Kent Academic Repository

Azzopardi Lane, Claire Lucille (2011) ***Sexuality and intimate relationships for people with learning disability in Malta: realities and potentials.*** **Doctor of Philosophy (PhD) thesis, University of Kent.**

Downloaded from

https://kar.kent.ac.uk/86478/ The University of Kent's Academic Repository KAR

The version of record is available from

https://doi.org/10.22024/UniKent/01.02.86478

This document version

UNSPECIFIED

DOI for this version

Licence for this version

CC BY-NC-ND (Attribution-NonCommercial-NoDerivatives)

Additional information

This thesis has been digitised by EThOS, the British Library digitisation service, for purposes of preservation and dissemination. It was uploaded to KAR on 09 February 2021 in order to hold its content and record within University of Kent systems. It is available Open Access using a Creative Commons Attribution, Non-commercial, No Derivatives (https://creativecommons.org/licenses/by-nc-nd/4.0/) licence so that the thesis and its author, can benefit from opportunities for increased readership and citation. This was done in line with University of Kent policies (https://www.kent.ac.uk/is/strategy/docs/Kent%20Open%20Access%20policy.pdf). If y...

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal* , Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies).

Sexuality and intimate relationships for people with learning disability in Malta:
Realities and Potentials

Claire Lucille Azzopardi Lane

A dissertation submitted for the degree of
Doctor of Philosophy in Learning
Disability

100,000 excluding quotations and references

Tizard Centre,
University of Kent,
Canterbury.

2011

UNIVERSITY OF KENT AT CANTERBURY

ACCESS TO A THESIS

In accordance with the Regulation, I hereby confirm that, if successful in my submission for the degree for which I am candidate, I shall permit general access to my thesis at the discretion of the University Librarian. I shall also permit a copy of my thesis to be deposited n the British Library Document Supply Centre. I agree that copies of my thesis may be made for libraries and research workers on the understanding that no publication in any form is made of the contents without my permission.

....

Signature **Date**

Azzopardi Lane, Claire Lucille

Notes for Candidates

1. The copy sent to the Library becomes the property of the University Library. The copyright in its contents remains with the candidate. A duplicate sheet is pasted into the front of every thesis deposited in the Library. The wording on the sheet is:

   "I undertake not to use any matter contained in this thesis for publication n any form without the prior permission of the author".

   Every reader of the thesis must sign and date this sheet.

2. The University has the right to publish the title on the thesis and the abstract and to authorise others to do so.

CERTIFICATE ON THE SUBMISSION OF THESIS

I certify:

that I have read the University Degree Regulations under which this submission is made;

that, in so far the thesis involves any collaborative research, the extent of this collaboration has been clearly indicated and that any material which has been previously presented and accepted for the award of an academic qualification at this university or else where has been clearly identified in this thesis.

Signature **Date**

Sexuality is an area in which people with learning disability are disabled by social attitudes. Stereotypical views about the sexuality of people with learning disability range from asexuality, implying that they have no erotic or romantic inclinations, to hyper-sexuality which reinforces institutionalized sex segregation through the process of social exclusion. In Malta all these influences contribute to hinder the rights and the quality of life of people with learning disability.

The theory of the social model of disability underpins the research aims, while reflecting discourses of equality and rights. The research aims at giving a better understanding of the sexual lives of people with learning disability in a Maltese context, whilst eliciting the opinions and beliefs of people with learning disability themselves, their parents and their service providers. Qualitative data, collected from people with learning disability, their parents and service providers is interpreted using phenomenological analysis. A sex education intervention pilot project is also run as part of the research, being informed by the findings of the same research.

Findings identify ideologies, highlight missing structures and illustrate feasible future strategies. They reveal a lack of community support and emphasise the need of platforms where people with learning disability can form and maintain friendships and relationships. The dearth of any adequate form of sex education currently available for people with learning disability across Malta as well as the lacuna in policies related to sexuality, and particularly referring to the sexuality of people with learning disability is also uncovered. Recommendations reflecting findings from the main research study and the pilot project mainly target the necessity of sex education, policies and procedures surrounding sexuality in the context of people with learning disability in services across the islands.

This dissertation would not have been possible without the guidance and the support of several individuals who in one way or another contributed to the progress and conclusion of this research project. First and foremost, my utmost gratitude goes to Professor Glynis Murphy and Paul Cambridge who have seen that I overcome each hurdle in the way towards the completion of this research work. The young people with learning disability and their parents, who I have worked with for the past sixteen years and who have been my inspiration all the way through. Ms. Justine Cutajar for her patience at proof reading the completed work. My adorable pets for their precious company through the past five years of constant work. All those who believed in me and gave me moral support when I so much needed it. My mother whose will power and determination I have genetically inherited and those who have not made it to see me complete my studies, my granddad Percy and my late Dad.

Chapter 1: Sexuality

Chapter 5: Methodology 167

Chapter 6: Findings: People with Learning Disability 218

Chapter 9: Pilot Intervention Sex Education Groups in Malta

Chapter 10: Discussion and Interpretation of Findings

Chapter 11: Concluding Recommendations 391

CHAPTER ONE

> *" We are sexual from birth to death*
> *and given appropriate permission,*
> *information and opportunity*
> *will discover ways of*
> *expressing that sexuality".*
> **Timmer, DuCharme & Jacob (1981)**

SEXUALITY

This initial chapter presents a review of literature concerning the relationship of sexuality to gender. Additionally this chapter evaluates further implications in relation to sexuality and gender as a result of learning disability, leading to concerns about abuse and vulnerability for both men and women with learning disability. Sterilization, contraception and motherhood for women with learning disability are discussed with an international perspective, while the influence of culture upon notions of sexuality such as masturbation and homosexuality are explored.

