

**Facilitated Sexual Expression in the Independent
Living Movement in Ireland**

Submitted for the Degree of Masters of Arts in Disability Studies

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Abstract

Are disabled people sexual beings? Should PAs assist their leaders to engage in sexual activity? What are the legal and ethical implications of facilitated sexual expression in the leader/PA relationship?

This paper explores facilitated sexual expression in the Irish Independent Living Movement. The work of respected academics such as Colin Barnes, Jenny Morris, Mike Oliver and Tom Shakespeare, is used to set the experience of disabled people in Ireland, into the context of the wider international disabled peoples movement.

Issues of Access and Opportunity and Identity and Belonging are explored in chapter four, in relation to disabled peoples sexual expression. Sexuality and morality and the practical, ethical and moral implications of this form of assistance are discussed in chapter five. Chapter six discusses the legal implications and recommends that a Code of Practice and Grade of Facilitation be developed.

This paper concludes with recommendations for progressing the issue of facilitation for disabled people in Ireland. These recommendations advocate for the provision of appropriate sexuality education for disabled people in education and long stay institutions, that the existing content of PA Training be developed to include sexuality and that the legal implications of this form of assistance be further researched and addressed.

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1. Introduction

This dissertation is entitled '*Facilitated Sexual Expression in the Independent Living Movement in Ireland*' and the research question that I have set is

'How widespread is facilitated sexual expression in the Irish Independent Living Movement? What are the legal and ethical implications of this form of assistance in the leader/personal assistant relationship, particularly with regard to the Irish social, legal and moral environment?'

The aim of this research is to highlight facilitated sexual expression and its' implications and set it into an Irish context.

The key objectives of the research are to:

- document the current position of the Irish Independent Living Movement in relation to facilitated sexual expression;
- explore the legal implications for both the disabled person and the personal assistant;
- highlight that there is more to disabled peoples lives than just employment, health care or education;

- initiate debate on this issue among disabled people in Ireland.

1.1 Boundaries and Limitations of Research

Due to resource and time constraints, and the fact that this is only a Masters Degree dissertation, this is not a representative piece of research.

I will define sexuality in chapter two, however it is important at this stage to note that the parameters of sexual expression set within this paper range from the most basic level of dressing up or dating, up to sexual intercourse. At no stage in this research have I dealt with or discussed alternative sexual expression. This is further discussed in Chapter Four. I am also aware of the debate surrounding the issue of devotees who are “*men attracted to women with amputations and other disabilities*” (Kafer, 2000), however I will not be dealing with that issue in this paper.

I have not explored the issue of facilitated sexual expression with regard to learning disabled people. This is because I have neither encountered, nor heard of, any learning disabled Leaders

in the Irish Independent Living Movement. All of the disabled people interviewed for this research were people with physical impairments.

There are two parts to this research question. The first is to explore how widespread facilitated sexual expression is in the Irish Independent Living movement. In order to do this I selected a small group of interviewees from the Movement and this is further detailed in Chapter three.

The second part is concerned with exploring the legal and ethical implications of this form of assistance, particularly in an Irish social context. Therefore I interviewed Professor Gerard Quinn and two of his colleagues from the Law Faculty of the National University of Ireland, Galway. I also interviewed Donal Toolan, co-ordinator of a national Irish disabled peoples organisation and experienced activist and social policy commentator.

1.2 How the Research Question was Chosen

Although I have had a physical impairment all my life, and have been a wheelchair user since the age of ten, I only started to identify as a disabled person, in my early twenties. Since I

started working in the disabled peoples movement I have been interested in the area of sexuality and disability, and I was one of the organisers of a key disabled peoples conference on sexuality in Ireland.

In September 1996 I started to work for the Center for Independent Living Dublin, and was introduced to the concept of personal assistance. I later read the *Sexual Politics of Disability* (Shakespeare, Gillespie Sells and Davies, 1996) and one of the issues raised in it was the role of the personal assistant in assisting the leader to express his/her sexuality and to realise their right to engage in an intimate relationship.

“It is not uncommon for disabled people to organize personal assistance in the workplace or to get them to and from a social event. However, assistance that goes beyond the mundane, such as assistance with sexual activity, has to be negotiated without ground rules or guidance.” (Shakespeare et al, 1996:37)

For example, if a leader has a significant impairment and needs their personal assistant to assist them with tasks such as eating

or washing etc., it is highly likely that the Leader may also need assistance with sexual activity.

Although I have always been interested in the area of sexuality and firmly believe that disabled people are, and have a right to be, sexual beings, I had never considered this question and it intrigued me. After reading this book I discussed the issue with various disabled people in the independent living movement and they agreed that they had not given this area much thought either.

In 1999 I completed a short project in this area as part of a training course I was pursuing. This project produced more questions than it answered; therefore I decided that I would use it as the catalyst for more in-depth research in the future. When I was accepted onto the Masters Degree in Disability Studies, I realised that this was my opportunity to explore the issue.

Through dissemination of the completed dissertation I intend to generate debate on the issue in the wider disabled peoples movement. I will discuss my dissemination strategy for this paper in Chapter Three.

1.3 Structure of Dissertation

This dissertation is seven chapters in length. There is also a detailed bibliography and appendices.

In chapter two 'Facilitated Sexual Expression – *The Bigger Picture*', which is the literature review, I have set out my research topic in the context of work which has been done in this area in the wider disabled peoples movement worldwide.

In chapter three 'Researching Sexual Expression Using an Emancipatory Paradigm', I explain how I carried out the research for this paper. I demonstrate that I, a disabled person conducted a piece of emancipatory disability research which will benefit other disabled people. I illustrate that this research used both qualitative and quantitative methods and that the methodology was both theoretical and empirical.

Chapter four deals with the question of 'What is facilitated sexual expression?' In order to answer this question I first explore the area of sexuality and sexual expression for disabled people. I then use both theoretical research findings, and material from

the qualitative interviews, to focus on the area of facilitated sexual expression. An exploration of this form of assistance with regard to the leader/PA relationship then takes place.

Having explored and defined facilitated sexual expression in the previous chapter, chapter five explores the practical, ethical and moral implications and questions surrounding this form of assistance. This chapter commences with an outline of current Irish society with regards to sexuality in general, and disabled people's sexual expression in particular.

Chapter six deals with the legal questions surrounding facilitated sexual expression such as Irish employment law, laws relating to abuse and protection and any other relevant laws governing sexual expression. This chapter also explores what a Code of Practice for Facilitated Sexual Expression in the leader/PA relationship and a Gradation of Facilitation might contain.

Chapter seven is the concluding chapter of this dissertation. Here I will highlight that key areas to move forward in this area are; peer support and peer counselling, training, comprehensive debate and thorough legal examination leading to a Code of

Practice and a Gradation of Facilitation. I conclude this chapter by looking to the future of the Irish Independent Living Movement particularly with regard to facilitated sexual expression in the Leader/PA relationship.

1.4 Definitions

I believe that it is important at this point to define certain concepts, which are discussed or are underpinning this research. This dissertation is underpinned by the Social model definition of impairment and disability. (UPIAS, 1975: 3-4) This model is a two-tier classification of Impairment and Disability, which defines disability as being socially constructed and not as the result of an individual's impairment.

Independent Living means living just like everyone else. Having the opportunity to make the decisions that affect your own life and being able to pursue the activity of your own choosing. Traditionally, disabled people have been treated as passive and dependent. The philosophy of Independent Living challenges this, and is about enabling disabled people to take back control of their own lives. It is about disabled people making their own decisions and taking on the responsibilities and

duties, which equal citizenship entail. As disabled people we see ourselves as the only real experts at defining our needs and requirements because we have the closest possible knowledge and experience of life as a disabled person.

A key Leader in the International Independent Living Movement is Dr. Adolf Ratzka of the Institute on Independent Living in Sweden. He defines Independent Living as:

“The right of all persons regardless of age, type or extent of disability to: live in the community, as opposed to living in an institution; have the same range of choices as everyone else in housing, transportation, education and employment; participate in the social, economic and political life of their communities; have a family; live as responsible respected members of their communities, with all the duties and privileges that this entails, and; unfold their potential.” (Ratzka, cited in Bruce 2000: 17)

A **Leader** is a disabled person who uses the services of a Personal Assistant (PA). The term Leader will be used throughout out this dissertation. The disabled person leads the PA as to what they want done, when and how; hence the title

'Leader'. This is an employer/employee relationship, which enables the leader to have choice and control over how their needs are met. Therefore the disabled person can achieve independent living. A **Leader Co-ordinator** is a leader who is employed by a Center for Independent Living (CIL) or personal assistance service provider to support and advise leaders.

A **Personal Assistant** (PA) assists the Leader in activities of daily living ranging from personal care and domestic tasks to education, employment or social and leisure activities. PA tasks are often described as those that the leader would personally carry out, if they did not have an impairment.

"A personal assistant is recruited, trained, supervised and if necessary fired by the disabled consumer. The distinguishing feature of a personal assistant service is that it is the consumer, not the provider who directs the provision of assistance". (McGettrick, 1994: 14)

In some countries a PA is referred to as a Personal Care Attendant (PCA).

1.5 Conclusion

In this chapter I have shown that I intend to explore facilitated sexual expression in the Irish Independent living movement and that that this dissertation will highlight the legal and moral implications of this form of assistance in the leader/PA relationship, particularly with regard to the Irish social, legal and moral environment. The dissemination of this research will ensure that the findings are highlighted and that they are used to generate discussion on the right to sexual expression, which all disabled people should be supported in exercising, if they so wish.

In Chapter two which is the Literature Review I will expand on the research question while setting it in the context of current literature (Morris 1989, Shakespeare et al 1996), and theoretical sources such as journal articles and papers, and relevant websites and mail groups (Earle 1999, Tepper 2000).

2. Facilitated Sexual Expression – *The Bigger Picture*

I have outlined in the previous chapter that this paper explores facilitated sexual expression in the Irish Independent Living Movement and the legal and ethical implications of facilitated sexual expression, set in the context of Irish society.

