

### ***The Problem with Normative Codes***

When normative codes are endorsed as mere conveniences for decision-making, there is no need to think further about what judgement statements they might create and how these statements might affect material possibilities. Social ways of doing become fixed in “their relative positions and into clear narratives” (Kuppers, 2003, p. 2). It becomes very difficult to suggest that normative codes might not be so much about the outcome of even handed comparisons made by rational individuals, as they are about creating sets of ordered positions that represent an unattainable ideal self, in relation to which all are measured, including the “good *and* bad, sick *and* healthy, mad *and* sane (Carahine, 2001, p. 279, *italics included*).

As an example, Davis (2002) observes that normative categories in the bio-medical field are premised on the assumption of an ideal embodiment of a healthy individual. Professional intervention becomes the determiner of which categories will verify what is judged ‘healthy/normal’ and what is judged ‘sick/abnormal’. Thus when an individual goes to the doctor for treatment, they are not treated as a material body but as an instantiation of a pre-determined ideal. In this case, this idea is expressed as suitable conformation to the embodiment of the “physically active, successful, healthy and attractive“(Rapala & Manderson, 2005, p. 165) citizen who does not require



medical services. In this scenario normative codes mask the assumption on which they are based, that is that no one material body can ever completely match the ideal. Further these codes also mask the idea that, in relation to the presence of this bodily 'ideal', all bodies can be said to have to work hard to conform, with the disabled person only representing a striking example of not conforming (Davis, 2002, p. 115-118)

Similarly, the concept 'ability', or the capacity to think rationally in relation to an ideal position, is achieved by certain codes of behaviour named 'abled' being constructed and confirmed through a series of favoured/non-favoured binary comparatives. While 'ability' remains fixed to the presence of certain named behaviours, the comparison and differentiation processes that substantiate these linkages ensure that the safety nets and forms of support that help those termed 'abled' appear to make it on their own remain obscured. Yet what is also concealed is the idea that conformation to 'abled' is entirely dependent on the presence/support of its non-favoured disabled counterpart.

### ***The Power/Knowledge/Language Nexus***

As I moved more deeply into examining epistemologies of disability support, I became convinced of the centrality of language to the production of any interpretation made of any social or material reality that constructs the disabled/support nexus. In relation to the disabled aspect of the binary, I found that language is not only implicated in the meanings made of material causes and effects related to impairment/disability, but is also critical to how these meanings are further interpreted, explored and (re)enacted in material circumstances (Pilgrim & Rogers, 1997). It is in the very position of 'talking about' that language and its use becomes a key emancipatory tool in relation to both impairment effects and disabling conditions, in that the power/knowledge relations implicated in the linguistic terms constructing the process of meaning making are also sites of struggle over the outcome effects of the social power these meanings hold (Court, 2001).

### ***Language and Normative Positions***

Within modernism, language is a transparent or neutral medium that communicates an objective reality (Vadebonceur & Torres, 2003). Within postmodernism, language is the medium through which systems of (normative) ideals are created, circulated, understood and enacted (Lapinski & Rimal, 2005). Thus the role of language is central to the creation and operation of power/knowledge effects and the relationships they hold. Placed inside of the operation of power/knowledge/ideal effects language becomes the vehicle through which epistemology and day-to-day life experiences are mediated (Burman & Parker, 1993). Thus language is intrinsic to the development of the broader cultural movements that shape how individuals perceive and experience the world around them. In turn these movements shape how individuals behave in relation to the effects of the normative creating perceptions and experiences language holds.

### ***Language and Discourse***

Linguistic expressions, or social orderings, or discourses, comprise socio-historical ways of seeing and knowing through which normative related power/knowledge effects become “available to people to make sense of their lives and experiences” (O’Neill & Morgan, 2001, p. 264). For example, when an individual relates something that has happened, a lot more is taking place than just that an amount of information is being recalled. The words used also clarify how power/knowledge effects inhering in prior linguistic constructions structure what people do in relation to what they experience in relation to their individual sense of self at that time (Edley, 2003). In this context, discourse encompasses (written or verbal) phrases that are historically produced, that are found within the social and institutional contexts that give rise to them and that are subject to, and the subject of, the social power created through their ongoing use in particular circumstances. Such power/knowledge effects are also created through signs, symbols and bodily activities.

### ***Discursive Power, Language and Making Choices***

Wider social ways of doing positions, constituted and maintained through language-effects, also enable discourses to deploy a range of competing ways of constructing

material possibilities. To construct possibilities, individuals “make choices” (Edley, 2001, p. 196) within a range of possible discursive constructions created when language is used to make sense of the circumstances they inhabit. Within modernism, the primacy of ‘the rational individual within a fixed universe’ view enables the choice of certain normative-related discursive effects to be seen as so obviously right or natural that no further consideration is necessary. However, naturalising the notion of ‘making a choice’ represents a range of power/knowledge effect ‘choices’ that normative related discourses rather than rational individual choice-makers make available (Heshiusis, 2002, p. 102).

In postmodernism, it is assumed that ‘making a choice’ does not consist of the outcome of even-handed considerations of elements of equal power held by autonomous, rational individuals. Choice is only enabled through prior agreement to the effect that some linguistic /sign/symbol constructions over others have already been taken “seriously as objects of knowledge” (Allen, B, 2005, p. 96). By their ongoing successful use, some discursive effects are more culturally intelligible than others (Butler, 1993). For example, within particular social locations some topics are easier to speak about than others. However, it is also acknowledged that while these effects may be accepted “as commonsense” (Court, 2001, p. 87) for a period of time, they do not remain fixed. Agreement about what is regarded as culturally intelligible is always open to contestation. Thus contesting, assessing and re-establishing of power/knowledge positions relative to prior-agreed normative judgements remains ongoing.

### ***Re-Framing Sexuality***

The third part of this chapter re-frames the term sexuality in line with the adoption of a post-modern position in relation to the notion of disability support. Chapter One outlined an initial definition of the term. This definition included two identifying points. The first point equated sexuality with biological/chromosomal characteristics. The second proposed sexuality as a social descriptor, covering the “arrays of acts, explorations, pleasures, identity formations and knowledges” (Sedgwick, 2005, pp. 83-85) spectrum of positions available between the most intimate and the most social

acts involving human beings. However, while both points highlight a biological and a social aspect, they do not include an understanding that language has already ‘naturalised’ these arrays of elements into pre-formed specific material and social locations from which these descriptors originate. Thus this definition could not be used to pinpoint how deeply influential this naturalisation process is to how the term sexuality is (re)created, maintained and challenged in the disability/support location.

### ***Sexuality as Discursive Formations***

Like disability, sexuality is also re-viewed as a series of larger systems of representation that are culturally rather than bio/socially perpetuated. It is suggested that these representational configurations also assume, through negotiation, certain binary logics deriving from modernist inspired assumptions about how the euro/western world operates. Further, the premise of favoured and non-favoured power/knowledge effects is implicit in and through the creation of these logic positions.

Following Foucault, the term sexuality is understood as including sets of power/knowledge effects that have networked together over time to produce the “stimulation of bodies, pleasures, knowledges, controls and resistances” (Foucault, 1978, p. 103) that construct the term. Further these discursive configurations constitute “an especially dense transfer point” (Foucault, 1978, p. 103) for deployments of multifaceted discursive power/knowledge effects that directly connect to notions of a material body (Allen, B, 2005). These points of entry are highlighted through key normative/ideal instantiations that include “heterosexuality, marriage, monogamy, privacy, penetration, age and blood-kin appropriateness, and reproduction” (Bell, 2005, p. 194). Further, binary relationships productive of these key discursive positions are acknowledged as deriving from and sustaining the “intensity of passions” (Warner, 1999, p. 17) through which favoured and non-favoured ‘choices’ of actions that relate to these discourses are regulated and mandated.

Within this view, rather than sexuality being a notion that is fixed in time and space, the term is flexible and choreographic, moving backwards and forwards between

binary notions of public and private, local and universal, historical and contemporary, theoretical and practical, never quite “settling comfortably” (Bell, 2005, p. 198) in any one location. Yet all the while, the physical social and emotional ‘truth’ effect intensities of passion that fix the power these discursive effects create and maintain seek to foreground certain material acts as prescriptively normal, natural, inevitable and consistent over time.

Reconsidering what sexuality means enables movement beyond the idea that sexuality is an either prescribed or proscribed set of material acts/performances. Sexuality-as-(bodily)-sex becomes the outcome of complex physical, social and emotional power/knowledge effects that structure the activation of material possibilities. This alteration of view enables identification of how (normative) prevailing codes of conduct connecting sexuality to material bodies infiltrate, produce, uphold and contest support worker performance.

### ***Sexuality and Binary Codes***

For Warner normative codes in the sexuality area are established through a series of binary distinctions that enable an accurate mapping of interlinking systems of prescribed and proscribed material activities that differentiate “good sex from bad” (1999, p. 25). These binary distinctions provide the means by which “truths about sexuality” (Carahine, 2001, p. 275) become fixed over time. These truth effects continue to enhance and maintain ‘idealised’ understandings about how sexuality operates in the material world. For Warner (1999) these comparative codes include the following dimensions.

<b>Good/Normal/Natural/</b>	<b>Bad/Abnormal/Unnatural/</b>
Heterosexual	Homosexual
Married	Unmarried
Monogamous	Promiscuous
Procreative	Non procreative
Non commercial	Commercial
In pairs	Alone/in a group
In a relationship	Casual
Same generation	Cross generation
In private	In public
No pornography	Pornography
Bodies only	With manufactured objects
Vanilla	Sadomasochistic (Warner, 1999; p. 25-26)

Warner further suggests that it is the intensity of passion these binaries evoke, activated by the coercive power of “sexual shame, disgust and moralism” (1999, p. 114) the term already contains, that upholds the ‘ideal’ prescribed/preferred sexual behaviours that individual “members of the group can enact” (Lapinsky & Rimal, 2005, p. 128). Thus, if your behaviour is found to be on the non-preferred side of the binary you risk being stigmatised in a way that can cause you social and material damage (Warner, 1999). However for Wilkerson, rather than an outcome of individual stigmatisation creating the difficulty, what generates the emotional passion inhering in the operation of these binary differentials is the pathological fear of “social upheaval and chaos [and] the loss of all social order” (2002, p. 33) that strict adherence to the maintenance of the socially favoured aspect of these behaviours prevents. Thus, while Wilkerson’s view suggests that conformation to the preferred represents a shared necessity to preserve the fragility of social cohesion, for Warner the motivation to conform represents a more intensely personal response.

Further, as Carahine notes, while these binary distinctions “create sex” (2001, p. 268), they also use, interact with and are mediated through related discursive effects. For

example, these binary differences are mediated by and through key power/knowledge effects contained in the more intangible “axes of social difference” (Wilkerson, 2002, p. 35) that construct the terms femininity, masculinity, gender and desire. These effects enabled the term sexuality to differentially impact in a variety of social and material spaces. For example, gays, lesbians and bisexuals have been especially vulnerable to the shaming effects of moral judgments associated with transgressions of sexual norms (Warner 1999, p. 8). As these discursive effects produce differing social and material outcomes in relation to the constitution of differing subject positions within differing socio/historical locations (Foucault, 1978, Carahine, 2001), how sexuality is constituted by and through these allied configurations is a key point of interest both for Foucault and for the examination of support work practice undertaken in the following chapters.

### ***Sexuality Power/Knowledge Effects and Support Work***

Relocating sexuality within a post-modern perspective enables a review of how the workers are positioned in relation to support practice in this area. Principally it enables a new point of entry to an exploration of the productive force of normative-related discursive effects on workers and their actions. It also isolates potential antecedent positions from which worker responses might be generated (O’Halloran, 2005). Although workers are still seen as taking action in their practice they are no longer positioned as necessarily the autonomous originators of these actions. Nor are their actions ‘naturally’ considered prescriptive or proscriptive. Rather sexuality support practices are viewed as primarily the product of powerful discourses whose binary effects attempt to normalise the concept of ‘sexuality support’ in an agency service residential home setting

Worker actions become signifiers of powerful convergences of cultural meaning from which support systems derive, and through which support actions are performed, through this relocation. In turn, other configurations of discursive effects within formal areas of worker practice, including the impairment conditions of those they support, plus formal and informal policies of the organisation they work for, link to broader ‘sexuality’-related power/knowledge discourses. These systems further inter-link through broader social ordering meta-discursive effects that include ‘family

members', 'professionals', 'academics' and 'members of the wider public'. Lastly discursive effects inhering in these terms are themselves constituted and reconstituted through the power/knowledge effects these binary code markers create.

### ***Power as Repressive and Enabling***

Structuring worker's practices within a post-modern framework does not completely eliminate the necessity of including a view of these practices derivative of modernist frameworks. The in-collusion position adopted for this part of the analysis suggests that support workers may have certain investments in the deployment of particular power/knowledge effect outcomes. Thus aspects of worker actions will also reflect the behaviour of individual agents who operate within a discourse of individual purpose for an individual gain outcome. Questions relating to who decides what the normalising codes of conduct are that are the 'good' ones in the area of sexuality and intimacy, and who might benefit from the appraisals made about practices, create the collusion with modernist thought position necessity to recognise and foreground the discursive role of 'individual purpose' within the support worker practice matrix (Heshusius, 2002).

Foucault's ideas too suggest that any power/knowledge effects considered repressive, rather than actually being repressive also signal the presence of a discourse of moral judgement, itself is sited within the 'dense transfer effects' of wider power/knowledge discursive systems created through the sexuality/disability nexus. The analysis undertaken in the following chapters seeks to value both the direct experiences of support work and the degree of individual purpose brought to these experiences. It does so through an examination of the broader "texts and contexts" (Clear, 1999, p. 343) in which these material experiences are placed.

### ***The Difficulty With Revisioning Disability***

Prioritising the support position as the primary focus of this research reflected the idea of disability as a descriptor of the negative relationships experienced by impaired people, rather than the term indicating of the presence of a biological condition. As Young remarks, after utilising social model inspired ideas to explain the lives of



disabled people “it becomes difficult to revert to a world that describes some people as simply and unfortunately having ‘special needs’” (Young, 2002, p. xiii). However, when I looked more deeply into how the divide between disabled and abled was constructed, it seemed to me that these positions ultimately derived from the same essentialist/idealist world-view, albeit while originating from a different conceptual starting point within this parameter. While normalisation/SRV principles relate primarily to easily recognisable ideal-type physiological parameters, social model principles are grounded more pragmatically within the parameters of “whatever it is that the disabling environment or prejudicial social attitudes are tailored to favour” (Scully, 2005, p. 64). However, in both views the notion of a ‘tailored to favour’ world, which is either aspired to or struggled against, remains the accepted central point from which the support position is created.

I had come to realise that there were degrees of discomfort to be understood in relation to the positions of people for whom access to socio-material circumstances, critical to the ongoing maintenance of everyday life, remained constantly a matter of negotiation. Thus who might be sceptical of how the use of a theoretical approach that appeared to downplay these difficulties could effect any lasting changes to less than adequate material circumstances. If disability were constructed by ideas that lay beyond a social-material context then much of the ground under which any assumption that the provision of access to the appropriate material circumstance would enhance the autonomy of any impaired person, would disappear. This lack of a solid, enabling epistemological base is a position many disabled people have experienced in the past and have no wish to return to (Scully, 2002).

My difficulty centred on how to overcome the problem of seeming to work against a theoretical model that “effectively asks us to choose between the extremes of reality determinism and discourse determinism” (Corker, 1999, p. 3), while keeping in mind the distress caused by a lack of access to material effects and the consequences of this lack that continues to be a day-to-day reality for many impaired people.

### ***Why Re-Focusing is Important***

Set against the difficulties of adopting a re-visioned epistemology to investigate worker practice I outline above were the hours spent in training rooms talking about support processes to sometimes up to forty front line, often tired, overwhelmed and sometimes very angry workers. For many training sessions providing information about what they ought to be doing equated to little more than negative appraisals of their current performance. Some of the issues workers were trying to deal with slowly emerged during that time. However, many workers did not talk about the problems that troubled them. These sessions were the most difficult to run of all the workshops I facilitated. What concerned me most about these sessions was that it seemed as if a significant number of workers had lost hope of being able to change the conditions they worked in, let alone felt able to make their voices heard. These workers did not, to me, represent sterling examples of the independent, productive citizens ‘who did not require care’ support aspect of disability. Finding a theoretical position that could take these experiences into account was also a very important consideration.

In the next chapter I explain the method and methodology I use to complete the data analysis section. However, I make further comments about the value of a post-modern perspective to this thesis and to the advancement of the disability studies field in the final chapter.

### ***Footnotes***

- 1) *I take Tremain’s point about the concept of bio-power as “vital for any Foucauldian analysis of disability”(2005b, p. 3). However, it has been a consistent tension in the production of this thesis to represent the support position as symbiotic to the concept of disability rather than synonymous with disability oppression. This position seemed to lie against the grain of current ways of thinking about disabling conditions and what they contain. I believe that this problem continues to present a barrier to the consideration of more workable theoretical framework in respect of the support needed aspect of ‘disability’. For this purpose, the exercising of power (in a Foucauldian sense) by and through the support work position relies on the prior effects of*

*power/knowledge discursive formations that already-deploy 'in relation' to all material bodies.*

- 2) *As an aspect of this theoretical framework I had originally included Foucault's four iconic sexual figures, as some of the discussions held with support workers resonate with these figured representations. However, these turned out to be only of limited use for this analysis, as an important figure is left out of his epistemological line-up. Like Timms (2002) I would also have liked him to add the sexually satisfied male figure to his list, as I too challenge the assumption Foucault makes through this omission, that masculinity is unchanging, unconstructed and easily normative.*

## Chapter 6

### *Methodology and Method*

*Autobiography, if there is such a thing, is like asking a rabbit to tell us what he looks like hopping through the grasses of the field. How would he know? If we want to hear about the field on the other hand, no one is in a better circumstance to tell us – so long as we keep in mind that we are missing all those things the rabbit was in no position to observe. (Golden, 1997, p. 1)*

### *Introduction*

This chapter describes the methodology and method through which the thesis data is linked to the wider social context in which the key issues informing this study - sexuality, intellectual disability and the support position, are embedded. The first part briefly outlines the methodological problems international researchers have found gathering intellectual disability and sexuality support data. Examples from the literature review are included. These problems inform the data gathering method. I then summarise information about the participant group. A brief participant profile, ethical safeguards taken to protect all participants involved and an outline of the interview process are included.

I put myself into the methodological frame in the second part of the chapter. I outline the troubling questions the interview process raised. I detail how I begin to work retrospectively and reflexively in respect of the unease these questions created. This part of the chapter includes a deeper consideration of the influence of the interview site as a specific socio-cultural space in which the workers interviewed and I were both located.

I then validate a post-modern/interpretive perspective as the framework from which the data is analysed. I draw on key ideas from the works of Burman & Parker (1993),

Weatherall, Taylor & Yates (2001) and Denzin & Lincoln (1997). These articles bring together a variety of deconstructive approaches to qualitative data analysis. My take on these ideas forms the 'methodological toolkit' (Court, 2001, p. 84) I use to isolate the presence of key discursive effects from the information gathered. Finally the difficulties of working with a deconstructive/interpretive approach to qualitative data analysis are expanded on. I briefly examine possible pitfalls inherent in the use of this method in an academic context. The chapter ends with further reflection on my position within the process of sexuality research, including recognition of the need for more support for those undertaking studies in this sensitive area.

### ***Literature Review Findings***

The initial part of this research project included scrutiny of a broad spectrum of research surveys in the intellectual disability and sexuality support field. What was immediately noticeable was that this data set contained very few studies compared to the volume of studies undertaken in other support areas. This lack of data gave credence to the recent opinion expressed, that sexuality support is a tricky investigative area and one that contains significant research pitfalls (Test et al., 2003).

I found that worker's talk was rarely used as a source of information. Data collection invariably relied on pen and paper methods, despite the problems these methods posed. In particular, problems of adequate participant engagement remained a significant obstacle in studies using this approach. For example, some researchers noted that questionnaires distributed to workers covering aspects of sexuality support often resulted in significantly low rates of return (see, for example, Christian, et al., 2002). Other research papers described workers as either refusing point-blank to take part in written surveys about sexuality support or as returning questionnaires with the sections about sexuality and intimacy left unanswered (see Craft & Brown, 1994). Analyses of completed questionnaires were found to include weightings towards certain kinds of respondents, for example older rather than younger workers, raising questions about the possibility of skewed data findings. In addition, a prevalence of responses from female workers in particular has continued to be noted (McConkey & Ryan, 2001). Chronically low rates of completion and return seemed to have be

accepted by the researchers concerned, perhaps seen as an inevitable by-product of the nature of the topic about which little could be done.

In New Zealand the sexuality support research area had been so tricky I could only find one published study about the subject (Chapman & Pitceathly, 1985). However, neither did I find any corpus of published data that focused directly on support worker views in any support area. What I did uncover was one unpublished in-house survey of what were called, in the language of the day, direct care residential staff (Turner, 1984). This interview-based survey had been completed as a general survey of workers for training requirement purposes, thus not particularly slanted towards an exploration of sexuality support. But it contained an interesting and intriguing comment. This author noted that “meeting with the genuine carer is a unique and enlightening experience” (Turner, 1984, p. 146), a remark providing a stark contrast to the more negatively framed appraisals of worker performance outlined in the international review studies. Turner (1984) also noted that although the interviews he undertook were designed to capture training related information, they often “ranged far from the specifics of the interview form, to be terminated reluctantly when the time for the next appointment arrived” (Turner, 1984, p. 146).

In view of the difficulties survey-type methods experienced and in view of Turner’s (1984) comment noted above, I decided to use an interview format for my data gathering method.

### ***Gathering Participants***

Interview participants were gathered through personal contact and through a call for volunteers made at two sexuality-focused workers training sessions I attended in the summer of 2006. After initial contact, interviewees were spoken to by phone to organise a meeting time. I had arranged for a room in the university to be made available if needed. However, meetings ended up being held in a variety of locations to suit the requirements of the participants. Two interviews were held in workers own homes, four in a room within the service organisation they worked for and three in a room in the interviewee’s workplaces. While these locations were less than ideal from some perspectives, they represented the best chance workers had of being able to set

aside the time I requested. Worker's being able to choose their interview location also gave me some assurance that the sites they opted for were considered by them to be suitable for the nature of the topic (Sin 2003).

Thirteen support workers were interviewed, including eleven women and two men. It had been suggested by a member of the committee that I offer interviewees the option of bringing a support person with them as an aspect of the ethical approval process. Three people chose this option and brought a person with them. I recognized these people as workers who had attended one of the two training sessions I had previously spoken at. In view of their knowledge of what was involved in the research, and with the agreement of the interviewees concerned, those who came as support were offered the option of contributing to the interview discussion in their capacity as front line staff.

I explained that the contributions they made would be subject to the same ethical considerations as those involved in a single person interview format. All were willing to participate. As a result, seven people took part in a single interview and six were interviewed in three two-person groups. All participants involved signed the Consent Form for Support Workers approved by the ethics committee for interviewees involved in the study (see Appendix 3). Those interviewed as a two-person group also signed the approved Group Confidentiality Agreement Form (see Appendix 2). Thus all participants became part of the verification of information gathered and the guarantee of anonymity and confidentiality processes outlined in the ethical approval forms.

### ***Participant Information***

Participants were not asked to reveal their ages but from prior knowledge all fitted the age and qualification aspect of the profile of a current New Zealand support worker - as an "unskilled worker in her 40's and 50's" (Chai, 2003a). Participants were asked how long they had worked in this role, what service areas they had worked in and what level of responsibility they held within the service they worked for. Lengths of service varied between two months and twenty-six years. Levels of responsibility also varied with those identifying as workers on Level 1 having less responsibility that

those identifying as on Level 4. Those on Level 4 held less responsibility than those on Level 6.

From my experience of organisational processes, the areas of responsibility these levels covered varied depending on a number of factors, including whereabouts in New Zealand the worker is employed. In general, those at a higher number usually have more direct responsibility for house budgets and/or for the overall operation of the staff roster system within the houses they worked in. Higher levels are also tied to support positions where assistance is given to intellectually disabled people with high degrees of physical and cognitive impairment. However, this designation can also refer to remuneration for length of service, with long-serving workers often earning more than their newer counterparts. The differences in level of responsibility noted raises questions about how well this factor is taken into account as existing literature that usually refers to all workers as either ‘staff’ or ‘workers’. This convention suggests that power differentials found within this level system are not always taken into account.

All participants were currently employed full time as support workers. Four interviewees identified as Maori, and one had Maori affiliations. The names of the participants and other people mentioned during the interview have been changed by agreement signed by all interviewees.

An asterisk indicates where the worker identified as having a disabled family member. Three workers have or have had an intellectually disabled sibling, indicated by the use of \*\*. Four other workers have a disabled family member they identified as being part of their immediate family (‘immediate’ including uncles, aunts and first cousins). This relationship is indicated by the use of \*, and includes family members who represent a variety of physical, cognitive and emotional impairment conditions. The high number of workers in this study with a disabled family member was surprising, and reflects a dimension to the support work position that is rarely overtly acknowledged.



***Table of Participants***

<b>Pseudonym</b>	<b>Number of years</b>	<b>Organisational Level</b>
P**	4 years	Worker/Coordinator
G*	3 months	Support Worker
J	12 years	Worker/Level 6
Ju*	15 years	Worker/Level 6
C**	26 years	Worker Level 6
S**	7 years	Support Worker
H*	9 years	Support Worker
T	2 years	Support Worker
Jo	11 years	Worker/Level 4
V	4 years	Worker/Coordinator
Co	6 months	Support Worker
M*	4 years	Support Worker
Joa	3 years	Support Worker

***Conducting The Interviews***

Interviews were conducted using trigger questions reflecting broad theme areas drawn from literature review sources (see Appendix 5). The structure of each interview session was slightly different. Theme areas varied within each interview and all question areas were not covered to the same depth or extent. What was covered came to depend on the individual workers breadth of experience in the position, the areas of support they were familiar with, the assistance needs of the person they supported and the gender of the interviewees. However, all interviewees were asked what their definition of disability was, what their definition of sexuality was and what they thought the word sexuality might mean to a person or people they supported. Each interview took between one and one and one half hours to complete. All participants were assured that they did not have to respond to any question they felt uncomfortable answering to address levels of comfort.

*C: If ...you think no, I don't want to answer that or no I feel too uncomfortable, just tell me.*

*J: Ok*

*C: ... because it is a difficult area.*

*J: Yeah (J 2005, p. 1).*

Interviewees were also invited to indicate that the tape be turned off at any stage if needed. The tape was turned off during the course of two interviews, once for a participant to answer a phone and once to deal with a work issue that had arisen. Interview transcripts were sent back to interviewees for comment and revision as negotiated before the interview and one interviewee sent back additional comments during this period.

At the time I took this lack of further engagement as indicating that workers trusted the process, that they were comfortable with what they had said and what I was going to do with the information. In hindsight I am now more wary of how readily I made this assumption, rather than thinking this 'lack' position might indicate the possibility of a 'something more going on' issue that needed deeper consideration (1). I expand on aspects of this point later in the chapter.

### ***First Readings***

The transcripts I made catalogued a series of definitions related to support work and sexuality. They described instances workers recalled from their day-to-day support practice and the practices of other workers. They also contained support worker opinions on issues related to self-care, training, stress and organisation management.

First readings of the information strongly reflected the accuracy of international literature review findings outlined in the initial chapters. Interviewees recognised that some of the people they supported had the same sexual needs and desires as those without intellectual disability (Wolfe, 1997). However, if their attitudes had adjusted accordingly, their practices seemed to have remained either in the 'Stop Position' - where expressions of sexual expression are either forbidden or so many barriers placed in the way that it is effectively not an option, or in the 'Polite Position' - where workers are supportive and encouraging, yet hold back from practical assistance or

are constrained by the reluctance of others (Brown, 2000). When workers did recount instances of pro-active support practice, these few initiatives prioritised support for acts of sexual intimacy that were set within very narrowly defined social and environmental boundaries.

In many respects, the intellectually disabled people who were supported by the workers concerned were still treated as if “they don’t have a desire for intimacy ... and so long as no-one discusses sex and sexuality, hopefully the individuals with DD/MR will not be inclined to focus on it” (B Allen, 2005, p 127). The proposed “new era of acceptance” (Hingsberger & Tough, 2002, p. 15) in sexuality support could not be said to have influenced these worker’s practices. Nor had workers a “clear and realistic idea about the nature (and limitations) of their work” (Mattison & Pistrang, 2000, p. 16). All but one worker expressed confusion about what their role was in this area, while some expressed ambivalence about how they might assist the person they supported in a relationship in any context. Yet, workers were also very concerned about their own practice and the practices of others in this area. All stated that they were not doing enough for the people they supported and all expressed at least some willingness to change their practice. In some cases, individual workers expressed frustration about when this change might begin, what direction it might take and what their input into the process might be.