1.1 Defining Sexuality

Giving a universally accepted definition of sexuality may neither be possible nor realistic (McAnulty & Burnette, 2001; Lofgren-Matenson, 2004). The difficulty stems not only from the ambivalence in the topic but also from the extraordinary variability in human sexuality. There are also vast cultural differences in sexual attitudes and practices (McAnulty & Burnette, 2001; Kon,1987), and one must not underestimate the change over the course of history in sexual attitudes and behaviours (Jackson, 1996). Sexual relations vary across cultures and are highly specific to social context, and while biological development provides certain parameters, society with its expectations, opportunities and rules provides others (Brown, 1994). It is also maintained that sexuality is certainly different at different stages of our life (Shakespeare, 2006). In summary, human sexuality is characterized by extraordinary diversity (Aron, 1991).

Selina (2008, pg. 41) explains that there are:

> *"...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 make-up, if we flirt, how confident we are in life and the relationships we form are all influenced by, and in turn influences, the development and expression of our sexuality. Having the opportunity to express our sexuality in turn enables us to define our identity."*

Many have given their interpretation of human sexuality. Aron (1991) asserts that the human species is more sexual than any other species besides being one of the few species that engages in sexual activity for pleasure only. He defines sexuality as consisting of all the sensations, emotions and cognitions that an individual associates with physical sexual arousal and that usually give rise to sexual desire and/or behaviour. Furthermore Oakley (1996) agrees that sexuality inovolves the whole area of personality related to sexual behaviour. Feminist writers such as Jackson (1996) assert that sexuality cannot be separated from the relations between the sexes; neither can it be treated in isolation from the cultural ideals of love or the institution of marriage. Brown (1994, pg.137) maintains that sexuality rather than being a natural force in itself, is a created factor and that "*what is accepted, wanted and acceptable is highly dependent on one's social position and status*".

Way (1982) portrays sexuality as a social phenomenon and argues that a person's social development, beliefs, attitudes, values, self-concept and self-esteem cannot be separated from it. On the same line of thought, Edwards & Elkins (1988) assert that the sexual and the social- self cannot develop in isolation from other aspects of identity. Important aspects related to human sexuality are sexual esteem and body esteem. Sexual esteem has been defined by Snell, Fischer and Walters (1993) as a generalized tendency to positively evaluate one's capacity to relate sexually with another person. It can also be understood as the value a person places on him or herself as a sexual being, including sexual identity and perceptions of sexual acceptability. Body esteem refers to the overall positive or negative evaluation of the body. Jackson (1996) claims that within our species there is a vast range of possible styles of sexuality, and that the attitudes and behaviours found in any society are produced by social learning. She emphasizes that sexual behaviour is social behaviour and not just the consummation of biological drive. Thus;

> *"..female sexuality cannot be seen as a repressed version of male sexuality and neither male sexuality nor heterosexuality can be taken as the norm of human sexual being".*
>
> Jackson & Scott (2010, pg.814)

Haffner (1990) concludes that a definition of human sexuality needs to embrace the sexual knowledge, beliefs, attitudes, values and behaviours of individuals. It must deal with the anatomy, physiology and biochemistry of the sexual response system; with roles, identity, and personality, with individual thoughts, feelings, behaviour, and relationships. Likewise it should address ethical, spiritual, and moral concerns, and group and cultural variations.

1.2 Women and Sexuality

Feminist researchers such as Oakley (1996) assert that femininity and masculinity are constructed socially. Differences in the sexuality of males and females have been attributed to differences in anatomies and hormonal functioning, while personalities and psychologies strongly depend on the culture one is subjected to. Weeks (1989) argues that there are different rules on sexuality for men and women, which tend to subordinate women's sexuality to men's. Understanding how the process of sexual learning operates, and how it is related to other aspects of social learning, enables an understanding of how female sexuality develops (Jackson, 1996). Feminist research confirms that within our society women are assumed to be less sexual then men, with female sexuality reputed to involve long arousal and slow satisfaction, lower sex drive and romantic idealism rather than lust. Jackson (1996) argues that women must not resign themselves to say that women's sexuality is repressed by the demands of a patriarchal capitalist society, but rather that the relationship between society and sexuality is conceptualized through the process of learning to fit in with the current situation, ideology and morality of that society.

The starting point of the theoretical framework of female sexuality (Jackson, 1996) begins from an understanding that sexuality is not just genital sexual activity. Instead it incorporates all the attitudes, values, beliefs and behaviours which have sexual significance in our society, since sexual acts become sexual when socially learned meanings are applied to them. To understand why female sexuality takes this form one needs to examine cultural notions of femininity, attitudes to sexuality and the connection between women's private life and the construction of society. An example of this is Oakley's (1996) report that in women's magazines and fiction dealing with sexual relationships, female sexuality is theoretically receptive, both in a physically structural way as well as in personality. It regards women as passive, submissive, non-aggressive and dependent.

Feminist literature demonstrates how men are at an advantage in their sexual relationships with women (Thompson, 2001). Such imbalance is illustrated by Dworkin's (1996) portrayal of pornography, which gives an insight on another dimension of women's sexuality. In this position women are seen as a commodity; as they exist to sexually serve men, in an industry created by men. Dworkin (1996, pg. 297) refers to the derivation of pornography from the ancient Greek word 'porne', meaning "*graphic description of vile whores*". Dworkin insists that 'whores' exist only within a framework of male sexual domination, and the valuation of women's sexuality in pornography is representative of how women are realistically regarded and valued. Pornography as a form of representation affects and may shape men's ideas and desire for and about women and their treatment (Butterworth 1996; Cameron and Frazer 1996). Butterworth (1996) continues by adding that pornography is an act of dominance and of sexual exploitation, expressing and reinforcing the stereotype that both these two are justified. Just like pornography, prostitution is also seen by feminists as a consequence of women's subordination, as it objectifies women's sexuality and is related to violence against women (Alexander, 1996). Prostitution plays upon gender power where men have the ability to buy their access to women, while women have the power to request payment for their services.