In this chapter I will discuss the research question in the context of existing literature. I will also demonstrate the current debate surrounding facilitated sexual expression. I started my theoretical research for this paper with the presumption that I would not find any literature written in Ireland on the topic of facilitated sexual expression for disabled people, and with the hope that this presumption would be proven incorrect. By the conclusion of this chapter I will have shown that I was in fact correct in this assumption and therefore the empirical research, which I carried out for this dissertation, is the key method I employed in meeting the objectives of this research.

However before I progress, it is important to explore why there has been such a silence in Irish society about disabled people's sexuality and sexual expression. Firstly, It is significant to note

that in Ireland there is a general dearth of literature written by disabled people. Indeed over the past two years of this Masters Degree, more than 95% of the books and websites, which I have used have been written by disabled people from outside Ireland.

I believe this can be partly attributed to the fact that until quite recently there has not been an academic focus for disability studies in Ireland. It is my hope that as there is now a Chair of Disability Studies in University College Dublin (UCD), disabled academics and activists will be supported to explore and document the experience of disabled people in Ireland.

With specific regard to sexuality and sexual expression, there are two key reasons why there has been such a silence on this issue.

- Traditionally there has been a taboo around discussing sex and related matters in public. Sex was for marriage and procreation, and disabled people were not expected or encouraged to experience either.
- Access to transport, housing, personal assistance, employment, education, and getting our rights enshrined in legislation have been the priority for the Irish disabled

peoples movement for the past 30 years. Social, leisure, relationships and sexual expression have been pushed way down the list of priorities, while disabled people have fought to achieve a better quality of life and independent living.

When I discussed this issue with the leaders who participated in this research, one said that sexuality had not been a priority of the Irish disabled peoples movement because "*It hasn't been seen as important as some of the other battles*". (Kyle: Interview 01/07/02)

Liz Crow echoes this opinion in Tom Shakespeare's paper *Disabled Sexuality: Toward Rights and Recognition*. She says

"I've always assumed that the most urgent Disability civil rights campaigns are the ones we're currently fighting for – employment, education, housing, transport etc., etc., and that next to them a subject such as sexuality is almost dispensable. For the first time now I'm beginning to believe that sexuality, the one area above all others to have been ignored, is at the absolute core of what we're working for [...] It's not that one area can ever be achieved

alone – they're all interwoven, but you can't get closer to the essence of self or more 'people-living-alongside-people' than sexuality, can you?" (Crow cited in Shakespeare, 2000: 165)

Over the past three decades a lot of research has been engaged in, which has explored independent living for disabled people (Barnes 1991, Campbell and Oliver 1996, Bruce 2000). In particular, the past fifteen years has yielded many studies on personal assistance (Morris 1989, McGettrick 1994). However as Sarah Earle highlighted in 1999

"facilitated sex is an issue that has received very little attention by the disability movement [...]. Perhaps because sexuality is still a taboo subject, but also because the issue of facilitation is one fraught with moral complexity". (Earle, 1999a: 309)

Mitch Tepper echoes this in his paper *Facilitated Sex: The Next Frontier in Sexuality?* When he says *'there is little published research exploring the use of PCAs to help with sexual expression'* (Tepper, 2000a)

Cecilia Gray of the Spastics Society in Australia, in her paper 'Addressing the Issues of Sexuality and Disability in the Spastic Centre' says

"While there has been plenty of information about people with disabilities being seen as asexual and therefore denied the opportunity and support to have interpersonal relationships there has been a dearth of literature or evidence on 'how to do it' without the fear of legal ramifications". (Gray, 2001: 1)

2.1 Society's Expectations of Disabled People

As I mentioned in Chapter one, the traditional view of disabled people was that of dependent people in need of care. Traditionally society's view of disabled people was very medicalised, disabled people were something to be cured, fixed or rehabilitated.

"During my teenage years attempts were made to "normalise" me. Surgery and drugs, the doctors hoped, would fix my "deformed" body. Drab clothes would deal with my quiet rebelliousness, so various social work folk believed". (Boot, 1999a)

Disabled people were often viewed as childlike and therefore asexual. Displays of sexual feelings were seen as deviant and inappropriate.

“Societal notions of asexuality and infantilization of people with disabilities have glazed over the fact that adults with disabilities have choices and rights that include sexual and reproductive health” (Mona, in press, a: 10)

Due to the lack of accessible employment, housing and transport and the absence of personal assistance, disabled people did not have the opportunities or choice to achieve independent living. Therefore, many disabled people grew up in hospitals, institutions or the family home where the ‘carers’ were family or medical professionals. In *‘Independent Living: gender, violence and the threat of violence’* many of the respondents in the study were quoted as saying that *“the parental care situation extended parental control over their lives, keeping them as children despite their years”*. (Hendey and Pascall, 1998: 423)

“Parental overprotection is often cited as a hindrance to social experiences”. (Baker and Donnelly, 2001c: 74) Parents tend to overprotect their disabled offspring, treating them as unable and childlike. Children do not have sexualities and so parents find it difficult to see their disabled offspring as sexual beings, and not as vulnerable and impressionable people at risk.

When I had my first serious relationship at age 19 my parents genuinely believed that I was vulnerable and ‘being led astray’ by my boyfriend, purely because I was a disabled person. I watch them now with my three siblings who are in their teens, and non-disabled, and my parents are a lot more lenient with them than they were with me.

Although I was diagnosed with an accredited impairment at age six, I walked until I was almost eleven years of age. From the moment I sat into a wheelchair my mother tried to get me to walk again, even though I was quite content with my life. As I reached my middle to late teens and it became quite obvious to my mother that I wasn’t really bothered about spending hours in physiotherapy trying to learn to walk, she tried many tactics to try to change my mind. She often told me that men would only go

out with me out of pity and once the pity wore off they would dump me. She was not trying to be unkind; she hoped that I would believe her and that it would make me try to walk.

In *Pride Against Prejudice*, this sentiment is echoed by Pam Evans' list of assumptions which society makes about disabled people. She states "*That any able-bodied partner we have is doing us a favour and that we bring nothing to the relationship*". (Morris 1991: 21) I always thought that my mother was just trying to motivate me because she couldn't understand that walking has really never been all that important, however I now see that she was also echoing a general assumption that is often made about disabled people and relationships.

There are numerous studies and articles that document that many non-disabled people genuinely believe that disabled people are incapable of sexual expression or sexual pleasure (Morris 1989, Owens and Child 1999, Shakespeare 2000). Many never consider that disabled people also require access to services related to sexual expression such as adult shops, family planning clinics, adult websites, pubs and clubs and other places where social relationships are formed, or services are provided.

Traditionally, key issues usually pursued for service provision or rights are; education, training, housing and health. It is really only in the past decade, particularly with the growth of the disabled peoples and independent living movements, that disabled people are starting to question why social, leisure, relationships and sexual expression have not been addressed with regards to access and support services (Equal Status Act, 2000)

“Government policy tends to assume that social exclusion is about not having a job, and that the only way to be socially included is to get qualifications, training and paid employment. In the first stage of the research project, four groups of young disabled people were asked about what social exclusion meant to them: They said it was: [...] finding it difficult to do the kinds of things that non-disabled young people their age do, such as shopping, going to the cinema, clubbing. etc” (Morris, 2001)

Disabled people are not equipped by society to be sexually responsible. Relationships and Sexuality Education in

mainstream schools does not include information specifically relevant to disabled people. An example of such information would be Table 1.1 in *The Baby Challenge* by Mukti Jain Campion. This table is a Chart on 'Reproductive and Contraceptive considerations for women with physical disabilities'. (Campion, 1990: 8-9) This table lists a range of 13 impairments such as Multiple Sclerosis, Spinal Cord Injury, Blindness and Epilepsy. It then gives an outline of the 'Female Reproductive Implications' of that impairment and the associated 'Female Contraceptive Implications' of using either a Diaphragm, Intra Uterine Device (IUD) or the Pill.

I have mentioned sexuality and facilitated sexual expression quite often thus far in this paper but what do those terms really mean? What is sexuality? What is facilitated sexual expression?

Expressing ones sexuality is not just about sex. Sexuality is about relationships, confidence, self-image and choice making. It is about how we as human beings see and express our personalities and ourselves. The Relationships and Sexuality Policy from the IHC in New Zealand defines sexuality as "Self-

image, self-esteem, relationships, choice making". (IHC New Zealand Incorporated, 2001: 5)

However as Jenny Morris said in *Independent Lives* in 1989

"many people assume we are asexual, often in order to hide embarrassment about the seemingly incongruous idea that such 'abnormal' people can have 'normal' feelings and relationships". (Morris, 1989a: 80)

Facilitated sexual expression is not just concerned with the personal assistant assisting the leader to have sexual intercourse or masturbate. Facilitation can also mean assistance with

"buying contraceptives, [...] making an appointment' (Williams cited in Cooper and Guillebaud, 1999: v) or accessing adult material, dressing up for a date, translating for a person with a speech impairment when they are chatting someone up or other assistance at a social event". (Boot, 1999b)

"Most people are not looking for sex itself, they are searching out intimacy, warmth, validation, connection,

relationships, and the importance of friendships, rather than sex. They are looking for physical touch, something often lacking in disabled people's lives". (Shakespeare, 2000: 164)

I have already highlighted that '*facilitation is fraught with moral complexity*'. (Earle, 1999b: 309) In Mitch Tepper's paper he refers to contact he had with Ray Aguilera of Berkeley CIL, Aguilera mentioned that although Berkeley CIL does not formally address sexuality issues, he has informally advised some disabled men on this issue. Aguilera said of the disabled men

"Oftentimes their PCAs are female, so the men are afraid the PCA may feel threatened or sexually harassed if they were to approach them. It's really a double-edged sword for people. They don't want their request to be rejected by the PCA because they want or need sex; at the same time, they may be terrified of a positive response because of how that could affect their relationship with the PCA"
(Aguilera cited in Tepper, 2000b)

2.2 Legal Implications

There are many legal considerations and implications such as employment law i.e. sexual harassment in the workplace, sexual abuse and laws governing what constitutes prostitution. Some of these issues are discussed in Mitch Tepper's' paper.