### ***A Period of Reflection***

From my knowledge of what workers had said about their support practice in the sexuality training sessions I had attended, I recognised that the interview data did not fully capture the complexity of responses these sessions had revealed. Much of the talk gathered was evasive, difficult to follow and contained many hesitations, verbal qualifiers and periods of silence. Finding this degree of talk difficulty in workers statements was a surprise. Because of my prior experience with workers in training sessions, I had initially been sure that I would be able to collect detailed and comprehensive information for analysis. However, an underlying unease began to erode aspects of this confidence during this period. I was unable ignore some persistent queries that would not go away. This feeling began a process of questioning and reflecting through which I re-examined what I had been trying to do.

I initially reflected on the sample aspect of the process. I had not been looking for numbers-related representations, but did I need to interview more workers? If so, how many more interviews would I need? How much more information might I obtain this way? I had thought that being a familiar person for the workers concerned would eliminate some of the difficulties workers were recorded as having providing information about this topic. Could my prior position in the agency be mixed up in the queries I had? I began to reflect more deeply on my own position within the methodology, specifically tracking what I might have brought to the process of data gathering, as I too was involved as an active participant in this research landscape.

### ***Research/Practice Tensions***

Between designing the questionnaire and undertaking the interviews, I had left the organisation I had been working for. At the time I had become overstretched by my commitment to my employers and to the thesis I was working on. Through reflection, I recognised I had also become alienated from and disenchanted with much of what was happening within the service environment. This tension this difficulty created had limited my effectiveness as ‘an agency worker’.

At the time I was also concerned that some of the information contained in the research studies about workers practices did not give enough consideration to the complexities inherent in agency service workplaces and how they operated. In particular I had deep concerns about how the information gathered by researchers was then used to make certain recommendations about sexuality support practice that did not fully account for this complexity. As research recommendations did not always capture the difficulties inherent in the support role, they were not always helpful. I had made the decision to leave the agency service to concentrate on completing the research. Yet I continued to struggle with whether it would have been more productive for me have continued to work for change inside rather than outside of the organization. Had aspects of this struggle affected the data gathering process? Had it also limited what I was trying to achieve as ‘a researcher’?

### ***Unpacking The Interview Room as A Socio/Cultural Space***

In view of the difficulties I outline, I also began to reconsider the context in which the information was being gathered. Within modernism, the interview process involves the abstraction of information from its context and the promotion of the researcher as a detached and neutral observer/writer of the subject under review (Lather 1991). Both interviewer, as “the investigator” and interviewee, as “the investigated object” (Bevan & Bevan, 1999, p. 16) are seen as independent of the material and social environments in which they are located.

This way of viewing data gathering had shaped my initial understanding of how the information was to be collected and underpinned how I thought the process would be written up. Reconsideration of this position within post-modernism meant re-examining the interview process as examples of interactive and specific socio-cultural spaces that reflected the context in which they operated. In these spaces overt and covert negotiations regulating how individuals moved through the interview ‘encounter’ became a significant part of the data gathering process. To further examine my own position in this significant space, I posed the following questions: What kinds of movements through the interview encounter might have affected what workers were prepared to say? How might my position within the interview space have influenced these dynamics?

### ***Elements Contained In Unstructured Interviews***

I use Fontana & Frey’s (2000) outline of the six basic elements involved in unstructured interviews to unpack and write up the interview as an interactive site within the methodology. These elements form the parameters that shape the following account of how aspects of these negotiations of space were conducted between my self and the worker’s concerned.

### *1) Accessing the Setting*

As this was a study of direct care workers employed within a service agency I had to obtain permission from the agency they worked for to interview participants. This process involved submitting a letter (see Appendix 4) and copies of my approved ethics proposal to two senior people involved in organisational management and quality control. I had a brief meeting with one of these managers who gave verbal permission for me to start the interview process. Obtaining approval was made easier because I was a former employee of the organization and was able to use the goodwill I had established with this manager. This connection was fundamental to being given permission to interview service employees. However, being a former employee created it's own difficulties. While my insider status was positive in that it got me started, it subsequently influenced my ability to "position myself in the field" (Saunders, 2004, p. 79) as a researcher in a less than positive way. In particular, given my prior association with the organisation and the workers concerned, it rapidly became very difficult for me to try to work in any way other than very openly within the service environment. How this might have affected what was said at interview is explored below.

My need to work openly within the service that employed the interviewees was reflected in how the interview room at the agency office was used. This space was located at the front of the building that housed the branch office of the organization, but was off to one side of the main entrance to the administration/management areas. While it was an acknowledged part of the office, it had the advantage of affording visual privacy to workers who could enter and leave without being noticed by either administrative or management staff. Office employees and managers knew in general what this space was being used for. What I kept confidential was the information obtained and who gave it (see Appendix 3). However, although this space was visually private, it also remained a 'room in The Office' that retained particular contradictory emotional meanings for the workers being interviewed (Davidson & Milligan, 2004).

Attending the sexuality training session also acknowledged my need to remain transparent about what I was doing within this system. At the call for volunteer

sessions mentioned above, I distributed flyers about my research. The flyers contained an undertaking to protect the confidentiality of participant's, details of how workers could volunteer and including my contact phone number (see Appendix 1). Each session was attended by between 20 and 25 support workers. A total of five participants approached me with their contact details. These workers came forward from inside this space. During the follow-up period one of the men who initially volunteered decided not to proceed. He thought that the topic would be too difficult for him to talk about. He also acknowledged feeling apprehensive about how knowledge of his involvement might subsequently be used by the agency concerned.

## **2) *Understanding the Language and Culture of Respondents***

As a former employee, my role included facilitating training sessions involving groups of support workers. I developed a number of training programmes and one-day sessions to enhance new and experienced support worker's skills and expertise in a number of key areas in this position. These included the following teaching/learning areas: ethics, teaching skills, stress management, communication skills, and disability related attitudes and values seminar sessions. Much of this work was couched in the language and culture of the disability support field. I was involved in a very large number of training sessions. Key aspects of this prior position came into the interview sessions with me, and I expand on this point below.

## **3) *Locating an Informant***

Although I had left the agency at the time I undertook the interviews, I had retained contact with a person who had spent 34 years in a variety of support and management roles within the organisation and within the intellectual disability field. She contributed her skills, expertise and time throughout the research process. A short time before I left, she and I developed a one-day sexuality training session for support workers. We did this because the session being offered by the specialist sexuality worker did not seem to be addressing some of the practical needs of the workers. While this session addressed many issues, it did not perhaps go far enough to enable workers to change their current workplace circumstances. Little was made of the theoretical and conceptual links that could help relate the material in the sessions to

worker practices. In addition, because of the amount of material presented, workers had little time to discuss what was currently happening in their workplaces.

The session my colleague and I wrote was designed to create a space for workers to talk in small groups about their current experiences in this area. We facilitated this session twice and some of the stories that workers told and the intensity of emotions that accompanied them remain etched in my memory. As they were told within the parameter of confidentiality required of all participants at these sessions, they remain in memory. These experiences shaped how I structured and developed the interview material I was given ethical approval to gather and I make further comment on this in the analysis chapters. However, whether these sessions affected worker's decisions to participate or not in an interview is something I am still unable to quantify.

#### **4) *Collecting Empirical Material***

I used a small audiotape to collect interview data. This was placed on a table in clear view. I also put my questions on the table. Prior to undertaking the interviews, I had decided not to take written notes at this time and to write down what I remembered after the sessions. In reality, I did not write anything down after the interviews. All I did was to drive home. As planned, I transcribed each interview as a way to familiarise myself with the interview material.

It was only much later on that I realised my prior position as agency adviser had enabled me to obscure any areas of personal discomfort I might have had with the term sexuality in an interview location. I had already isolated a being unable to write anything down position through the literature review process. Although not overtly stated, this difficulty had been noted as indicating of at least some degree of personal difficulty with the topic by worker's concerned. Yet, like the rabbit in the field, I had unable to 'see' that I too had been affected by this difficulty (Golden 1997). How much did this discomfort influence what went on in the interview room?



### **5) *Deciding How to Present Oneself***

As a former employee based in the regional office of the agency involved, I was an authority figure for the workers concerned. I had felt uncomfortable with this position when I worked for the organization. I had tried to deal with these feelings through comment and dress (Guy & Banim, 2000), so to take the position of ally (Marks, 1999) at times when I felt this was possible. This tactic had not always worked and aspects of the organisational/authority-figure image my former position created also entered the interview room.

While I was able to acknowledge that this ‘ally/authority’ binary might affect the data gathering process in some way, I did not begin to appreciate how it would affect my sense of self as ‘a researcher’ until I tried to decide what to wear to the first interview session. Dressing became a long and involved process and I watched myself go through a significant number of changes of clothing before I was comfortable enough to leave the house. Even so, I noticed myself taking two jackets with me in the car, on a day that was warm enough for me to have left both at home. This difficulty too did not register as significant at the time.

On reflection I was able to acknowledge that the difficulty I had that day with what (not) to wear did not relate so much to “the structural positioning of women in patriarchal, capitalist societies”, my usual problem, but reflected more how this present/prior disjunction had already been “stitched up” (Guy & Bamin, 2000, p. 314) in conflicting discourses of representation to which I was about to add the position of ‘doctoral researcher, researching in the sexuality area’. These difficulties came into the interview room with me.

### **6) *Gaining Trust and Establishing Rapport***

My former position as learning and development adviser coloured how trust and rapport was established in the interview process. Power/knowledge effects inherent in the ‘adviser/advisee’ position that had characterised my former role in relation to that of the interviewees was not fully resolved during the interviews, and perhaps could not be under these circumstances. Did workers take me at my word when I suggested that they didn’t have to answer if they felt too uncomfortable with the questions being

asked? My own discomfort with the topic was also unacknowledged, yet present. Anderson & Jack (1991) suggest that, for women in particular, speaking in public about a deeply private issue such as sexuality can create difficulties. Did this difficulty also inhibit talk? These questions remain open. Yet they must have had an effect on what workers felt able to reveal.

### ***Data Gathering in a New Zealand Setting***

In addition to the six basic elements of unstructured interviews outline by Fontana and Frey (2000), I include a further dimension to these categories. New Zealand is a very small country inhabited by four million people. As Tolich suggests, there is much to be said for treating the gathering of data of any kind in this country “as if the research (*were taking place*) in a small town” (2002, p. 9). This comment is especially pertinent for anyone interviewing within the New Zealand intellectually disabled support community. Data acquired by personal interview within New Zealand, irrespective of how sympathetically it is then treated, poses many problems. These include how to adequately disguise not only the interviewees concerned but even where the interview took place (Court, 2001). These problems pose major ethical difficulties in guaranteeing confidentiality.

When I undertook to guarantee confidentiality realistically I could not guarantee this unconditionally. My results were to be written up and released into this very small public domain. In particular, how was the confidentiality of intellectually disabled people ultimately going to be guaranteed? While anonymity for members of this group could be more easily obtained through using pseudonyms and scrambling other identifying features, nothing could be guaranteed absolutely and the workers and I knew it.

Asking workers to talk about their experiences on the job with these provisos in mind was to enter a covert process of negotiation with them about what they felt able to say in view of this small town factor. I did not attempt to challenge what workers said, even at times where I strongly felt that there was more going on than interviewees were prepared to reveal. As experts in how the informal culture of their organization worked, I left it up to them to judge what aspects of their work they would ‘keep

secret’ (Salazar, 1991) and what they would reveal. I comment on aspects of these tactics of resistance as part of the data analysis section.

### ***Moving On to Analysis***

Despite the difficulties outlined above, somewhere in the information offered by the workers concerned was a rich source of information about sexuality and support processes. Retrieving it was not going to be the straightforward process I had thought it would be. I had encountered reticence, difficulty and discomfort, including my own. However, in view of the problems the research review studies had encountered, it could gainfully be said that I should have expected difficulties and more fully anticipated their arrival.

At this point a post-modern methodological perspective enabled me to go beyond the notion that this data sample might just represented information from limited selection of what could be seen as aberrant and un-cooperative workers. I was able to see that workers had become “stitched up” (Guy & Bamin, 2000, p. 314) in conflicting discourses of representation that affected what they said and how they said it. Being able to explore these discourses in talk, and to track how these effects might influence support practice represented the most productive way forward from the difficulties the data gathering process had raised. In addition, this approach gave me the chance to recognise the socially and emotionally ambiguous positions I too inhabited within the data collection process and, as an academic researcher, to begin to engage productively and effectively with the problems these positions presented.

### ***The Process of Transformation: From Data to Text***

In this part of the chapter I outline the conceptual tools I use to work with the data. I briefly outline the standpoint position I come from in relation to the development of this approach. I clarify how the conceptual tools I use are applied on the understanding that the information I collected is to be viewed as discursive accounts through which key power/knowledge effects that shape worker’s responses in the sexuality support area can be isolated and unpacked. I then summarise key significant

dilemmas researchers using this approach have encountered when treating ‘authentic autobiographical accounts’ as representations of discursive constructs. This aspect of the chapter provides further verification of the methodology employed to deconstruct the textual data.

### ***My Own Position***

A thorough literature review was central to the development of the analysis section of this thesis. The most striking thing to emerge from this review was the lack of significant or sustained engagement with the influence of wider social and emotional factors on worker’s practice in the sexuality support area. Recommendations from papers contained in the review seeking to influence the expectations and operations of the worker role also lacked significant engagement with these difficult to elucidate yet very important factors. This lack raised two key questions. While the impact of the wider social and emotional issues from which worker’s actions derived remained unexamined, how could the outcome of research undertaken in this area be of good use to service organizations and those who work in them? Would unpacking something of what these contexts contained and how they impacted on the worker position enable a more holistic view of the actions of individual workers? How I engaged with these questions shaped where I was to stand in relation to the analysis I undertook.

An examination of lines of theoretical discussion about the nature and function of the terms ‘disability’ and ‘sexuality’ influential to how individual workers behaved was the other key aspect that shaped the development of the analysis section. Through the review process I had found that underpinning assumptions about worker’s moral and personal attributes were intrinsic in these discussions. These debates grounded these assumptions in idealised yet often unstated examples of certain socially valued attitudes and behaviours. These attributes constituted ‘the truth’ about sexuality support from which the practices of ‘good and bad’ workers had been created and considered. I had come to believe that while workers continued to be judged relative to idealised versions of what ought to be happening in the area of sexuality support, intellectually disabled people’s access to this area of their lives would continue to be compromised. What conceptual tools I used to verify this belief was a very important

consideration in view of the adverse judgement calls that can be made worker's support practice. I expand on this point below.

These ideas fixed the position I take for this analysis firmly within an interpretive, rather than a critical, feminist or phenomenological post-modern framework. In raising the questions I outline above, I had 'interpreted' a particular set of underlying meanings from the academic texts I had read. In doing so I had committed myself to developing the analysis within the ambit of an interpretive framework. Within this framework certain aspects of text are presented and probed not as examples of fixed, descriptive statements but as fragmented moments of intention and interaction in which wider discursive effects can be located and unpacked. Significant wider social meanings related to the terms 'disability' and 'sexuality' within a support context contained in these textual moments are uncovered and commented on.

In choosing an interpretive post-modern position I was also committing myself to keeping this analysis as flexible as possible, as a deliberate intention. Readers are not exhorted to either agree or disagree with the interpretive statements they read. However, readers are asked to engage with the underlying social 'positions' uncovered by the moments of intention and interaction presented for interpretive scrutiny. Readers are asked to evaluate these moments not only in respect of already-present idealised views of sexuality/(intellectual) disability and support work, but also in relation to their own theoretical and experiential knowledge of the wider social impact of these terms on the attitudes and behaviours of individual citizens. Such an evaluation I believe may help to produce different knowledges about the operation of sexuality support work, and thus may open up further possibilities for the development of the socially transformative practice sought by research initiatives already undertaken.

However, as Salazar suggests, participants in research studies can be put at "grave risk of manipulation" (Salazar, 1991, p. 313) through the use of unreflective data transcription process. Being clear about how the information is to be viewed is necessary because by its very act, data gathering represents an intervention in already present systems of power/knowledge effects that researchers are in a far better

position to leave than are the research subjects. The inherent inequalities contained in these effects, with their potential for “treacherousness” (Salazar, 1991, p. 313) are difficult to avoid, while the effects of this kind of judgement call on those who give information can be powerful (Lamb, 1996). How these difficulties are taken into account and worked through in a post-modern context are outlined below.

### ***Representations and Ethical Problems***

For Burman & Parker, adopting a post-modern approach to data analysis means working within a conceptual structure that enables examples of material practices collected at interview to go through a “formal process of accounting” (1993, p. 175). This process transforms the data into representative textual accounts. However, a number of issues are raised through this re-positioning of interview material. These issues include a key consideration, how to show respect for the inner experiences of the people interviewed while assessing the discourses that form the talk on which their lived experiences are based. Issues also cover the challenge this process makes to the idea of the validity of the data as authentic material. In this case, the challenge this process makes to the status of the data as representative of ‘the truth’ about what is going on in the support role. If accounts collected for academic research purposes cannot be definitively regarded as ‘the truth’ about the subject under discussion then what are they, and what value do they hold?

Both difficulties contain implications for any ‘researcher’ position within an academic institution. Salazar’s (1991) description of the difficulties researchers encounter when confronted with the collection and transcription of research data accounts provides a useful way forward in consideration of these points.

### ***Transforming Accounts into Texts***

For Salazar (1991), any position where a spoken account becomes a written text represents an inevitable and significant inroad into the ‘true account’ status of any material. This incursion compromises any researcher’s ability to present as ‘the truth’ any information taken from spoken dialogue, thus to present this information as completely authentic to the speaker. This process of destabilisation begins with the

loss of openness and authenticity, which happens when texts are produced as transcripts of verbal remarks. This loss includes the lack of emotional animation, voice tone and pitch, (bodily) performance elements and the silences, not easily contained in written accounts.

During this time of transformation, interventionist strategies designed to modify and shape the information are also used. These strategies are highly influential. They include the chronological patterning placed on the material itself as it is subject to editing, processing, re-processing and finally “being given a title” (Salazar, 1991, p. 98). Given these changes, interview data can no longer be considered completely ‘accurate’ or ‘true’, or as completely representative of any one individual. Any written text made through transcription can no longer be said to be definitive or tied to any specific location.

The advantage of decoupling the information from the participants concerned for this thesis is that new possibilities for exploring more diverse ways of creating alternative support possibilities can be developed. That the data gathered for this project will be pre-read before publication by a number of people provides a significant safeguard against potential negative outcomes in respect of how the information gathered is subsequently used. The analysis chapters will be scrutinised for their degree of fitness and conformation to the academic qualification sought. Academic supervisors and final assessors are important moderating influences on interpretive analyses at these times, as their assessments pay attention to how respectfully the data is handled in respect of the methodology and method used. As text material has also been handed back to interviewees for scrutiny and re-editing, workers themselves too have had an influence on the analysis process.

### ***The Methodology***

To provide a pathway through the texts, I distinguish between post-modern methodological approaches that use a critical discourse analysis starting point and approaches that use the idea of uncovering a series of discursive positions within texts

approach. Both approaches share many common elements. Critical discourse analysis methods draw on post-structuralist representations drawn from socio-political contexts (for example, Fairclough, 1989) and from ideas that underpin critical linguistic theory (for example, Van Dijk, 1985). Analyses from this position chiefly focus on issues of social relations, identity and knowledge/power as constructed by written (for example, policy documents) and/or spoken texts (for example, transcribed interview data). While these methodologies can draw on insights gained from the analytical process itself, they remain principally focused on possible messages imbedded in the texts and matters arising from that point. For example, Mcnaughton's (1993, pp. 52-72) analysis isolates one pre-determined discursive, macro-level position, that of the "Category of Nature". Four different category constructions of "the concept of nature" are then followed. These are isolated through a discursive examination of a large amount of text data using different spoken and written accounts taken from a series of public enquiry sessions held with a variety of community agency groups.

A "discovering of discursive positions' framework identifies more strongly with the more interpretive aspect of post-modernist thought, drawn from prior psychological/analytical/feminist traditions. This positional framework upholds the idea that "reality, behaviour and subjectivity are always in texts" (Burman & Parker, 1993, p. 6). Deconstructing how binary oppositions work within certain texts reveals the "embeddedness of different social values" (Court, 2001, p. 87) these texts contain. In addition, within this framework one side of the binary will be privileged over the other, while the less powerful term is defined in relation to the more favoured one. Insights are drawn from the interplay of these binary processes themselves. Interpretive 'readings' based on assumptive effects uncover key aspects of the socially constructed nature of how objects/subjects are 'created' through the texts concerned. This more inferential view can be used with a large amount of textual information (analysis on a macro level) or a small amount (analysis on a micro level). This view enables deeper insights about the form and content of the material to become part of the analytical process.



However, as Weatherall et al. (2001) note, it is often difficult to put qualitative data, including discursive qualitative data, into concise form. Thus a small data set is more likely to be used. Horton-Salway (2001, pp. 147-188), for example, uses data from three different excerpts of talk-as-text taken from one interview discussion between three people about the M.E. debate. These excerpts are then subject to a micro-level analysis. This inferential exploration of the issue uncovers how a number of competing discursive power/knowledge effects can be shown to represent the current debate about the causes and effects of this illness. What these effects contain and what information is left out of these discussions a result of this process are then isolated and explored.

The approach I adopt for my analysis is influenced by both Mcnaughton's (1993) and Horton-Salway's (2001) approaches to textual interpretation. I start by isolating one meta-discursive position contained in the interview texts as a whole. This position derives from the overall 'reading' made of the information gathered. While Mcnaughton (1993) pre-determines the initial category used, this meta-discursive position emerges from the texts themselves. However, this meta-discourse also represents a significant category position already identified in the research review findings. This pre-identification provides a further point of validity for its use. While Mcnaughton (1993) goes on to isolate further category positions within his meta-category, I uncover and substantiate a variety of contrasting binary systems that uphold and cut across the power the meta-assumptive contains. These binary formations are found primarily in the texts obtained from dyad interview data as these texts include the "shared knowledge aspect of focus group responses" (Robinson, 1999, p. 2) that enable a more finely grained series of interpretive responses to be made.

I also draw on aspects of Horton-Salway's (2001) macro-analytic approach to obtain further insight into the key allied discursive natures and forms of talk this material also contains. However, this aspect of the approach differs from Horton-Salway's, in that I include further material from other worker's talk and I further reference these insights to the material gathered from the literature review. This aspect of the analysis allows for a more complete and grounded verification of the of broader

power/knowledge effects I uncover in the text statements I work with than the verification process utilised in Horton–Salway’s work.

### ***Discursive Methodologies and Power/Knowledge Effects***

There does not seem to be any one methodology in the literature that provides a definitive guide to how to gather and unpack discourses from texts. Much is said to rely on the intuition of the writer (Burman & Parker, 1993, Denzin & Lincoln, 1997). However, a discursive analysis can be said to begin at the point where the researcher “begins to feel as though you’ve heard it all before” (Edley, 2001, p. 198) in a key area of the material gathered. This sensation signals that a significant substance, or meta-discourse, or wider assumptive understanding held within the material, has been reached. Further significant understandings in relation to this position then emerge through scrutiny of how the interplay of related power/knowledge effects uphold and fracture the initial substance located. These effects create the contradictory points of discussion held within the texts under examination. How those who are talked about are ‘positioned’ through the texts calls attention to the subjectivities that form the material link between the texts, the effects of the meta-discourse and outcomes of these related power/knowledge effects. Subject positions are located at the point where a particular social self becomes located “within particular discourses or dilemmas” (Edley, 2001, p. 210). Subject positions offered and taken up are revealed by inferring what a text statement or set of statements might reveal about who is saying them.

### ***Analytical Guidelines***

While approaches to a discursive analysis remain flexible, I outline three specific points of reference I use as verifying guidelines for this project.

- 1) A discourse analysis will reveal an interest in the “variety of ways language produces and constrains social meaning” (Parker & Burman, 1993, p. 3). It will show sensitivity to language use within the text exemplified through tracing the researcher’s involvement in the development of intuitive ways of looking at the text material (Widdicombe, 1993). These sensitivities will

be further demonstrated by the researcher making overt the deductive pathway used arrive at the particular interpretation of the content of the text.

- 2) A discourse analysis will show that the reflexive and interpretive style chosen does more than let the data “speak for itself” (Parker & Burman, 1993, p. 12) in a phenomenological sense. That the language of the text goes further than only standing for what it represents needs to be shown in the analytical frame. The researcher drawing the reader’s attention to how discursive effects enabling the interpretations made are constituted within wider social frameworks achieves this ‘going further’ position. Further, these effects will resonate as culturally intelligible to those who engaged with them (Butler, 1993).
- 3) A discursive analysis will elucidate specific points of view that are left out of the text. Explicating the presence of unspoken effects is achieved by showing an understanding that what is revealed also presents an “unstated (binary) absence” (Burr, 1995, p. 196). Attempts to answer the question what is left unsaid here will confirm that notice has been taken of these absent presences. Consideration of these textual gaps can also be shown to have taken place when the researcher makes explicit what this lack might mean for those about whom the statements are made.

Two further interpretive positions have also been influential in developing the analytical framework. The first concerns the idea that talking performs a variety of discursive functions other than the simple transmission of information. The second involves the idea that there will always be a variation in accounts given and that consideration of this variation may be “more important than the ‘consistency’ of their talk” (Parker & Burman, 1993, p. 6).

### ***Tensions within a Discursive Methodology***

Researchers who use a deconstructive methodology as a tool have uncovered problems in the interpretive analysis of discourses and their power/knowledge effect

positions. Burman & Parker (1993) suggest that tensions contained at the micro-level, including the relationship between the discursive intent and the substance of the interpretation, comprise a major dilemma for researchers who follow these methods. The following questions concern these tensions and their resolution.

- i)* Could it be said that the reading was more ‘ideological-critical’ than discursive?
- ii)* Does the reading just pose “a particular set of statements” (Parker & Burman, 1993, p. 11) made by the text in relation to one central point?
- iii)* Do key elements of the reading try to go beyond a ‘particular set of statements’ point?

In addition, at the macro-level, tensions will be felt between “the text and the context” (Parker & Burman, 1993, p. 11) of the subject under review. These dilemmas are signalled by the question: how far from the text can a researcher go in order to arrive at an interpretation of what might be happening? Tensions emerging at this level indicate that the analysis might infer a great deal more than what can comfortably be intuited from the information to hand. Being able to assess reliability and validity in discursive-related research findings also creates its own contradictions, as these two factors depend at least in part on external perceptions of the quality of the interpretation.

Difficulties can also arise when working with the idea that even the most ably constructed interpretation can also be the subject of its own deconstructive reading and counter-interpretation. Questions such as: which interpretation might supply the best solution to the problem under consideration and how can accurate assessments of what assumptions are at work be determined if discourses only emerge within the interplay of ‘readings’ of the texts themselves, become hard to answer. These queries also suggest that any interpretation of the work of discourses-within-texts cannot constitute the only possible set of readings available. Thus any definitive analysis of the information gathered is not possible.

### ***Overcoming the Tensions***

There seems to be no clear way of surmounting the difficulties Parker & Burman (1993) outline. However, Denzin & Lincoln's (2000) edited compilation of researcher's points of view and Salazar's (1991) work suggests these tensions can equally be found in modernist research endeavours. They note that all academic research studies are interpretive, in so far as all are guided by background sets of beliefs and feelings about the ontological and epistemological world. Some of these beliefs are taken for granted and remain largely invisible. Others will be highly problematic, visible and controversial. However, each belief will make an impact on the research process, impinging on the questions asked as well as structuring aspects of the interpretations researchers bring to them. Thus any piece of research is already moulded by assumptions about how the world should be understood and studied. Further these ideas provide acknowledgement that all research processes provide important insights and knowledge into the subject under review. In reality no specific method can be privileged over another.

Yet while these issues raise problems that cannot easily be solved, a discursive analysis can allow room for the development of further insights into the issues. In turn, developing insights can generate more considered and reflective future debates about support performance. Thus, this analysis is less concerned with "making a point" (Mills, 1991, p. 5) about support work than it is about exploring the possibilities of interpreting worker's actions from within the discursive complexity inherent in the role.