1.3 Women with Learning Disability, Sexuality and Culture

> *"The impact of cultural beliefs and values related to sex and sexuality can further hinder women with disabilities from expressing themselves as 'sexual beings".*
>
> Yoshida, Li, Odette, (1999, pg. 321)

According to Kagawa-Singer (1994), culture serves the purpose of providing the beliefs and values for the individual to develop an identity and to establish the rules for behaviour that support an individual's sense of self-worth. Here we take Yoshida's *et al.* (1999) view of culture, which is seen as a world view for a particular group, comprising of a system of beliefs, behaviours and values which delineate reality. On a more elaborate note, Landman (1994, pg.40) defines culture as;

> "A*n identity which everyone has, based on a number of factors such as memories, ethnic identity, family attitudes to child rearing, class, money, religious or other celebrations, divisions of family roles according to gender or age. Cultures are neither superior nor inferior to each other. They are constantly evolving for individuals and communities".*

Carballo, Cleland, Carel & Albrecht (1989) assert that while biological human sexuality capacity is universal, its expression is influenced by social cultural forces, and as Field, Johnson, Wadsworth & Welling (2004) claim , sexuality is given meaning through cultural norms. Waxman & Finger (1989) and Kallianes & Rubenfeld (1997) both argue that in today's culture, sexuality is closely linked with aesthetic ideals, perfection and health, that emphasize symmetry and wholeness on a superficial level. These ideals exclude women with disability from traditional positions of feminine beauty and attractiveness while also influencing non-disabled people to look at the sexuality of people with disability with unease (Kallianes *et al.*, 1997). Some cultures are known not to consider sexuality as a priority and to recognise a conflict between the values of the particular culture and sexuality issues (Malhotra & Mellan, 1996). Such situations are witnessed in Mediterranean cultures where women are traditionally seen as being either fallen or not yet fallen, depending on their state of virginity, here women's sexuality is seen as extreme and perilous and in need of control (Holloway, 1996). Although there is literature in the areas of culture, sexuality and disability, literature consisting of any combination of these three is scarce (Yoshida *et al.,* 1999). It appears that sexuality and disability are sensitive areas among many cultures, with prevailing stereotypes and negative perceptions about disability. Both culture and disability separately and collectively, pose significant barriers to the expression of sexuality and their opportunities with respect to marital and parental relationships (Yoshida *et al.*, 1999). Block (2000) for instance relates that cultural perceptions that view people with learning disability as perpetual children allow parents to influence or control all aspects of their adult lives. Yoshida *et al.* (1999) report that research in the area of women with disability and sexuality is limited to the sexual functioning rather than the psychosocial, cultural or ethnic implications of sexuality for these women. Their findings show that the effects of culture constrained women with disability from expressing themselves as sexual individuals, especially where learning about sexuality, relationships and family planning was concerned. Malhotra & Mellan (1996, pg.9) conclude that; *"...the whole issue of culture and sexuality is emotionally charged and complex".*

1.4 Women with Learning Disability and Sexuality

Gender power relations both reflect and shape women's and men's sexuality. Futhermore the experience of disability is also gendered, as 'disablism' is inseparably interwoven with sexism (Thomas, 1994). Men and women with learning difficulties experience sex very differently, while findings (Waxman 1993; McDonald *et al.* 2007) confirm that each gender believes the experience of disability of the other gender is less difficult. Men with disability believed that women got more help due to the assumption that they were less able because they were women. Kallianes & Rubebfekd (1997) contend that our patriarchal society has kept a close control over women's sexuality and acceptable sexual activity, while disability augmented the perceived negative aspects of the femininity of women with disability (McDonald *et al.* 2007).

> "*Women with learning disabilities are often not acknowledged as women at all. Their gender is overshadowed by their identity as people with learning disabilities*".
>
> Rodgers (2001, pg.7)

Williams (2007) explains that women and people with disability suffer from negative stereotyping, a common element in the process of marginalization and subordination of oppressed groups. These stereotypes often tend to be contradictory, for instance women and people with learning disability are considered to be "*both submissive and dangerous, both irrational and cunning, both holy innocent and tainted, both virgin and whore, both innocent and social menace*" (McDonald *et al,* 2007, pg.151). What is of particular interest though is the convergence of the negative stereotyping experienced by people with disability and the sexist stereotyping experienced by women in general. Both these groups of people are wrongly believed to be "*irrational, submissive, volatile, passive, manipulative, unable to make their own choices or decisions, excitable and possessed of a hidden but* *dangerous sexuality"* (McDonald *et al.*, 2007, pg.150). McDonald *et al.* (2007) confirm that unlike non-disabled women, cultural expectations for women with disability exclude sexuality, employment and motherhood. Women with physical disabilities are most often perceived as asexual due to the visibility of their impairment that distinguishes them from non-disabled women, and reinforces their exclusion from expectations of sexuality (McDonald *et al.,* 2007; Killoran, 1994). In her study of women with learning disability in Ireland, Walsh (1988) affirms that women with learning disability were more likely than men to live protected lives, whether at home or in an institutionalised setting. They also had fewer opportunities to enjoy independent living. The lives of the women in Walsh's study followed a more restricted pattern of domestic duties and, rather than engaging in social activities for leisure, they would watch television instead. These women were also more skilled in domestic duties but less capable at personal care such as menstrual care and independence skills, they were also more unlikely to travel on public transport then men.

Another issue that is important to all women but not as easily accessible to women with disability is information about their body, sex and sexuality (Thompson, 2001; McCarthy, 1993). This information has been difficult for them to obtain, due to negative assumptions related to wrong perceptions about women with disability, perceptions ranging from lack of desirability to over promiscuity (Yoshida *et al.*, 1999). Notions related to traditional female roles and what is acceptable conduct from women are amongst the difficulties encountered by women with disabilities. While often families would often not consider the need for a woman with disability to have an intimate relationship, women who are sexually active and have overt sexual behaviour tend to be labelled negatively, very often as promiscuous (Craft, 1994). Violation of privacy when requiring assistance in these matters may also negatively affect women's sexual identity (Welner, 1997). Research also reports that for women with a severe degree of disability, especially those still living in institutions, opportunities to develop sexual relationships are restricted (Williams,1992; Garbutt, 2008).