“When does assertiveness in asking for sexual assistance cross the line to sexual harassment? When is taking a risk seen by a PCA as an unwelcome proposition? And what about the employment relationship between a disabled person and a PCA, or the intimate relationship between the partners? If both partners have an assisting attendant, then the circle grows. If one or both partners have an assisting attendant, then the circle grows. If one or both partners are under 18, yet a new set of considerations arise. An additional level of complexity is added by relationships taking place in a hospital, nursing home or other institution”. (Tepper, 2000c)

In chapter six, ‘Legal Implications and Questions’, I explore these legal issues in an Irish legislative context. I do this through using material from the interview, which I conducted with

Professor Gerard Quinn and his colleagues Shivaun Quinlivan and Mary Keys.

Are Disabled People Included? which is the exposure document on the violation of disabled people's human rights (Hurst, 1998) relates Article 12 of the Universal Declaration of Human Rights (1948), to Rule 9 of the UN Standard Rules on the Equalisation of Opportunity of people with disabilities.

Rule 9.2 of the *UN Standard Rules on the Equalisation of Opportunity of people with disabilities* which deals with Family Life and Personal Integrity states

“Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. [...] Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies”.

(United Nations, 1994: 9.2)

The UN Standard Rules recognises disabled peoples right to sexual expression but legislation underpinning rights is only

useful if people are given the necessary support to exercise these rights. It is also important to note that international laws are only effective if individual countries adopt them into domestic law.

The key piece of Irish literature that I have sourced which discusses disabled peoples sexuality and relationships is *A Strategy for Equality* which is the 1996 Report of the Commission on the Status of people with Disabilities. Chapter eighteen specifically deals with sexuality and disability and contains 15 recommendations for what the Irish Government should provide or fund in order for disabled peoples sexual and relationship needs to be met. None of these 15 recommendations refer to facilitated sexual expression. (Commission on the Status of People with Disabilities, 1996a: 55-57)

2.3 Conclusion

While reading for this paper I accessed numerous articles relating to disabled peoples sexual expression through media archiving services such as *Ananova* (www.ananova.com). These articles covered issues such as Belgian and Dutch local

government authorities paying for disabled people to access prostitutes, to brothels in Australia being made accessible to wheelchair users. Issues raised in these articles echo current debates in the disabled peoples movement such as access to services mainstream society takes for granted, and the fact that sexual expression and sexual relief are a need and not just a want. (Earle, 1999)

In this chapter I have conducted a literature review of materials and issues relating to the research topic of facilitated sexual expression. The key issues identified were:

- Many people assume that disabled people are asexual
- A lot of disabled people lack the level of support they need to achieve the level of sexual expression to which they aspire
- Facilitated sexual expression is practiced successfully in many countries, therefore the difficulties and implications pertaining to this form of assistance are not insurmountable, if the will to address them exists.

I have set the research question in the context of work by authors and academics such as Morris, Shakespeare et al and

Earle. This chapter has also demonstrated the wider debate surrounding facilitated sexual expression and this will be set more specifically in an Irish context in chapters four, five and six. The structure of the qualitative interviews will be discussed in Chapter three which also outlines the methodology I employed for this research.

3. Methodology

In the introduction to this dissertation I outlined the objectives of the research. In this chapter I will demonstrate that in order to achieve the previously stated objectives, I used both theoretical and empirical methodologies.

The principles of the emancipatory disability research paradigm include *“involving participants from the outset in a research project which focuses on their experiences”*. (Vernon, 1997: 163)

Therefore as I am endeavouring to engage in a piece of emancipatory research, it was vital that I also used an empirical research methodology.

In the previous chapter I highlighted the fact that I commenced the research for the literature review with the presumption that I would not find theoretical materials on facilitated sexual expression in Ireland and that this presumption had been born out. Therefore I have relied on empirical research in order to explore facilitated sexual expression with regard to the Irish social, legal and moral environment.

Before I continue, it is important to stress that I have situated this research within the emancipatory disability research paradigm. Emancipatory disability research, is research designed and controlled by disabled people, which is used to set disabled people free from oppressive social conditions.

“Emancipatory disability research must “illuminate the lived experiences of progressive social groups; it must also be illuminated by their struggles. Theory adequate to the task of changing the world must be open-ended, nondogmatic, informing, and grounded in the circumstances of everyday life”. (Lather, 1987: 262 cited in Oliver, 1992a: 107)

Ontology

The key ontological claims for emancipatory disability research are trust, respect, participation and reciprocity. (Oliver, 1992b: 107) These are the key principles, which underpin this paradigm and below I have outlined each principle with regard to my research for this paper.

- *Trust*: I knew most of the interviewees quite well prior to the research. In fact over the past few years I have had the opportunity to work with some of them on projects and

actions in the independent living movement. This was very useful because it meant that these interviewees knew that they could trust me;

- *Respect:* Respect is very important, particularly when researching such a sensitive issue as sexuality. I have a good reputation in the disabled peoples movement and I know that I am respected;
- *Participation:* In total, eight disabled people directly participated in this research through one to one interviews. However through informal peer consultancy, many more disabled people have had the opportunity to actively participate;
- *Reciprocity:* This paper will be disseminated to interviewees, key Irish disabled peoples organisations and through the NDA library. I hope that this paper will lead to other disabled people and organisations in Ireland conducting research and engaging in projects in the areas of disability and sexuality.

I will further discuss the principle of 'reciprocity' later in this chapter when I detail my dissemination strategy.

Epistemology

“What is the nature of knowledge? What is the relationship between the knower and the would-be known?” (Guba and Lincoln, 1994: 3)

Since Mike Oliver coined the term ‘emancipatory disability research’ in 1992, there has been a lot of debate over the epistemological assumption that disabled people are the only experts on issues pertaining to disabled people. This is because such an assumption challenges the traditional notion of the researcher as expert-knower and the disabled person as research subject.

I believe that this paper is a good example of emancipatory disability research, because I have been a disabled activist in the independent living movement for the past nine years and I have also been a leader for the past three years. However, I cannot say that I share an epistemology with the leaders who participated in this research, because I only require personal assistance for work and domestic duties. I do not need assistance with personal care and I do not have personal experience of facilitated sexual expression.

3.1 Theoretical Research

The theoretical research for this dissertation has been conducted through sourcing books and magazine articles, and papers in journals, which have been written on topics associated with sexuality and disability (Shakespeare et al 1996, Earle 1999) or which contain references to this area. (Morris, 1989)

An extensive Web search has been conducted and relevant sites such as Scope (www.scope.org.uk), Bent (www.bentvoices.org) and Accsex (<http://groups.yahoo.com/group/accsex>) yielded useful articles and contacts.

A key part of the research question is exploring the legal and ethical implications of facilitated sexual expression in Ireland. However I am not a legal expert, so I discussed these issues with Professor Gerard Quinn and his colleagues.

Relevant email discussion lists such as Danmail and the Disability Research list have also been utilised and have yielded useful information and contacts (ICH, 2001; Tepper and Gray, 2001).

3.2 Empirical Research

I conducted eleven qualitative interviews for this research. These interviews are broken down as six leaders, two personal assistants, one activist and social policy commentator, one interview with a group of three legal experts, and one peer counsellor.

Contrary to popular belief disabled people are not a homogenous group and therefore to be truly representative one must take into account the fact that disabled people can be single, married or in a long term relationship, male, female, gay, heterosexual, young or old and from various ethnic origins. However as I only had limited resources and time, this is not a representative piece of research.

Through the research that I have engaged in for this dissertation I have come to the conclusion that the area of facilitated sexual expression for disabled people is a very complex one with many legal, ethical, moral and logistical issues which need to be resolved. The time and resources available for a Masters Degree are not sufficient to resolve such issues, however as I

have stated in chapter one, an objective of this research is to generate debate in the Irish Independent Living Movement. As the next stage of my academic career I intend to pursue a Doctorate in Disability Studies. The research for my doctoral thesis will be focussed on a specific area of the facilitation issue.

I endeavoured to choose six leaders who had a diverse range of life experiences. Of the six leader interviews, I intended to select four leaders whom I knew very well, and then source two leaders who were not previously known to me.

I contacted experienced leaders and asked them to talk to their friends and colleagues about my research and to assist me in trying to locate leaders who would be willing to be interviewed. However this was not fruitful and leaders that were not known to me did not come forward. Therefore I selected four leaders whom I knew quite well, and two, with whom I was only acquainted.

Although the six leaders interviewed are either activists in the Irish Disabled Peoples movement, or very active in the Irish independent living movement, they did not want to be identified.

The interviews with the leaders, PAs and peer counsellor were strictly confidential and these seven interviewees agreed to participate if anonymity was guaranteed. Therefore the names of these interviewees have been changed and only a general collective profile will be supplied in this dissertation.

It is interesting to note that although these disabled people are active in the movement they were not willing to be identified as speaking out about sexual expression and facilitation. Two leaders indicated that they would be interested in doing something around sexuality in the future but not specifically in relation to facilitation.

Profile of Anonymous Interviewees

- Leaders: There were three male and three female leaders interviewed. Two are in long-term relationships; one is gay and all live within the Dublin region. The age range of these interviewees is 20 to 50 years old.
- PAs: I interviewed one male and one female PA. One PA has over four years experience and the other has less than one year's experience.

- Peer Counsellor: I interviewed one female peer counsellor who has over four years practical experience and has been fully qualified for over three years.

All the interviews took approximately one hour each. I travelled to each leader and met them at a time and place of their choosing. With the exception of one, all leader interviews took place in the leaders home. PAs were not present for these interviews. I travelled to Galway to meet with Professor Quinn and his colleagues. Due to scheduling difficulties and illness both on the part of one PA and myself, the PA interviews were carried out over the telephone. All interviews were recorded on minidisc. As the PA interviews were conducted over the telephone, recording them was very difficult.