### ***Further Reflection***

As the data gathering process proceeded it became clear that issues of discomfort and tension needed to have been more fully addressed. Very little has been written about the impact of disability and sexuality-related research on those who choose to explore this topic. That I could only find one completed New Zealand based academic study attests to the degree of social and emotional difficulty that continues to surround this topic at academic level in this country. This chapter suggests that the difficulties

sexuality-related research can raise for researchers needs more thoughtful consideration at ethical approval stage. Specifically, more consideration need to be given to how researchers themselves and those who supervise them can be supported during the information gathering and analysis process.

Further consideration may also need to be given to the ongoing influence of service and support structures on the process and outcome of intellectual disability research. In some respects I believe it would have been more productive for all concerned if I had, like Turner (1984), come into the organisation involved as a complete outsider, knowing little about the day-to-day practicalities involved in the support process and nothing personally about the individuals involved. Yet I have also speculated at length whether or not I would have been given permission to undertake the interviews if I had not been 'known'. I have also wondered whether, if I had been in Turner's shoes, workers themselves would have been willing to be interviewed. Workers too can be sceptical of those they consider to be 'outsiders'. Yet, those who agreed to take part definitely chose to do so, Further, they trusted me enough to put themselves forward in the knowledge that their support practice was about to be scrutinised. Thus the prior-agency position I outlined as a barrier could also have been the opting-in deciding factor for both workers and those involved in the wider agency service.

The next three chapters begin the analysis process. This process includes a series of 'interpretive decompositions' (Pilgrim & Rogers, 1997) of textual excerpts abstracted from the data gathered. In this context, an interpretive decomposition comprises close readings of specific lines of narrative held in these texts (Horton-Salway, 2001). Decompositions of these lines of narrative separate aspects of the text into a variety of binary slippages that deploy through the meta-incapacity discourse to produce possibilities for material support practice.

In keeping with an interpretive position I note three further significant aspects of self that influence the form and content of the analysis to follow. In particular, a feminist perspective gives me a degree of self-consciousness of the ways in which modernist derived epistemological and structural inequalities of power define, uphold and exclude women in the sexuality and intimacy area. However, this position remains

partial in this thesis meaning that I do not take up an overtly feminist position, as I also want to understand how all dynamics of power inequalities operate at a local level. Yet a feminist position also enables me to recognise that structural inequalities in the sexuality area have been mirrored in my relationships with individual men as well as women and I draw on the outcome of these real-time experiences within this reflexive position. As a white woman I acknowledge that my experiences of inequality and power in the sexuality area are qualitatively different from the experiences of women of colour. In relation to the disability aspect of disability support, as a sibling of two family members with adult onset physical/psychological impairment conditions, I also bring a clearly delineated emotional connection with key disability issues that connect individuals to wider structures of power inequality.

### ***Footnotes***

- 1) *Feedback I received on the penultimate draft of this chapter from a supervisor included the comment that this something more may only include that idea that “most people just want to get on with their lives”. Perhaps I am making more of this silence at this point than was intended. Yet, sexuality support was such a big issue within the organization, this presence of absence needed more reflective consideration.*
- 2) *See Lather (1991) for a very useful distinction between post-modern and post-structural approaches. I also take Burman & Parker’s point, in respect of the “positivist echoes of its history in structuralism” (1993, p. 6) that can influence post-modernist approaches to textual analysis. Because of the collusion with modernism position taken the effects of both can be seen in this analysis.*

## Chapter 7

### *Discourses, Ideal Figures and Sexuality Support*

#### *Introduction*

Close readings of the data produced a particular ‘I’ve heard it all before’ (Edley, 2001) point through which intersections of social meaning located in worker’s talk form a coherent ‘they’re not sexual because they’re disabled’ meta-discourse. Given the numerous references that verify this assumption as the culturally dominant understanding about disability and sexuality in euro-western society, locating this key assumption and its lines of influence was no surprise. As Timm (2002) suggests, sexuality in our society is seen as so antithetical to disability that there is no need to discuss any possibilities in this area for people in this category group. This assumption also draws from the series of physical, social and cultural effects that already link these two terms. These linkages contain the three wider community beliefs about (intellectual) disability and sexuality found in the literature review:

- i) that intellectually disabled people have no sexual drive
- ii) that intellectually disabled people cannot function sexually
- iii) that intellectually disabled people lack the necessary cognitive capacity to be responsible for their sexual behaviour.

In particular the third assumption upholds the ‘they’ don’t’ aspect of the meta-discourse through the term ‘intellectual’ in ‘intellectually disabled’ reinforcing the idea that those who fall into this category continue to maintain an “inferior, abnormal, unequal and subordinate” (Richardson, 2005, p. 517) position relative to their non-disabled counterparts.

However, while this meta-assumption is held as a universal truth about people in this group, it is crossed by acknowledged occurrences of sexualised behaviour evidenced in worker’s talk. This disruption signals the active influence of a destabilising ‘they’re



sexual because they're able' series of oppositional effects. These effects, although less overtly commented on, have also been isolated in literature review findings (e.g. Keywood, 2001). Both sets of effects substantiate certain actions as indicative of what is considered normative/ideal sexual behaviour in wider society. In turn these representations regulate the kind of sexualised behaviours sanctioned as acceptable within agency service group homes.

This chapter examines how workers become caught up in the maintenance and regulation of allied already held social locations of meaning that substantiate how the relationship between the terms 'sexuality' and '(intellectual) disability' operate in the group homes they work in. These effects interlock within an ideal/norm-referenced meta-belief about sexuality that shape worker's practices into behavioural responses consistent with already held views about sexual relationships and how they are to be enacted.

### ***What the Chapter Contains***

This chapter is divided into three sections. Each section follows a key excerpt of worker talk that probes aspects of a 'they are/they aren't' binary placement upholding the meta-assumptive position. The first section explores how notions of competency shape the operation of this binary through following a talking-about-sex-difficulty position found within the texts as a whole. That worker's find talking about sex difficult destabilises a central assumption that underpins literature review suggestions as to how support is enacted in this area. Workers are ordinarily considered the competent ones within the intellectually disabled person/support worker dyad in relation to all matters sexual. This assumption is undercut by uncovering a usually unacknowledged, 'disabled/ignorant/incompetent' aspect that also infuses the worker position. The second section isolates key ideal, norm-related image through which the 'sexual' aspect of the 'they're not sexual' side of the binary is upheld and reinforced. The third section captures worker's talk related to specific competencies the intellectually disabled people they support need to exhibit to be judged as able/capable in the sexuality area.

### *How the Chapter is Constructed*

As I was dealing with the disquieting queries about the information gathering process I outline in Chapter 6, plus a changed understanding of how I was going to work with the data, the suggestion made by one of the ethics committee members, that interviewees should be able to have a support person along if they needed, proved extremely useful. Data collected from these interviews were substantively different from responses made by single respondents. Conversation flowed far more freely in the dyad interview setting. Workers talked to each other, revealing more by way of experiences and views as they shared information. This “shared knowledge aspect of focus group responses” (Robinson, 1999, p. 2) became the central point from which the key discursive considerations that form this chapter are uncovered and interpretively deconstructed.

I use the device of expository text subjects to present worker’s talk as text rather than as an example of the neutral transmitter of information about the subject under discussion. The shared knowledge aspect responses inhering in ‘Jo and Jan’s talk’ become the interpretive lense through which ideas about texts as definitive or true accounts of individual experiences is decentered and probed, and through which discursive effects that locate and uphold the experiences from which these talk statements derive are unpacked and commented on.

However, I also construct ‘Jo and Jan’ as an expository device to remain mindful of the inner experiences of all interviewees who volunteered for this project. Using ‘Jo and Jan’ as representational reminds me that the statements I use do not come so much from the voices of deficient workers as these lines of shared discussion indicate the depth and breadth of the damaging discursive effects that ultimately shape worker’s behaviour in the sexuality support area. I use ‘Jo and Jan’s talk’ to provide an initial map onto which further convergences of textual power/knowledge effect statements are overlaid (Kuppers, 2002). However, while these positions are interpretative, I also draw on a central modernist-inspired strand of thought in respect of workers and their role. ‘Jo and Jan’ typifies literature review findings that identify the characteristics of the majority of New Zealand support workers as an “unskilled

and low-income female worker in her 40's and 50's who has family commitments, including children, at home" (Chai, 2004a). Thus, the use of this analytical device is also underpinned by the discursive effects related to this statistical 'norm' as verified by the literature review studies (Scully 2002).

### ***Part 1: "What Does That Word Mean To You? "***

Recommendations made by researchers contain numerous suggests as to how worker's competencies in the sexuality support area can and should be developed and improved. Yet aspects of this text challenges the pre-eminence of the 'they're abled' assumption that constructs the workers position in relation to those they support. A key 'not-able' worker position, one that has little to do with competence and much to do with the social locations of meaning inherent in the term 'sexuality', is unpacked through a deconstructive interpretation of 'Jo and Jan's' talk.

*Carol: thinking about the area of sexuality, for yourselves as people, at the moment, what does that word mean to you?*

*(Pause)*

*Jo: sexuality?*

*Carol: Yeah*

*Jan: Feelings I suppose. I haven't really thought about it.*

*Jo: Because in our house, no-one's terribly sexual at all.*

*(Laughs)*

*Carol: So if I was going to say to you what does the word 'sexuality' mean to you, it'd be feelings or*

*Jan: Feelings, I think*

*(Long pause)*

*Carol: it's different than sex eh?*

*Jan: yeah, yeah*

*(pause)*

*Jo: yeah well, if you say sexuality I think about, you know*

*Jan: Relationships*

*Jo: Yeah, just*

*Jan: Whether*  
*Jo: Well, a straight relationship or a gay relationship*  
*Jan: Gay relationship*  
*Jo: Or a*  
*Jan: Or something. Yeah, that's probably what I think too*  
*Carol: Yeah, cause I think too it is a real social issue*  
*Jo: No*  
*Jan: Yeah*  
*Carol: With the people you support in the house, if you said to them 'what does the word sexuality mean to you?' what would they say to you?*  
*Jan: Oh they'd just*  
*Jo: They wouldn't have a clue*  
*Jan: Helen (service user) would just look at you and Fiona (service user) and Britney (service user) would say 'Don't be stupid.'*  
*Jo: Yeah*  
*Jan: Of course Rachael (service user) would just take the sex bit out of it. She wouldn't understand the 'ality' piece of it.*  
*Jo: and I don't think they, half of them don't know what sex is, do they?*  
*Jan: I don't think so*  
*Jo: I mean, if they were interested, like if they asked me anything about sex, I'd tell them*  
*Jan: yeah that's right*  
*Jo: But they never do. They don't*  
*Carol: so it's, that's a word that's not there for them?*  
*Jo/Jan: No*

While the extract begins with a request to define the term in relation to their own knowledge and understanding, Jo and Jan initially experience difficulty clarifying what sexuality means. At first the word is repeated while the second response also elides the personal reflection requested, linking sexuality to “*sexual*” then to a place of employment. An initial talk difficulty is uncovered when both qualifier and elision are set against the idea that all participants knew that the interview questions would pertain to the topic of sexuality and intimacy support. That there is an difficulty, in

that they haven't "*really thought about it*" despite the circumstances that have led to the interview, point to a series of wider power/knowledge effect difficulties that might prevent workers from tackling the subject head on. These effects and their operation are tracked in further text statements.

***"it's hard to talk about it"***

In the following statement, frequent pauses and examples of phrases left unfinished reveal facets of the 'flux of cultural movement' undercurrents that shape the parameters that constrain talk possibilities. These constraints undermine the position of worker's as essentially able/competent to talk about this subject.

*Yeah, OK [pause, sigh] sexuality [pause] bit of a [pause] not much was said when I was growing up about it [pause] Dad would never discuss sex, never (C 2005, p.5)*

A background of not talking about sex/sexuality within the family of origin and where the subject was never talked about between father and daughter signals the presence of powerful antecedent discursive effects that continue to shape possibilities of free and open discussion. The following statement, characterised by frequent pauses and two uses of 'I don't know' as a preamble to the admission of not having really thought about it despite the interview context, also reveals this hesitancy.

*[pause] I don't know [pause] haven't really thought about it actually. For me, it's um I don't know, when it crops up I talk about it, but I, otherwise, you know (G 2005, p.5)*

However, "*when it crops up*" a response can be given. Here rather than sexuality being a global 'no talk' difficulty, problems only arise when having to initiate conversation. Thus when "*it*" already been mentioned, this talk indicates the presence of already-present permission to enable conversation to take place. As this participant is male perhaps this is a factor. Echoes of this convention are present in this excerpt, involving a male worker.

*Carol: but if you sat the guys down that you work with and go like what does the word 'sexuality' mean to you?*

*P: well if I asked you know well if I was to be straight excuse my language*

*Carol: No go ahead we're on the topic*

*P If I was to ask one guy I mean he'd go sure [indistinct] I mean sexual behaviour what does sex mean to you? The chap would go, oh having a root" (P&G 2005, p. 4)*

The next excerpt indicates that the talk difficulty position as a binary upholds and maintains the less favoured position of women workers in respect of who is enabled to talk. Further, these discursive effects layer through time.

*Though I have to admit as we were growing up there were lots of funny conversations about sex [laughs] especially from the boys um [pause] a lot of um [pause] I guess we knew a bit more than we let on [laughs] (C 2005, p. 6)*

While this statement suggests that these wider social orderings are less influential on younger people of either gender, it is boys who are the active participants in this scenario, leaving girls/women as the passive recipient of sexuality-related talk. However, significantly, the “*we knew a bit more than we let on*” reveals the girls/women as passive recipients position is mutable. They too have information to share, but they also work within a double-blind injunction in that such information is not to be talked about freely and openly.

Generational ‘talk difficulty’ effects are also present in this text excerpt.

*A lot of people don't like talking about sex. You know won't talk about it. I don't know whether it's sort of brushed on because the older generation wouldn't talk about it, and I don't [pause] Of course, there's a lot of staff that are [pause] Like I'm just turned 48 and there's a lot of staff that are a little bit older again than me and so they're in that sort of halfway stage of Oh do we mention it or not (J 2005, p.7)*

In this statement, the “*lot of people*” who either “*don't*” or “*won't*” talk about “*it*” statements link to the “*older generation*” descriptor. Whether this category will only contain women or if this assumption includes men as well remains open. That these talk difficulties might be mixed up in historical problems of decency and modesty

(Warner 1999) is hinted at through the “*don’t like talking about sex*” remark, while the “*won’t talk about it*” remark suggests a legacy of earlier, perhaps more stringent moral constraint. Where this generational cut off point might occur also remains open, although identified at one point being located with (genderless) “*people*” over the age of “48”. However, a “*sort of half way stage*” is also isolated. Those in this position are seen as in confusion about whether to mention the topic or not because of an even “*older generation*” who “*wouldn’t talk about it*”. In this statement younger people are seen as perhaps more capable of being able to talk more openly, as suggested by the “*there’s a lot of staff that are*” sentence that has no ending.

However, the next statement suggests that talking about difficulties only inhabits certain discursive frameworks.

*Like Maori um coming from that side, we’re people that um care are, we open our arms out to people, um yeah Maori are very supportive but from that other side of sexuality [pakeha/European] I come from a lot of history that its kept closed, yeah (J&J 2005, p.5)*

Here a view of Maori sexuality as open is contrasted with the “*other side*” euro-western perspective that sets issues of sexuality and emotion aside from the confines of a support environment. Keeping it “*closed*” i.e. not being able to talk about sexuality, can affect how much workers might be able to admit that they know, can affect their ability to communicate the knowledge they have, thus what kind of expertise they will bring to their support practice. The outcome of these wider power/knowledge effects can be seen in the repetition of the “*I don’t know*” phrase in the next text statement.

*I asked my superiors if they could enrol me in a, in a sex class because I was feeling very, very inadequate. Very! All these questions, very powerful questions [pause] She was being deadly serious. ‘How much semen does a man produce when he ejaculates?’ ‘I don’t know’ ‘Where does it go?’ And I said ‘ooh it soaks into the sheet I think’ She said ‘I’ve had a lot where can it be?’ You know, stuff like this ‘How does a man’s penis hang when he’s not having an erection?’ I said ‘I don’t know’. She said*

*'How long have you been married if you don't know that?' You know all that, but they were very important to her. Very important and I felt very inadequate after that. You know I need to have [pause] I need to be more informed [both laugh] Mind you I just said 'I don't know' and I guess that's instead of making anything up. I just said 'I don't know' (T 2005, p. 6).*

In this scenario "*feeling very, very inadequate*" suggests that workers may recognise they are caught up in the effects of talk-difficulty binaries. Workers can be competent and "*know all that*", yet they can also be unable to talk directly "*about that*" with the person they support. In this statement, this binary further layers through assessments of competence as a mutable position. "*Mind you I just said that*" indicates a purposive position where the worker concerned chooses not to display knowledge they have, yet "*instead of making anything up*" signals that a lack of knowledge in this area may also present difficulties. It seems to be difficult for at least some workers to know exactly how much they do know.

### ***Talk Difficulty in a Service Agency Setting***

While Jo and Jan experience problems reflecting on the term sexuality, a negative comparison links a key aspect of the term and the homes workers work in. The "*in our house no-one's terribly sexual [laugh]*" remark is deconstructed to unpack further power/knowledge effects this phrase contains. These deconstructive probes explore how these effects might influence assistive practices.

The "*no-one's terribly sexual*" remark is prefaced by the phrase "*in our house*". One of the conventions in service agencies is that workers describe the residential home they work in as either 'our house' or 'our home', as these brief comments reveal.

*She was a new staff to our home (J 2005, p. 17)*

*We've got one lady in our home (H 2005, p. 8)*

*I've got a cousin that's in one of our homes (J&J 2005, p. 24)*

*Our house is classed as a behavioural home (M&J 2005, p. 1)*

*Sexuality in our home has got to be, to do with safety levels (P&G 2005, p. 25)*



This linguistic convention is discouraged by the agency concerned as it connotes ownership of the home by workers rather than those who live in it (O'Brien 1994). Yet the descriptor persists and the continued use of it in worker's talk raises a number of queries. Does this "*our house, our home*" phrase reveal workers setting themselves up as owner/authority figures in the homes they work in, as O'Brien (1994) has suggested? Is this position then used to discourage material instances of 'sex(uality)' as Hingsberger & Tough (2002) note? Or does the use of this phrase allude to the presence of a greater complexity of power/knowledge effects that shape worker performance in this area in these homes/workplace environments.

At first reading the "*in our house no ones terribly sexual*" comment provides a clear, 'facts of the matter' indication of what happens in the home concerned. This power to authenticate demonstrated through this remark draws on the already established 'able' worker position. Being closest to the action, workers should know what is going on in the homes they work in. Yet, while the "*no-one*" part of the statement signals an invitation for the remark to be taken as a global statement, this response ends with a laugh. Rather than affirming this information as accurate and credible this laugh also indicates a credibility limit to this knowledgeable position, in that that this remark may not indicate the complete truth about the behaviour of the people who live in the house. Sexually related activity might actually be going on and workers know that they don't know about the substance of them, hence the laugh. The laugh may also indicate that sexual activities are going on and that workers do know about the substance of them and that they don't want to, or are unable to, talk about these activities directly. Finally, as the comment concerned is offered in the knowledge that this information may ultimately become public knowledge, this laugh may also indicate that being open about sexualised activities in an agency service home might create subsequent difficulties for the maintenance of any worker's good employee status.

Within a broader context, where service agencies receive funding to support the development of the ordinary lives of those who use the service (O'Brien & O'Brien, 1991), support for the sexual aspect of the lives of intellectually disabled people ought to be an active part of all workers job descriptions. Offering such support is also

stated as a policy directive in this service agency workplace. Talking openly about the absence of these activities is problematic for any worker when negative appraisals of their performance could be the result of an admission such as this. The “*no-ones terribly sexual*” statement may also indicate the existence of a culture within service agencies that means while overtly stating that support is to be offered, in practice proactive support in this area in the workplace is discouraged. Thus, this statement may also indicate that workers ensure that they are on record as doing the job that is expected, in that they are there to uphold the informal agenda of the agency they work in, that no sexually-related activities are going on in the residence. Finally, the laugh may also signal that this aspect of a worker’s role contains other significant problems.

### ***Talk about Sexuality and Social Locations of Meaning***

Other text examples show how worker’s actions are shaped by the complexity created by the effects of discourses of talk difficulty. This statement gives an indication of how activities that include personal care areas produce social and emotional tensions-in-talk that makes the production of objective assessments what might be going on in the support environment involved very difficult to unravel and assess.

*The staff person, this is where I get uncomfortable, the staff person took a comment that was made and um made a complaint to the manager and it um, she was accusing the dad of um inappropriate touching because this person was actually in a wheelchair and needed personal cares. Nothing ever happened because um dad felt like I did, that he would never put himself in that position to be construed as doing anything other than actually doing the personal care. Um but if the staff person had been allowed to speak about it outside the bounds of her work it could have caused a lot of problems (C 2005, p. 15).*

In this statement, it is not clear who made the original “*comment*” initiating the resulting series of talk activities but it is assumed that it originates from another worker, or from the intellectually disabled person herself. It is also assumed that the initial comment included discussion about a sexuality-related issue. The “*staff person*” talks to the manager, implicating a family member in the commission of alleged socially transgressive behaviours in relation to his daughter. How this

circumstance is talked about between “*the manager*” and “*the dad*” is not stated, but “*dad*” and this worker also talk, and this worker takes him at his word. It can be assumed that the manager does likewise, as the “*staff person*” concerned is warned about “*speaking about it outside the bounds of her work*”.

Complex wider power/knowledge effects infuse all positions outlined in this narrative, including ‘the person in the wheelchair’, ‘the staff person’ ‘the dad’ ‘the manager’ and ‘the other worker’. How these positions are created, linked and ‘read’ through talk will have both positive and negative social outcomes for all involved in these interactions. In this text example, deeply ambiguous socio-emotional positions are revealed in these talk effects, positions that have material implications for the support practices of all concerned.

### ***Summary***

Each text statement points to the presence of powerful wider power/knowledge effects that shape, uphold and contest how key discursive effects of sexuality talk infuse the support location. Prior socio-emotional positions can make speech production about “*it*” i.e. sex, difficult for workers. Powerful antecedent regulatory social orderings related to gender that have closed off “*talking about it*” opportunities in the past may continue to influence particularly, but not exclusively, women worker’s support responses. Antecedent talk difficulties can be exacerbated by the emotional tensions created when wider social meanings infuse behaviour within the agency service work place. In these cases, power/knowledge effects invested in the worker position significantly impact on how instances of sexual behaviour are interpreted and supported by the workers concerned.

However, these talk-difficulty positions are refracted through a variety of differential densities of power transfer points. Although influential, these points are not fixed across space and time. Thus, the extent to which any or all of these effects might shape current worker practice remains an unanswered question. For example, the statements related to the worker who reported not having any conversation with her father about sex/sexuality when she was growing up had no trouble talking to “*the*

*dad*” in the workplace. Yet, how much might this prior family experience have shaped the response she makes to the event she recalls?

Another set of talk-difficulty effects can be found in all excerpts used above. In all narratives, it is noted that “*it*” is used interchangeably with sex/sexuality as a specific linguistic strategy. While this convention might circumvent the social constraints use of the more emotionally loaded linguistic signifiers hold for both men and women, “*it*” is also used to either separate sex from sexuality, or to retain ambiguity about what is being referred to. This difficulty may point to a further linguistic problem, in that there is a lack of clarity about what word might adequately fit the occasion. Perhaps neither the term ‘sex’ nor ‘sexuality’ adequately fits “*it*” as Sedgwick (2005) suggests. However, this usage further obscures what material practices “*it*” might contain.

## ***Part 2: Sexuality Equals a “Couple Doing Normal”***

In the second part of this chapter, material practices represented by “*it*” and the discursive effects this representation draws on and substantiates, are unpacked through an interpretative deconstruction of the second segment of Jo and Jan’s text. A series of allied discursive effects reveals an idealised vision of sexuality from which worker’s assistance is derived. How this ideal is constructed and regulated through worker talk is examined in detail. Importing other textual extracts substantiates this deconstruction.

### ***“If you say sexuality I think about...”***

After the “*no-ones terribly sexual*” remark, the “*relationships*” prompt provides a significant descriptor of the term “*sexuality*” as located within the parameters of key allied discursive effects that prioritise a series of social as much as physical interactions. Yet the next statement re-defines the parameters of this term within specific combinations of allied power/knowledge effect positions. “*Straight*” (male and female) and “*gay*” (male and male/female and female) re-sites “*relationships*” within a series of discursive assumptions whose effects regulate what two physical

bodies can do together. “*Straight*” indicates the hetero-normative codes of conduct (Warner 1999) these allied effects create and draw on, while the placement of the term first within the straight/gay binary signals that this assumption as the favoured, “hegemonic one in the culture” (Vance, 1989, p. 14). Wider discursive effects that quantify and uphold the hetero-normative assumption that guides these remarks are further amplified through other talk statements.

### ***Unpacking Hetero-Normative***

The statement below describes the content of a video a young intellectually disabled woman was shown at a local day service.

*They were trying to sort out the difference between the things, of closeness, of parents, of friends and partners. So I do think they need to have more of those but not porn, natural lovemaking and that stuff. More natural like say in a relationship situation yeah, maybe a couple doing normal. They have tea and they have dinner and some wine and, like they have a bath and candles around or whatever, you know. A video that is more natural. It's got to be a really natural thing and I think it should only be for people that are actually in a relationship. And in an obvious relationship, in the appropriate places, like in your own room with the door closed. That's ok (S 2005, p. 11).*

Here, the “*stuff*” that indicates “*a couple doing normal*” evokes a central social truth that ensure that “*natural*” in this setting comprises a series of key antecedent choices of behaviour (Carahine, 2001). These choices sanction certain behaviours as ‘ideal/acceptable’ for members of euro-western society (Lapinsky & Rimal, 2005). These acts are initially verified in relation to a global set of bad sex “*porn*” effects not elaborated on in this statement, but echo Warner’s (1999) ‘good sex/bad sex’ inventory. However, ‘good choice’ effects of the preferred “*natural*” series of social actions are stated. These include key aspects of hetero-normative behaviour defined as “*a couple*”. These effects include monogamy as in “*actually in a relationship*”; in pairs, as in “*partners*”; privacy, as in “*in your own room with the door closed*”; penetration, as in “*a natural thing*”; and blood-kin appropriateness, as in “*the difference between the things, of closeness, of parents, of friends and partners*” (Bell,

2005). All elements come together to create “*a relationship situation*” that echoes the euro-western model of practice that “*naturally*” differentiates “*good sex from bad*” (Warner, 1999, p. 25).

Significantly, this set of descriptions does not directly indicate the gender of “*the couple*” referred to. This omission may indicate the custom in agency service settings, of talking about intellectually disabled people without reference to their gender (Burns, 2000). However, it may also indicate that the choice of hetero-sex is so normative and the resultant image so strong that the gender of the couple does need to be mentioned. The following text excerpts endorse the latter assumption.

### ***Unpacking “The Ideal Couple”***

In this statement the lack of difficulty a particular worker would have broaching the subject of sexuality with those they support is indicated.

*If they, say for instance you came up to me and said ‘Look I need you to talk to Joe Blogs about his relationship he’s having with Mary James’. You know, ‘What sort of things do you want me to talk about?’ whatever. I wouldn’t have a problem with that (V 2005, p. 14)*

At one level this statement appears to contradict the earlier line of discussion, that women workers can find talking about sexuality difficult. However, uncovering the hetero-normative placement on which the “*couple*” are founded indicates how far this discussion might be able to contain behaviours that lie beyond any aspect of the ideal. In the next statement, heterosexuality-as-preferred is also suggested, through the “*young lady*” and “*young man*” descriptors.

*We have a young lady in \_\_\_\_\_. We have a young man here. They’ve been together for years. She’ll often come for weekends and stay at the house that he’s in, but they don’t sleep in the same room [pause] so I often wonder if, you know, they have cuddles and kisses and things like that but as far as sex goes I’m very unsure (C 2005, p. 9)*

Wider social locations of meaning relating to sex/sexuality that enable conformation of this scenario to the ideal include the two people being of similar age and in an already established partnership, both key proscribed normative binary code behavioural markers. Why the worker might be “*unsure*” whether the people concerned might be having a sexual relationship relies in part on a lack of conformation to a key aspect of this idea, seen in the “*don’t sleep in the same room*” norm-slippage. Doubt is created in the absence of this significant marker.