Women with disability are found to have delayed sexual experiences compared to their non-disabled counterparts. They have their first date later, their first kiss later, and have sexual intercourse later (Walter, Nosek & Langdon, 2001; Lee& Oh, 2005; Weigerink *et al.* 2010). Attitudinal and environmental barriers such as fewer opportunities for social interactions, and stereotypical attitudinal barriers such as the belief that women with disabilities are seen as asexual, may play a large part in explaining these delayed experiences. Women with disability also tend to be regarded as heterosexual if not celibate, and only capable of having a relationship if they function independently. They are not regarded as being capable mothers, while in sexual relations they are seen as "*too fragile for vigorous sexual activity*" (Corbett & Bregante, 1992, pg. 279).

In her research with women with learning disability, McCarthy (2001) maintains that women with learning disability often do not have the opportunity or the concept of making choices based on their feelings, needs or desires, with regards to their sexuality. In other circumstances McCarthy (2001) states that these women are not allowed to make choices as their male partners make decisions for them. McCarthy (1996b) reports that women with learning disability do not have a way of expressing their sexuality that is autonomous from men's sexuality; neither do they have outlets for their sexual feelings as men have. McCarthy (1993) asserts that the fact that women's sexual experiences are inextricably linked to men means that women have no way of understanding any sexual feelings or experiences outside of that context. She explains that for these women sex becomes something that they do not only with men but for men; "*sex was primarily for men's pleasure and that the men took their pleasure at the expense of the women's*" (McCarthy, 1993 pg. 278).

1.5 Menstruation

Menstruation not just as a biological phenomenon but as a marker of femaleness interpreted by women according to their social understanding (Rodgers, 2001). Furthermore menstruation makes women with disability undeniably women, capable of bearing a child. Rodgers (2001) adds that in some cultures menstruation is looked at as a taboo while in others it carries social rules. These social rules distinguish between the different social status experienced by women and men. Hamilton (2010) refers to an unwritten menstrual etiquette rule that deems this aspect of women's lives to be kept hidden from public view in white British culture (Rodgers, 2001). One of these social rules in white western culture as well as in Muslim culture requires menstruation to be hidden from men. Research (Rodgers, 2001; Servais, Jacques, Leach, Conod, Hoyois, Dan Roussaux (2002); Rodgers, Lipscombe & Santer, 2006; McCarthy, 2009) brings to light the experiences of women with disability and menstruation, highlighting the lack of knowledge about menstruation and menstrual management (McCarthy, 2009). There is sufficient literature regarding the elimination and suppression of menstruation through medication or surgery, yet Rodgers (2001) affirms that no literature so far recalls the experiences of women with learning disability with regards to menstruation. In her findings Rodgers (2001) confirms that women with disability's experiences of menstruation were negative, revolving around physical pain and feeling unwell, difficulty dealing with menstrual flow and embarrassment. Other issues involving women with physical impairment revolved around being physically able to deal with hygiene. Rodgers (2001) recounts situations when women with disability did not have access to necessary medication to ease the effects of their menstruation or the adequate sanitation as this was at their carer's discretion. McCarthy (2009) on the other hand explores the interference of contraceptive measures with women's menstruation. Although many women with disability were found to be in favour of medication and medical interventions, which were deemed common, they were found to have not been informed about the nature of the intervention or its possible side effects (Rodgers, 2001). As in the case of sterilization, contraceptives or interventions were commonly seen as a way of protecting women from unwanted pregnancy, although again the risk of sexual abuse and sexually transmitted disease was not addressed. Such situations are regarded by Rodgers (2001) as attempts to neglect and ignore these women's femininity.

The provision of menstrual care by male carers was not favoured by women with disability and carers alike, underlining the value of receiving care from someone who has similar body experiences (Rodgers, 2001). This is also reported by McCarthy (2009) with regards to women with learning disability preferring female doctors for these particular health issues.

1.6 Sterilization of Women with Learning Disability

Block (2000) states that women with learning disability have historically been portrayed as either socially threatening or as sexually vulnerable. In the U.S. in the 1920's when segregation of so many so called 'feeble minded' women was becoming common but also expensive for the state, sterilization came to be seen as a more economically viable solution. These so-called feeble minded women who were considered pathological, were depicted as less than human yet able to corrupt and transform society and therefore in need to be extracted from society.

> "*The stereotypes of feeble-minded women as immoral, carriers of venereal disease, bearers of defective children, promiscuous, over-fertile and a cause of potential social, economic and moral decline*".
>
> Williams, (1992, pg. 153)

Rights of people with learning disability "*to maintain bodily integrity and personal inviolability*" (Hamilton, 2010, pg.3) as recorded by Spicer (1999), were absent from any kind of documentation. Even recently, parents have sought sterilisation for their daughters with learning disabilities, yet parental approval towards sterilization is criticized as disproportionate to the sought and evaluated opinions of the women with learning disability themselves. Sterilization of women with learning disability for less than acceptable reasons such as lack of appropriate judgement and responsibility (Katz, Bizman, Shemesh, 2000), can be traced throughout the centuries. While better hygienic control is one reason which reports high satisfaction rates amongst parents and guardians of women with learning disability towards sterilization (Servias *et al.* 2002).