All interviews were semi structured. I had six to eight questions prepared for each interview but they were open questions, which encouraged the interviewees to open up and explore the research question. The questions were used as a prompt to progress the interview. The Leader and PA interviews were divided into four sections: Personal Assistance, Sexuality, Facilitated Sexual Expression and the Future. All interviewees

with the exception of Professor Quinn and his colleagues were asked what their understanding of facilitated sexual expression was and if they thought society views disabled people as sexual beings. Other core questions asked were:

Leader

- Have you ever approached a PA for assistance with sexual expression? (if yes, what assistance did you request and what was the outcome? If no, why?);
- What support do you feel you need as a Leader in order to deal with this most sensitive issue?

Personal Assistant

- Have you ever been asked to assist a leader with sexual expression?
- If yes in what way, if no, how do you think you would react if asked?
- Do you feel that as a PA you should have (*if you feel you don't already have such*), formal support in dealing with issues of this nature?

In this research I also examined the role, rights and responsibilities of the PA in facilitating the disabled persons expression of their sexuality. The data for this research was gathered through the aforementioned interviews with people from the Movement in Ireland.

Donal Toolan outlined sexuality and morality in Irish society in general, and the issue of disabled people and sexual expression in particular.

I also tried to engage in a small piece of quantitative research. I wrote to the 30 CILs in Ireland and asked them to inform their Leader co-ordinators of my research. Due to time and resource limitations I did not interview or survey these co-ordinators, but I invited them to input into my research via either telephone or written submissions. In the letter I explained my research and I posed three questions. These were:

- What is your understanding of facilitated sexual expression?
- Has a leader ever approached you for assistance with a matter of this nature (if yes, what was the difficulty and the advice/support given);

- What support do you feel you need in your role as Leader Co-ordinator in order to deal with this most sensitive issue?

Due to time limitations, I did not follow up these letters, as any input I gained through this would enhance the research, but not be a vital part of it. Of the 30 CILs written to, only three responded. This response was by telephone.

In my opinion, the response from CILs was so low because sexuality and sexual expression is not considered to be as important as gaining access to employment, education, housing, personal assistance and transport. Therefore, in a lot of CILs, my research was probably not considered a priority. It is also interesting to note that the three responses, which I did get were quite diverse. One was very positive, one very negative and one was requesting further information but was also fairly negative.

Analysing and Using the Empirical Data

The recorded interviews were reviewed and the key points summarised as notes. Similarities in responses were particularly

noted and key quotes were highlighted for use throughout this paper.

3.3 Dissemination Strategy

I was awarded a scholarship for this dissertation and therefore the completed paper will be available in the library of the National Disability Authority (NDA) in Ireland. This paper will be disseminated to interviewees, and key Irish disabled peoples organisations. I have also had requests for copies from disabled people and various people working in the disability sector.

Through this dissemination I will have the opportunity to contribute further to the disabled peoples movement. I also hope that my research will encourage other disabled people and organisations to engage in research and initiatives in this area.

3.4 Conclusion

In this chapter I demonstrated that I have explored facilitated sexual expression in Ireland through using the emancipatory disability research paradigm. In order to research this paper I employed both theoretical and empirical methods of data collection.

I am confident that the dissemination strategy, which I intend to employ for this paper, will ensure that a variety of people in the disabled peoples movement and beyond will have access to my research. I will also be available to meet with groups to discuss my research in greater detail.

In the next chapter, I will explore in detail “*What is Facilitated Sexual Expression?*” I will start though by discussing sexuality and its’ relationship to gaining a sense of identity and belonging in life. I will then progress on, to the core issue of this research, which is ‘Facilitated Sexual Expression in the Leader/PA Relationship’.

4. Sexuality and Facilitation

In this chapter I am first going to relate sexuality to identity and gaining a sense of belonging. I will then outline the current issues and debates around disabled peoples sexuality and sexual expression. This will include the current key issues such as access, opportunity and information.

I will define and explore facilitated sexual expression in general and then progress to the content of the qualitative interviews. These issues will be specifically set in an Irish context in the next chapter.

As I outlined in chapter one, this research does not include reference to alternative forms of sexual expression as for example fetish. This omission is not intended to imply that disabled people do not participate in such acts. Indeed, British disabled actor and activist, Mik Scarlet, who is a wheelchair user, once said in a television interview that he prefers to frequent fetish and bondage clubs because he is not treated as a curiosity or made to feel unwelcome. I have omitted these forms of alternative sexual expression from my research because I

believe that the relationship between disabled people and fetishism is so complex that it could be the subject of a dissertation in it's own right.

4.1 Identity and Belonging

Identity: There are many events in life that influence how we identify with the world around us. As I have discussed in chapter two (IHC New Zealand Incorporated, 2001), many elements join to form our identity, and our sexuality is an important part of that. People express their sexuality in many ways. How we dress, if we wear makeup, if we flirt, how confident we are in life and the relationships we form are all influenced by, and in turn influence, the development and expression of our sexuality. Having the opportunity to express our sexuality in turn enables us to define our identity.

Belonging: People gain a sense of belonging from having the opportunity to express their sexuality. However forming and maintaining non-sexual relationships with family, friends, work colleagues or relevant communities of interest can also provide this comfort.

I have discussed the importance of 'Identity and Belonging' with regard to sexuality, in general for all people, and I will now progress to specifically explore 'Impairment and Perceived Asexuality' with regard to disabled people. Multiple identity is also a key issue with regard to identity and belonging as there are many gay disabled people, disabled women etc (Shakespeare, 2001).

4.2 Impairment and Perceived Asexuality

"If we wanted to we couldn't, and if we could we shouldn't" (Glen: Interview 17/6/02)

Sexual expression is just one part of the overall communication of our self. However for many people it is a very important part of their life, and of how they express their identity. To travel throughout life constantly being denied this type of expression has had a detrimental effect on many disabled peoples confidence and sense of self worth.

There is a predominant attitude in society that disabled people are asexual. This is not an attitude that is exclusive to Irish society however one interviewee 'Glen' suggested that in Ireland

this belief can be traced back to Catholicism. He also mentioned that from his knowledge the only countries where facilitated or assisted sexual expression for disabled people have flourished are countries that are not particularly Catholic countries.

“Let’s face it, society does not think of us first and foremost as sexual beings. Most of us are considered objects of care, somebody one has to be nice to. Disabled people are often seen as sick. Sick persons are not expected to have a regular life with social responsibilities such as work. Sick people are definitely not expected to start a family. In many countries disabled people are begging in the street. Elsewhere well-intentioned politicians try to mobilize taxpayers’ money for disability programs by depicting us as the weakest members of society. In both instances our unproductive image does not help our self-esteem, it does not contribute to our sex appeal. Who wants to fall in love with a sick person, who would want to spend the honeymoon with a beggar?” (Ratzka, 2002)

Society at best finds the thoughts of a disabled person being sexual repulsive and at worse presumes they are asexual.

Parents often treat disabled adults as children. In a paper entitled '*Sexuality and People with Disabilities*', Rachel Martin commented that

“Encouragement and support around teenage relationships may be denied. Indeed many disabled people report being told they would never have a relationship. Over all adolescents with disabilities have been found to have lower self-esteem and self-confidence than their able-bodied peers. They also have less sexual experience and knowledge although not necessarily less interest in such matters” (Martin, 1995a: 14)

The first question on sexuality that I asked each of the disabled people that I interviewed was “Do you think that society views disabled people as sexual beings?” All of the interviewees gave negative responses such as

“Not at all. No. We are just there to be cared for and we don't have any desires or any needs ourselves and who could love us anyway is what society at large thinks, I think” (Rose: Interview 03/07/02)

“I really don’t think that Irish society in general has come to recognise that people with disabilities have a sexual side to them like everybody else. That it is a ‘normal’ part of every man and woman’s life, and that people with disabilities aren’t any different. Maybe I’m being pessimistic but I really don’t think so” (Angie: Interview 22/06/02)

In response to this question, disabled activist and journalist, Donal Toolan answered

“I could suggest that society in general quite often doesn’t view those who are disabled as people, and [...] increasingly, developed societies can only engage with very perfect, very competitive, very strong and defined global notion of people who party excessively, compete, make lots of money and live short lives actually. And therefore any kind of support, or need, doesn’t sit comfortably with that dominant model.” (Toolan: Interview 22/06/02)

'Valerie', the peer counsellor whom I interviewed believed that society *absolutely* does not view disabled people as sexual beings. She also went on to say that society is

"horrified at the idea that people with disabilities are having sex, or in relationships [...] and they are very inclined to think of us as asexual beings. Although we might be in couples, it's a very sexless relationship. I think they are more comfortable with the idea that when we're in a relationship, it's a companionship rather than a sexual relationship" (Valerie: Interview 16/07/02)

During the theoretical research, which I engaged in for this paper, I noticed that sexual relief has been referred to as a need, which is similar to pain relief, whereas sexual expression is referred to as pleasure and a want or desire. (Earle, 1999; Owens, 1999; Dagblad, 2001) Therefore one of the questions, which I asked the interviewees for this research was 'Is sexual expression a need or a want?' All of the leaders interviewed believe that sexual expression is a need. One interviewee said

"Yes it's a need. I can't think of anything sadder than any individual with a disability, or without, who wants to do something sexually and who never, ever got the chance to

do it. Choosing celibacy is fine but many people with disabilities have a forced choice not to participate” (Glen: Interview 17/06/02)

I thought it was very interesting to get this response from ‘Glen’ as it echoes the opinion expressed by Dominic Davies in *The Right to Be Sexual – A Radical Proposal*

“it is fine to be celibate and single, if it’s by choice. However, ableism, body fascism, and economic disadvantage are key social factors that cause many disabled people to remain single and isolated against their will.” (Davies, 2000a)

I also asked the two PAs this question and one said that they didn’t know if it was, but that they knew of a lot of people who were much happier when they were in relationships. The other PA felt very strongly that sexual expression was a want and that it was dangerous to call it a need.