In the next example, the (hetero)couple normative is centred through a robust image of domesticity that secures these behaviours as generally favoured, despite some misgivings.

*David goes and stays the night at their place and Ann goes and makes up this big double bed for him and she [Ann’s mother] said “When it’s all made up, Ann sneaks off to her bedroom and goes and grabs her nightie and tries to hide it under his pillow”. And Mum says ‘I don’t actually encourage it but what they do when I’m asleep I have no idea’ (C 2005, p. 9).*

In the next statement, the socially favoured effects of “*the couple*” are substantiated through the production of a strongly emotive domestic/private image conveyed through the “*dinner*” descriptor. In turn this descriptor links to wider social assumptions that uphold the notion of sexuality-as-sexually-active within a scenario that includes a man and woman “*going into her bedroom*” at the end of the evening.

*He’d go in and have dinner at her home and they’d go into her room and they were having a sexual relationship. We had to give them privacy you know, it’s their place as well. It was his first relationship and he loved it (J 2005, p. 17)*

This statement also prioritises the in-private normative code marker (Warner 1999) substantiated by the workers concerned. These text statements reveals that the ideal “*relationship*” will include a clean, wine and dine male and female, engaging in a series of culturally intelligible behavioural activities in a double bed, behind closed

doors, illuminated by the natural lighting necessary to smooth out the transgressive impact of any bodily defects.

However, in Jo and Jan's text this ideal is interrupted by an overt placement of a disruptive straight/gay binary. While "gay" relationships can now be considered more usual in some social areas, it is still unusual for this position to be so openly stated (Richardson 2000). The descriptor "*gay relationships*" disrupts the idea of the straight/heterosexual/man-woman image as the dominant unmarked, socially favoured position.

### ***Exploring the Slippage***

It is not clear whether the use of the term "gay" also encompasses the experiences of women's bodies, as the word 'lesbian' is not directly used, although perhaps implied in the unfinished "*or a*" phrase. In New Zealand, it is a convention that "gay" relationships, when stated, are usually taken as including both men/men and women/women relationships. Yet lesbian is available for use. That this term is not used testifies to activation of the linguistic "occlusion that covers over difference" (Shildrick, 2004, p. 1) that masks the variety of sexual behaviours that can take place in the wider socio-cultural context. In addition the terms 'transgender' or 'bisexual' do not appear, yet perhaps the idea remains, also implied in how the "*or a*" phrase might have been finished. However, these occlusions elide the idea that sexually-related behaviours might be fluid rather than fixed.

### ***Summary***

Discursive effects isolated in worker's talk reveals that the term 'sexuality' equates to a socially favoured 'ideal' practice enacted by pairs of specifically gendered individuals. However, to what degree these sets of social meanings influence worker's support response has yet to be quantified. Although the (hetero) "*couple*" can be said to represent the ideal material practice, this term can also include "gay" relationships, suggesting that aspects of this ideal position are not necessarily fixed within worker's understanding.



### ***Part 3: Unpacking “They Wouldn’t Have a Clue”***

Part Three of this chapter discursively probes the last part of Jo and Jan’s talk statement. It further follows the ‘no-talk’ effects that uphold and contest the capacity aspect of the ‘they’re not sexual because they’re disabled’ binary. Destabilisation of this aspect of the binary reveals an underlying fluidity of position. How this fluidity of position affects the assistance workers offer in sexuality area is then unpacked and commented on.

#### ***The Knowing/Clueless Binary***

After defining sexuality as “*relationships*” comments are made about what intellectually disabled people think the term sexuality might mean. These responses initially fix people in this group in the ‘other has/is the problem’ non-favoured/lack binary position through drawing on already-established bio-medical systems of categorisation that uphold and maintain the idea of intellectually disabled as incompetent. However, an underlying fluidity that contests this binary categorisation as fixed through time is revealed through the action of asking a usually defined as not-knowing intellectually disabled person to engage in a theoretical discussion. The response “*they wouldn’t have a clue*” attempts to re-instate the binary destabilisation this consideration has opened up, by reinstating the parameters of the not-knowing position. However, subsequent remarks create further tensions for this (re)placement move, revealing the notion of who is competent and who is not as a shifting field through which workers and those they support seek to clarify their relationship to each other in respect of “*what sex is*”.

#### ***Exploring the Clueless Response***

If intellectually disabled people do usually conceal the extent of their knowledge in this area (Gobel 1999; Sinason 1992), then “*don’t be stupid*” may well be what would be said if intellectually disabled people were asked ‘*about what sex was*’. What is intriguing is how this remark is initially signalled and then modified in this text statement. This interchange suggests that at least some of the intellectually disabled people worker’s support have a level of understanding of the term. It also suggests

that workers recognise that “*clueless*” in respect of the intellectually-disabled-people-as-incompetent binary placement is not fixed and that they often distance themselves from this realisation, as the following statement suggests.

*And I think a lot of people think, with our clients being disabled, you know they're um I think they think they're mentally disabled at times. 'Oh they don't know' and you know 'They won't remember' and, but sometimes they're brighter than half the staff. I think that's a lot of the problem [laughs]. Yeah, they can outsmart the staff and yeah they do. They've got memories, good minds and just because they're disabled it doesn't mean, you know, they haven't got all their facts and figures together (J 2005, p. 18).*

Commentators have pointed out how adjectives such as “*stupid*” and “*dumb*” can act powerfully to stigmatise an individual as a social outcast “because of a perceived lack” (Bird, 1994, p. 108). That intellectually disabled people can be shown to be “*brighter than half the staff*” could be construed as a gross social insult. In these phrases not only do such potentially humiliating social effects come into play but also what is also exposed is the liminal position competence holds in the support position and the discomfort this fluidity causes for some workers.

### ***One of the Three Secrets***

What is also intriguing about “*don't be stupid*” is what the people who live in the house might be referring to. Does this statement uncover an in-house convention? Is there an unstated rule within service agency homes to the effect that anyone talking about sexuality, including workers, risks positioning themselves as “*stupid*”, therefore no-one is willing to bring up the topic? Do these remarks indicate that workers and those they support are not making autonomous choices about how they behave, but are behaving within the limitations set by the social effects of these not-stated assumptions? If this is the case, to what degree do these structures circumscribe the provision of pro-active support?

***“You’ve got a cheek” - a wider view***

The following remark confirms the operation of an underlying social convention.

*As soon as you mention the word [sexuality] they’ll say ‘oh don’t be stupid you (J&J 2005, p. 8)*

When asked what “*don’t be stupid*” might mean the following response was offered.

*To even ask the parents when you do your information documentation, ‘does your son or [pause] understand about sexuality?’ And they go ‘you’ve got a cheek to ask me that’ (J&J 2005, p. 8).*

Even a general inquiry “*about sexuality*”, vague as the term may be, within the more depersonalised “*asking for information documentation*” context, does not alter the emotional difficulty involved in talking about sexuality in this instance. How broaching the topic is segued signals how this discomfort is concealed/revealed in this setting. These remarks further suggest that power/knowledge effects located in the terms ‘sexuality’ and ‘disability’ also infuse the relationship between intellectually disabled people and their family members. In this response too, the pause indicated after “*son or*” may allude to the omission of the word “*daughter*”. This gap may indicate even more complicated sets of emotions are involved when using the terms in relation to girls and women.

***Re-working the Knowing Worker***

As a result of the “*half of them don’t know what sex is, do they?*” statement, the worker’s position as capable/known is revealed as fluid and mutable. Despite this mutability the “*if they were interested, like if they asked me anything about sex, I’d tell them*” declaration fixes the solution to any (incapacity) problem between the workers and those they support as again residing in the already established intellectually disabled side of the binary. Through this re-instatement worker competence is once again established.

The ‘we have the resources/information/time/money available if people ask for them’ justification is familiar to many disabled people who use agency service systems. That disabled people do not ask provides the necessary justification for the lack of action. This interchange has been said to reflect the limit position adopted by service agency personnel in respect of disability support provision (Oliver, 1990). However, this interpretation can mask wider allied power/knowledge effect constraints that shape the limits to capacity that constrain both side of this binary. Capacity is not unlimited, but is seen as productive of the same wider social forces that have initially created this binary tension and the power/knowledge effects it produces.

However, to turn “*they don’t ask*” back onto those who are supported is to mask any in-competent effects the support position itself contains, including power/knowledge effects that fracture worker’s capacity to talk about sex/sexuality freely and openly. In this case it also means that the idea, that if it is difficult for workers to initiate sexually related conversations it is probably equally as difficult for intellectually disabled people to do likewise, remains hidden. In this scenario, the “*they don’t ask*” thus we don’t need to say becomes a binary system in which both parties remain trapped.

### ***Summary***

Textual responses that make up Jo and Jan’s statements draw on already-established incapacity discursive effects that uphold and maintain an intellectually disabled as (sexually) incompetent binary position. Reconsidering the notion of incapacity/capacity as a fixed binary reveals ‘they’re not sexual because they’re disabled’ can be expressed as a series of constantly remade negotiations enacted between intellectually disabled people and those who work with them.

### ***Probing ‘Ideal’ and the Able Side of the Binary***

Mutability of position opens up possibilities for attributions of capacity to operate on the usually non-favoured side of this binary, as shown in the following statements.

*It really means that they may be disabled you know just in certain aspects but don't clump them all together because they're all individuals and a lot of them actually are very clever people (T 2005, p. 2).*

What the “*certain aspects*” attributes are that intellectually disabled people need to have to be distinguished from the “*clump*” in the sexuality support area are further unpacked in the following statements. These reveal the presence of discursive effects through which an ideal image of those who are deemed to be as sexually capable and those who are not are shaped and contested. These statements suggest the parameters of the physical and social capacities that create and affirm this judgement call.

### ***Being Able Equals Showing Physical Capacity***

In this text statement, the idea that ‘being disabled’ is held in binary tension is openly stated.

*You've got to divide it because there's a lot that don't know what the word means. My ladies at A {a service agency residential home} wouldn't know. I've got quite a lot of guys that do know what it means, who are switched on (J 2005, p. 5).*

Here knowing “*what the word means*” creates the “*dividing it*” slippage that enables certain intellectually disabled people to inhabit a liminal position in respect of these two categories. In this statement, wider power/knowledge effects inhere in the “*switched on*” metaphor, a linguistic phrase that refers to the wider consensual meaning that upholds capacity as containing “specific kinds of recognitions” (Bird, 1994, p. 97) that link both sides of the ‘they’re incapable’ meta-discursive assumption.

As an example, “*switched on*” is counter-pointed to an example of ‘switched off’, as “*my ladies at A*”. A prior description of the “*ladies*” reveals a group of women “*who live at A, which was a high-needs home with multiply disabled clients who need complete care*” (J 2005, p. 1). In the convention of agency service talk “*multiply disabled*” refers to high levels of physical impairment while “*high needs*” refers to high levels of cognitive impairment. Taking this statement as binary, those who

represent ‘the able’ against whom those in the “*high needs home*” category become an (unstated) group of ‘physically able men who need minimal (cognitive) support’.

### ***Being Able Equals Showing Social Competence***

This statement draws on similar assumptions in shaping the division between those who qualify for consideration of sexual capability from those who do not.

*Some of our guys because they’re a little more [pause] we’ve got others who know a little bit more have [pause] been involved in a sexual relationship (C 2005, p. 6).*

In this statement “*able*”, while not further defined hints at the physical attributes that allow the intellectually disabled person concerned to conform to the “*couple doing normal*” image uncovered in the previous section. These attributes include for example, the ability to eat food unassisted, the ability to engage in bathing activities unassisted and the ability to walk to the bedroom unassisted. However, this statement also shows that possessing social knowledge in knowing “*a little more*” plus having had certain experiences, through having “*been involved in*” certain behavioural activities, are also central points of recognition that affirm an ‘abled’ attribution. This affirmation also draw on the power/knowledge effects of the “*couple doing normal*” in that these effects afford some assurance that what is to happen after the “*couple*” close the bedroom door will correspond with the normative expectations of sexual activity this image holds.

In this example, the use of the term ‘*guys*’ leaves the gender of the people described as open to speculation. “*Guys*” can be used as a global descriptor denoting a group of people in common usage in New Zealand English or as a term in binary connection with ‘*gals*’ that, although a less common descriptor, is also available for use. As a stand-alone concept this term presumes the inclusion of women. As a binary, it excludes women from being a part of any sexually competent placement. In this statement too the difficulty worker’s experience making the distinction between the two groups can be seen in the pauses separating each remark. These linguistic expressions of face indicate that commenting on how this binary works in this setting is problematic (Kendal, 2004). In particular, such remarks can be seen to constitute a

individual judgement about ability which, although accepted as necessary to a euro-western world view, can be fraught with other social difficulties (Bird, 1994).

### ***Physically Capable but Socially Incapable***

While physical attributes are powerful indicators of being viewed as able within the ‘they’re not because they’re disabled’ meta-context, a perceived lack of certain social attributes can challenge and subsume the power effects these usually favoured attributes deploy.

*Like, like um, because you know, he knows. Whereas the other client that I was talking about was autistic and um wasn’t, didn’t have his head quite around things as to what was what. Like, you know, you could tell him but I don’t think he would, it would sink in you know. And um he would go and tell people, where this other one is more alert and in the know. More normal and so he, he understands. You know, in a big way (J 2005, p. 10).*

Not knowing ‘*what was what*’ and not being able to display knowledge/competence of ‘normal’ social ways of talking about sex defines the parameters in which this incompetency judgement is placed. Being able to show that you have ‘*your head around things*’, that you can ‘*understand in a big way*’ and will not “*tell people*” about what you know, indicates competence. The judgement call that upholds the workings of this binary are indicated by the “*you could tell him*” phrase. However, the use of “*you*” does not indicate exactly who makes this call, thus how far in this case, the worker’s own beliefs might be implicated in the maintenance of this decision.

The next statement reveals that incompetence also involves wider social sites of meaning and their power/knowledge effects.

*‘Me and my girlfriend, making love to my girlfriend’ That’s what he’d say. What he means by that I’ve got no idea. Because I don’t think, I don’t think that he has, but then I might be wrong. And I said to his Mum ‘we have sexual programmes down here and, you know, would you be interested in allowing Peter to go?’ And she said ‘well,*

*um will they be calling the different pieces their proper names?’ And I said ‘I’m sure they will’ and then she said, ‘oh no, I don’t think that men with DS [downs syndrome] are fertile and we’ll leave it at that’. Yeah! and I, really, I mean ok we can plod along, but for how long?’ (T 2005, p. 5).*

In this statement, Peter’s assumed level of physical capacity, although unstated, enables this display of socially competent talk to cross the larger incapacity position this intellectually disabled person usually inhabits. “*Making love to my girlfriend*” calls on the wider series of discursive effects invested in the “*couple doing normal*”. These effects enhance the potential for Peter to be judged as an at least potentially competent player. However, the absence of material proof i.e. “*I don’t think he has*” creates difficulties for how a knowledgeable worker might affirm this Peter-as-knowing position. Peter may say “*making love to my girlfriend*” but what evidence is there that he really knows what he is talking about? How far does he have his “*head around things*” as the previous text statement queries? Does he understand “*in a big way*” what he is saying? At first, the worker admits that she has “*no idea*” then that she doesn’t “*think that he has*” while finally she admits “*I might be wrong*”.

In this case, allied discursive effects through which these positions are at once fixed and contested further complicate resolution of the liminal positions Peter and this worker inhabit. An assumption that ‘mother knows best’ coupled with the socially powerful bio-medical ‘fact’ of infertility in men with downs syndrome cuts across the notion of procreative potential that shores up the pre-eminence of the hetero-couple as a reproductive economic unit. Peter cannot access the power these favourable effects enable, nor can this worker support him to do so at this time.

### ***Summary***

The ‘*clueless*’ remark reveals that the central ‘they’re not sexual because they’re disabled’ assumption is the principal point of negotiation through which who is seen as capable and who is not is fixed and contested within the support relationship. These points of contestation are created by key wider socially favoured/socially unfavoured power/effect systems through which attributions of physical and social competence are located and upheld. Judgement calls about these competencies draw their power



from how well they sustain conformation to key aspects of the ‘couple doing normal’ parameter of social acceptability that underlie these competence calls. Showing physical capacity is the central consideration after which being able to negotiate social competence through talk is also important.

### ***Chapter Summary***

Probing worker texts reveals that sexuality support for intellectually disabled people is compromised by prior social difficulties created through talking about the topic. These include:

- gender issues: women workers, in particular, can find talk difficult.
- service issues: talk about sex is discouraged in agency service workplaces
- personal issues: workers and those they support share the same understanding, that talking about sex is difficult and should be discouraged, that is: that it is indecent and immodest to talk about it.

Further these difficulties stem from wider “axes of social difference” (Wilkerson, 2002, p. 35) that suggest that power/knowledge effects operate to create and maintain binary sets of practices that signify the difference between good sex(uality) and bad. These discoveries are broadly consistent with already held understandings about the barriers to sexuality support uncovered in the literature review. However, the significance of this point is its relationship to the idea that these difficulties constitute “an especially dense transfer point” (Foucault, 1978, p 103) of discursive effects that deploy within the support location. These effects create the belief systems that shape and guide support practice. These effects also link to wider discursive assumptions that shape the degree to which workers are able to maintain a knowing/competent position in relation to those they support. The importance of this finding is that it challenges literature review assessments of worker’s practice that assume workers already inhabit a knowing position, and that their own beliefs are the barrier that needs be overcome.

These findings might look like remarks that ought to go without saying. However, when these effects are viewed as especially dense transfer point convergences of socio-cultural meaning that include the “shame, disgust and moralism” (Warner, 1999, p. 4) that infuse them, the assumption that competent workers will find it easy to put these broader social difficulties aside is urgently in need of reappraisal. As Shildrick notes, the presence of these limit-effects must be “clearly articulated” (2004, p. 1), lest their influence be downplayed or ignored.

### ***Moving to Worker Practice***

Text statements reveal clear examples of how workers can police their display of knowledge in the presence of an outsider/third person (Benwell & Stoke, 2005). In the example below both participants are quick to agree that sexuality is something the people they support would know nothing about.

*J: I mean, if they were interested, like they asked me anything about sex I'd tell them but they never do. They don't.*

*R: So it's that's a word that's not there for them?*

*J & M: No (M&J 2005, p. 8).*

Yet after this affirmation that sexuality is a word that isn't “*there for them*” the following response is made to a question I put.

*Carol: So if you sat a couple of people you support down and said ‘what do you know about sexuality?’ they might give you something?*

*J: A lot of them might actually be quite interesting (M&J 2005, p. 8).*

In contrast to the quick “*no*” noted above, this admission reveals a view of intellectually disabled people as knowledgeable individuals, whose talk draws on a significant level of experience in this area. Chapters Eight and Nine follow this insight through a deconstructive interpretation of the experiences of a group of intellectually disabled people who live in an agency service group home. An interpretive reading, assisted by an analytical approach is used in these chapters as “a source of expression and of explanation” (Clear & Gleeson, 2001, p. 137) of the tensions and ambiguities

the statements included reveal. The contradictions these statements hold pinpoint significant points of negotiation through which wider discursive power/knowledge effects shape the material practice of sexuality support. Although these stories are brief, I also tease out wider implications that the cultural climate of the interview setting may have inhibited. I also link these interpretations to other discussions I had with workers.

These narratives are also followed as an aspect of my commitment and the commitment on the part of the workers who shared these experiences to continue to engage with and work through the discursive effects in infused the interview setting.

### ***Isolating Gender***

The following two chapters recount eight support practice narratives in which particular discursive effects related to the ideal couple image are located and unpacked. These narratives establish residential homes as gendered and sexualised spaces where those who live and work in them uphold and subvert the discursive effects of hetero-centric discourses that sustain the ‘couple doing normal’ image (Caudwell, 2002). These vignettes also reveal how allied effects cohering in this image maintain and sustain the actions of workers and those they support. These storylines provide a point of entry into an explanation of what material events signify the ‘*terribly sexual*’ descriptor in the phrase *in our house’ no-one’s terribly sexual*’.

Both chapters are premised on literature review suggestions that sexuality support for intellectually disabled women and men operate in different way within the wider “axes of social difference” (Wilkerson, 2002, p. 35) through which the parameters of assistive practice are upheld. Chapter Eight unpacks key discursive assumptions that create, uphold and fracture considerations of sexuality support for intellectually disabled women. Chapter Nine unpacks the assumptions about sexuality support for intellectually disabled men.

## Chapter 8

### *Sexuality Support: Positioning Women*

#### *Introduction*

This chapter involves a deconstructive interpretation of text statements made by workers relating to the support offered to four intellectually disabled women in the area of sexual relationships. Each statement is brief yet contains significant convergences of social meaning related to ‘intellectual disability’ and ‘sexuality’ that shape assistive possibilities. While this interpretive analysis assumes that these effects link to support outcomes, it also works with the idea that other effects interweave within an ambit of allied assumptions about sexuality that uphold key socially favoured euro-western representations of femininity and (bodily) desire (Stephen 1997). All effects come together through the socially favoured ‘*couple doing normal*’ ideal. Further, this ideal shapes worker’s actions into certain kinds of “assisting behaviour” (Maidment, 2006, p. 119) outcomes that broadly consist of enactments of a no-support needed position.

This chapter derives from the central post-modern idea that it is primarily the discursive effects of wider social ways of doing rather than any one individual’s attitudes and values, that influence worker’s material practices. However, I also interrogate the role of the power/knowledge effects of ‘individual purpose’ (Heshusius, 2002) within these discursive interplays as a specific set of features influential to how workers assist those they support. To do so, references to the multilayered dimensions contained in the support role outlined in Chapter Two are included. These dimensions highlight the interplay of emotional connections in which the support role also operates. How the influence of these emotional effects link to the degree of purpose individual workers deploy in the support role are probed, then explicated. Finally, aspects of the in-collusion position noted previously are also assumed to be in operation, in that discursive effects relating to ‘a material truth about

what is going on' also deploy through these narrative storylines. To this end 'tangible' (Rapala & Manderson, 2005) elements from other worker texts are inserted into this deconstructive undertaking, so to pinpoint additional microphysical power relations positions uncovered through these vignettes.

### ***Discursive Assumptions and Support Positions***

#### ***Helen: 'She's Too Old For It'***

*M: I don't think that Helen has any idea*

*J: No...*

*M: ... about sex and relationships....*

*J: ... 'cause she's sixty... (J&J 2005, p. 10).*

Statements made about Helen are few and far between. In the four statements located, an already established (intellectually-disabled) incapacity meta-discourse initially engages the basis for the 'too old for it' assumption that drives the production of real-time support in this excerpt. Here, the (she doesn't have) '*any idea*' discourse of cognitive incapacity links to allied discourses, which draw power from prior-established socially significant truths relating to 'ages and stages' norms of bio-physical development and decline. These bio-medical effects, fixed thought the '*sex*' aspect of the '*sex and relationships*' remark, further cements the link between sexuality and the social approval given to certain normative actions that constitute the preferred practice of the ideal couple.

This approval is contained in the unspoken assumption this talk contains, that sex is only to be engaged in by the young and beautiful. This assumption is further enhanced through the social effects of an "hierarchy of attractiveness" (Sinason, 1992, p. 279) of shape and appearance to which all women, including intellectually disabled women, are encouraged to conform so to be able to be identified as holding the potential for active sexual status. It becomes just a matter of common sense to recognise that older appearance will also count Helen out of any capacity to either

present herself, or to be seen as a sexually viable figure. The influence of this counting out process is more overtly stated in this excerpt taken from another talk statement.

*Here's a lovely old gentleman there and he's seventy-five, and there's a wonderful lady that lives over one of the other homes. And they're starting to ring one another up you see, and they want to form a friendship but they reckon it's a stupid idea because he's a seventy-five year old and this lady's a fifty two year old.... and one of these other staff goes "Oh I couldn't see them having sex" (J&J 2005, p. 13).*

While these especially dense transfers of power/knowledge effects mitigate against Helen or any older intellectually disabled woman being seen as capable in this area, they also create and uphold the power of knowing workers to speak the truth about any older person's lack of capacity for 'sex and relationships'. These larger social orderings are productive of the particular intensities of passion through which the actions of both Helen and the workers are regulated and mandated.

### ***Exploring the Knowing Worker Position***

Very little additional information is volunteered about Helen's past. However, a brief comment made later on reveals she has spent a long period of time in a large institution fairly close to where she currently lives. It is not known how long she had lived there nor what her life might have been like, but this comment indicates the ambivalence she still feels about her time in 'C' (the institution).

*You wouldn't even be able to put her in the van and say lets go to Smalltown, because that's C (the institution) ... (M&J 2005, p. 21).*

Research findings related to institutional living and the wide variety of unwanted sexual behaviour experienced by intellectually disabled women raise the idea that, rather than having 'no idea' about sex, Helen very possibly has had at least one past sexual experience. It is also possible that this experience was concluded under conditions that were less than pleasurable and that may have resulted in Helen being punished (McCarthy 1999).

### ***The Emotionally Distant Worker***

How much workers know about the problem of how sexual expression was managed in institutional settings cannot be gauged. Thus how much '*she's sixty*' might reflect workers desire to protect Helen from further abusive sexual interactions also remains impossible to assess. Research findings suggest that there has been a lack of assessment and documentation of what has happened to intellectually disabled people in the past, thus any knowledge workers may have is probably partial and more than likely inaccurate (Bigby, 2005). However, fixing Helen in the '*no idea*' position can also relate to the 'perhaps we prefer not to know' stance Mattison & Pistrang have suggested that workers can take up in their support practice. In this case, it may be "easier simply to attend to the more physical and practical aspects of their care" (2000, p. 7) than to deal with the complexity of any prior issues that further support for the development of a quality intimate life for Helen might raise.

However, while workers may be accurately gauging the wider 'truth' of the support matter in this instance in that they have produced an accurate reading of how Helen is currently placed in respect of dominant socio-cultural assumptions not only about disabled but older women living in New Zealand, that the terms '*sex*' and '*relationships*' are used interchangeably creates a very difficult problem. Where the word '*relationships*' has come to mean material experiences of sexual activity, this meaning narrows the capacity for the term to include support for any other kind of closeness that can be shared with another person or group of people.

No further mention is made of plans for any ongoing support initiative to maintain, develop or extend any kind of friendship relationship with other people. Whereas it might go without saying within such parameters to legitimately equate no interest in sex with older age, it is far more difficult to uphold '*cause she's sixty*' as authentication for the lack of support to develop friendship relationships in general. Broadening the scope of this remark reveals that this common sense assumption may also contain elements of purposeful deployment by workers to mask their lack of exploration of more general relationship support options on Helens behalf.

### ***Further Discussion***

Discursive effects that form the basis for the support position outlined in this vignette contain intersections of wider social orderings relating to sexuality, gender and older age as well as power/knowledge effects related to intellectual disability as a meta-status. The '*couple doing normal*' ideal that centres and upholds the interplay of these effects masks possibilities for workers to positively recognise older women as having either capability or interest in this area. While this ideal renders workers support responses culturally intelligible these effects also fracture possibilities for older women to think of themselves as either sexually desirable, sexual capable or as being a person for whom the sex act might be important. What these effects do is cut off possibilities for older people to be supported to develop any (sexually) non-physical, but deeply affectionate, pair and group relationships.

How these effects deploy in this location correlate well with literature findings that note the overall lesser emphasis placed on support for the social participation of older intellectually disabled people by service agency providers. As the average age of people who use agency services in New Zealand is now over fifty, these positions pose problems for future support outcomes for those who continue to use agency services in older age. Yet in a wider context neither these workers in particular or support workers in general, or intellectual disability service providers as a whole, are alone in being caught up in and/or purposefully deploying the 'no sex necessary in older age' assumption.

A relatively recent article written for the New Zealand Disability Studies Journal related to the support for the process of aging and intellectually disabled people also makes no mention of how support provision should be enacted for either older women or men in this area of their lives (see Sewell, 1996, in Hamilton, 2006). In this article, a similar common-sense understanding, that being older renders thinking about how to structure support in this area unnecessary, infuses the position these writers take in respect of assistance needed. No discussion about the need to develop and maintain support practice initiatives in the sexuality and intimacy area appears anywhere.