Many states in the U.S. carried out mass sterilization in the 1920s, while the U.K. carried out more individualized cases of sterilization. Block (2000) recounts the story of the Kallikak family, who were studied by psychologist Henry Goddard in the early-twentieth century. Goddard claimed that the gene for feeble-mindedness was passed down in this family for five generation, ignoring the effects of social deprivation on ability. In another well known case, the sterilization of Carrie Buck in 1927 in the U.S. was carried out on the grounds of mental deficiency, after she had become pregnant as a result of being raped; her sister was also sterilized at the age of 16. Still in 1994 Cindy Wasiek was subjected to sterilization as a means of contraception since the mother feared she might be raped and become pregnant (Block, 2000). Keywood (2001) refers to other cases of sterilization in the U.K. such as *Re.L.C.* in 1997, *Re.X* in 1999, *Re. Z* and *Re S.L.* in 2000. Dorozynski (1997) and Diederich & Moyse, (2001) both report European cases of sterilization, of women with learning disability without the appropriate consent and for purpose of contraception. One of the most recent of cases of sterilization occurred in 2007 in the U.S., where a nine year old girl known as Ashley X had her womb and her immature breast removed, and was fed on estrogen to stunt her growth (Gravelli, 2007).

Nowadays there still is concern about the sexual nature of women with learning disability, in medical, legal and popular cultural discourse. Hamilton (2010, pg. 27) reported in her research study that sterilization and menstrual issues of women with learning disability were seen as *"not a suitable topic for discussion"*. She adds that such claims are potentially and significantly damaging concepts in the debate on these emotionally charged topics. Williams (2007) asserts that society's concern that growing sexual awareness in women with disability leads to pregnancy may be based on the assumptions of these women's promiscuity or extreme passive vulnerability. In the past institutionalization and segregation solved the 'problem' of women's sexuality, but moving on to community care has seen parents and service providers requesting sterilization for more than one reason. Amongst the reasons given for sterilisation are protection from pregnancy, childbirth and the responsibility of bringing up children, contraception and menstrual care (Williams, 2007; Keywood, 2001).

In a recent study by Stanfield, Holland and Clare (2007), referrals for sterilization were in most cases of people with *'intellectual disability'* even though a sexual relationship was not being experienced at present and was not thought to be a future possibility. Yet still the court ruled that sterilisation would be in the person's best interest. The majority of referrals made for sterilization in this study carried out between 1988 and 1999 in the

U.K. by Stanfield *et al.* (2007) were sought by the mothers of the people with disability. During this period the application for sterilization had to be made by a parent or someone responsible for the person with disability or from the professionals intending to carry out the medical treatment. As from 2001 in the U.K., following the release of *Valuing People* (Dept. of Health, 2001), which underpinned principles of rights, independence, choice and inclusion (McCarthy,2009), the applicant asking for sterilization intervention is required to be a local National Health Service Trust or other responsible representative body. None the less laws underpinning such issues continue to vary widely from country to country (Hamilton, 2010), and choices about contraception are often made by general practionioners, staff in services and parents, rather than the person with learning disability themselves (McCarthy, 2009a).

Hamilton (2010) claims that since 2000 research has cross examined the use of contraceptives versus sterilization in greater detail. It is for instance evident through various sources of research (McCarthy, 2009a; Servias *et al.* 2002), that patterns of contraception use in women with learning disability are much different from that of non-disabled women, while in the last 5 years in the U.K. sterilisation has become rarer: Stanfield *et al.* (2007) report that there was only one authorised sterilization as recent laws have requested Judges to review the necessary factors when considering the best interest of an individual with learning disability subject to this kind of procedure (the factors which need to be considered include broader ethical, social and moral issues). The decision is not taken as it was formerly, for the therapeutic benefit of the person's well being, but also for the emotional, psychological and social benefit of the person (Stanfield, Holland & Clare, 2007). Nowadays in the UK sterilization of women with disability carries the same general principles that apply when medical treatment is concerned. When a person is unable to consent the courts must be satisfied with the evidence that such a procedure is in the women's best interest. This involves considering the likelihood of pregnancy, the risks and benefits of pregnancy and parenthood, the effectiveness of alternative contraception and the level of supervision that might limit the possibility of parenthood. Experts are instructed to advise the court accordingly. A psychiatrist or psychologist advises the court on issues relating to capacity and the best interest of the person lacking capacity to consent to sterilisation and a gynaecologist advises on issues relating to sterilisation, contraceptive options and potential risks had pregnancy to occur (Stanfield, Holland & Clare, 2007). In the case of women with learning disability the main reason for requesting sterilization was perceived risk of pregnancy as well as menstrual difficulties. Yet again Stanfield *et al.* (2007) and Williams (2007) both underline the fact that sterilisation does not protect against the psychological consequences of abuse or against sexually transmitted disease, therefore undergoing this procedure because of the fear of the unexpected is not acceptable.

In the past year the United Nations has been seeking to ratify a Convention on the Rights of People with Disabilities, which has already been signed by 80 countries and by the European Union. Article 23, (c), of the Convention regards "Respect for Home and the Family" and requires people with disabilities, including children, to retain their fertility on an equal basis with others.

1.7 Women with Learning Disability and Abuse

Sexual abuse of adults with learning disability went unacknowledged until the mid 1970's, and being a taboo subject that met with resistance and denial (Hogg, 2001). Abuse can be defined in many different ways, but it always tends to have a criminological, a social or a clinical basis. Most definitions include contact abuse, involving physical contact between the perpetrator and the victim, sexual assaults, vaginal or anal rape, unwanted sexual fondling and non-consensual oral sex. Some definitions include non-contact abuse where the perpetrator makes no physical contact with the victim, such as exhibitionism and voyeurism. All definitions seem to have a common understanding, that of sexual behaviour perpetrated either without the victim's consent or when a victim is defined as unable to consent (Murphy, 2007).