4.3 Access and Opportunity

Access: Inaccessible social and leisure activities inhibit or preclude disabled people from socialising and forming relationships with disabled and non-disabled peers. Lack of relationships and sexuality education in the home, school or institution disempowers disabled people from developing and expressing their sexuality. Lack of access to personal assistance means that disabled adults are forced to be dependant on family or live in hospitals or institutions. One interviewee commented in relation to access to appropriate education and peer contact that

“There was never any education in terms of sexuality. The one thing in the institution was there were the female ‘wards’ and the male ‘wards’ and we never really got to see each other except in school maybe, or across in the corridor”. (Rose: Interview 03/07/02)

Opportunity: Traditionally, many disabled people have been hidden away, either in the parental home or in large institutions. Disabled people living with their family were often dependent on parents or family members for personal assistance including personal care. If they had the opportunity to go out and socialise

it was often with family members. One interviewee who spent her entire educational life from age five to twenty in an institution said

“When I was at home we lived in a two storey house in the local neighbourhood, so it was only my family or one or two of my friends that took me out, but there was nowhere for disabled people to go. Then we moved house and I don’t know the area very well, but I was going out with my sisters and brothers. But, between the two there wasn’t much of a chance for me to get out”. (Ruth: Interview 23/06/02)

This quote from ‘Ruth’ paints a typical picture of how many people with significant impairments have been raised in Ireland. Although fewer people with physical and sensory impairments are growing up in institutions in the Ireland of the 21st century, there are still many barriers in society which preclude disabled people from becoming independent, active, valued members of the community. The result of these factors is that disabled people have often been denied the opportunity to develop or explore their sexuality and they have certainly had little opportunity for sexual expression.

In Ireland, the majority of the long stay institutions have been run by religious orders or the state. The key focus in these institutions has been to meet basic needs and as many of these places were also hospitals there was a high instance of medical intervention to 'cure' the disabled residents of their impairments.

With regards to leisure and socialising, one interviewee said

“at best you’d go to the pictures but someone else would chose the picture and if there was sexual content in it and you were in a Catholic institution like the Sisters of Charity or whatever, then you never got to see anything with a sexual overtone” (Glen: Interview 17/06/02)

Before I move on to specifically explore facilitated sexual expression, there are three other areas under 'Access and Opportunity', which I believe are important to mention. These are Information, Education, and Income Adequacy.

Information: In Ireland, it is very difficult for disabled people to find useful and relevant information on sexuality or issues related to sexual expression. Many agencies produce leaflets on issues

such as contraception or sexual health, and some make these leaflets available in alternative formats. However, the bigger barrier is that the content is not very relevant to disabled people's needs or abilities.

In chapter two I referred to the chart on contraception, which is in '***The Baby Challenge***' by Mukti Jain Campion. This is the sort of practical information that disabled people in Ireland should be able to access however to date I have not found such information being produced. I have only seen this issue positively addressed once in Ireland, where the Gay Men's Health Project produced a booklet on safe sex for gay learning disabled men.

Income Adequacy: There are approximately 360,000 disabled people in Ireland. Although Ireland has experienced a period of immense growth in our economy, unemployment and welfare dependency remains extremely high in the disabled population. Many disabled people live in absolute or relative poverty and therefore the issue of income adequacy has been high on the agenda of disabled peoples organisations for the past decade. Recommendation 6.7 of '*A Strategy for Equality*' states

“People with disabilities need income support and assistance with costs relating to their disability for two reasons. Firstly, many of them are not in employment and, therefore, do not have an income from work. Secondly, disability gives rise to extra costs in areas such as equipment, care, travel, telephone, fuel, food, clothing and laundry.” (Commission on the Status of People with Disabilities, 1996b: 124)

Lack of income also impacts on disabled peoples opportunity to express their sexuality. Activities such as buying fashionable clothes and makeup, going to pubs and clubs, hiring accessible transport, purchasing or accessing adult material, hiring a prostitute or going on accessible holidays can be prohibitively expensive.

4.4 Facilitated Sexual Expression

I now intend to specifically explore the area of facilitated sexual expression. I will not however, explore the practical, moral, ethical and legal implications as these are dealt with in chapters five and six. Facilitated Sex in the leader/PA relationship can range from the PA assisting the leader to prepare for a date,

right up to assisting the leader to masturbate or engage in other sexual activity (Boot, 1999; Earle, 1999).

When scheduling the leader interviews for this paper I consciously avoided defining 'facilitated sexual expression' because I wanted to get a snapshot of the general understanding of the concept. All interviewees suggested similar definitions to the one listed above. However one interviewee also mentioned that she had heard of a PA assisting a leader to have text sex by typing their messages into their mobile phone for them.

Before I continue to discuss facilitation in the leader/PA relationship, I think it is important to highlight a different form of assistance that exists in a number of countries. This is called 'Surrogacy'. Although this is quite different from facilitation in the leader/PA relationship, I believe that it is important to briefly discuss surrogacy, and its' key difference to facilitation.

Surrogacy:

"Individual professional sex surrogates working with therapists in California and a few other states in the US

have disabled people among their clientele. In the Netherlands and Denmark the state runs a dedicated licensed brothel for disabled peoples' needs.” (Davies, 2000b)

The most important difference is that with facilitated sexual expression the personal assistant does not personally engage in sexual intercourse with the disabled person. This is a vital point to remember when discussing and exploring facilitation, and this will become more evident in chapter six, in relation to the legal implications of facilitation.

The first part of my research question is ‘How widespread is facilitated sexual expression in the Irish Independent Living Movement?’ When I set this question, I knew that it would be difficult to answer it accurately, without engaging in an extensive survey of all the leaders throughout Ireland.

However, through the qualitative interviews, and informal discussions which I have had with colleagues in the Movement, I have come to the conclusion that basic levels of facilitation, such as preparing for a date, are taking place fairly regularly.

However the more contentious levels such as assistance with sexual activity are more rare.

The leader/PA relationship is a difficult balancing act at the best of times. Traditionally, most disabled people have received assistance throughout their life from a 'carer' and have therefore not been in control of their assistance. It can be very difficult to then adjust to the role of leader, because in this role the disabled person is the one in control.

When exploring this issue with Donal Toolan he highlighted that

“Personal assistance works on the basis of a dynamic and a relationship that evolves on principles being employed which demonstrate peoples capacities to communicate, and have an absolute rigid understanding of their role as a support to somebody’s decision making”. (Toolan: Interview 22/06/02)

It is common practice for new PAs to start working with leaders without any prior formal training. This is because the leader is the principle trainer, and therefore provides 'on-the-job' training.

The only formal instruction that most PAs receive is in Health and Safety, and Moving and Handling.

One of the other issues raised was that sometimes the fact that the PA has assisted the leader with sexual expression can negatively affect the rest of the PA's duties. This is because one or both of them feel embarrassed of how intimately the PA had assisted the leader.

This difficulty was expressed by 'Ruth'

“the next day my PA has to come in the next morning and clean me up and stuff, so you do get embarrassed about that kind of thing. That's why I don't [...] know how comfortable I'd be using my PA for that and then telling them to wash a floor next. Bizarreness”. (Ruth: Interview 23/06/02)

Another side to this difficulty was highlighted by Rose, who said that she has asked some PAs to assist her in dressing for intimate evenings with her partner. However, what she has found most difficult is that

“they are quite willing to assist you in putting on your clothing but the next day they might expect kind of a ‘report’ not so much a report but ‘let’s be girly friends here and tell me all about it’, which I don’t obviously and the next day can be quite difficult because they are expecting some sort of chat or whatever” (Rose: Interview 03/07/02)

Despite the varied difficulties and implications attached to this level of assistance in the leader/PA relationship, all the disabled people interviewed agreed that this level of support should be available to disabled people. However it was also agreed that PAs cannot be coerced into facilitating their leader. Therefore there should be a range of supports available, because as one interviewee asked, *“If somebody is a perfectly good PA in every other respect what do you do?”* (Kyle: Interview 01/07/02)

This is a very valid question, particularly as it can be so difficult in Ireland to find suitable people to work as PAs. If you are satisfied with your PA in very other way, except for the fact that they are not willing to assist you to engage in sexual activity, how will your need or desire for sexual expression be met?

One suggestion I put to the interviewees was that perhaps there should be a separate type of PA trained specifically for this area. There was a mixed response to this, some felt that it would be too impersonal and would lack spontaneity if this specific type of PA had to be 'booked'. It was also feared that confidentiality could pose a problem. However interviewees also felt that this alternative should exist so that people are afforded the opportunity to choose the form of assistance they wish to access.

4.5 Conclusion

In this chapter I have discussed sexuality and sexual expression with regard to disabled people. I have highlighted that in general society does not view disabled people as sexual beings, and that this denial of sexual expression greatly impacts on disabled peoples confidence and quality of life. I also discussed how Access, Opportunity and Information impact on disabled peoples sexual expression.

I then progressed on to explore the area of facilitated sexual expression, particularly in the leader/PA relationship. I have also demonstrated that there are many aspects to be considered in

relation to facilitation, such as how successfully negotiating facilitation with a PA, may affect the general Leader/PA working relationship.

Many people will be shocked to consider that PAs could assist disabled people in this way. However I believe it is very important to constantly highlight that this form of facilitation is *not* the same as surrogacy. PAs should not act as sexual partners to their leaders, and facilitation is purely that, *facilitation*.

In the next chapter I will explore the practical, ethical and moral implications of facilitated sexual expression. I will begin this chapter though by providing an outline of current Irish society with regards to sexuality and morality in general.

5. Practical, Ethical & Moral Implications

To understand the practical, ethical and moral implications of facilitated sexual expression for disabled people in Ireland, it is important to first understand the shape of morality and sexuality in Irish society. Therefore I interviewed Donal Toolan who is a disabled activist, journalist and respected social policy commentator in Ireland. I asked him to outline a historical perspective of sexuality and morality in Ireland in general, and to then relate disabled peoples experience to this.