***Fiona: 'It's Her Choice'***

*I've talked to Fiona about sex. Cause we were a bit scared ... when she came to us she had been on the contraceptive pill ... She said it was because of her periods ... Now, Fiona's quite on to it and I said that "It's not because you want to have sex?" and "Do you know what sex is?" "No I'm not doing that". She's adamant she's not doing that... we had a big talk about it (M&J 2005, p. 22).*

Fiona is thirty-five. Her story is also only briefly outlined, although not as briefly as lines of discussion offered about Helen. Her history too is initially said to be largely unknown. These lines of text reveal interplays between allied discursive assumptions whose effects shape and substantiate negotiations undertaken between Fiona and the workers concerned about the implementation of any sexuality support option. Discursive effects sustaining this interplay at once enable and constrain how both parties engage with a key representation of the ideal couple that shapes this support outcome. This interplay presents a significant challenge to the disabled binary that elides the interrelationship in which the positions of Helen and the workers concerned are mediated and contested. This challenge calls into question the assumption that assumes workers to be the always-knowing figure in the support relationship. How this challenge operates is unpacked below.

Anxiety about the unknown cause of Fiona's recounted pill taking behaviour enables the '*big talk about it*' pro-active support initiative. This '*big talk*' is also enabled through an attribution of capacity inherent in the '*quite on to it*' remark. This admission disrupts the power this meta-discourse usually deploys in this location. Fiona's response to why she is on the pill draws on already-established wider social ways of doing that link a transgressive effect of reproductive capacity, in that Fiona is not married, to Fiona's pill taking behaviour.

However, the truth position this capacity-to-make-unwanted-babies linkage creates, although a normative position that many women in New Zealand are recognised as 'taking the pill' in respect of, is questioned as the sole enabler of Fiona's position. The '*it's not because you want to have sex? And do you know what sex is?*' queries uncover further discursive effects that Fiona's pill taking response sidesteps, effects

that do not fit quite so neatly into the mechanics of the '*couple doing normal*' image. The '*want(ing) to have sex*' and '*knowing about sex*' remarks query the pill as being taken only so that Fiona can keep her social and (perhaps also tainted?) biological capacity safely in check. Rather this behaviour hints at the presence of a 'knowledgeable' Fiona, who has had sex for the enjoyment of it and who (knowledgeably) takes the pill in respect of any unwanted outcome this material instance of unmitigated desire might accrue.

How much the idea of supporting the behaviour of a sexually desiring woman, rather than an unmarried (intellectually disabled) woman might underpin both the '*scary*' depth of feeling attributed to the worker position and the strength of Fiona's '*adamant*' position is impossible to accurately gauge. However, altering the scenario of the ideal couple image created through the text reproduced in Chapter Six as "... *He'd go in and have dinner at her home and they'd go into her room...*" to read "she invited him to have dinner and she took him into her room", reveals a difference that is more than just a matter of semantics. When She takes Him into her room, a core social dynamic has altered.

### ***The Problem with 'My Choice'***

Deployment of an 'individual's right to choose' position empowers Fiona's (credible) words, while it also enables the lack of necessity on the part of those who support her to work with her to re-evaluate her position. This process leaves open a number of queries about the role of discourses of individual purpose in respect of judgement calls about support options in this case. If Fiona had said, 'yes I want to do that', especially in respect of the query about wanting '*to have sex*', would workers subsequent responses have been as whole-heartedly supportive? Or would workers, knowingly, have then have actively (re)constituted Fiona's position as 'intellectually disabled therefore incapable' and then queried her ability to completely understand the implications of what she is saying? There are no ready answers to these questions.

Attributions of capacity ensure that Fiona's talk is not seen as just (uninformed) talk, but becomes material proof that legitimises both Fiona's and the workers positions. No further support becomes necessary in this case because it's Fiona's choice. The

emotional force of the ‘intensities of passion’ (Warner, 1999) that deploy in connection with women’s sexuality and notions of individual choice intertwine to uphold this position. This narrative suggests that central aspects of this interaction may lie inside of ideas about female sexuality that neither Fiona nor the workers have sole power to choose over in this area, and the force of these intensities is considerable.

### ***Probing the ‘Adamant’ Response***

*J: She had had sex though... so someone had told her ...*

*M:... apparently she was abused by another client in a home ... which was a long, long time ago... (M&J 2005, p. 22).*

Later on it is revealed that Fiona has had an unwanted sexual experience in a prior service placement. While use of the term ‘*abused*’ indicates an appreciation of her position as unwilling party to an unwanted form of sexual behaviour, nonetheless such acts transgress the discouragement of sexual interaction position that shape the boundaries of the incapacity meta-position on which worker practices are based. As has been suggested, within institutional settings those who conform to the requirements of the setting receive less attention from those in authority, while non-conformist behaviours accrues negative attention (Barton, 2005). Through this act of sexual engagement was abusive and unfulfilling, in having had a sexual experience Fiona has failed to conform. Thus the strength of her ‘*I’m not doing that*’ remark can also be seen as an attempt at re-affirming conformation. This conformation is necessary because her prior experience lead to negative attention, one result of which was her having to leave the place she was living in. Thus this endorsement of her position can also be seen as a positive move, in that it is helping to ‘keep Fiona safe’ from the negative attentions of a service structure imbued with the idea that ‘they’re not sexual because they’re disabled’.

### ***The Emotionally Distant Worker***

Fiona’s experience in this area is endorsed by research studies as common to at least some women who are supported in service agency group homes (Frawley, 2003).

However, this description anchors the incident firmly in the past, despite the ‘*apparently*’ inference. As other worker talk statements suggests, the ‘*long, long time ago*’ rhetorical device can cover over talk difficulties workers experience when asked to recount incidents they know of or have been involved in, where the possibility exists of ongoing psychological and emotional damage to the intellectually disabled person concerned. Placing talking about these experiences into the past removes the immediacy of the problem while also implies that these practices no longer exist in service settings.

In the statement below a support problem a worker was involved in left this person feeling extremely uncomfortable and powerless. This problem echoes not only aspects of the difficulties outlined in this vignette, but also the difficulties worker’s face when the boundaries between what they believe to be socially acceptable and socially transgressive behaviours are crossed, and when these difficulties are not resolved in the workplace.

*We had an older gentleman that lived down the road... and the lady that was living in the home I was working ... and, um, this person ... wanted to start a sexual relationship. But the lady didn’t and then we got told by up above that “No it’s ok, he can just have his time, an hour in the room with the female and it’s all right” ... And a lot of us didn’t know how to handle that... that would be about thirty years ago (J&J 2005, pp. 8-9).*

Although this incident was said to have happened thirty years ago it was later revealed that this worker has been working for the organisation for fifteen years. It is also noted that handling this incident did not include workers being able to make their feelings of unease known. This talk statement uncovers the strong sense of powerlessness workers can feel when being ‘*told by up above*’ about the kind of support practice to be followed constitutes wider management of these complicated issues. In these cases, workers may ‘*handle that*’ by withdrawing emotionally from the people they support. In Fiona’s case, not wanting ‘*to have sex*’ may end up ultimately as a position both workers and Fiona endorse because of the possibility that any future sexual experience for Fiona may also contain abusive elements. If so, the

support both she and the worker could call on may only result in negative external intervention and management of both the workers and Fiona's responses.

This example is also included because of a conversation I had with a worker after a training session I facilitated in the organisation I worked for. They outlined a very similar incident in the house they were working in and wanted my opinion about the same proposal being mooted in relation to the women they were supporting, and the intellectually disabled man who lived up the road. Identifying as Maori, this worker was already dealing with this sexuality issues from within another cultural perspective, which would not have condoned such a support practice.

### ***Further Discussion***

In this narrative power/knowledge effects that uphold key socially favoured aspects of women's sexuality intertwine with prior-existing incapacity discursive effects to shape the 'no long-term support offered' outcome. Literature review studies suggest it is very difficult to see where intellectually disabled women who are in a similar position will be able to gain the support they need in this area. These studies also note that these issues should be addressed rather than downplayed, otherwise beliefs that maintain the sexual wellbeing of women in this group as being of lesser value and importance than those of other groups will be maintained (Stone, 1995). This narrative upholds the ongoing validity of these comments. However, it can also be said that systems that uphold this lesser value position reach far beyond the purposeful practices of the individual workers concerned. 'No-support necessary' outcomes are enabled and maintained as much through larger intersections of power/knowledge effects as by the agency of any individual worker alone.

This narrative also reveals that power/knowledge effects relating to the socially favoured effects of individual choice also verify the no-support-necessary outcome. Discursive effects related to the wider concept of individual choice ensure that Fiona and the workers remain fixed in "their relative positions and clear narratives" (Kuppers, 2003, p. 2) that continue to occlude the powerful presence of the social complexities related to gender that the more insidious effects of 'my choice' obscure. Within the fixed universe paradigm the notion of 'individual choice' offers it

may be as difficult for Fiona to change her mind as it is for workers to challenge the repressing effects 'her choice' has on Fiona's future prospects of entering a satisfying intimate relationship. Further, these power/knowledge effects mask any necessity for either the workers or Fiona to identify and challenge the wider socio/cultural barriers to a satisfying sexual life for women that the concept of rational autonomous choice obscures.

***Rosemary: 'Does She Want It?'***

*J: ... although didn't someone say once that Samuel was found romping around... rolling around the, with Rosemary ... but Rosemary was enjoying it too, wasn't she ... but nobody's actually asked Rosemary, no we've never said anything about sex*  
*M Well she (the manager) had a talk to Rosemary about it and went down to the day-base and explained to her what sex was, and Rosemary said "I'm not doing that, that's disgusting" (M&J 2005, p. 16).*

Rosemary is forty-two. This narrative is not contained as a stand-alone piece but is held within lines of discussion given as a workplace example of sexualised behaviour. In the lead-up to these statements a worker has been outside hanging clothes on the washing line. She re-enters to find Samuel and Rosemary together on the lounge floor. The knowing worker position that accompanies this entry through the door is initially upheld by the in/capacity meta that already-fixes Rosemary's incapacity to either set up or be involved in a sexualised interaction. However, the power this discourse deploys is challenged by what is going on in the lounge. The interplay of effects this fracture creates reveals how much the worker's position and the support outcome offered depends on Rosemary's already-established incompetence placement, and how difficult it can become for support practice when the power this knowing position invests is destabilised.

The '*romping around*' statement initially positions Samuel and Rosemary's behaviour within a playful context, in which both parties are deemed co-participants to this essentially enjoyable and light-hearted occasion. However, the '*romping around*' descriptor is then (ex)changed in favour of '*rolling around*', indicating that a less

light-hearted, co-participatory and more overtly sexualised revisioning of the event has also taken place. The tensions created for the worker position when the parameters of the 'they're incapable' aspect of the meta binary become diffuse, are indicated by the '*but Rosemary was enjoying it too, wasn't she?*' query that follows the '*rolling around*' descriptor.

Further difficulty is created because the behaviour does not conform to a key aspect of the socially favoured '*couple doing normal*' position. While the couple in this case are man and woman, the '*in your own room with the door closed*' socially favoured location has become 'on the lounge floor'. It is a short leap from this point to a further assumption, that one transgressive act may indicate that other non-favoured, perhaps also abusive, sexual behaviours could be going on. To re-establish the knowing position, worker validation of Rosemary's intent in this interaction is necessary so to coordinate how to respond 'knowledgeably' to this incident.

### ***Unpacking the Distant Worker***

While the behaviours outlined remain framed as the innocent escapade implied in the '*romping*' descriptor, no further action related to sexuality support is needed because nothing untoward has happened. '*Rolling around*' positions Rosemary more as a willing (knowing) participant thus further support action is required, if for no other reason than to establish the normative location for such a behavioural event.

However, in respect of these two interpretive positions the next phrase, '*but nobody's actually asked Rosemary, no we've never said anything about sex*' is intriguing. On the one hand Rosemary is at least partly positioned as actively sexual and as '*enjoying*' the experience. Yet this assessment is set against the '*we've never said anything about sex*' following remark. If this worker really has '*never said anything about sex*', this statement may indicate a desire for it to be generally known that no talk from their quarter has put any sexuality-related thoughts into Rosemary's head. Thus this worker is distancing themselves from having to take on any responsibility for problems arising from behaviours Rosemary has entered into, of her own accord. Why the worker concerned might feel the need to underline this position at this point is explored below.

### ***Being Active/Being Passive***

Another worker's text statement is used to unpack the complexities that inhere in the appraisal of what Rosemary is doing. This statement holds another line of narrative that echoes aspects of the difficulties '(not) knowing what's going on' poses when power/knowledge effects relating to the meta-assumption of (sexual) incapacity are displaced by a 'sexualised' incident. This narrative outlines the experience of another intellectually disabled woman who uses the same agency service.

*We had a young lady that was um being touched by a young man in places yeah in her private places, to her were her private places... in the workplace... She was given counselling for that because she was obviously very distressed about it. So she was given counselling through ACC.... she couldn't deal with it because she hadn't been taught or told that if somebody touches you and makes you uncomfortable you are within your rights to say "No, back off", you know? "Get away" or "Don't touch me like that I don't like it", you know? (C 2005, p. 5)*

In this case, the prior established incapacity meta-discourse links the '*was being touched*' phrase to the '*lady*' sexually passive descriptor that establishes the young woman's innocent position within this scenario. That the incident contains a sexualised element inheres in the '*in her private places*' phrase, a remark that also contains overtones of naivety that reinforce the '*given counselling*' support response. Yet while the passivity of the young woman's position is foregrounded, this person's '*very distressed*' active response may indicate the presence of allied discursive effects the support response outlined obscures.

The assumption that this touching episode is to be seen as unwanted and abusive is created and upheld through the '*back off*', '*get away*', '*don't touch me*' and the more explicit '*I don't like it*' expository phrases. However, it may be that it is not so much that the touch this woman experiences is unsolicited that makes her so '*terribly upset*', but that her reported reaction indicates the strong sense of shame and embarrassment she feels at being exposed as sexually capable in such a public location (Warner, 1999). This woman's response may also call on a deeply felt ambivalence in relation



to being seen to be involved in a possibly wanted in a physical sense and unwanted in a wider social sense, touching episode. In this view, the '*distressed*' reaction may indicate the fear intellectually disabled people experience, not so much at a manifestation of sexuality *per se*, but at the possible negative consequences that can follow discovery of these actions in the 'public place' of a service setting. Further this response may indicate the extent of the shame literature review findings note that intellectually disabled women in particular have to contend with (McCarthy, 2001).

### ***Another Difficult-To-Talk Position***

In the case of the '*young lady*', the referral to a counselling service means that possibilities of developing options that acknowledge and support the presence of an active sexually desiring woman can be put to one side. In this example attributions of capacity, held in the '*she's quite verbal*' remark, cut across the incapacity meta to further endorse this support option as being if not her own choice, the best outcome for all concerned. This view is also upheld by the further assumption that the young woman has the ability to object to the counselling support outcome if she wanted to. In reality, it would be very unlikely that this young woman would or could suggest that the incident represented a desired experience. However, as well as this option underscoring a further assumption, that any intellectually disabled woman who might have sexual feelings and who wants to express them needs therapy, this outcome also frees anyone working for the agency from having to explore any other issue arising from this incident, including interrogating any questionable agency practices this support option exposes.

Both examples raise wider tricky questions about how willingness on the part of women involved in 'sexual behaviour' behaviours is read within a support environment where, as literature review studies reveal, a substantial number of intellectually disabled women continue to be sexually assaulted. In Rosemary's case, the '*she was enjoying it too*' remark may refer to the idea that unlike the young woman, she did not look and act '*terribly upset*' enough when she '*was seen*' in a sexualised position in a less than ideal physical location. Do the observations of Rosemary's actions draw on larger normative assumptions that set a standard in relation to how woman should respond when they are seen (caught?) in a

compromising position? What if workers had entered the room and Rosemary had screamed? Would this have been interpreted as fear, pain, or pleasure? Or is the idea that Rosemary *'was enjoying it too'* because she didn't look or sound as if she wasn't, purposefully deployed by workers to mask the possibility of having to view her/respond to her as a sexual victim? The questions posed are not easy to answer, however comments from another worker gives some indication of what might also drive support perceptions about Rosemary's response within this context.

*We did an exercise at training on Thursday and it was about two of our guys in a compromising position with no clothes on, in the act in the lounge and you walk in the door and ... (pause) ... yeah the reaction was, how would you react to it? And I said "Shock". And it got, and people thought I meant I was absolutely horrified at what I'd seen, but I said "The shock is that you don't expect to walk into a lounge and find two naked people ...(laughs)... on the floor" And what would you do? Most probably to my mind I'd be embarrassed and just have to walk away, and yeah, two or three of them actually said ...um... they'd walked in and um yeah it was shock. You just weren't expecting it, I guess its just nature (C 2005, p. 11).*

What is also interesting about these comments is that I had made up the scenario given at this training session, and I did not include the couple being *'naked'* at the time.

### ***Workers Obscure Talk Difficulty***

In Rosemary's narrative it is recounted that she is taken aside after the incident and given an explanation about *'what sex was'* by a manager. It remains speculative as to what kind of information might elicit the *'I'm not doing that, that's disgusting'* response Rosemary is said to have made. However, this response correlates with literature review findings that note that intellectually disabled people find the explanations about *'what sex was'* given in agency settings "embarrassing and irrelevant" (Frawley, 2003, p. 4) to their needs and wants.

Further justification for the *'no-talk'* position assumed in this case is offered later on in discussion.

*But I wouldn't feel comfortable doing that, because I wouldn't say to another forty-two year old woman, "Would you like to have sex?" (J&M 2005, p. 19)*

Yet this is exactly what Fiona was reported as being asked in the prior narrative. Perhaps the difference in age, between 35 and 42, is significant. However, in Rosemary's case intervention by an external person enables workers to remain (competently) at a distance from both the event and any requirement to take matters further. However, this intervention also ensures that any lack of capacity to talk about the issue that inheres in the worker position remains masked.

### ***Further Discussion***

In this narrative, microphysics of allied discursive effect deployments relating to incapacity, gender and sexual desire maintain a normative, manageable representation of sexuality support in this location that endorses no active support reaching beyond the talk stage. However, it also reveals how material fractures to the incapacity meta-binary contest how this representation operates within worker's practice. These fractures suggest that workers, far from being independent, rational, cogniscent individuals, are also bound up in power/knowledge effects that inhere within wider socially favoured ideals about femininity and sexuality through which the management of sexual behaviours within agency service group homes are at once fixed and contested.

Yet the view of Rosemary as '*enjoying it*' sits at odds with the negative view held by many support personnel of intellectually disabled women's attempts to form satisfying sexual relationships (Clements et al., 1995). The deployment of the '*didn't someone say once*' remark that initiated Rosemary's narrative, a phrase that echoes the '*long time ago*' deployment that prefaces the telling of a socially difficult narrative, may also indicate how hard it is for workers to cross the 'its unsatisfying' normative that is the usual view of sexually active intellectually disabled women's relationships. This finding also raises questions about how difficult it might also be for workers to purposefully cross this victim position, and to regard the women they support as actively desiring sexual beings.

***Britney: 'It's Not Normal'***

*J: Britney's obsessed with Rosemary...*

*M: Britney's got this fascination... She's got fifty odd barbie dolls ... but she's also got this doll that's like a baby. Well she was lying on the couch in the lounge with this doll, kissing it properly ... calling it Rosemary and then she's lying on top of it trying to have, well humping it, to be perfectly frank ... (laughs) ...I said "Britney, you can't do that in here because you're upsetting the other people. You take your dolls and go to your bedroom" ... And it stopped (M&J 2005, p. 16)*

Britney is twenty-one and is reported to have expressed a desire to begin a relationship with Rosemary whose experience has just been explored. Prior discursive effects related to the incapacity meta initially site Britney's behaviour within the socially unfavoured side of this binary, while also empowering the statements made by workers as expressing 'the truth' about Britney and her desires. The power these text statements invest is also enabled through links, in respect of their sexualised element, to key aspects of the socially favoured '*couple doing normal*' ideal of material practice. Further these connections substantiate the reported actions of this intellectually disabled person as additional evidence of the transgressive quality of these desires. However, as these positions remain mutable, how the power/knowledge effects they draw on are contested in this interrelationship are explored through this deconstructive reading. Unlike prior narratives, Britney's 'problem' and the support given is the subject of lengthy consideration. This consideration attests to the particular intensities of passion that drive the operation of the wider hetero-centric series of meta-social orderings in euro-western society that infuse this setting. Key aspects of these deliberations are unpacked through the excerpts included below.

***Female Desire is Socially Transgressive***

At the start, Britney's feelings are described by workers as '*obsessed*' and '*fascinated*', both words siting the behaviours witnessed within the effects of already established bio-medical categorisations of disordered behaviour patterns indicative of emotional states characteristic of mental disorder (Potter, 2005). This non-normative

placement is initially verified through the '*Barbie dolls*' remark that links this disorder to '50-odd' repeating images of hyper-femininity. However, this link is not pursued, perhaps because it could be said that fascination, if not obsession, with this top-of-the-hierarchy female form is more generally shared to a greater or lesser extent by both women and men in euro/western society.

A further link then attaches these behaviours to another image, this time one that includes a body shape that looks '*like a baby*'. The common sense assumption that upholds this remark, that any doll that looks '*like a baby*' ought to be treated '*like a baby*', re-asserts the power/knowledge effects of the discourse of deviance on which this narrative and its support outcome is based. Britney's ostensible lack of appreciation of how to behave in relation to this iconic body form interlinks to her prior incapacity status through an additional assumption to the effect that, if she is unable to treat this doll like a baby, any other culturally intelligible action she may display does not have to be taken seriously. In this view, that she is using this doll in a particular way, '*kissing it properly*' and '*calling it Rosemary*' becomes more evidentiary proof that re-asserts her deviant placement.

These effects are further upheld by the '*humping it*' New Zealand English vernacular expression. This remark signals that the sexualised interpretation made of this behaviour references to a 'missionary position' normative that substantiates the in-private behaviour of the '*couple doing normal*', against which Britney's behaviour '*on the couch*' is unfavourably compared. This further deviation, complete with Britney actively '*lying on top*', also substantiates the behaviour as aberrant rather than indicative. Thus consideration of any pro-active support for Britney and her desire will merely add to the existing problem. Any action that might help foster the potential for the development of a loving sexual relationship between Britney and the person she desires becomes as unnecessary as would be socially unhelpful to either Britney or Rosemary in the long run.

However, that Britney is reported as kissing the doll '*properly*' implies that recognition of some kind of competence has crossed this disordered meta-placement.

This disjunction reveals an underpinning mutability that enables a wider view of the complexities that uphold and contest the social effects of this discourse of deviance.

### ***Probing The Discourse Of Worker Purpose***

The reported ‘*you can’t do that in here*’ response to Britney’s behaviour relies on allied discursive effects activated through suggestions of ‘fitness of purpose’ that shape how the behaviour witnessed is interpreted, is then linked to the agency service group home location Britney inhabits. Yet these considerations are not deemed initiated by workers on their own behalf but on behalf of ‘*other people*’, although it is not clear how many ‘*others*’ other than workers themselves were present at the time of the ‘*on the couch*’ incident.

Deploying the opinions/feelings of others as a barrier to the enactment of support practices that it is implied would otherwise be initiated, features in talk about the management of sexualised behaviour in people worker’s support in the homes they work in. While discussing the possibility of whether two people who live in the same house should sleep in the same bedroom, the following remark was made.

*It would need to be discussed with the rest of the house to make sure they’re comfortable too (C 2005, p. 6).*

Both remarks draw on wider social ordering effects that draw on the assumption that it is the opinion of the majority that is the ultimate judge of what kinds of sexual behaviours are to be sanctioned and condoned, rather than the opinion of workers or willing participants alone. Yet literature review findings suggest that the idea that all who live in agency serviced homes agree to live with the people they share a house with in the first place is a largely unfounded assumption. These findings raise a number of questions about the strength of the position ‘*the rest of the house*’ may actually occupy in this scenario. Are the opinions of others who live in the house acted on their benefit, or for the benefit of workers, or for the benefit of both? Are workers obscuring their own feelings about Britney’s behaviour behind assumed difficulties of the ‘*other people*’? These questions remain open in this location.

### ***Exploring the Knowing Position***

*And she said “Now I’d like to sleep with Rosemary” ... and I said “Oh, what do you mean sleep with her?” ... “In my bed with me”... And I said, “Well you’re both grown women, you don’t actually sleep ... Rosemary wouldn’t want to sleep with you Britney” ... “ Oh put the mattress down by my bed, she can sleep in there” ... (laughs)... Rosemary mightn’t want to (M&J 2005, p. 18).*

Later on it is revealed that Britney has expressed a desire to be supported to sleep with Rosemary. This statement reveals the mutable space through which the actions of Britney and workers concerned are at once upheld and contested within the parameters of the ‘*couple doing normal*’ ideal. In this interchange, the socially favoured ‘knowing’ position passes between Britney and the worker concerned. A talk difficulty discursive position also affects how this request and the responses made to it are worked through in these statements.

Although at one level ‘*now I’d like to sleep with Rosemary*’ suggests clear evidence of intent, the ambiguity held within the phrase leaves open what ‘*to sleep with*’ would look like in material form. The worker’s ‘*Oh what do you mean*’ response also leaves open how ‘*sleep*’ is configured. Is this phrase deployed in its literal sense or as a metaphor, equated to ‘having sex with’? The workers invitation-to-clarify response, in which these two options remain viable, is equally matched by Britney’s either literal or subtle ‘*in my bed with me*’ stated rejoinder. However, this statement is read as ‘*sleep*’ being metaphorical and this interpretation empowers the now-knowing workers next response.

At this point, the socially favoured location of the ideal couple enables the ‘*grown women*’ don’t sleep together remark on which the lack of active support for Britney’s desire is finally configured. These discursive effects also verify the ‘*Rosemary wouldn’t want to sleep with you*’ remark as being the truth about this matter that should settle any question that active support in this case might be warranted. Britney’s ‘*oh put the mattress down by my bed*’ response re-calls the double meaning of the ‘*sleep with*’ analogy that cuts across the power/knowledge effects of ‘*sleep*’ as

a metaphorical interpretation, leaving open possibilities of taking up other positions related to sleeping near at some future point.

### ***What Degree of Worker Purpose?***

This interchange substantiates ‘knowing’ as an open and fluid position in which power/knowledge effects of discourses of individual purpose also deploy. In practice, the ‘*Rosemary wouldn’t want to sleep with you*’ remark is set against evidence that grown women in New Zealand do sleep together, although aspects of these actions and knowledge about them remains at the periphery of the more socially accessible and socially acceptable displays of adult sexual activity (Welch, Sunny & Collins, 2000). It is hard to imagine that workers would not know about these practices. However, as they remain largely socially unfavoured, it can also be suggested that intensities of passions enact the coercive power of “sexual shame, disgust and moralism” (Warner, 1999, p. 114) that underpins this non-supportive response.

On the other hand, as she is reported as having this conversation with the worker rather than with Rosemary, it is more than likely that Britney too knows Rosemary does not want to sleep with her, in any sense of the word. What may be ‘the truth’ of this matter is that Rosemary probably does not want to ‘*sleep with*’ Britney for a number of reasons that both Britney and the worker are more than likely aware of. These reasons may including dealing with any possible homophobia on the part of the workers concerned or on the part of the intellectually disabled people who also live in the home (Abbott et al., 2005). Yet perhaps it is only the thought of experiencing the effects of the socially alienating outcomes of the homophobic reactions of others is what is stopping Rosemary, and perhaps it is the wider implications of this idea that the workers want to avoid dwelling on.

### ***Britney, Workers and Social Ambivalence***

The first part of this vignette reveals that key discursive effects crossing the power of the knowing worker involve a same gender sex/transgressive as well as incapacity meta-incapacity binary. This rupture substantiates the non-favoured position ascribed to Britney’s feelings and desires. However, the lines of power these assumptions



generate are fractured and contested through an evident ability to articulate desire on Britney's part, and the reality of non-normative practices undertaken by other non-intellectually disabled, therefore less vulnerable to questions of rationality, wider community members.

In this case both Britney and the worker's concerned could be said to have become "stitched up" (Guy & Banim, 2000, p. 314) in the social and emotional ambivalences created through a desire for what is seen as a breach of the '*couple doing normal*' ideal. For Britney, any support outcome in favour of sleeping with Rosemary has its drawbacks. In New Zealand lesbians are associated with particular mental health needs because of the high rates of affective disorders, substance abuse and suicidal behaviours found to relate to the difficulties women in this group experience living in local communities where practices of heterosexual normalcy permeate material, social and cultural practices (Welch et al., 2000). Any support given by workers will also contain many difficulties. Literature review information notes that support for lesbian or bisexual intellectually disabled women within service agency settings is virtually non-existent (McCarthy, 1999; Abbott et al., 2005). When presumptions about heterosexuality dominate service provision at all levels and where service agency support itself mirrors the largely homophobic global social context within which the agency is placed, what workers themselves might safely be able to offer remains an open question.