In the document *No Secrets* (2000) the Department of Health in the U.K. specifies that abuse is *"a violation of an individual's human and civil rights by any other person or persons"*. In giving substance to that statement it recommends that consideration is given to a number of factors (Sect. 2.6). The document underlines that abuse may consist of a single act or repeated acts. It may be physical, verbal or psychological, it may be an act of neglect or an omission to act, or it may occur when a vulnerable person is persuaded to enter into a financial or sexual transaction to which he or she has not consented, or cannot consent. Abuse can occur in any relationship and may result in significant harm to, or exploitation of, the person subjected to it. Peckham (2007) quotes O'Hara & Sperlinger (1997, pg. 158) who specify that sexual abuse takes place;

> *"..whenever someone is subjected to a sexual act to which they do not or cannot consent, or where they have been unduly pressured".*

Brown, Stein & Turk (1995) suggest that in the U.K. there are approximately 1,400 new reported cases of sexual abuse involving people with learning disability each year. Research suggests that there are considerable similarities between the experiences of people with disability and people without disability who have been sexually abused. Such similarities included the gender of the victims, as many victims are female, the gender of the perpetrators who are almost always male, and the fact that victims usually know the perpetrator (Murphy, 2007). Research asserts that men and women with disability are twice as likely to experience physical and sexual abuse as non-disabled people, due to their dependency relationships which make them more vulnerable (Shakespeare, 1999; Cambridge & Carnaby, 2000; Grieveo *et al.* 2006). Murphy (2007) also reports that people with learning disability are not included nor identified in many surveys done to establish a prevalence of victims of sexual abuse.

The Sexual Offences Act (2003) (of England and Wales), Section 30 to 33 lists offences against *"a person with a mental disorder";*

> *"Sections relate to situations where a person (A) involves another person (B) in sexual activity where* B *has a mental disorder, and because of that* B *is unable to refuse involvement in the sexual activity"*

Sections 34 to 37 cover inducements, threats or deception to obtain agreement to sexual activity with a person with a mental disorder. While Sections 38 to 41 create "*specific offences for a care worker that has sexual activity with a person with a mental disorder receiving care in the setting they work at*" (Sexual Offences Act, 2003).

In their work with people with learning disability, Brown & Turk (1993b, pg.197), define sexual abuse as:

> *"..occurring when a perpetrator exposes his/her genitals or looks at or touches certain pats of a victims' body (breasts, buttocks, thighs, mouth, genital or anal areas) or requires the victim to perform sexual acts, for the purpose of gratifying or satisfying the needs of the first person."*

Brown & Turk (1993b) continue by specifying that in these circumstances the victim would be withholding consent, or would be exceedingly pressured into this situation. They also specify the possibility that the victim would be unable to give consent due to an intellectual disability that limits the understanding of sexual behaviour. Perpetrators of abuse against people with learning disability usually include staff and family members, local shopkeepers and volunteers, while a large number are other people with disability using the same service (Turk and Brown, 1993a). Turk and Brown (1993a) also reveal that day and residential services are more likely than family homes to be the setting where abuse might occur, although abuse by family members could be under reported. McCarthy & Thompson (1996, pg. 216) in fact assert that "*learning disability services have unwittingly allowed sexual abuse to be designed into the system*". Most sexual abuse is reported to be committed against people with mild and moderate learning disability, although this could stem from the limited communication skills restricting people with severe and profound learning disability from disclosing abuse (Murphy & O' Callaghan, 2004). This group of people in particular are unlikely to develop keeping safe and decision making skills, through sex education services. Therefore policies and procedures are particularly crucial for this group (Murphy & O' Callaghan, 2004; Murphy, 2007). Reports reveal exhibitionism is the most prevalent of sexual offences while rape is the least common, but they do not specify if this is true for only disabled or both disabled and non-disabled people. People with disability are often reported to have multiple incidents of abuse, while the type of abuse reported is serious involving vaginal or anal penetration. Yet this could also be because of underreporting of one-off or non-contact incidents, which would be underestimated (Murphy, 2007).

Isolated care environments have been associated with abusive service cultures (Cambridge, 1999). When reporting incidents of abuse, people with learning disability often have to rely on their family, their carers and staff working with them. Researchers (Lyall, Holland & Collins, 1995 cited in Murphy, 2007), found in their research that staff in day and residential services are reluctant to report such incidences because of various issues including fear of scandal. One of the issues refers to the appropriateness of the ethos of the services where there abuse took place. Mc Brien & Murphy (2006) report that only 50 percent of services investigated have policies to guide the reporting of incidents to the police. Otherwise cases are prosecuted according to the alleged victim's credibility (Carson, 1992), though there is a stereotyped belief that people with learning disability are not credible or reliable witnesses (Diesfeld, 1996) as the level of general understanding of a person reflects his/her capacity to be a witness in court (Diesfeld, 1996). Furthermore, Diesfeld maintains that the decision regarding competence to be a witness should be left to a judge, basing judgement on evidence and witness examination, not to staff in services. Diesfeld (1996) recommends that self-advocacy, advice and counselling are provided to people who have been victims of abuse so as to enhance the likelihood that sexual abuse is reported and prosecuted. Another problem is that if the alleged perpetrator has a learning disability then carers often think that the alleged perpetrator needs help rather than the intervention of the law (Murphy, 2007). This may be part of the reason why various studies report that few crimes against people with learning disability reach court.

McCarthy (1998b, pg. 544) asserts that "*women with learning disability experience a great deal of abuse from their male peers*" while Turk & Brown (1992) report that the sexual offences committed against others show males mainly as perpetrators of women. The Mansell report (2007) also draws attention to vulnerability of women with learning disability, claiming that;

> *'In mixed-sex houses they may be more vulnerable to sexual harassment and assault; they may experience greater restrictions in the expression of their sexuality than men".*
>
> Mansell, (2007, pg.14)