5.1 Sexuality and Morality in Ireland

I have highlighted in previous chapters that Ireland is a traditionally Catholic country. Therefore historically, Irish morality has been dictated and shaped by the teachings and beliefs of the Catholic Church. There has been an uncomfortably close relationship between Church and State and this has had a number of implications for Irish citizens.

- In the Irish Constitution, sexual expression is only recognised within marriage;

- Contraception was legalised in 1979, but until recently the vending locations were strictly restricted;
- Homosexuality was only decriminalised in the late 1980's;
- Divorce has only been available in Ireland since 1996;
- Women and girls still have to travel out of the country to access abortions.

With the advent of the 'global village', Ireland has had the opportunity to access, and engage with, a diverse range of cultures. One result of this is that the Church does not have the same level of influence on society that it had. When I discussed the changes that have taken place in Irish society over the past two decades with Donal, he highlighted that

“As the Church goes down the tubes, we don't know actually what the moral code is, other than perhaps people actually engaging in a level of excessive behaviour. Excessive drinking, excessive enjoyment and it's interesting because all this is happening when Ireland's economy is going into the most extraordinary period of wealth” (Toolan: Interview 22/06/02)

However this progress has not had much impact on disabled peoples sexual quality of life. In relation to this issue Donal said that

“It’s difficult to talk about sexuality and the experience of disabled people in the context of what’s taking place in Irish society generally. A lot of disabled people’s experiences are still quite different, and still dealt with in a way that means, how disabled people perceive their identity may not mirror what is taking place in personal autonomy and sexual autonomy in mainstream society”
(Toolan: Interview 22/06/02)

Traditionally, Irish society has not been comfortable talking about sexual activity. The growth of the gay, and feminist movements in Ireland, the legislative changes cited above and the immense influence of the media have all contributed to changing this silence. However as I noted in previous chapters, even the disabled peoples movement has not considered sexuality and support for sexual expression a lobbying priority. In 1995 Rachel Martin highlighted this issue when she said that

“There is an astonishing lack of research about the attitudes of Irish people towards their sexuality and almost

none about the views and experiences of people with disabilities. While our sexuality is an inherent element of each individual's life and life path, it is clearly influenced and defined by culture and society, which sets the standard for feelings and behaviour which are acceptable or unacceptable.” (Martin, 1995b: 7)

Now that I have outlined the sexual and moral environment in Ireland, I intend to progress specifically on to exploring the practical, ethical and moral implications of facilitation in the Irish Independent Living Movement.

5.2 Implications of Facilitated Sexual Expression in Ireland

In order to understand the implications of facilitated sexual expression in Ireland it is important to understand the nature of personal assistance provision in Ireland. We do not have a system of direct payments, whereby the disabled person receives funding to directly buy in the services they need. In Ireland, disabled people are not entitled (by right) to such services. They are allocated services as determined by professionals and these are provided as benefits to the disabled person. As the disabled person is not empowered to directly buy

in the services they need, they often have to spend months, or years on waiting lists in order to access under funded and overstretched public services.

In Ireland there are two main methods of personal assistance provision. These are through FÁS, which is the national training and employment agency, and the Department of Health and Children (D/HC) via the Health Boards.

FÁS: Each CIL, apart from the original one based in the Carmichael Centre in Dublin, are FÁS Community Employment (CE) Schemes. Through these Schemes, which were originally designed to address high levels of unemployment in Ireland, the CILs hire personal assistants for local disabled people.

It is important to acknowledge that without these Schemes the independent living movement in Ireland would not have been able to bring personal assistance to as many disabled people outside the Dublin region as it has in the past ten years. However, it is generally acknowledged that this is not an ideal method of PA service provision, for a number of reasons:

- The key purpose of the CE Scheme is to retrain people for re entry to the workforce therefore there is a high annual turnover of participants;
- Participants are bound by the rules and criteria attached to CE Schemes such as: they can only work for nineteen and a half hours per week, and they must live within the catchment area of the Scheme
- Due to the low levels of unemployment, it has become increasingly difficult to fill places on these Schemes.

Government is currently phasing out this system, so CE schemes which have a health or social service function are being transferred to the Department of Health and Children (D/HC). This transition will have a significant impact on the CILs.

Unfortunately, the raison d'être for a lot of the CILs has been to provide PA services, and once these services have been transferred the funding they currently receive from FÁS will also disappear. Therefore it is now time for most CILs to evaluate their current activities and to strategically plan for the future with regard to activities, funding and sustainability.

Department of Health and Children (D/HC): Since 1995 the Department has been funding a Personal Assistance Service (PAS) in the Dublin region. This service originated in 1992 as the INCARE Programme from the Center for Independent Living and was transferred to the Irish Wheelchair Association (IWA) in 1995. Since then the PAS has grown from the original 15 leaders and 45 PAs, to approximately 70 leaders and between 150-200 PAs in the Dublin region. In the past couple of years funding for this service has been extended outside Dublin through the Health Boards.

This is a much better system because it is needs based. Following interview and assessment leaders are allocated a set weekly amount of hours. The leader can then advertise for a PA and the IWA Assisted Living Services section will function as the employer. However not every leader is allocated the full amount of hours that they request, or need, due to insufficient Government funding.

Some fears have been expressed in the qualitative interviews that opening up this issue and inviting discussion could be quite dangerous. Access to personal assistance funding is not a

legislative right and there is a fear that funding bodies and service providers may be alarmed by the concept of PAs facilitating their leader's sexual expression and that this alarm will in turn threaten the funding of personal assistance services.

There are various levels of facilitated sexual expression and some of these levels are quite innocuous. Activities such as assisting a leader to prepare for a date or to chat someone up, do not have significant implications attached. However, higher levels such as assisting a leader to access adult material, or to engage in sexual activity, have many implications.

So, what are the practical, moral and ethical implications of this higher level of assistance?

5.3 Practical Implications

The legal implications of facilitated sexual expression will be discussed in the next chapter. However, there are a number of practical considerations arising from this form of assistance.

Training and Education: Appropriate training and education around sexuality and sexual expression is not currently available

to, or provided for, leaders and PAs. 'Kyle', one of the leader interviewees for this research, mentioned that in the early days of personal assistance

"When the Center for Independent Living was doing the PA training, they did have some sessions on the whole area of sexuality, but not since it's been handed over". (Kyle: Interview 01/07/02)

I have been told anecdotally that sexuality has been mentioned in passing at some PA training sessions. One of the PAs whom I interviewed, mentioned how a PA at a training session which they had attended, had been told by a trainer that *"it was ok to masturbate their leader, if that was what the leader wanted"*. (Joe: Interview 08/07/02) Of course, this raised a number of issues around health and safety for the PAs, however as this workshop was not developed to include a session on sexuality, the discussion rapidly moved on to another topic, and a prime opportunity to explore the issue with the PAs was lost.

Two's company, three's a crowd: In the next section I will refer to the moral implications of facilitated sexual expression. However there can also be practical implications for disabled

people who need assistance with sexual activity. As one interviewee 'Angie' explained

"In the past one of my ex partners PAs would have assisted us in this, and it was very uncomfortable because he (my partner) was actually more uncomfortable than I was. Both of us had significant disabilities and his would have been quite more significant than mine, so it was a nightmare". (Angie: Interview 22/06/02)

She went on to say that she and her partner had *"negotiated it successfully, but it wasn't successful when it was negotiated!!"*

Insurance: As I have explained earlier in this chapter, due to the current funding of personal assistance in Ireland, disabled people are not the direct employers of PAs. Therefore there could be insurance implications to be addressed in relation to this high level of facilitation.

Sourcing PAs: In Ireland there is a general lack of available PAs or people willing to train as PAs. This problem is even more significant outside urban areas. Raising an issue such as

facilitation could drastically reduce the number of people willing to work as PAs.

Many PAs currently working in Ireland are non-nationals who come from different cultures and have different religious and moral beliefs. Language is also a difficulty in this regard so explaining and negotiating facilitation could prove difficult.

Institutional Accommodation: As I have discussed in chapter four under 'Access and Opportunity', most institutions and long stay hospitals are, or were, originally run by religious orders. Many of those institutions who are now owned, or managed, by non religious organisations still operate by the original rules, or similar conservative policies. This makes it very difficult, and in a lot of cases impossible, for the disabled residents to develop and express their sexuality.

5.4 Moral Implications

The traditional notion of sexual expression in Ireland is between two people of opposite sex, and it is preferable that they are in a married relationship. If you have a significant impairment, and need the assistance of your PA in order to have sex, this then

means that there are three people involved. If both you and your partner are people with significant impairments, it is possible that you will both need your PAs to assist so then there are four people involved. This has huge moral implications for all parties concerned.

Not all female leaders employ female PAs, and a significant percentage of male PAs actually employ female PAs (Tepper, 2000). This mix of gender can cause difficulty with regard to facilitation. This is particularly difficult if the leader and PA are not of the same sexual orientation.

If the PA is married or in a long term relationship but has agreed to facilitate their leader as part of their job; this may have implications on their relationship with their partner. This issue is further discussed in chapter six, under 'Protection and Choice'.

5.5 Ethical Implications

There are many ethical implications for this form of assistance. One implication is the issue of transference, which is a concept often faced in counselling and psychiatric fields where the client or 'patient' develops an emotional dependency on the counsellor

or therapist. A concern would be that through having such a degree of intimacy in the Leader/PA relationship, the leader would develop feelings for, or an emotional dependency on, the PA.

5.6 Conclusion

In this chapter I have outlined the current moral and sexual climate in Irish society. I have highlighted that although Ireland has progressed significantly in relation to sexual expression since the late 1970's, this progress has had very little positive impact on disabled peoples lives.

I have explained the two methods of personal assistance provision in Ireland. The practical, moral and ethical implications for leader and PA with regard to this form of assistance have been explored under subheadings such as Training and Education, Sourcing PAs and Institutional Accommodation.