### ***Unpacking the 'Nice Guy' Assumption***

Despite overtly upholding a no-active support necessary position, further statements reveal a deep concern about a deterioration noticed in Britney's behaviour, as this excerpt reveals.

*J: ... you said to me 'Britney's tied herself up'*

*M: I know...*

*J: ... tied her arms up and ...*

*M: ... if you'd worked into the house you would've sworn to God that the staff had done it to her...*

*J: Yeah she'd tied all her arms up like this (demonstrates hands crossed and tied at wrists) 'what are you doing Britney?' 'Rosemary tied me up to punish me. I'm being punished' (M&J 2005, p. 19).*

Moves towards a more pro-active form of support for Britney are undertaken as an outcome of this concern. Britney and Rosemary attend a local dance where the recounted event takes place.

*I said 'Rosemary's already dancing with someone. Why don't you get that nice young man over there?' Well she wasn't interested at all really and she turned round and held onto the table and danced with the table. And he said to me 'She's dancing with the table' ... (laughs) ... and all she was really doing was holding onto the table and looking to see where Rosemary was (M&J 2005, p. 29)*

Such is the power of the *'couple doing normal'* that it overrides the incapacity discourse to shape the *'why don't you get that nice young man over there?'* suggestion. A common sense assumption, that all young women will want to *'get'* nice young men if the chance materialises creates the socially favoured normative that enables this encouraging remark. Yet while this initiative can be seen as a move towards positive sexuality support in the case of this intellectually disabled woman, *'nice young men'* can also deploy more negative sets of discursive effects. While in many instances the outcomes of dancing with *'nice'* young men are benign, when women openly identify as lesbian these effects can subsequently lead to experiences of sexual harassment from the *'nice young men'* who are themselves caught up in wider discursive effects that affirm that an heterosexual intercourse is all that is necessary to *'cure'* the problem of hetero-normative reluctance implicit in the term lesbian (Hillyer, 1993).

Britney's reported body language also fractures the favoured aspect the *'nice man'* image deploys. Rather than being a genuine invitation to enjoy company on the dance floor, this suggestion only represents the outcome of a power/knowledge effect of the *'couple doing normal'* ideal. In this case the power this position holds ensures that no

subsequent comment is reported as made to Britney about the presence of any nice young woman she might enjoy dancing with.

### ***Further Discussion***

In Britney's case, discursive effect held in the '*couple doing normal*' as much as the discursive effects of the incapacity meta deploy to represent, manage and control demonstrations of sexualised behaviour and sexuality support practice. This discovery is unsurprising, as hetero-normativity is acknowledged as forming the socially preferred aspect of the straight/gay binary that substantiates the ethos of the wider community in which support work is undertaken (Lofgren-Martenson, 2004). However, being on the socially non-favoured side of the binary in this case can also be said to be empowering if only by default.

Britney's narrative provides a counterpoint to the support offered to the other three women in that the '*nice man*' option could include possibilities of a more flexible, albeit hetero-centric support process being put into place at a later stage. Yet as research has shown, in the past support workers have been documented as repressing homosexual behaviours in institutional settings until members of the opposite sex were included "whereupon it switched to repressing any expression of heterosexuality" (Gordon, 1979, in Szollos & McCabe, 1995). How long support might be enabled under a heteronormative-by-default position remains a question that cannot easily be answered. In addition, perhaps the '*nice young man*' offer was made for forms sake alone, tendered in the knowledge that a heterosexual experience is definitely not what is wanted. In this view, knowledgeable workers act in awareness that any such initiatives will continue to be rejected while it can now be said that at least they have genuinely tried to be supportive. However, this interpretation of the deep dilemma Britney and the workers face is a very cynical one and does not take into account that workers themselves need support to be able to negotiate a space where Britney's feelings, and their support in relation to them, can be treated as unquestioningly socially desirable and easily normative.

## ***Chapter Summary***

As this deconstructive interpretation of the vignettes show, a variety of allied discursive effects bind the positions intellectually disabled women and workers take up in respect of sexuality support options. Aspects of these effects represent significant culturally intelligible ‘social truths’ about (intellectually disabled) women’s sexuality that position all participants in certain ways within the parameters of the ‘*couple doing normal*’ ideal. These truths intertwine to create the ‘no active support needed’ responses that limits creative possibilities for the development of satisfying relationships for the women concerned. Power/knowledge effects of discourses of individual purpose also drive the production of these support responses, however it remains difficult to gauge how much of an effect these frameworks have on the kind of assistance offered.

Viewing these narratives as examples of material truths about what is going on in the support location reveals the difficulty any behavioural openness shown by intellectually disabled women in the sexuality area can create. Support responses orientated towards minimising, inhibiting and downplaying any sexualised meaning these actions might suggest can be seen as attempts to deal with the problems posed by these difficulties. However, these examples of talk also include the ‘presence of absence’ of certain support responses that would also address these difficulties, but in a more pro-active way (Burr, 1995). Key support talk-absences are briefly commented on below

### ***Noting Presences-of-Absence in Worker’s Talk***

When a sexualised behaviour example is recounted worker’s talk contains no examples of the intellectually disabled woman talking directly to others who are involved. The following option is briefly mentioned in the case of the young women sent to/offered counselling after the touching episode.

*The day people wanted them to actually be together for this (the counselling session) so they could talk about it, but I thought that was a bit rough ‘cos she was terribly upset with the situation to start with (C 2005, p. 7)*

In this excerpt, the feelings of others, in this case the feelings of the young woman concerned, is again mooted as the reason why this option is not taken up. Yet why is there no talk of her being asked?

In Rosemary's excerpt no mention is made of either participant being supported to talk together about what had happened. This omission does not necessarily mean that this conversation did not take place, but that it is not mentioned attests to the lack of significance placed on this option as a potential way forward for either individual. In Britney's case no mention is made about enabling Britney and Rosemary to talk together. What is noted is that a referral to a specialist behaviour support service was made. This person suggested that Britney write her feelings down on a piece of paper and then rip the paper up and throw it away, as a way of getting her desire '.... out of her system...' (M&J 2005, p. 13). Britney uses this idea to attempt to communicate directly with Rosemary, as this excerpt notes.

*So Rosemary will be sitting eating her meal ... and Britney'll come out ... and she'll scream something at Rosemary and if she's done something on a piece of paper and ripped it up like she's been told to she'll throw it and say "Take that Rosemary" and slam the door shut again (M&J 2005, p. 14)*

Lack of communication with the person concerned as a means of addressing how behavioural issues are dealt with may point to the effects of contingent sets of dynamics influential to the support relationship uncovered by contemporary research findings. It can be suggest that these examples indicate a failure on the part of workers to enable the intellectually disabled person to take control and to speak on their own behalf (Armstrong, 2002) while workers are enabled to maintain control over the outcome of sexualised behaviours in their workplaces (Hingsberger & Tough, 2002). However, minimising support options may also downplay the emotionally ambivalent aspects that infuse the work of those who support intellectually disabled women.

Not supporting Britney to talk to Rosemary may be the way workers circumvent the problem of facing her frustration with their inability to provide her with what she

wants (Sinason, 1992). Adopting a no-support necessary position with Fiona and Helen may be a way of circumventing the feelings of responsibility for the problems created by the lack of a quality of life for these two women that other workers have reported (Mattison & Pistrang, 2000). This idea also fit with the suggestion the review findings raise, that it may be difficult for workers to “think about the meaning of client’s difficult behaviours because of the ‘unbearable feelings’ underlying such behaviours” (Mattison & Pistrang, 2000, p. 155).

A recent research finding notes that many workers lack the emotional support they need to do their jobs well (Cambridge, 1999). In Britney’s case, the following comment suggests that workers themselves lack a supportive environment in which to talk to each other about the issue her support raises.

*Well you talk about it at the (pause) like, oh meetings and things but it’s just sort of made out to be a big joke (M&J 2005, p. 17.)*

Recently an extensive examination has been undertaken of the tradition of involvement of large numbers of women in community and social work practice. Barton (2005) suggests that a large part of the role women play in their support practice is the facilitation of the social control of the conduct of the less fortunate women for whom the services they work in have been designed. Women workers reshape the actions of those they support through modelling culturally acceptable practices of conduct. In the absence of clear support for workers within the intellectual disability or any other service field these traditions, including ‘we don’t talk about it’ convention, will continue to be influential.

### ***The Use of Planning and Assessment Tools***

Another presence of absence noted in these narratives concerns the absence of reference to any planning and assessment tools related to support or care management used to augment assistance. This lack of talk does not necessarily indicate evidence that the women concerned do not have individualised support/care plans or that the processes outlined in them are not being followed. However, it does indicate these support mechanisms are not seen as significant enough to warrant inclusion in worker

talk. This conclusion bears out recent research related to evaluations of long-term planning mechanisms. These studies note that preparing individual plans may only be a paper exercise and that these support mechanisms remains disconnected to the everyday lives of those who use agency services (Cambridge & Carnaby, 2005).

The final presence of absence I note is that any assistive practices, however partial, only apply to women whose appearance and behaviour enable them to be considered as disabled only in '*certain aspects*', or women who exhibit key capacity effects consistent with being physically able and in need of minimal (cognitive/physical/social) support. The (lack of) sexuality requirements of women with high support requirements only features in one talk example. This lack indicates the extent of the social difficulties the '*couple doing normal*' idea presents for considerations of how women in this group are assisted.

## Chapter 9

### *Sexuality Support: Positioning Men*

#### *Introduction*

Chapter Eight deconstructed lines of worker's talk relating to sexuality support for four intellectually disabled women. This chapter probes statements related to the assistance offered to four intellectually disabled men. It explores how significant capacity-related effects held within the 'disabled' aspect of the 'they're not sexual because they're disabled' meta-discourse shape assistance outcomes. It follows the idea that allied discourses of masculinity and (sexual) desire also interlink to further influence how support possibilities are thought through and acted on. It is assumed that key effects of these deployments regulate the production of the culturally intelligible 'choices' workers make in respect of the support possibilities these statements outline. These effects refract through the intensities of passion the '*couple doing normal*' image generates. As in Chapter Eight, the extent to which the influence of discourses of worker's purpose actively deploy within the support options are also commented on. In addition, information found in the literature review and examples given of other worker's talk statements, further verify the influence of these discursive effects on support options offered.

Two support experiences are reviewed. These narratives are explored because they allow for a length of consideration to be given to how interplays of key discursive intersections substantiate practice outcomes. However, they are also included because they concern the activity of the men who live or have lived in the same home in which the four women whose experiences form the vignettes in Chapter Eight also live. These experiences allow for gender-specific points of comparison to link the discursive effects found in both chapters more clearly to the '*couple doing normal*' ideal.

The second part of the chapter probes the unusual position literature review finding outlined in Chapter 3 (e.g. McCarthy & Thompson, 1977). These narratives relate to



aspects of the ethos of care said to play a role in the difficulties affecting women worker's ability to set and maintain manageable boundaries in relation to pro-active assistance. How key discourses and the assumptions they contain construct, maintain and challenge this ethos is uncovered and commented on through probing the operation of a provocative/not provocative binary deployed through these extracts.

### ***Working In-Collusion***

While it is assumed that the outcome of discursive effects construct the social forces through which the support position operates, the idea that worker's talk contains a level of real-time truth about what is going on in daily practice is also probed. These particular narratives also feature because they provide further substance for what the phrase '*in our house no ones terribly sexual*' looks like in this support location. In addition, other statements provide further illustration of how 'real-time' environmental barriers contribute to the responses workers make in respect of those they support. These additional statements resonate with research studies already undertaken and with discussions I had with workers in service training sessions.

### ***Discursive Assumptions and Support Positions***

Samuel is the person whose actions form an aspect of worker's comments about Rosemary's experience. Socially transgressive underpinnings that shaped her position are reflected in the hesitation and uncertainty with which appraisals are made of her behaviour on the lounge floor. In contrast, statements relating to support for Samuel are offered without hesitation, signalling an already-established acceptance of a socially favoured placement that, although at odds with the incapacity meta-discourse, sit comfortably in this location. How this favoured position is created and upheld in this case and what this placement means for worker's assistive practices is probed below. How credibility is sustained through the power/knowledge effects this binary creates is also discursively examined.

***Samuel: 'He Needs Sex'***

*J: ... but Samuel was very ... Samuel would have loved to have sex. And Samuel masturbated all the time.*

*M: it was only when he was in his room and um one of the girls must've walked passed his room one night and said to me "Samuel must be hot because he's got, he's got no clothes on". But you know Samuel quite often slept with no clothes on and masturbated all night because you could smell it and that ...*

*J: ... you could see it on his sheets...*

*M: ... only ever did it in his room and he was quite good about it eh. But he, he actually made a, he actually needed to go and visit a prostitute. He needed to have sex (M&J 2005, p. 3).*

***Creating the Case for 'He Needs It'***

The open declaration, that Samuel '*would have loved to have had sex*', fixes this assumption within wider social ways of doing that uphold and validate this social location as the 'easily normative' (Timms, 2002) position for (capable) men to inhabit. So easy in fact that this statement is offered openly in a place where the effects of a 'talk difficulty' discourse can be a substantive inhibiting support factor. Evidential proof of the validity of this men-are-intrinsically-sexual wider underlying assumptive is tendered through the masturbating '*all the time*' observational descriptor. His ease of fit in respect of this position is further endorsed through linkages to allied bio/physical discursive effects that locate the ever-ready sexual male as an idealised standpoint position in euro-western culture.

More evidence substantiating this noteworthy degree of stamina, although reduced to '*all night*' in a subsequent line of talk, inheres in the next set of descriptive phrases. Here specified attributions of competence continue to shore up this socially favoured placement while they also link to and substantiate the power held in this judgement call. In addition, enabling Samuel's capacity this phrase also reaffirms and upholds a worker-as-able position within this binary (1).

Samuel's place within this assessment of competency is additionally configured through certain material performances that connect his behaviour to key aspects of the

*'couple doing normal'*. Samuel knows what clothing to wear on these occasions, as in *'no clothes'*. He also displays sensitivity to the (normatively) appropriate place for the expression of the actions described as in *'only when in his room'*, albeit that his door remains ajar. Worker opinion as to the length of time Samuel spends showing this now-established *'appropriate-to-gender'* behaviour, matched with additional bio/physical proof indicated by the *'you could smell it'* and *'you could see it on his sheets'* descriptive statements, provides additional reinforcement of the *'he's competent'* placement Samuel inhabits in this scenario. That *'he was quite good about it, eh'* deploys as a final reinforcer of Samuels social as well as physical proficiency. By implication, it also reinforces this worker as savvy about universal ideas related to what is appropriate and what is not in such cases.

However the *'Samuel must be hot because he's got ... he's got no clothes on'* remark attributed to one of the intellectually disabled women who lives in the house, destabilises the pre-eminence of male sexual prowess on which this judgement of competence is based. Although it could be said that *'he must be hot'* is offered as evidential proof of the incapacity on the part of *'the girls'* to recognise the sexualised implication of what is actually going on, it represents far more than that. This remark re-locates Samuel's sexualised/capable placement as an aspect of a mutable binary against which intellectually disabled women are usually located as sexually incapable/naive. The assumed primacy of men's sexual *'need'* driving this narrative can be interrupted by an interpretation of *'hot'* as not physically warm, but as signalling a socio/sexual meaning that covers the possibility of Samuel's behaviour looking sexually inviting to a knowledgeable and desiring woman. As an in-comparison position, the phrase also opens up possibilities that includes a subtle attempt on the part of *'the girls'* to competently circumnavigate the ignorant-about-sex no-talk, *'that's disgusting'* position they usually occupy.

### ***Enabling Support for Samuel***

Whether the workers concerned are unaware of the implications this subtlety contains or whether they are unwilling to entertain what being aware of what competence on the part of *'the girls'* this remark might suggest for their support practice, remains unclear. Whatever lies behind the offering of this remark, how Samuel is positioned in

relation to *'the girls'* is significantly important as this lack position legitimises the 'need' for the *'visit a prostitute'* support option then mooted on his behalf. The underlying hetero-centric orientation of the *'couple doing normal'* upholding the *'visit'* suggestion deploys through use of the term *'prostitute'* as a global rather than used in conjunction, as in either male prostitute or female prostitute. This use draws on wider discursive assumptions that link this assessment to a further series of effects that make it almost impossible to imagine that Samuel would visit a man for this purpose.

The term *'visit'* also deploys a social seal of approval by (women) workers on an action that remains culturally questionable for at least some women, if not for some men, in New Zealand society. The exposition of the more social aspect of this view, as *'visit'* rather than the more materially exploitative *'use'*, also occludes any difficulty that can ensue for the woman whose body is being *'visited'* so to translate this suggestion into action, as this excerpt from another worker's talk statement suggests.

*Now unfortunately a year or so ago ... the Hometown scenario ... where a person wanted it so they sent him to an accommodating home in other words they sent him to a parlour or whatever ... that got out of hand (P&G 2005, p. 10).*

### ***The Influence of Individual Purpose***

To what extent discursive effects of individual purpose assist in shaping the support response offered in Samuel's case is debatable. The phrase *'visit a prostitute'*, while ensuring that the image of the *'couple doing normal'* is as fully upheld as possible, also ensures that no part of this ideal will be accommodated in this domestic setting. However, what part of this outcome is attributable to workers purposeful intent and if so what that intent encompasses, is a question that is difficult to answer. Do workers advise the off-site *'visit'* to ensure that *'the Hometown scenario'* does not take place with one of *'the girls'* in the house they work in? Do they choose to support this option so to protect intellectually disabled women from the possibility of emotional exploitation, as suggested by this other worker's comment?

*I would like to be able to think that those men that she's choosing are, um, going to be able to treat her right, you know, to know that she's going to be safe. Safe to be able to share her feelings and emotions without any, um, you know, anger management. Just the things that these young fellows might, might have (J 2005, p. 11).*

Samuel's open door could be taken as indicating an invitation to the women of the house to choose to enter and take part in what is going on 'in his room'. The 'he must be hot' phrase could be interpreted as this woman showing an interest in being supported to participate in a sexual experience offered in a non-threatening way by a competent, caring individual who is also trying to circumvent the twin no-sexuality-no-talk positions that are the unwritten rules of a service agency group home. In addition, that this example is offered suggests that Samuel's behaviour has raised issues for consideration. Have workers considered this more sexualised perspective? At what point was recognition that other kinds of assistance could be possible shut out of worker's support deliberations? While these questions are impossible to fully answer in this case, other comments taken from other lines of discussion suggest that influences beyond any one individual worker's direct control may also affect possibilities of alternative, more generative support positions being adopted.

*His family didn't mind him forming a relationship but he had to be with someone without a disability (J&J 2005, p. 6).*

Another workers comment suggests that working through these external influence issues can take time.

*They would love to get engaged and get married and ... but no way can they do it while the two great aunts are still alive (J 2005, p. 15).*

### **Further Discussion**

In Samuel's narrative power/knowledge effects relating to key aspects of the 'couple doing normal' ideal inhering in larger discourses of heterosexuality, privacy and penetration interlink within the already-existing 'men need sex' meta-discursive assumption (Bell 2005). These effects create the space that allows room for Samuel's

competent placement in this narrative. This socially favoured judgement call provides a stark contrast to the appraisal of the position of the intellectually disabled women covered in the previous chapter. However, while Samuel's 'need' is easily recognised, this recognition only provides access to the idea of support for a very limited set of mechanistic experiences that are to take place away from the home he lives in. To what extent discursive effects of worker's individual purpose motivate this recognition and the solution offered cannot be definitively gauged as these effects interweave within multiple wider social ways of doing that also uphold this support suggestion.

***John: 'He Doesn't Need Sex'***

In contrast talk statements about John reveal a substantive difference to textual statements held in the prior narrative.

*M: ... he actually doesn't need companions... he's quite happy by himself*

*J: John's not interested in friends or...*

*M: ... he has to be pushed to do things or otherwise he'd quite happily lie on his bed all day. Everyday.*

*J: No, no he's got no preferences as long as someone's there and he's going to get his tea.*

*M: He's got no loyalties at all*

*J: No, no (J&J 2005, p. 6).*

These statements reveal the comments offered as framed through the already established incapacity aspect of the 'they're not sexual because they're disabled' meta-discourse. These effects also create and uphold the workers 'knowing' position. How the no-support needed outcome inhering in this vignette is shaped, to what extent discourses of worker individual purpose might drive the no-assistance-necessary outcome position they ultimately occupy and what assumptions these discourses might contain is probed below.

### ***Creating the Case for ‘He Doesn’t Need It’***

In the initial statements that frame support for John, incapacity is initially verified within the ambit of a series of allied “psychological mechanisms” (Vance, 1989, p. 14) discursive effects that uphold key aspects of the *‘couple doing normal’*. These assumptions at once undercut the socially favoured ‘men need sex’ assumption already-substantiated through John’s being-male position. Further, they substantiate the power of the knowing worker through which these no-support necessary appraisals are referenced. Being uninterested in *‘companions’*, *‘in friends’* or in independently doing *‘things’* verifies the lack of emotional interest John is said to show against the binary of emotional engagement that configures the rationale for the sexualised behaviour of the ideal couple. Lacking these vital social mechanisms enables the unfinished *‘or’* of the second statement to make room for a further unstated assumption, that John would probably not be interested in being supported to have a sexual relationship either. Being positioned as incapable of *‘loyalty’*, a highly esteemed social quality, additionally endorses the incapacity placement. It is then just a short step to a final assumption, that any co-productive values and attributes usually associated with *loyalty’*, such as caring, fidelity, trust and liking, are also likely to be lacking. Therefore support for John is really going to be unnecessary, with the second *‘no, no’* statement validating the probability of this position continuing over time.

Power/knowledge effects inhering in the incapacity meta are also verified through the portrayal of John *“happily lie(ying) on his bed all day, everyday”*. This image provides a linguistic reinforcer for the already-present socially incapable placement while also hinting at the idea that physical adherence to the *‘couple doing normal’* image is not going to be possible for this (sexually) docile body to achieve. The absence of an actively masturbating body that works in Samuel’s favour creates a final perception of this individual as socially and emotionally passive, only noting in a general way if *‘someone’s there’* and when that someone *‘gets his tea’*. The intensities of passion inhering in the unstated presence of the *‘couple doing normal’* these talk statements draw on, testifies to the power of this image to create these support responses. Further this image overrides possibilities of alternative interpretations being made of John’s social or physical prowess. In addition, these appraisals are

further fostered by the appearance of wholehearted agreement between these two knowing workers.

However, the assumptions that ‘stitch up’ (Guy & Bamin, 2000) worker’s support practice in this case occlude a material reality, that of John’s physical ability to conform to key aspects of the ‘*couple doing normal*’ image. As the following excerpts show, the continuing presence of favoured attributes that remain outside of the John-as-lacking universalised view create difficulties for the ongoing maintenance of the no-support–necessary position. These difficulties are unpacked through probing subsequent lines of discussion about John’s responses. How far the John-as-lacking impression deploys power/knowledge effects of workers individual purpose is also investigated.

### ***Unpacking the Discourse of Worker Purpose***

The following statements describe an incident relating to John’s past behaviour. These remarks cut across the lack of strong emotional states of mind and passive body image initially established in prior lines of discussion. This fracture reveals a series of allied discursive effects that lie beyond the ‘he’s passive’ assumption that configures the initial judgement call.

*J: I used to be scared of him ... the first time he started running through the house and throwing things through the window ... and clapping and screaming ... I thought “Oh my God”. I was like this ... (shows fright)... But you actually get used to it.*

*C: So what made you stay that day?*

*J: You have to. You’re the only one there (both workers laugh)*

*(J&J 2005, p. 7)*

A strong sense of capacity for emotional response underpins the ‘*running through the house*’, ‘*throwing things through the window*’ and ‘*clapping and screaming*’ descriptors. These statements draw their negative force from a what-normative-behaviour-in-a-home-ought-to-look-like binary echo, as in waking through the house, leaving windows alone and keeping noise levels to a minimum. The socially



transgressive placement these actions inhabit are so strong that they evoke an initial ‘*Oh my God*’ fear response.

### ***Exploring the Fear Response***

This ‘fear response’ correlates well with findings of the negative emotions some workers can experience in relation to incidences of socially transgressive behaviour (Mitchell & Hastings, 1998). Literature review studies note that such responses fall into two broad categories: depression/anger and fear/anxiety. Here, it is not clear which emotion guides this worker’s initial response. Does John’s ‘being a man’ means that this behaviour is harder to bear for women workers than similar behaviours exhibited by a man? This worker’s strong response decreases over time as she ‘*gets used to*’ the times when this behaviour takes place. Yet what the emotional costs are when workers are ‘*the only one there*’ during such incidents is difficult to quantify. Thus, it is difficult to assess how much this emotional response might influence subsequent purposeful deployments of a lacking/passive assumption and its no-support-necessary outcome.

Other worker’s statements suggest there may be a definite strength of purpose behind women workers in particular seeking to minimise the potential for the men they work with to develop competencies in areas that contain strong emotional and physical responses. A worker outlines behaviours she negotiated on a daily basis with the man she worked with in the following statement..

*Every shift I had, he would smash a window or smash his glasses. We had to wait 2 to 3 days to get his glasses fixed ... if he couldn’t break his glasses there was always something else to break. Throwing things through the window, um we put perspex in the window, and when he threw things they actually bounced back, which was funny at the time but ...(laughs)... wasn’t fun because it inflamed the situation ... I think I put up with that sort of nonsense for about two and a half years (C 2005, p. 5).*

Some workers being interviewed laughed during or at the end of recounting incidents where the potential for physical harm in relation either to themselves, the people concerned or other people who lived in the houses, featured in their responses. As it

is clear that *'that sort of nonsense'* must have been no laughing matter at the time, this response provides some sense of the strength and complexity of the emotional ambiguity these behavioural difficulties can create. This laughter may also indicate that aspects of these emotional responses continue to be felt by some long after the actual event. In this context, the laugh could also indicate this workers sense of shame and embarrassment at having to recount that such actions had been commonplace in her work environment and that she had not been able to change these circumstances. However, what this excerpt also reveals is that putting *'perspex in the window'* constitutes neither a suitable support option for the intellectually disabled person concerned nor a safe and supportive work environment for this agency service employee.

### ***The Isolated Worker***

It is usual for workers to spend periods of time in agency service group houses on their own. Although two workers support the household during the day in John's home, only one works overnight. While workers are told to contact their manager when problems occur, managers are not always available to assist. In some small towns line managers can live least an hour's drive away from the homes they manage. Experienced workers develop skills to be able to diffuse times of tension.

*If they're already grumpy you know that something's not quite right. Just keep an eye on it and you can actually steer them away from the others because you've got to protect the others as well as yourself (C 2005, p. 4).*

However, this is a competency new workers need to learn. Many acquire coping skills without significant guidance and this may be a factor in why review findings have indicated that some workers can initially find the job difficult (eg Test et al., 2003). It may also indicate why, if they choose to continue in the position, workers may end up appearing to be emotionally distant from those they support (eg, Felce, 1998). Workers who stay *'get used to it'*, but the cost of these initial experiences for some worker's subsequent level of pro-active support in areas of strong emotion may be high.

### ***John's Narrative Continued***

Further talk about John reveals that one response to the difficult behaviour outlined has been for the agency concerned to provide additional support hours during the day (*M&J 2005, p. 1*). This arrangement and the consistency of the support offered, has enabled John and the workers to build a degree of trust in their relationship. A few lines further on this comment is offered, suggesting interactions with John have become easier to navigate.

*He's just a big, gentle pussycat really (J&M 2005 p. 7).*

At this point talk turned to a different topic, again leaving an impression of the physically docile, emotionally disinterested perhaps even feminised John the first talk statements create. However, this further remark is offered near the end of the discussion.

*M: We thought he wouldn't, there would be nothing going on in that direction, but there is, isn't there or we discovered that...*

*J: ... just recently. Yeah it freaks me. I didn't even... (J&M 2005, p. 21).*

This contradictory line of discussion once again fractures the emotionally disinterested, docile John image, while it also reveals the anxiety/fear that continues to infuse this dynamic, despite the '*pussycat*' remark. Whether what is '*going on in that direction*' indicates a potential for sexualised behaviour remains unspoken, thus what the possible implications are of what workers have '*discovered*' is left unstated. However, the '*freaks me*' descriptor indicates that a depth of feeling accompanies this change in perception (2).