In his research Thompson (1997) argues that the majority of victims of sexual abuse are women and very often the perpetrators are other men with learning disability, as these tend to have the opportunity and the access to women who are vulnerable to abuse. Jupp (1991) claims that it is important to state that sexual behaviour problems are not gender neutral, since such behaviour tends to have different origins, implications and meaning for the perpetrators concerned according to their gender. Malhotra & Mellan (1996) and McCarthy (1993) underline the fact that the gender of the victims has to be seen in a social context, as well as the fact that women with learning disability are vulnerable both because of their disability and because they are women. Women with learning disability are also known to be victims of abuse by other men, including their father, step-father, father figures and much of the abuse takes place during their childhood as well as in their adulthood. It is also reported (McCarthy & Thompson 1997) that women tend not to recognise abuse as it would often be taking place in an ongoing and valued relationship. Salter (1988) as cited in Murphy (2007) reports that sexual abuse often takes place in secret and many victims do not report the incident especially when the victim is a child. The incidence of sexual abuse committed by staff on women with learning disability has been described as a phenomenon that has been taking place for many years, especially in long stay institutions (McCarthy & Thompson, 1997). There is ongoing debate about whether same sex staff should be preferred when carrying out intimate care and support (Baxter, 1996), although there is generally a higher number of female staff who perform intimate bodily and social care duties then male staff (Hamilton 2010). Same gender intimate care policies are adopted by some services to manage the risks of sexual abuse by male staff and carers although there are conflicts for gay and lesbian staff members. Heterosexual assumptions do not take into consideration that gay men and women may also be vulnerable in these situations. Cambridge & Carnaby (2000) assert that intimate and personal care exacerbate the risk of sexual and physical abuse, especially if there is a high degree of learning disability including lower levels of communication skills and sex education.

> "*Intimate care here relates to the care tasks associate with bodily functions, body products and personal hygiene which demand direct or indirect contact with or exposure of the sexual parts of the body*".
>
> (Cambridge & Carnaby, 2000, pg. 14)

Researchers have reported the seriousness of the consequences of abuse for non-disabled people, including symptoms such as anxiety, insomnia, eating disorders, fears and phobias, depression, guilt, shame, disruptive behaviour, sexualized behaviour, anger, hostility, lack of trust in others, difficulty with social and sexual intimacy and low self-esteem (Murphy, 2007). More recent studies associate these symptoms to those of Post-Traumatic Stress Disorder (PTSD), which involve intrusive thoughts, recollections and flashbacks, exaggerated startle response, self-blame, detachment, estrangement, withdrawal, difficulty with concentration and self-harm. However studies focusing on psychological symptoms of abuse in people with learning disability are limited (Murphy, 2007). These studies indicate that people with learning disability who have been sexually abused also show PTSD symptoms and show more challenging behaviour. Their symptoms include behaviours such as physical violence, aggression, self-injury, soiling or sexually inappropriate behaviour. O' Callaghan, Murphy & Clare (2003) suggest that much of the abuse encountered by people with learning disability is long term and few people have received treatment from qualified professionals. Studies revolving around treatment following sexual abuse for people with learning disability encourage exposure, relaxation training and sex education in order to alleviate the symptoms of PTSD (Murphy, 2007). Prevention of sexual abuse is mainly tackled through the training and information made available to people with learning disability and the development of policies and procedures at service level, yet sexual abuse in intimate relationships might still be overlooked (McCarthy & Thompson, 1996). Self-advocacy is suggested to be an important way of reducing abuse and coercion as women with learning disability learn more about their rights, learn to speak up for themselves and are less prone to abuse.

1.8 Women with Learning Disability as Mothers

Disability rights advocates suggest that the politics of eugenics underline the repression of the sexuality and reproduction of women with learning disability (Kallianes & Rubenfeld, 1997; McCarthy, 2009a). As young girls, women with learning disability are not expected to become girlfriends or lovers and are often told that marriage is not a possibility. This can lead to a feeling of asexuality (Welner, 1997; Kallianes & Rubenfeld 1997; Lee & Oh, 2005). Women with learning disability also find there is a lack of opportunity if not an opposition to meeting potential partners, as well as community pressures not to have a child because of their disability. Women with learning disability are often not accepted as having an adult status and even less a status of motherhood (McCarthy; 2009a,200b). Reinders (2008) opposes the position which many times people with learning disability find themselves in, where choices over parenting are decisions that others make for them. He concludes that parenting is based on a principle of equal citizenship not parental competence.

Parenting by people with learning disability is often perceived as negative (Stenfert Kroese *et al.*. 2002). While motherhood is an important and natural part of a women's identity, it is a forbidden issue for women with learning disability (Rodgers, 2001). Medical choices concerning contraception and surgical irreversible methods such as sterilization are often performed without their consent, with the aim to protect against unwanted pregnancy (Servais *et al.* 2002). Kallianes & Rubenfeld (1997) report that women's movements and disability rights movements have given sexuality and the reproductive rights of women with disability insufficient importance. While reproductive rights have been interpreted as the right to be free of unwanted pregnancy, to obtain contraception and safe, legal abortion, women with disability believe it also includes the right to bear and raise children (Kallianes *et al.*, 1997). Raising children in today's society is seen as an undervalued occupation, but even so Killoran (1994) asserts it is a challenge for women with disability to overcome the culture's refusal to recognise them as potential mothers. This could be due to the fact that people with disability are considered to exist outside the boundaries of reproduction (Waxman & Finger, 1989; Kallianes *et al.* 1997; McDonald *et al.* 2007). Women with disability very rarely decide for themselves whether or not to have children and moreover do not have children due to social barriers rather than to physical impairment (Kallianes *et al.*1997). Their capability to act as mothers is often negatively evaluated by others, who have not considered the difficulties encountered by these women such as a low social and economic status. Family planning is also constrained by the community's negative perceptions and assumptions. There is evidence (Booth & Booth, 1994; Pixa-Kettner1998, Reinders, 2008), that parenting for people with disability is overshadowed by inter-related problems, such as low income, the risk of more than average health problems, ineffective professional support and social networks as well as negative public responses. There is also often the concern that women with disability will produce a child with similar conditions (Lee & Oh 2005), although research (IASSID, 2008) has proven that parents with learning disability had children with average IQ levels which was above 70 and were developing in accord with or above age expectations. The greatest of concerns seems to revolve around the ability of a mother with disability to raise a child and their presumed incompetence (Killoran 1994; Lee & Oh 2005; Reinders, 2008). Killoran (1994), Begum (1996) and Kalliniances *et al.* (1994) report cases where children are taken away from mothers with disability, because the mothers are deemed unfit, sometimes with legal procedures starting prenatally. Kalliniances *et al.* (1997) claim that this puts pregnant women with disability in a position in which they appear to have committed a crime against society. Booth & Booth (2006) report that one in every six children who are subject to care proceedings in the U.S. have a parent who has been assessed as having learning difficulties. These children were more likely to be removed from their homes and families and to be freed for adoption than any other child in care. This places questions about the social definition of parenting, as if this is measured by physical capacity rather than love and nurturing (Kalliniances *et al.*, 1997). In their findings Lee & Oh (2005) and Kalliniances *et al.* (1994) report that women with disability who wanted to have a child believed that this was a possibility with the appropriate social support. Killoran (1994), Kalliniances *et al.* (1997) and Lee & Oh (2005) all underline the need for supportive networks for these mothers with disability.