In the next chapter I will explore the legal implications and questions surrounding this form of assistance. The interview with Professor Quinn and his colleagues provides the legal opinions in regard to these implications. Under 'Protection and

Choice', I explore the need for a Code of Practice and Grade/Scale of Facilitation to protect both the leader and PA and suggest content for both of these.

6. Legal Implications and Questions

In this chapter I will explain how this issue is legally complex and fraught with implications, particularly in the context of existing Irish legislation. I will then highlight the need for a Code of Practice and Grade of Facilitation to be developed and will suggest some basic content for both.

6.1 The Law and Sexual Expression

Domestic laws such as those, which relate to sexual expression are key elements for addressing the issue.

In Holland prostitution is legal and their laws governing sexual expression are arguably more advanced than in Ireland. A benefit of this is that it is easier in such a country for disabled people to express their sexuality and to have their sexual needs and wants met. For example: A disabled man in Tilburg, Holland receives a monthly allowance from his local authority towards the cost of visiting a prostitute. (Dagblad, 2001) Specific disabled peoples rights legislation, either domestic or international, would not have given him access to this service if prostitution were illegal in Holland.

In 1979, Tuppy Owens founded the UK based 'Outsiders Club' for people with 'physical or social disability'. In an article commemorating the Club's 20th anniversary Ms. Owens said that

"Through the Sexual Freedom Coalition, we campaign to have the laws surrounding prostitution abolished, so we can train specialist sex workers to offer education as well as fun and avoid clients becoming dependent". (Owens, 1999)

It is true that decriminalising prostitution may lead to greater opportunities for sexual expression for some disabled people. However, I believe that it is highly inappropriate for disabled people to be used as a reason for changing the laws related to prostitution.

6.2 The Law and Facilitation in the Leader/PA Relationship

In the Sexual Politics of Disability, which was my key inspiration for this research, it is said that

"assistance that goes beyond the mundane, such as assistance with sexual activity, has to be negotiated

without ground rules or guidance." (Shakespeare et al, 1996: 37)

In order to explore the legal issues relating to facilitated sexual expression particularly in the Irish legal context I met with Professor Gerard Quinn of the Law Faculty in the National University of Ireland in Galway. Two of Professor Quinn's colleagues, Shivaun Quinlivan and Mary Keys also joined us. Professor Quinn is very respected in the disabled peoples movement and is currently immersed in the developing '*United Nations Convention on the Rights of Disabled People*'.

At the beginning of the interview the question of 'capacity to consent' was raised by Shivaun Quinlivan. She wondered if the question of capacity was relevant to the area of facilitated sexual expression. I believe that this is a very relevant question. As I have illustrated in my literature review, disabled people are often treated as childlike (Hendey and Pascall, 1998; Baker and Donnelly, 2001; Mona, in press) and children are not considered to be sexual beings.

Any facilitation of sexual expression that currently takes place in the Leader/PA relationship in Ireland does so in an environment bereft of developed policy, and where appropriate legislative provisions have not been made. Therefore it is possible that a parent/guardian or professionals could question a disabled persons capacity to consent to facilitation, even if the disabled person has no history of mental health or learning difficulty.

During the interview we explored the legal implications of facilitated sexual expression in the Leader/PA relationship, under three headings:

- Employment law;
- Laws relating to Abuse and Personal Protection;

➤ Laws relating to Sexual Expression.

Under each heading I will outline a possible scenario, explore the implications and then provide the opinion expressed by Professor Quinn and his colleagues.

Employment Law

Scenario One: *A leader is interviewing for a new PA. In the interview the Leader mentions that part of the PAs duties would be to facilitate sexual expression with tasks such as assisting them when dating, or when sexually active.*

Implication: If the interviewee indicated that they would not be willing to facilitate the disabled person, and the disabled person then decided not to hire that interviewee could that be viewed negatively under employment law?

Opinion: Professor Quinn said that if facilitation were a “*bona fide level of requirement*” in the job description then the disabled person would be legally entitled to hire a personal assistant who is willing to meet that requirement. However the difficulty is in legally making facilitation a ‘bone fide’ job criteria.

A very clear job description and employment contract would need to be written, and one of the aspects that the legality of including facilitation in this contract would depend on, would be the degree of facilitation required. Ms. Quinlivan said that she was “*not aware of anything that says that only certain things can be job criteria*” (Quinlivan: Interview 27/06/02) but that legally the two areas that would have to be considered in relation to facilitated sexual expression in an employment contract would be corruption of public morality (in a legal sense) and public policy.

In order to negotiate facilitation and to write it into an employment contract “*levels of facilitation would have to be defined by the Leader in advance*”. (Quinn: Interview 27/06/02) I will deal with the issue of developing a Grade of Facilitation and a Code of Practice later in this chapter in the section entitled ‘Protection and Choice’. However, even if a Code of Practice and a Grade of Facilitation existed, and if an employment contract were written to reflect this, it could still be legally difficult due to public policy considerations. If the level of facilitation required was at the higher end of the scale, such as the PA

hiring a prostitute, assisting with masturbation or assisting the disabled person to be physically intimate with a partner, this could be seen as a “*corruption of public morals*”. (Quinn: Interview 27/06/02)

“Sometimes a court ignores what’s written in a contract because they say the person who was looking for the job didn’t have equal enough bargaining power in that situation” (Quinlivan: Interview 27/06/02)

When a person is looking for employment, the prospective employer has more ‘bargaining power’ because the employer is the person offering the job. In this regard there could be a concern that the interviewee might agree to facilitation at the interview because they need the employment.

Scenario Two: *The leader did not feel comfortable about raising the issue of facilitation at hiring stage and waits until the leader/PA relationship has been established. They then try to negotiate for facilitated sexual expression with their PA.*

Implication: Could raising the issue at this stage be viewed as sexual harassment in the workplace, and if the PA does not feel comfortable with this and resigns as a result, could they then sue for constructive dismissal?

Opinion: *“Bringing it up after the employment contract has started could be viewed as sexual harassment”* (Keys: Interview 27/06/02) Professor Quinn stressed that it is *“infinitely preferable”* to discuss facilitation at the beginning of the employment contract. If the PA indicates at that stage that they are not willing to facilitate the Leader, the issue should not be raised with that PA again as that could also be viewed as sexual harassment.

By waiting until the working relationship has been established, the Leader is placing him/herself in a precarious legal position. Not only do they run the risk of being accused of sexual harassment in the workplace, but also if the PA feels that they must leave the position, because the issue has been raised, they could realistically sue for constructive dismissal.

Laws relating to Abuse and Personal Protection

Scenario: The Leader has successfully negotiated facilitated sexual expression with their PA. Both parties are over 18 years and the Leader decides that as this is a private matter there is no reason to discuss it with family or professionals.

Implication: If this agreement comes to the attention of others i.e. family of the disabled person or professionals if the disabled person is living in an institution, could the PA be charged with abuse?

Opinion: This scenario brings us back to the previous issue of the disabled person's capacity to consent and whether this capacity can be legitimately questioned. As I have previously mentioned society often views disabled people as asexual and incapable of sexual expression. Disabled people are often considered to be vulnerable and

"largely inert: acted upon rather than active". [...] The disabled person in the individual model is rendered childlike in their perceived inability to speak for themselves." (Barnes, Mercer and Shakespeare, 1999: 26)

In Ireland, parents and professionals are particularly conscious of the need to prevent abuse, and in the past three years the appalling treatment of disabled children and adults in the industrial schools and hospitals from the 1920's right into the 1970's has started to come to light. (Rafferty and O'Sullivan, 1999) There are also many high profile cases going through the courts at the moment in relation to incidents of abuse that took place in the past ten to fifteen years.

The most effective way to "*protect both people so that a third party can't say that the disabled person is being exploited*" (Keys: Interview 27/06/02) would be the development of a strict Code of Practice, which would have to be adhered to by both the Leader and PA. If the aforementioned 'Grade of Facilitation' were negotiated at the beginning of the Leader/PA working relationship, and written into the PA's contract it would be proof that the PA was not influencing or abusing the leader.

Laws relating to Sexual Expression

Scenario: The PA procures the services of a prostitute for the Leader, or agrees to assist their Leader to masturbate.

Implication: As prostitution is illegal in Ireland, could either the leader or PA be charged with soliciting, and as a PA is a paid employee could they be seen under the law as a prostitute if they assist the leader to masturbate?

Opinion: There are two separate issues here so I will first deal with the question of the PA procuring a prostitute. The leader may face charges, because they have instructed the PA to commit a criminal offence; but the PA would be the key person to be charged because 'vicarious responsibility' is not allowed in Irish employment law.

"Vicarious responsibility in employment law is where the employer is responsible for the actions of the employees. This is not permissible in Ireland". (Quinlivan: Interview 27/06/02)

However, if the PA were to assist the leader to access a service such as prostitution in a country like Holland where it is legal, they would not be committing a criminal offence. This is because the right to '*free movement of goods and services*' is enshrined in Irish legislation.

Personally I believe that the ethical and moral implications of a PA assisting a leader to masturbate are much more significant than the legal ones. However the legal implications are very complex and as this is unchartered legal territory in Ireland, it is difficult to give a definitive opinion. As I have explored the ethical and moral implications of this form of assistance in previous chapters I will only address this question here from a legal point of view.

This level of assistance could place both the leader and PA in a difficult legal position. If the issue were to be presented in court, it is possible that the court could look very negatively on the matter. It is possible that they could measure this assistance by what they believe should or should not be happening rather than measuring it using the PA and Leaders standards.

“Any skirting of public policy is out of bounds but what is public policy in this regard?” (Quinn: Interview 27/06/02) This is difficult to answer because accepted public policy is ‘nebulous’, therefore dependant on the courts interpretation.

Other Issues/Questions Raised

Wrongful birth: Wrongful birth certainly would not be an issue. Unlike Surrogacy, the PA and leader would **not** engage in sexual intercourse or in any act that would lead to either the PA or leader becoming pregnant.