This feeling raises some queries relating to the points made in the literature review about the ambiguous role women workers play in the lives of the men they support (Brown, 2000). Does what might be '*going on in that direction*' produce a 'threatening-John' scenario in this worker's mind, one in which John becomes as interested in who produces his tea as he is in the meal itself? How disturbing is the

idea that John might begin to display a being-capable position specifically in the sexuality area? While these questions cannot not fully answered in this narrative, other worker statements uncover an area of vulnerability within support practice hinted at in these brief remarks.

### ***Exploring Worker Vulnerability***

To what degree the behaviour of intellectually disabled men who live in group homes may be a source of anxiety for the women who work in them remains an open question. Most interviewees made no mention of times where they felt unsafe. Yet this presence-of-absence is set against the lack of a safe and supportive work environment finding, as well as findings that suggest that reported incidences of sexual abuse in particular seem to decrease “the further away from individuals with learning disabilities a researcher goes for information” (McCarthy & Thompson, 1996). Although unusual in the talk statements gathered, this excerpt indicates a difficulty one worker faced, as the only person ‘on’ in her workplace late one night.

*(He) came to the door stark naked. And I was stuck in the staff room ... I said “Look, this is my area, you go back to your room” ... while I was talking I was unlocking the window ... Don’t ask me how I was doing it ... and the person just stood there with this sort of glare in his eyes ... I just said to him “Look this is not good at all. I would not support you with anything. Go back to your room” ... and he did.... and I locked the door (J&J 2005, p. 12).*

This excerpt uncovers an area of potential vulnerability for women workers and the men they support relating to problems inherent in workplaces in which a powerful ‘men-need-sex’ assumptive shapes appraisals of the behaviour of intellectually disabled men, where rates of sexual abuse are high, where workers are ‘the frontline’ in respect of the possibility of abuse taking place and where agency service providers neglect their obligation to provide a safe and supportive work environment for either their employees or those who live in the houses they manage. The next excerpt suggests that workers have limited input into key process decisions made in relation to some of the circumstances in which they operate, even when the outcome of these

decisions may directly impact on aspects of their emotional and physical wellbeing while on the job.

*We've got one of our service users that's in hospital at the moment. And he's schizophrenic and his family said that over Christmas he's like a zombie. And they've said well, to his doctor they want him off some of his drugs. Now that frightens me a little bit that they have decided that he's like a zombie. Which he probably is but how much... So when he comes back with everybody's ... its written in the book, and they'll be aware that when Len does comes home that they've reduced his drug intake. Now we don't know what the reaction will be so it will become busy here (laughs) who else is on with me? (T 2005, pp. 10-11).*

### ***John's Narrative Continued***

Although one interpretation of statements about John's recent behaviour is that his actions raise levels of anxiety for workers, brief remarks made at the end of the interview indicate that whatever might be '*going on in that direction*' in respect of the presence of any discourse of capacity and the anxiety this set of effects may cause, is once again masked.

*M: He's got no attachment or feelings whatsoever, he's autistic so ...*

*J: So we've never had a sexual issue with him with anybody and probably never will I would say (J&M 2005, p. 25).*

In these statements prior fractures to the passive-John '*pussycat*' image are subsumed within a redeployed '*there's no issue*' knowing-worker assumptive position. Any behaviour that might link John in a sexual way to either worker safety or the safety of those who live in the house is also subordinated through '*with anybody*' global assertion. Thus any future assistance to develop an intimate relationship is largely discounted as referenced by the '*probably never will*' statement. Any necessity to deal with any potential difficult-to-negotiate behaviours that an emotionally attached and feeling John might want to show are sidelined through a continuation of the no-support necessary position, upheld through '*he's autistic*' remark. Yet, what also becomes shelved are possibilities for future support options that take into account

what the workers have discovered, here presumed include some material evidence of a sexually able, capable individual.

### ***Further Discussion***

Allied wider social ordering effects related to the performance of certain levels of physical and social competence that foster recognition of ‘actively male’ status in respect of the ‘*couple doing normal*’ influence how the men workers support are assisted in these two narratives. In Samuel’s case, discursive effects that shape ‘being competent’ and ‘being male’ enhance attributions of capacity that enable an unqualified endorsement of active sexual status. However, these effects are also bound up in other very specific wider social ways of doing that ensure that maintenance of this status is only guaranteed in respect of his ability to sustain the ‘in private’ aspect of this social imperative. In a service agency residential home, however, it is suggested that in private will only equate to off the premises, as can be seen by this remark offered during a point of discussion where it is revealed that Samuel now lives in another house.

*C: So what happened to Samuel?*

*J: Oh he went to another house ...*

*C: Because of this?*

*J: no, no... (J&M 2005, p. 8).*

How much assistive options might have been offered and then withdrawn by purposeful workers for their own ends in respect of Samuel’s support in the house they work in cannot be fully quantified. Thus, how much Samuel taking his display of sexual competence out of his bedroom and into the lounge with Rosemary became a factor in this relocation remains an open question. Nor can it be stated exactly what the ‘*no, no*’ response conveys in this excerpt, apart from a negation of this possibility as offered in an interview setting.

In lines of narrative about John, a lack of capacity relative to key aspects of social and physical competence discursive effect fractures the power of the ‘being male’ assumption to influence the ‘no sex because they’re disabled’ meta position

intellectually disabled people usually occupy. Whether ‘*no feelings and no attachments*’ is purposefully constructed by knowing workers or discursively deployed through the worker position cannot accurately be pinpointed. However, what can be suggested is that linguistic inconsistencies in the lines of talk may indicate that part of the no-support-necessary position worker’s adopt includes actively not wanting to support the idea of a sexually capable individual.

Causal factors influencing the adoption of this position include how to address issues of personal and emotional safety in their workplaces when workers offer assistance in the sexuality area. The next two statements outline a specific apprehension related to being asked to assist in the sexuality support area.

*We were talking about assisting someone so that they could masturbate and you put yourself in a position where perhaps it could be misconstrued ... our guys say a lot of things and you need to assess are they just saying that, or did it actually happen (C 2005, p. 13).*

The following excerpt reveals another aspect of this apprehension, touching on a further vulnerability the shaping effects of discourses of heterosexual desire contain for women workers and the men they work with.

*We did have this client who was um, ah, um, used to be quite up in arms at times. And so our manager, this is years ago, said to us when it first sort of started, suggested that “Well, maybe he’s frustrated”. Maybe he needed one of us staff to teach him how to masturbate so that then he could um, get all his tension out. And we sort of, us female staff sort of said “Oh no, no”. And I sort of, yeah, you know I don’t mind you know if he does it himself in his own area and place and time but, um in his bedroom or wherever. But um, when it comes to female staff showing male clients how to do it, no. No way. Because he, he would then probably like, get to like it and, and um want us to do it all the time (J 2005, p. 14).*

In this example, the response of the ‘*male client*’ is focussed on, while the binary effects of this position on support outcomes remains unexamined. Thus the idea, that workers too might ‘*get to like*’ it does not enter as a point of discussion.

### ***The Being/Not Being Provocative Binary***

The second half of this chapter moves away from initially uncovering discursive effects that shape support responses within a residential home setting to probing the allied effects that shape interactions between women workers and the intellectually disabled men they work within a wider agency setting. The probes reveal how key interplays of discourses of femininity, masculinity and (sexual) desire shape worker’s support performance. These effects interrelate within the meta-discourse of incapacity to sustain the presence of an ‘ethos of care’ (McCarthy & Thompson, 1977) through which worker actions and the actions of the men they work with become intertwined. How these effects influence how sexuality support is either enabled or constrained is followed through a not/being provocative binary found within lines of discussion. Specific discursive effects related to the degree of individual purpose are also explored.

#### ***‘He Liked Big Boobs’***

*Lance was autistic and he liked nice looking women and um when we worked there you couldn’t wear a lot of white blouses, see-through clothes. He loved white shirts because he could see your bras and everything and so we realised what was setting him off and so staff sort of had to... We were careful about what sort of clothes... You know, especially in summer, brief little tank tops and things which was a shame cause you get hot and things. But you know we just wore a bit more respectable shirts and things like that that he couldn’t see through and ... a new staff had started once. I walked into the lounge and he was cuddled right into her chest as hard as he could because she had whopping big boobs ... we realised what was setting him off and so we just wore a bit more respectable shirts (J 2005, p. 13).*



In this narrative Lance's actions '*in the lounge*' of his residential home are recounted. Key prior assumptions about behaviours deemed usual between individual men and woman who are not in a '*couple*', that is who are not in an intimate relationship, provide a central point of departure for the socially transgressive judgement call made about these actions. These effects interlink to Lance's already-established subject position, reproduced as '*Lance was autistic*', to create and uphold a universalised not-knowing subject position. However, while this binary (re)creates the non-favoured/lack position, it remains mutable in that aspects of this placement can also be seen as advantageous. These 'lack' effects also enable these actions as construed from disabled rather than deviant sources. How specific effects inhering in this disabled-as-positive position destabilise the pre-eminence of the 'abled' location women workers usually inhabit in relation to the men they support is unpacked below.

### ***Isolating Worker Responsibility***

Positioning this person as not-knowing centres attempts to resolve the social difficulty being on the knowing side of the binary this vignette exposes. '*We just wore more respectable shirts*' becomes the socially responsible 'choice' made by those who know, i.e. workers, in respect of the social difficulty created by these transgressive behaviours (Carahine, 2001). Here discursive effects of 'abled' draw on allied effects related to legal precedent. These effects specify the obligation of any reasonable person faced with a significant social disruption initiated by someone who has been already-judged incapable. This placement is important because if Lance was judged as knowing, these actions could constitute sexual harassment. As he is not to be held competent, it must be what workers do that creates the problem. Thus in this instance, '*autistic*' becomes a vital social tool for Lance and the workers concerned as it protects both from any significant civil consequence of this social breach. '*Autistic*' ensures that Lance is not a perve, thus should not be treated this way, while it marks workers as the responsible party.

However, while '*autistic*' influences the actions of all concerned, just wearing '*more respectable shirts*' as a support outcome points to the influence of allied sets of discursive effects that also shape worker behaviours in this location. How these

effects might limit the extent to which workers can respond in other ways are considered through a series of allied discursive effects related to gender.

### ***The Gender Influence***

The '*nice young women*', '*bras*' and '*whopping boobs*' remarks activate discursive effects related to a 'typical male' subject position. These effects reveal Lance as capable in respect of certain specifics that associate the presence of particular female body parts to wider bio-physical and socio-cultural discourses of heterosexual male desire. These effects interlink within wider social ways of doing that valorise '*nice looking women*' and '*whopping bog boobs*' as a key element to a socially successful enactment of a material instance of the '*couple doing normal*'. Further endorsement of this position is upheld by the domestic setting in which this behaviour is located. These effects disrupt the assumption of reasonableness and rationality that initially verifies the worker's in-control 'choice' position, revealing the interrelationship between Lance and these women workers as moulded by the differential power/knowledge effects of wider social ways of doing. These consequences include the ambiguous position all women inhabit in relation to a socially favoured 'desiring male' image.

The strength of this position is located through the remark that suggests that covering up is not the wholehearted choice of all workers concerned, but is also is '*a shame cause you get hot and things*'. This sense of shame pinpoints the (un)acceptable aspect of the binary through which adult women's bodies can be viewed and the physical and social discomfort women can experience as a result of this ambiguous placement. Senses of shame cohere around the assumption that workers might be leading Lance on '*because he could see your bras and everything*', thus shaping these worker's 'choice' of response in this case.

### ***Probing Worker Purpose***

The '*we just wore a bit more respectable shirts*' action addresses the cause of Lance's behaviour, initially upheld as one of social incompetence, albeit through a 'no fault' assumptive position. However, further statements reveal worker's adopting other

strategies in their subsequent interactions with all the intellectually disabled men they work with in a day service.

*We tried not to cuddle other clients in front of Lance ... we tried to slowly cut it out, but we had one [other] male client that wants big cuddles straight away ... and he couldn't understand and thought "Oh what have I done?". So you try to give him, in the morning when he comes in ... "Hi, how are you?"... give him a quick cuddle and then "Oh no, no, no too busy, too busy the rest of the day for any cuddles" ... and one at the end of the night, but not always in front of Lance (J 2005, p. 7).*

While the actions of purposeful workers remains the dominant image, the behaviour of the one 'male client' who 'wants big cuddles straight away', cuts across the in-control/socially adept worker position that frames this text. The interplay between this 'client' and the woman workers concerned depends on the continuing presence of gendered effects that re-shape who is considered adept in this environment as a binary through which the subsequent actions of the 'male client' and the workers concerned are located.

Noting the other 'client' as 'male' reveals how the 'set-off-by-women' assumptive wields considerable influence in the interchange between workers, Lance and the other intellectually disabled men. These effects challenge the universalist position from which workers try to 'slowly cut it out', while they also contest the extent to which the 'clients' are fixed in the not 'understanding' category position. In so doing what is exposed is the vulnerability of both groups to the operation of a powerful social truth that suggests that actions related to giving and receiving 'cuddles' by men and women in euro-western society will contain different social messages (Agustin, 2005).

This vulnerability may pose future difficulties for all concerned. For example, the 'other client' may intuit a mixed message from this change in behaviour. Now he sometimes receives wanted physical touch out of sight of at least one of the other men present. In the absence of other information and in the presence of what could be seen as a precursor in-private expression of the couple ideal, this man might view this

change as special treatment with romantic overtones, a sign of a particular sexualised affection for him on the part of the worker concerned. Whether workers make sense of this binary position is probed in the following statements.

### ***Probing the ‘Affectionate Nature’ Discourse***

Further worker talk reveals a breadth of understanding of the social difficulties ‘cuddling’ can produce, as the following statement suggests.

*I’m a cuddly, kissy person and I’ve got a few friends and they are too, and we don’t kiss the clients ... we went through a stage where cuddling the clients wasn’t allowed ... but they (the clients) don’t understand that because they see us as really family and friends, a family/friend member... and when I see my girlfriend and when I leave her um, we cuddle each other you know. And if it’s at the flats or something and they, and we do the same to them as well (J 2005, p. 8).*

In these statements an underlying, universalised ‘females-are-affectionate’ series of bio-physically related discursive effects inhering in the ‘cuddly, kissy person’ descriptor, deploy to legitimise ‘cuddling’ as actions intrinsic to the genetic makeup of all women. Thus this action should be recognised as socially acceptable in any circumstance. The global placement this position locates is additionally authorised through the example of this worker and her ‘girlfriend... cuddling each other’ at the end of a period of being together. That this position is posed as universal is further reinforced by statements about the actions of the other presumably female friends, who ‘are (cuddly, kissy people) too’.

The ‘we don’t kiss the clients’ remark additionally substantiates ‘cuddling’ as (normal, female, non-sexual) affection rather than a display of any sexualised behaviour on their part, while negating any ‘leading-him-on’ implication the more suggestively sexual ‘kiss’ term might imply. However, while these statements validate and uphold a non-provocative purpose behind ‘cuddling’, the fixed binary on which they rely is undercut by elements of the ‘couple doing normal’ ideal that ensures that any up close and personal aspect of ‘cuddling’ between women and men will also

contain a potentially sexualised position. Just by re-siting '*the clients*' within a series of '*family and friends*' non-sexual power/knowledge effects placements does not alter the power this series of sexualised discourses contain.

### ***Going Beyond the Service Environment***

That the '*we went through a stage where cuddling the clients wasn't allowed*' remark also appears in this narrative hints that a more-than-affectionate aspect of '*cuddling*' has also be considered. Subsequent talk statements reveal further actions and responses concerning Lance and the workers who support him. This part of the narrative explores support practices initiated in response to what is happening outside of the service environment.

*We got pictures of mum and dad and um his sister and um "That's what you do to mums and not to, you know other ladies and not to..." yeah, cause he would go up to people in the street and everything as well. So we did a lot of training and teaching on he can't do that to other people and when you met people you shook their hands (J 2005, p. 11.)*

Whether the '*people*' Lance approaches includes men as well as women is not indicated. What kind of actions these approaches involve, thus whether they might include '*cuddling right into her chest*' remains an open question. However, the '*that's what you do to mum's' and not to, you know, other ladies*' phrase indicates the likelihood that it is women rather than men who are being approached, and that that the reactions of these women have not been shaped by cuddling-as-affectionate discursive associations. The '*we just wore more respectable shirts*' and '*we tried to slowly cut it out*' do not fit the '*in the street*' location, thus '*training*' to (re)shape Lance's behaviour into more socially responsible responses is undertaken. Pictures of his '*mum and dad and his sister*' are obtained as tools to teach an aspect of what ideal masculine behaviour related to blood-kin/non-blood kin appropriateness in certain cultural settings in New Zealand society constitutes. It is reported further on that it is now easier to work with Lance in community locations (J 2005, p. 8), the overall justification for the support strategies adopted in this case. However, while this behaviour is now seen as more in keeping with the requests of certain social

environments, questions remain about useful these strategies will be in the service agency environment in which Lance and the workers operate.

### ***Further Discussion***

In this vignette allied in/capacity and gender related discursive effects intertwine to create a complex and difficult picture of the wider social ways of doing assumptions that shape support possibilities. Gendered effects infusing these possibilities expose the in/capacity meta-discourse as a series of fluid effects that determine the actions of both Lance and the women who work with him. For Lance this fluidity is generative, finally allowing for a partial acknowledgement of competence, thus for a vision of this individual as a person who can be supported to take on some aspects of a socially acceptable adult male role. '*Shaking hands*' on meeting '*people*' who are not family members provides a socially favoured way of acknowledging Lance's (male) adult status. It also addresses the idea that Lance's behaviour may be more indicative of his desire to assert a masculine identity than it reflects a series of assumptive positions that make all '*cuddling*' behaviours men exhibit symptomatic of a request for an overtly sexual interaction (Clements et al., 1995). Yet it is not clear how far Lance will be supported to move forward from the "(hetero, upper-class, while) man" (Lambevski, 1998, p. 206) '*shaking hands*' response he has been trained into.

Despite the idea that intellectually disabled men can also display sexual behaviours that are socially difficult because of the absence of an ongoing, regular sexual partner (Thompson et al., 1997), nothing is said that might suggest whether supporting Lance to engage in a sexual relationship has been discussed either among the worker's concerned or with Lance himself. This does not necessarily mean that no discussion has taken place but that this option is not mentioned is indicative. While this way forward remains untapped, that idea that this intellectually disabled man's socio-sexual development remains severely compromised continues to remain unexamined.

The fluidity of the meta-discourse does not impact as favourably on the worker position. The wearing '*more respectable shirts*' phrase infers that workers alone have the power to decentre and change these discursive positions. If they do, this interruption is only partial and only operates within the ambit of the agency service

environment. Even in this environment behavioural change does not interrupt deployment of the power effects of wider social truths that invest women's bodies as the objects of male desire. Any '*respectable shirts*' type changes workers make continue to uphold these difficult social ways of doing while the behaviour of the '*male client*' who wants '*big cuddles straight*' remains an unsettling issue that continues to be shelved at agency level and beyond. While the effects of gender remain occluded it is impossible to fully address how these and related wider social ordering power positions are to be managed in a space that is at once a workplace and a domestic environment.

### ***'The Too Hard Basket'***

The final vignette outlined below gives some indication of how the physical and emotional safety of workers and the men they support is compromised when the wider social effects outlined above remain unexamined and unresolved in a service setting.

A worker recounts being touched '*on your breasts*' when she arrives at a residential home to begin her shift.

*"Ken gets his hands on your breasts. But I just take his hand away. I just take his hand away. 'Cause he's quite tall and I notice that if he has it, you take your hand away from there as well. And he's "Oh I'm so happy to see you" and you say "Don't do that Ken"... and sometimes it gets a bit you know, you know, even if you want to. Yep I just take his hand away but I wouldn't say that it was, that I was threatened by him or anything. No way. I just take his hand away (laughs) (T 2005, p. 9)*

Initially the worker describes being touched on the '*breasts*'. However, as the description lengthens behavioural details become hazy, hinting that a beyond-control series of discursive effects also infuses the 'choice' of assistance offered in this case. '*That if he has it*' does not clearly indicate what '*it*' is, neither is it clear who takes whose hands away from what other areas of whose body, not why being '*quite tall*' might be a significant factor. The reported '*I'm so happy to see you*' phrase could be read as this worker recognising the effects of a 'leading him on' discourse that enters the house along with her presence, and the vulnerability of both parties to the

outcomes this social position creates, despite the denial. While the '*sometimes it gets a bit you know, you know, even if you want to*' phrase is particularly enigmatic, it also signifies that the '*I just take his hands away*' phrase covers the effects of the more vulnerable, in-capable position this worker simultaneously occupies.

### ***Further Discussion***

In this statement the in/capacity meta-discourse frames the worker-as-competent position as a counterpoint to the incompetent placement in which the behaviour outlined is sited. This binary fixes the worker's 'choice' of response firmly within the capacity side of the binary. This location is upheld in this narrative through the professionalised, detached, descriptor tone that initially implies that these encounters should be matters about which it is just common sense to assume that no big issue needs to be made. This assumption validates the support response offered, a simple re-direction away from the points of contact. However, the capacity effects of the rational individual that upholds and validates the social value of this action is fractured by key movements of powerful allied gender effects also contained in this interchange. These movements limit the extent to which the support responses outlined might be viewed as a purposeful and in-control worker response.

This narrative contains no further support considerations beyond the implementation of the hand-away response. While it can be suggested that this worker has put the support needs of this intellectually disabled man into a too-hard basket, the repeated use of the hand-away positional phrase raises possibilities that allied power/knowledge effects also influence this worker's seeming lack of consideration. While '*I just take his hand away*' sites the worker as the thoughtful instigator of this action, alteration of the '*I*' to '*you just take his hand away*' also alters the assumption that it is this worker's purposeful choice that limits the assistance given. Does this phrase indicate that conversations have been had with others about this support dilemma? Has this worker been told, 'all you need to do is take his hand away' by another authorising agent? If this directive has come from a line manager, for example, it may be difficult for the worker to begin to initiate other support options.



This narrative marks how prior-existing in/capacity and gender related discursive effects interweave to reproduce the social and emotional complexities in which both parties operate within this support environment. It reveals how a fixed incompetent/competent binary position becomes stitched up in ways of doing that inhibit adoption of support strategies that would respectfully address the problems this interchange involves.

Unpacking the discursive effects these lines of discussion contain raises a number of salient issues about the lack of quality of agency support at least some adult men who use this agency service receive, as do all the narratives contained in this chapter. However, this excerpt in particular substantiates literature review remarks about the lack of esteem in which the support position is held (Marks, 1999). If a woman member of the public came to the door of this residential home and was touched '*on the breasts*' would '*training*' then become a priority for Ken? At what organisational level would this action be authorised? And what further allied power/knowledge effects might the wider consideration of such an authorisation raise?

### ***Chapter Summary***

These excerpts reveal that sexuality support outcomes for intellectually disabled women and men who live in agency service accommodation share several key qualities. While 'being disabled' is a major drawback to pro-active support initiatives, demonstrating key physical, social and emotional competencies that substantiate the development of the '*couple doing normal*' image allows both men and women to present a challenge to this placement, thus to be viewed as potentially capable in this area. However, significant 'being male' discursive effects increases the likelihood of this potential being translated into consideration of pro-active support options. In addition, 'being disabled' can hold a socially favoured position for intellectually disabled men in that this placement enables women workers to set aside the socially transgressive implication of some actions, as this further comment suggests.

*A young man who goes to a daybase and ... he'll often go up and hug them and pelvic thrust them. And I remember when he did it to me for the first time, not realising that that's just what he does (C 2005, p. 20).*

Yet the benefits of downplay, ignoring or misrepresenting the sexualised meanings these actions can contain are outweighed by the difficulties not addressing these testing behavioural interchanges within the support context can create for the support relationship.

As comparable sexualised behaviours by intellectually disabled women are less likely to occur or to be interpreted as socially favoured in a similar way, this point of access to enabling considerations of assistance needed is less likely to provide similar outcomes for intellectually disabled women. Non-disabled men are rarely employed to assist intellectually disabled women, thus it is impossible to quantify how a lack of access to men support workers might compromise intellectually disabled women's chances of being supported to an improved quality of life in the sexuality area. Even noting this lack as a issue worthy of consideration is problematic, engaging as it does allied power/knowledge effects that configure longstanding, already-held powerful negative assumptions about the suitability of fit between the social fact of 'being male' and the close, personal nature of support work. Power/knowledge effect outcomes relating to the sexualised aspect of 'being female' and the up-close nature of some support work are rarely considered, making the task of addressing and resolving the difficulties outlined in this chapter more difficult. However, at least some women workers realise that the gendered aspect of their relationship with the men they support can influence their actions and that this issue needs their more considered attention, as this comment reveals.

*You just make sure you don't go beyond your expectations.' Cause that's not what they want from you (J&J 2005, p. 22).*

How women workers ensure that they keep within their boundaries of expectation when 'what they want from you' can represent a hugely complex set of socio-cultural understandings. These understandings mean different things to different people and

both workers and intellectually disabled people can have limited control over how these understandings influence support outcomes. How to work with understandings of sexualised behaviour that encompass the requirements of all who inhabit the support environment is an issue requiring the input of all agency personnel at all levels of the service structure.

### **Footnotes**

- 1) *As Rapala & Manderson have recently suggested, duration may not always indicate evidence of “superhuman sexual performance (2005, p. 175) rather it may be indicative of some performance inadequacy.*
- 2) *In a supervision meeting I was asked why I hadn’t probed the interviewees further at that point. At the time I found what was being said extremely difficult. I was deeply shocked at the lack of meaningful support anyone in this home/workplace, including the worker’s concerned, was receiving from agency service managers. I also came to the realisation that I had until very recently been part of this wider group, and I too had done nothing. I recall thinking “what did they notice?”. Then the moment passed. Would knowing exactly what ‘it’ was make a difference to how this interpretation is crafted? In some respects most certainly, but I also think that it is not entirely necessary to know exactly what the behaviour is, to be able to see the difficulties John and the workers face at this time.*

## Chapter 10

### *A Post-Modern Approach and Future Directions*

#### *Introduction*

The analysis section of the thesis was concerned with pinpointing key discursive assumptions and power/knowledge effects held in worker's talk about their support practice in the sexuality area. It was also concerned with exploring how these effects shaped the assistance offered to intellectually disabled men and women who live in agency service settings. I found that a 'they're not sexual because they're disabled' meta-discourse intertwined within allied discursive effects of sexuality and gender to inhibit the adoption of pro-active support possibilities. As suggested earlier this finding is far from new, in that it resonates with a number of prior research outcomes uncovered in the literature review. However, what I also found was a method of tracking how these effects operated within worker's practice, a discovery I suggest will have application in the development of future support initiatives in the sexuality support area.

In this chapter, I review the exploration I undertook of the topic. I then comment on the value of a post-modern approach to considerations of disability and sexuality assistance in the development of research initiatives and support practices. I conclude with two recommendations that might assist workers, service providers and researchers to begin to do things differently in this very sensitive yet vital support area.

#### *What I Did*

I developed three broad strands of engagement with this topic in order to substantiate the value of the focus of this research. The first strand involved reviewing literature findings that explored relationships between the concepts 'intellectual disability', 'sexuality' and 'support' as they pertained to an agency service environment. This review uncovered the presence of significant social and environmental difficulties in

these relationships, problems that compromised intellectually disabled people's pathway towards an active sexual and intimate life.

Yet while these findings described significant aspects of the problems and commented on how they could be ameliorated, the parameters outlining what the concept of an active sexual life might contain remained largely unstated. However, these parameters were understood as being somehow derivative of certain kinds of activities individual intellectually disabled people would like to engage in that were currently missing from their lives. Further, these activities somehow shared a symbiotic relationship with other understandings, also largely unstated, that outlined what the activities were that the majority of (non-disabled) people were deemed to have open access to. These assumptions were crucial to the process of defining the difference between the 'good' and 'bad' support processes, definitions on which subsequent practice change recommendations were based.

The second strand of engagement developed alongside the first. This strand concentrated on engaging analytically with the three central epistemological concepts relating to disability support. I undertook this exploration to gauge how these conceptual frameworks elucidated the 'support needed' aspect of the term as this aspect was critical to the creation of accessible environments for expressions of sexuality and intimacy for intellectually disabled people. I hoped to find understandings within these concepts that defined 'support needed' in ways that could usefully address the difficulties that inhibited material possibilities of living a full sexual life. I found these epistemologies to concentrate largely on the current quality of fit between the idea of 'disability' and how life ought to be lived. In doing so, they provided few conceptual pointers towards the creation of a standpoint position that elucidated the support position itself and how it operated.