Should a PA inform their partner that they have agreed to facilitate their leader?: This question is more of a moral or ethical one but it would be relevant in a legal sense if there were a danger of an illness or disease being transmitted. It would really depend on what grade of facilitation was taking place. For example if the PA is assisting their leader to go to an adult shop, prepare for a date or chat someone up, there would not be any legal reason for the PA to inform their partner.

Professor Quinn suggested that a way to deal with this issue which would provide clarity, and protection for all concerned would be to write the grade/scale of facilitation into the PA's employment contract. In this contract the PA would be obliged to inform their partner of their actions only if they facilitated their leader past a certain point on the scale.

At the moment there is a lot of debate about whether PAs should wear gloves when carrying out any personal care task. Due to health and safety considerations both for the PA and leader, PAs are expected to wear gloves, however a significant proportion of leaders either discourage or will not allow this to take place due to the medical connotations. This is also relevant to facilitation. If the leader is engaged in sexual activity with a partner or is being assisted to masturbate, it is unlikely that they will want their PA to wear gloves. Therefore in a minority of cases the issue of transmission of disease may be a cause for concern.

6.3 Protection and Choice

To protect the personal integrity and rights of both the PA and leader it is vital that a Code of Practice is developed, which sets key groundrules and boundaries for facilitated sexual expression to take place in the leader/PA relationship. In order to afford the PA and the leader freedom of choice, a Grade/Scale of Facilitation should also be developed which could be included in the PA's employment contract.

Codes of Practice

A Code of Practice would set out the basic rules and boundaries of facilitation in the Leader/PA relationship. This could be based on the Codes of Ethics currently used by professional surrogates which were developed by the World Association for Sexology (WAS) and the International Professional Surrogates Association (IPSA). As I have previously mentioned surrogates become sexually intimate with their clients and PAs do not. However, there are aspects of the WAS and IPSA Codes that could be useful.

The aim of the WAS Code of Ethics is to provide “*rules of excellence for professional behaviour which could be applied in the presence of law*”. (WAS, date unknown) This code covers issues such as professional boundaries, confidentiality, the surrogates relationship with the ‘clients’, training and responsibilities.

The IPSA Code of Ethics is similar but it also states that it is the surrogates responsibility to “*take precautionary measures against the transmission of communicable diseases and infections*”. (IPSA, date unknown)

Code of Practice for the Leader/PA Relationship

A Code of Practice for Facilitated Sexual Expression would not be as detailed as the WAS and IPSA Codes. However such a Code should contain Professional Ethics and Respect, Confidentiality, Accepted Practice, Legal Boundaries and Health and Safety.

Grade/Scale of Facilitation

In her paper, *Sexual Options for People with Disabilities*, Linda Mona highlights that

“According to some PAs, preparing consumers for sexual activity (e.g., removing clothes, positioning, and retrieving erotic materials) was considered to be less problematic than direct participation with stimulation (e.g., PA placing her/his hands on the consumers hands to guide stimulation, helping two consumers with disabilities stimulate each other, guiding penile-vaginal/anal intercourse). Difficulties appear when there is confusion between “assisting with activities” and “engaging in activities””. (Mona, in press b)

As previously mentioned in this chapter, one of the measures that could be employed to assist the Leader to negotiate for facilitation with a prospective PA would be a Grade or 'Scale' of Facilitation. This would address the difficulties outlined by Mona, and would provide the PA with the opportunity to 'buy into' facilitating at a level that they feel comfortable with.

There are two ways which this could be developed. One is to create a generic Grade/Scale which could be inserted into a PA employment contract. However sexuality and sexual expression is such a diverse and personal part of life, I believe that developing a generic Grade/Scale would be extremely difficult, and would not reflect the diversity of peoples lifestyles.

I believe that it would be much more realistic for leaders to be supported in developing their own individual Grade/Scale which would reflect the diversity of their own sexual expression, lifestyle and aspirations. This Grade/Scale could range from either one to ten or one to five. Grade One could be assisting the leader to dress for a date or intimate encounter. This would then range up to the top grade, which could be physically assisting the leader to be sexually intimate with a partner or

whatever level of sexual expression that the leader aspires to. When negotiating the employment contract the leader and PA would discuss the Grade/Scale and agree the highest level that the PA would be willing to facilitate up to.

As an example of what a Grade/Scale of Facilitation might look like, I have developed a very basic one below. This could be adapted to suit any leader.

Sample Grade/Scale of Facilitation	
Grade	Action
1	Assist leader to dress for a date or prepare for an intimate encounter
2	Accompany leader when shopping for adult material, or visiting adult shops
3	Assist leader to flirt, chat someone up or send sexually explicit text messages
4	Assist leader to masturbate
5	Assist leader to access a prostitute or to have sex with a partner

6.4 Conclusion

In conclusion, there are many legal questions and implications attached to facilitated sexual expression in the leader/PA relationship. In order to protect both the leader and PA, the key legal considerations are: how to comply with employment law and public policy, and how to protect both parties from accusations or charges of abuse.

The key recommendations that emerged from the interview with Professor Quinn and his colleagues were:

- Facilitated sexual expression should be raised by the leader either at interview stage or when the job description and employment contract are being agreed;
- A Grade/Scale of Facilitation and Code of Practice need to be developed to address this aspect of assistance.

The Leaders I interviewed agreed that a Code of Practice and a Grade/Scale of Facilitation would be useful. However only one Leader strongly agreed that the issue of facilitation should be raised at the very beginning of the Leader/PA working relationship. One interviewee said

“I wouldn’t always inform them (PAs) at interview stage because from my experience you can actually scare them off. [...] I don’t believe in telling them everything at an interview because life is not like that, you do things differently every other day”. (Rose: Interview 03/07/02)

Another reason expressed for not discussing sexual expression at interview stage, was that one’s sexuality and sexual expression is a very personal and private issue, and Leaders would not feel comfortable raising this subject with a stranger.

Cecilia Gray of the Spastic Society in Australia said that *“there has been a dearth of literature or evidence on ‘how to do it’ without the fear of legal ramifications”* (Gray, 2001) and this would certainly be representative of Ireland.

In my opinion it will take a lot of debate and research to reconcile the difference between the legal requirements, particularly in relation to employment law, and the Leader’s need for time to build a working relationship with their PA. However in order to protect both Leaders and PAs it is very important that this issue is resolved as soon as possible.

7. Review

American disabled feminist Anne Finger said that “*Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain*” (Finger, 1992: 9 cited in Shakespeare et al, 1996: 5)

In the introduction to this dissertation I stated that I would explore facilitated sexual expression in the leader/PA relationship in the Irish Independent Living Movement. I intended to research and discuss this form of assistance in relation to the Irish Social, Legal and moral environment in Ireland, and to examine the related legal and ethical implications.

I highlighted that the parameters of sexual expression set within this paper would range from dressing up or dating, to sexual intercourse and that I would not deal with or discuss alternative sexual expression such as fetish in this paper.

I employed the principles of the emancipatory disability research paradigm for this research. Although I conducted theoretical research such as the literature review, I also focused on

conducting 9 face-to-face interviews and two telephone interviews, which I used to gain an Irish perspective on the issue.

Through the literature review, and the contributions made by the interviewees, I have demonstrated that disabled people are sexual beings. Through discussion with these interviewees, and further peer consultancy, I have come to the conclusion that at present a very basic type of facilitation takes place in the Leader/PA relationship in Ireland.

I demonstrated the key issues facing disabled people in relation to sexuality and engaged in an exploration of facilitated sexual expression with particular reference to PA service provision in Ireland. There are various difficulties in relation to pursuing facilitated sexual expression in Ireland, and these include:

- A limited pool of PAs or prospective PAs to choose from, so leaders can often be afraid to broach the subject for fear of losing, or being unable to hire, a PA;
- No system of Direct Payments available and access to personal assistance in Ireland is not a legal right;

- Numerous legal implications, with the key one focused around employment legislation, particularly sexual harassment and constructive dismissal.

In chapter five I explored sexuality and morality in Ireland and highlighted the significant influence that religion has had, on Irish society and legislature.

The legal implications of this form of assistance were explored with particular reference to employment law, and laws relating to abuse and sexual expression. A key issue that has surfaced in relation to recruitment and employment, is that in the opinion of Professor Quinn and his colleagues, leaders should negotiate for facilitation at the recruitment or contract negotiation stage. However, the leaders that I interviewed felt that it would not be appropriate to discuss such a personal and private issue with a new or prospective employee. The leaders felt that disabled people should wait until a good working relationship has been developed with the PA, because at that stage it would then be possible to judge whether or not it would be appropriate to raise the issue at all.

In summary, following an extensive examination of this issue, the following six recommendations have emerged from this research.

- There is a need for appropriate relationships and sexuality education for disabled people in education and long stay institutions;
- Existing content of PA Training needs to be developed to include sexuality;
- Sexual health information providers should provide information appropriate to the experience of disabled people as part of their mainstream service;
- A Code of Practice for Facilitated Sexual Expression needs to be developed;
- Leaders should be supported to develop individual Grades of Facilitation, which can then be negotiated with their PA. This will help to protect both the Leader and PA;
- Model contracts, which include ethical guidelines, must be developed.

Despite the difficulties, issues and implications which I have explored in this paper, it is important to remember that a lot of

disabled people are engaging in fulfilling sexual activities, getting married, becoming parents etc.

Ultimately my vision for the future is that Irish society will accept us as sexual beings. However this must start by disabled people taking ownership of the issue, debating it, and engaging in a personal and collective growth and development around sexual expression and sexuality.

In 2000, Mitch Tepper stated that

“Pleasure is an affirmation of life. [...] Pleasure adds meaning to our lives. Sexual pleasure is particularly powerful in making one feel alive. It is an anecdote to pain, both physical and emotional.[...] Sexual pleasure can enhance an intimate relationship. It can add a sense of connectedness to the world or to each other”. (Tepper, 2000: 288)

I agree with Mitch Tepper. Sexual pleasure and freedom is truly powerful and in this new millennium, not one disabled person should have to endure compulsory celibacy.

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