The third strand of engagement developed out of the first two, in that I developed a tool that could begin to bridge the gap between the 'what should be going on' current beliefs about what support needed should contain in respect of a sexual life, and the 'what is actually going on' outcomes of disability related sexuality support practices in agency service group homes. The results of this exploration revealed that everyday

experiences of sexuality support are inextricably linked to wider, socially favoured discursive elements whose power/knowledge effects shape both the individuals involved in the support process and the behavioural outcomes these relationships contain. By unpicking “the very structures and processes that are part of the production of these experiences” (Clear, 1999, p. 435), I demonstrated as my key ‘finding’ that a post-modern approach holds a specific value within analysis of the support process, a value that would be useful to further considerations of the support needed aspect of assistance in this area.

### ***Post Modern Epistemologies and Intellectual Disability Research***

I based my analysis of worker’s talk largely within a postmodernist/interpretive framework. I adopted this way of working because I wanted to explore how support in the sexuality area could legitimately be viewed as a complex, interrelated and emotion infused process, as much as a set of behavioural problems connected to individual worker attitudes and values about intellectual disability and sexuality. The value of a post-modern position for the development of this thesis has been that it allowed me to explore the complexity of power/knowledge effects inhering in the worker role as the analytical position, rather than concentrating on the behaviour of workers themselves as the investigative focal point.

Further, focussing on language rather than behaviour as the constituting force within the support relationship, enabled me to present a challenge to findings that prioritised notions of support that pre-assumed the existence of specific sets of moral virtues through which recommendations for change could be based. This exploration was important in view of the outcome problem associated with this vision, that these presumptions and the recommendations arising from them had not been helpful in initiating the changes to current worker practices that research studies continued to indicate to be necessary.

A post-modernist inspired foregrounding of language and its role as a powerful constituting force also enabled me to challenge a key modernist idea inherent in the research agenda in this area. It is not possible to translate an assumption of the efficacy of autonomous individual action into how change might be effected in the

operation of the interrelationship between individuals who are locked into interwoven sets of complex social circumstances without reference to the wider social ways of doing on which ‘autonomy’ in worker practice is based. Presenting this challenge has been important, as assuming individual autonomy without question can leave “little space to reflect on conditions that produce more ethical policies and practices in the area of interpersonal care” (Bacchi & Beasley, 2005, p 176).

### ***‘Needing Support’ as a Conceptual Position***

Examining the concept of support needed within a complexity of discursive positions allowed me to step beyond the idea that difficulties faced by workers and those they support could be overcome by reformulating the position of ‘the disabled ones’. I was able to show that this way forward could not fundamentally alter the underlying structures and processes that had allowed for the separation of those needing support from those who don’t in the first instance. I was also able to step beyond the idea that all support difficulties could be overcome by changing the actions of ‘the non-disabled ones’. Going beyond this duality allowed me to engage directly with the idea that it is the interplay of socio-material and socio-emotional discourses related to ‘supposed to be able to do’, as much as than the actions of individuals themselves, that ultimately produce ‘real-time’ social barriers.

Thus, to say that someone is disabled in any way is not simply to say that individuals cannot do something, either with support or without it. Rather it is only to say that they cannot do things that ‘ordinary’ expectations presume that certain individuals are able to do, or can be supported to be able to do. Even when ‘ordinary’ expectations are obvious or uncontroversial they remain appraisals that involve “judgements that are norm-relative and norm-dependent in complex ways” (Ann Davis, 2005, p 157). From this point I was able to engage with the idea that limitation in support practice also represented material outcomes of wider effects that themselves sustained and perpetuated an unquestioning acceptance of the existence of ‘an ordinary (sexual) life’. Further this notion included acceptance of the idea that it is possible to isolate the specific actions this ideal contains. This insight allows me to suggest that it is these largely unstated ‘ordinary (sexual) life’ norms that continue to shape the

practices workers and those they support and it is the role of the ordinary, or ‘the normal’, or the ideal itself that presents the difficulties.

### ***Challenging Traditional Notions Of Power***

Using a post-modern position also allowed me to find a point from which I was able to challenge positivist notions of power through which the operation of the support relationship is primarily researched and substantiated. I could begin to move away from ways of thinking that prioritised ‘sovereign terms’ notions of power and power effects, where power is concentrated in the hands of the few, emanates either from the top down or the centre outwards and is exercised instrumentally to dominate socially marginalised groups at the expense of the socially powerful. A post-modern approach allowed me to work with a more relational view, where instantiations of discursive effects become productive with/in a variety of social locations, material actions and individual subjects. Within this location, power is defined as an element dispersed through complex networks of relationships and practices that ‘tell’ people who they must be and what they must do by constituting the social ‘truths’ by which everyday life is lived.

Reconstituting notions of power allowed me to work with language in a way that revealed ‘deficient’ examples of socio-material and socio-cultural interactions within the support relationship. However, within a power-as-productive position, I could show that these examples of language use contained influential normative assumptions that were equally as damaging to workers and their performance as they were to those who were supported. Further, these examples could be viewed as instantiations of still larger intersections of power, whose effects deploy the assumptions that shape the thoughts worker’s have and the material responses they subsequently make.

### ***Moving Away from Fault and Blame***

Recently researchers have commented on a tendency within the disability support literature to seek ‘deficit position’ attitudes/behaviours within their analyses of worker’s practices (Drinkwater, 2004). As Lamb notes, the problem with the “general



tendency in people to blame others” (1996, p. 24) is that blaming is not productive, in that it is not possible to both blame and encourage another to take responsibility for their actions at the same time. It becomes harder to explore certain questions when a fault/blame position underpins recommendations for behavioural change. Questions such as: how far might individuals be controlled by the conditions of their lives? At what point in time could the person concerned have taken a different road, or made a different decision in relation to the subsequent actions undertaken? Blaming individuals in the case of unwanted outcomes also shuts down possibilities of moving to identify and intervene in wider cycles of abuse and deprivation that the presence of normative assumptions can create (Sinason 1992).

While undertaking the literature review I found some research studies had sought to understand the material and social constraints that compromised individual worker’s desires to perform well on the job. However, many recommendations from the review findings continued to rely on developing lines of consideration that concentrated on rectifying the deficiencies of those who work in the support role. While bagging workers and the support systems they work in may sometimes be warranted, it is demeaning of those who work in the support system and those who write about it. Destabilising the meta-position of ‘individual fault’ allowed me to work within a changed understanding about the worker position. It enabled me to begin from the idea that the interpretations workers make of the circumstances they inhabit are carried out by people who are in-relation to sometimes very problematic circumstances, rather than people who have problems, who are a problem or who create the problem (Crisp, 2002).

I agree with Roberts (2006), who suggests that when research studies are generated, it is important to try to find ways of doing that will make a difference to the position of those who are under review, as much as the position of those for whom the research is undertaken. Utilising a post-modern perspective allowed me to move beyond the idea that it becomes possible to isolate what it is that workers ought to be doing by concentrating on accumulating evidence of less than adequate support practices. Within a post-modern frame, the difficult positions characterizing the support relationship become real-time social orderings of especially dense transfers of

power/knowledge effects that shape what individual workers are able to achieve over time. In addition, these positions of compromise remain points of recognition that support practices contain many shifting qualities and that it is possible to interrupt fixed positions, thus re-shape the subsequent actions of those through whom discourses operate.

### ***Queries about a Post-Modern Position***

I decided to adopt a post-modern approach because it offered me the epistemological flexibility to explore ideas that the support role that were difficult to access and substantiate from within essentialist frameworks. However, acceptance of the alternative view a post-modern position allows within the disability studies field has not always been wholehearted. Some disability scholars and activists remain highly critical of the value of this perspective as a suitable epistemological tool from which to undertake research.

It has been queried whether the use of alternative approaches can effectively "tackle disability oppression and disabling practices" (Corker, 1999, p. 192). Some regard any movement away from socio-materialist forms of theorising as "flawed and misguided" (Oliver, 2004, p. 23) in view of the larger realities that comprise major causal effects of bodily impairment and disabling conditions, including poverty and war. In Parker & Clarks view in particular, the clarity the twofold definition of the terms 'impairment' and 'disability' social model-related epistemologies bring to the disability studies field, remains an extremely useful methodological tool (2002, p. 50). They believe that this substantive redefinition of language has already made a major contribution to the development of disability research and activism, and any "arguing about whether or not the original words apply to everyone" (Parker & Clark, 2002, p. 350) can only diminish the ongoing power of this model for political, policy and practice purposes.

Further, the utilisation of Foucault's work within a post-modern approach has been fiercely interrogated as an extremely dubious epistemological tool. For example, for Gelb (2003), Foucault's theoretical positions are used as an exemplar of the doubtful value of the use of any postmodernist-inspired perspective in the disability studies

area. Foucault's analyses are compromised by his personal quest for cruelty, seen by Gelb as the " 'limit' experiences ... that push body and mind to a point at which the boundaries between reason and unreason, pleasure and pain and death could be touched" (Gelb, 2003, p. 370). This cruelty is also evidenced through Foucault's admiration for historical figures, including the Marquis de Sade. Thus Foucault's ideas and from this point the ideas of all post-modern scholars, can only make sense when seen as a tainted personal ambition to denounce modern society through the breaking of all prohibitions that form and guide the positive development of 'normal' individuals. Gelb is also critical of post-modern scholarship itself, questioning the sincerity of post-modern scholars who produce the same "guidelines and scholarly style of the same scientific discourse that their analyses 'interrogates' and manage to get published" (2003, p. 371). Yet while Gelb may have a point, too few examples of a post-modern framework being used in research analysis in relation to intellectually disabled people can be found to either completely verify or refute his suggestions. In respect of this lack, it is reported that a number of academic journals have rejected articles written from within this perspective "out of hand" (Editor's Note, 2003, p. 363), while others have openly stated anti-post-modern policies in the recent past.

Accepting critiques of this approach meant having to wholeheartedly accept that definitions of impairment and disability used by social realist models would apply equally to everyone. I could not accept this premise, as everyone to me did not and could not apply equally to every disabled person. It could only apply to the (ordinary/normative) expectations that presumed what individuals are supposed to be able to do relative to any given circumstance. To my mind while the larger issues of gender, ethnicity, ability and age that make ordinary expectations a relative rather than a universal element remained unexamined, using social realist conceptual frameworks to promote lasting change at societal level for disabled people as a group would continue to be difficult. This difficulty would also continue to impact on support performance.

Being unable to accept that 'everyone' could apply to everyone left me with some problems to deal with, including having to accept the condemnation of disability activists for whom socio-material explanations of the adverse social and physical

conditions disabled people encounter had enabled them to sustain an intense and personally fulfilling engagement “in the serious political analysis of a society that is inherently disabling” (Barnes, 1998, in Corker, 1999, p. 5). In the view of disability studies researchers who come from this perspective, any disability-related issue should only be analysed within the context of the production of socio-material oppression (eg Goodley, 2003). These researchers can be “scathing” (Riddell, Baron & Wilson, 2001, p. 59) about approaches to any aspect of disability research that originates from alternative points of view (see Barnes, 1999, p. 580, for a useful example).

However, other commentators have suggested that post-modern shifts in theoretical perceptions might help to uncover important implications for the possibility of changing understandings about both the term disability and disabled people (eg Peters, 2000). For Danforth, post-modern perspectives attempt to challenge the common sense understanding that scientifically based knowledge will “light the way to more effective interventions or more complete understandings of specific disabilities “ (2000, p. 364). In his view, in the area of intellectual disability, Foucault’s (1975) explanation of the problematic relationship between structures of power/knowledge effects and scientifically based truth claims has been particularly useful. As Danforth further suggests, when one group of people declare truths about another group and then use these truths in efforts to change these people, truth and knowledge become “problematic acts of social power” (2000, p. 365, also see, for example Peters, 2000) that define some individuals as lesser, defective and deficient. For intellectually disabled people, thoughtful consideration of this point is absolutely necessary in view of the literature review studies that document their ongoing lack of access to life choices and life chances that many (non-disabled) people take for granted.

## ***Conclusion***

What I have demonstrated is that there is value in including a postmodernist centred input to disability and sexuality support that considers intersections of “sexualised and gendered subjectivities” (Potter, 2005, p 116) rather than an approach that continues

to endorse the concept of the problems of the unified, disabled subject. A post-modern position interrupts the meta-tendency to assume that there can be a universalised way of thinking about who people might be, why they are as they are and why they do what they do. This assumption can leave academics and practitioners alike open to “simply wallowing in the inertia of common sense” (Comebrook, 2002, p xiii) that makes it more difficult to really think about what might be going on, thus how the difficult and taxing social issues impairment raises can be most gainfully addressed.

I suggest that as researchers, we need to move away from being sure in our own minds about what support workers ‘need to do’ and from presumptions that we might know enough to make unequivocal comments about what ‘appropriate’ practice is and what its outcomes ought to look like. We need to allow our thinking to become much more complex in this area. Only then can we be sure that we do not become unwittingly implicated in the same discursive binaries that have created the problems, in particular upholding the central assumption on which support work is based, that people who use support are the only ones who need it. Only through examining the complexities of what support work in this culturally sensitive area might mean can we then be sure to avoid reproducing in our own remarks the same patterns and power dynamics that have been found in the relationship between the workers and those they support. Only then can we be sure that any transformation of societal patterns we recommend would challenge every-body’s sense of identity in ways that are positively meaningful to all concerned (Fraser, 2001).

### ***Suggestions for Teaching/Learning Environments***

Yet I also take on Yates (2005) suggestion, in that it is only by working with the people involved in specific situations can that the problems they face be addressed and unravelled. Within service systems, the development of teaching/learning programmes that challenge representations of disability and sexuality as contingent on an innate biological traits, in favour of promoting understandings about how “certain human acts, practices, behaviours or characteristics emerge as specific problems” (Yates, 2005, p 65), represents one way of working differently with workers to address the problems they face. A more direct appraisal of the role of culture and its impact on the disability experience in the area of sexuality and intimacy within such

teaching/learning programmes would also be extremely useful. This process could also be helpful to any exploration of the social complexities involved in the movement “from viewing ID people as patients to be cared for and protected, to thinking about them as citizens with rights” (Frawley, 1993, p. 36).

However, any teaching/learning initiatives need to be developed alongside more academic initiatives that focus on how to generate the conceptual underpinnings that will lead to the promotion of innovative change. Specifically academic research needs to prioritise the importance of theoretical concepts that factor in a “bystander focus” (Banyard, Plante & Moynihan, 2004, p. 62), thus theoretical approaches that go beyond an emphasis on the individual or a preoccupation with the practices of human service agencies alone, to focus on that which will facilitate the development of holistic social change at a wider community level.

Bystander research initiatives could include interviews conducted with key community agents in order to gain an understanding of where the wider community might be at in its receptiveness to changes in understanding about social norms that affect possibilities for intellectually disabled people. Such information, as well as providing a different perspective, places an emphasis on prioritising how to document the effects of receptivity and resistance to change at a community level. Such initiatives also promote an expression of research commitment to the full engagement of all community members in the process of challenging and changing unhelpful and limiting community norms. These initiatives may help to diffuse the negative impact of suggestions from research studies that continue to concentrate on finding out “who is seen as culpable for the problem and who is viewed as responsible for the solution” (Banyard et al., 2004, p. 67).

Finally I am in agreement with Lambeviski that “contemporary academic discourse needs to move away from the idea of sexuality as a fixed position, nicely and relatively stably wrapped under the epidermal cover of an individual human body” (1998, p. 305). Academic endeavours need to move towards ways of speaking about sexuality that include the embeddedness of the term within shifting cultural movements that include the physical acts, social habits and cultural desires that create

and constitute the term. Developing new ways of speaking about sexuality and sexual practices would also be useful for addressing difficulties currently facing service provision and support practices, in that they would open up new avenues for structuring practice that currently remain caught up in fixed and traditional ways of thinking. It is time for this work to begin.

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## **Appendices**

### ***Appendix One: Open Letter to Support Workers***

#### ***Information For Participants***

This letter provides information about a research project with support workers who are working with intellectually disabled people.

*What kind of research project is this?*

I would like to facilitate discussion with new and experienced support workers about their practice when they are supporting intellectually disabled people in the area of intimacy and sexuality. Discussion will be in a relaxed interview format with individuals or small groups of support workers.

*What is the purpose of this research?*

This research aims to explore the gaps between the current issues intellectually disabled people face in this area of their lives and the support given by practitioners in order to enhance the quality of life for people they support are given.

***Who is doing the research?***

I (Carol Hamilton) am a post-graduate student at Massey University. I have worked in the intellectual disability area as a teacher, advocate and researcher. I have also worked with Teacher Aides and Support Workers as a teacher and trainer.

I have supported a group of intellectually disabled adults in the area of intimacy and sexuality in the Wellington area.

I am very interested in the ethical and philosophical area of disability support. I am keen to find out how support workers solve the problems they encounter in this area of their work, and how they overcome the barriers they might meet.

*Why study this topic?*

There is very little written about the ideas support workers themselves have about the complexities of their work in this area. Some of the new policies that have emerged in the past 5 years in the area of support work and intimacy and sexuality seem to be distanced from the concerns of everyday support practice. The research aims to give frontline workers more of a voice in how people who use agency services can improve their chances in this area of their lives.

*What do I have to do to participate in this research?*

Discussions will take place in a quiet, private area to be arranged between the participant and the researcher. Each interview would take approximately one hour. If participants want to meet in small groups, discussions would be held for one hour approximately. You may want support at the interview. I am happy to arrange this with you before the interview date. How this person will support you during the interview will be decided through discussion before the interview takes place.

*Am I taking risks by talking about my experiences in this area?*

Talking about issues in your working life has the possibility of raising stress for you. I am an experienced facilitator of individual teaching/learning and discussion sessions and will work make sure that stress is minimised for all participants. You may also gain some benefit by talking about these issues in a non-work environment that is designed to be supportive, exploratory and creative in thinking about issues.

*What about my own confidentiality and privacy?*



To minimise any breach of confidentiality, ground rules will be set with all participants before interviews or small group discussions take place. Everyone will be asked to sign a confidentiality agreement. The discussions will be audiotaped. A professional transcriber will type the first draft of the discussion without being given any details about participants. I will then edit these and replace all names with pseudonyms. You will also have a chance to view transcripts and suggest changes to ensure privacy.

The tapes and transcripts will be kept in a locked filing cabinet when not in use and only you and I will see the full transcripts. The paper copies of transcripts will be shredded at the end of the project. Digital copies of the interviews will be kept on floppy discs (not a hard drive) and destroyed at the end of a five-year period, according to Massey University policy

*May I choose to withdraw from the study once I start?*

You may withdraw at any time up to the initial written draft of the study. If you withdraw before that time you may also request that all information that you have shared will not be used in any report made of the research findings and that your information be destroyed straight away.

*What happens to the information shared at the interview discussion?*

I will use excerpts of the interview discussions to write papers and chapters that explore the links between your support practice and the wider issues involved in supporting intellectually disabled people in this area of their lives. This may include anonymous quotes from the discussions

*How will I receive information about the findings of the study?*

I will keep you informed throughout the study about its progress, either by e-mail or by post. I will provide you with a summary of the research at the end and will be happy to provide a copy of any publication based on the findings.

***Ethical Approval***

This project has been reviewed and approved by the Massey University Ethics Committee, WGTON Protocol 04/36. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Acting Chair, Massey University Campus Human Ethics Committee, Wellington. Telephone 04 801 5799 ext 6358, e-mail J.J.Hubbard@massey.ac.nz

*For further information please contact:*

Carol Hamilton  
5 Manuka Terrace  
Eastbourne  
Lower Hutt

Ph 027 6742828

E-mail: Carol.[Hamilton@clear.net.nz](mailto:Hamilton@clear.net.nz)

## ***Appendix Two: Group Confidentiality Agreement Form***

### ***Group Confidentiality Agreement***

I understand that any information about other participants involved in these research discussions disclosed at our meetings, or about individuals mentioned during our discussions will remain confidential to this group. I agree not to disclose such information to any other party.

Signed \_\_\_\_\_

Name of participant (please print): \_\_\_\_\_

Date:

Signed \_\_\_\_\_

Name of researcher: Carol Hamilton

Date:

### ***Appendix Three: Worker's Consent Form***

#### ***Consent Form for Support Workers***

I have read the information provided by Carol Hamilton for the proposed project:

#### **Supporting People with Intellectual Disability in the area of Intimacy and Sexuality. What are the issues for support workers?**

I have had the opportunity to ask questions and have had them answered to my satisfaction. I understand that I may withdraw from the project and withdraw any information I have provided at any time before the initial writing of the research report. I understand that I do not have to provide a reason for my withdrawal and will not be disadvantaged by doing so in any way. If I decide to withdraw my comments would not be included in the analysis or quoted in any written account of the project.

I understand that anything I share with Carol or in any group of participants will not be accessible to any other person in the field of human services or at Massey University. Carol will be the only researcher present for the interviews, which will be audiotaped. Carol will then edit the draft transcript, replacing any names mentioned with pseudonyms. Transcripts will be kept in a locked cabinet in Carol's study at her home and only Carol herself will view the full transcripts. Digital files will be password-protected on Carol's own home computer.

Please read the points below. You agree by ticking next to the points

I agree to be take part in an interview about my views about the issues facing people with intellectual disability that I support in the area of intimacy and sexuality

I agree that information taken from my comments in the individual interview and/or from any group interview will be used for an analysis of the positive and negative

barriers people with intellectual disability experience being supported in this area of their lives

I understand that I will meet with the researcher (Carol) once over the course of the year, 2005

I understand that I may request to be part of a group interview and that in this case I will be asked to take part in no more than two group meetings – an interview to discuss the issues, and an interview to review the transcript if necessary.

I understand that only the researcher (Carol) will see the original transcripts of the interview and that on this transcript all participants' names will have been changed to pseudonyms.

I understand that I will be able to view draft transcripts of our discussion in order to suggest that any material that could breach privacy concerns be edited out.

I understand that the researcher (Carol) will use information from the transcripts to write journal papers and sections of a Doctoral thesis.

I understand that the subject to be discussed may bring up personal issues for me. I am willing to seek assistance to address these issues if necessary

I understand that if an example I use during discussion is found to contain an issue of risk or harm to either myself, another support worker or a person with intellectual disability the researcher (Carol) and myself will discuss what strategies will be used to address the issue in the workplace after the interview.

I would like to be contacted by:

Telephone/Post/E-mail (*circle one*)

Signed \_\_\_\_\_

Name of participant (please print):

Date: \_\_ / \_\_ / 05

Contact Details for Participant

Address:

Phone:

E-mail:

\*\*\*\*\*

To Be Completed by The Researcher

In my view consent was given freely and with understanding.

Signed \_\_\_\_\_

Name of researcher: Carol Hamilton

Date:

## ***Appendix Four: Letter to General Manager***

General Manager  
Central Region  
P.O Box 54-165  
Mana

Dear V\_\_\_\_\_

I am writing to ask formal permission to work in Central Region to undertake interviews for my project to complete the fieldwork aspect of my research.

Having worked for the organisation I understand some of the difficulties workers and managers face when providing support in the socio/emotional areas of the lives of people who use services. What the causes might be of these difficulties has been of growing interest to academic researchers in the disability field. I am concerned that some of the data results published in this area to date make recommendations for service agency practice that are perhaps more good ideas for 'ideal' workplace practice solutions than helpful recommendations for useful and workable ways forward for agencies, workers and people with intellectual disability themselves.

In addition, I want to complete this study because I have noticed that academic researchers who have had 'insider' access to the world of service agencies have been able to make more user-accessible conclusions from their data findings. I would also like to make a more rounded analysis of support provision in this area available to the disability support industry.

### ***The Process***

What I would like to do is to distribute a flier to support workers participating in a training session outlining the discussion topic and asking if they would like to participate in an interview. I would like to interview between ten and twenty support workers. If there are more willing than maximum numbers allow, participants will be

selected by an overall criteria mix. Length of time as a support worker, age, ethnicity and gender will be variables considered. I am hoping that a broad range of novice and experienced, young and mature, ethnically diverse and female and male workers will be represented.

My proposed schedule for completion of the research is as follows

Literature review completed	September 2004
Ethics approval sought	September 2004
Participants solicited from	November 2004
Trial Interview	November 2004
Individual/Group Interviews	Jan–April 2005
First Draft Data Write-up	May–July 2005
Second Draft of Data	Aug/Sept 2005
Final Draft	October 2005

### *Benefits*

Research studies reveal that this is an area that some workers find it difficult to talk about on the job, although it is an area that many feel that they lack significant expertise in. The interview offers support workers the chance to talk confidentially off the job about an area of work that can be very difficult to discuss. The interview also offers participants a chance to reflect on their current and future practices in this area.

I have found that an interview process has been useful to the organisation to initiate some ‘best practice’ ways forward to address a problem that has been isolated through a previous research undertaking (1). There may also be some significance of this research to the wider disability field where the findings may also provide useful information for relevant human rights and disability agencies working within New Zealand.



### *Disclosure Difficulties*

In line with organisational policy interview disclosures that identify the presence of risk or harm to either support workers or to people who use services will be acted on. I have informally asked M\_\_\_\_\_ K\_\_\_\_\_ if she would act as a consultant for his project. Her knowledge of the organisation is a guarantee for the organisation of ethical appropriateness and her position would also provide a cultural safety aspect for Maori support workers who might choose to participant.

People who take part in the interview also have the opportunity to receive a transcript copy of the interview and change anything they want to at that time. Participants can also choose to withdraw from the project at any time.

### *Visit*

I am enclosing a draft copy of the confidentiality agreement for participants a draft copy of the information flier mentioned for you. These drafts will also be given to the Massey Ethics Committee as an aspect of my ethics approval process.

I would be pleased to come and talk to you about any aspect of this letter. Alternatively, perhaps attending an RMT, if you like. I could come and talk (briefly) about what I am doing with all Area Managers and relevant people.

Kindest regards

Carol Hamilton

[Carol.Hamilton@clear.net.nz](mailto:Carol.Hamilton@clear.net.nz)

Ph 027 6742020

### **Notes**

*1) Hamilton, Carol A (2002): Doing the Wild Thing: Supporting an Ordinary Sexual Life for People with Intellectual Disabilities. Disability Studies Quarterly, 22(4), Society for Disability Studies, Hawaii, USA*

## ***Appendix 5: Interview Trigger Questions***

### ***Trigger Question Format***

#### ***General Questions***

What key roles do support workers play in the lives of the people you support?

What attitudes/attributes do you think makes a ‘good’ support worker?

#### ***General Sexuality Questions***

What did the word disabled mean to you before you started the job/now?

What does the word sexuality mean to you?

What do you think the word sexuality means for the people you support?

How have the people you support found out about sexuality?

How is sexuality and sexual relationships handled in your workplace?

#### ***Support Work and Personal Care***

How have you determined what touch is appropriate for you with men who use services?

How have you determined what touch is appropriate for you with women who use services?

What kind of guidance have you received about appropriate touch?

What would be the difference for you between supporting a person with toileting and washing and supporting someone to masturbate, or two people to have sex?

### ***Responses to Sexualised Behaviour***

Are there any kinds of sexualised behaviour by people you support that you find personally difficult?

Have you ever worked with someone where you have felt sexually unsafe eg have you been asked if you have sex with your boyfriend/girlfriend, or have you felt you had to protect certain body parts during your work with a person?

What kind of support did you receive at that time?

In your opinion, might other workers experience problems in this area?

Has there been any occasion in your work where you have been concerned about sexualised touching? Eg between a worker and a person they support, between two people who use services, between a person and a family member?

Did you talk about it? Who to? What happened? Are you happy with the outcome?

### ***Training and Information***

What kinds of support have you received to help you be able to provide positive responses to people's sexuality and sexual expression? What kinds of support would you like to have?

What information about support in this area has been covered by the training you've received?

What were the benefits of this information?

Were there any problems with the training you received?

What other kind of things would you like to know more about in this area of support work?

What kinds of training do you think intellectually disabled people need in this area?

### ***Sexuality Policy***

Have you read the sexuality policy? (Why not?)

How has the policy helped you to provide more pro-active responses to the sexual expression of the people you support?

What difficulties have you experienced putting the policy into practice?

### ***Change***

If you had the power to change anything about your work in this area, what sorts of things would you change? Eg attitudes, support systems, access to information?