In research conducted by Yoshida *et al.* (1999) and Kalliniánes *et al.* (1997), women with disability spoke about the lack of sensitivity health professionals demonstrate towards their women's rights of having a child, reinforcing beliefs that women with disabilities are unable to adequately care for their children. There is evidence that parents with learning disability can "*learn, apply new knowledge and maintain new skills*" (IASSID, 2008, pg.301). Yet Killoran (1994) and Kalliniánes *et al.* (1997) assert that the medical field and society both give out messages suggesting that women with disability are not eligible for normal societal female roles of lover, wife or mother. It is often the case that women with disability are not given information about sexuality and birth control as it is assumed they do not require it (Kallianes *et al.*, 1997). Begum (1996) reports that negative attitudes held by healthcare professionals not only affected how women with disability saw themselves but also restricted necessary information they required. It also affected their ability to make choices related to their sexual lives and procreation. Lee & Oh (2005) question whether the idea of disability, rather then gender and reproductive capacity, has put the focus on the women's disability rather than primary health issues, such as sexuality and reproductive health. Furthermore Reinders (2008) maintains that failure to parent lies in inadequate professional support and that learning disability is not necessarily an indicator for failure.

None the less Reinders (2008) affirms that since women and men with learning disability will be living on their own in the near future, rather than in institutions, under the control of professionals, more children will be born to people with learning disability. He concludes that; "*they do what other people do: find friends, fall in love and make babies*" (Reinders, 2008, pg. 312).

1.9 Men and Sexuality

"To be a man is to be powerful and vice versa".
Ragins (1989)

Researchers (Money & Tucker, 1975 as cited in Tepper, 1999) assert that gender identity and expected gender roles are learnt not innate. Masculinity can be said to be shaped by a variety of factors, such as ethnicity, class, culture, religion age and sexuality, and is thereby socially constructed rather than self-constructed (Wheeler, 2004). In this way it correlates with femininity which is also believed to be socially constructed (Oakley 1996; Jackson 1996). Male sexuality can also be seen as essentially defined in terms of social position and power (Brown, 1994). Zilbergel (1992) cited in Tepper (1992) argues that the social construction of masculinity begins as soon as we are born and continues for the rest of our life, while the most important lessons in male socialization have been learnt by the age of six or seven. Jackson & Scott (2010) additionally argue that sexual conduct can be guided by non-sexual motives, while it can occur in ordinary lives contexts and is shaped by wider social institutions.

Aspects of masculinity involve several characteristics attributed to the male species. The physical aspect encompasses being virile, athletic, strong and brave, unconcerned about appearance and aging, while the emotional aspect verges rather towards the unemotional stereotypical aspect of masculinity. The functional aspect is portrayed in terms of being the breadwinner and the provider for family, but none the less the mate in the role with friends. From a sexual aspect men are often referred to as a class that sees sex as power (Alexander, 1996) with importance given to being experienced but with a single status (Saltzman Chafetz, 1974). Stereotypically along with men's aggression in other fields, there is also an accent on aggression in the area of sexuality (Oakley, 1996).

Studies have demonstrated that over the last fifteen years men have become more concerned about their physical appearance (Hoyt & Kogan, 2001; Ricciardelli & McCable, 2001). The muscular ideal male is generally associated with socio-cultural views of the male sex role and of masculinity. Jones (2001) maintains that an ideal man is young, lean and strong, with a broad chest, a 'six pack' and strong biceps, he also needs to have attractive facial features, which make him strong, powerful, independent and efficient (Ricciardelli & McCable, 2001). Morris (1991, pg. 93) concludes that:

> *'The social definition of masculinity is inextricably bound with a celebration of strength, of perfect bodies. At the same time, to be masculine is not to be vulnerable. It is also linked to a celebration of youth and of taking bodily functions for granted".*

1.10 Masculinity, Men with Learning Disability & Sexuality

Definitions of masculinity such as those offered above; suggest that a man is a biological entity and that these above mentioned "*traits or behaviours are associated with being male*" (Wheeler, 2004 pg. 21). Male sexuality, traditionally conceived as phallocentric is one of the problems non-disabled men face, but it is more often encountered by men with disability as disabled masculinity focuses obsessively on perceived impotence and lack of manhood (Shakespeare, 1999). Research reports that men with disability tend to develop their sexuality later their non-disabled peers (Wheeler, 2004). Discussion of men with disability and sexuality tends to revolve around erection and infertility (Waxman & Finger, 1989), while if a man is young and physically healthy then sexuality is seen as an unimportant aspect of his life (Wheeler, 2004). Men with disabilities may be seen as incomplete men for their failure to live up to the assumption of masculinity, which emphasizes capability and strength, therefore their disability seems to detract from the perceived benefits of their masculinity (McDondald *et al.,* 2007). In his research, Shakespeare (1999) confirmed that male participants with learning disability felt they were not "*real men*", as they did not have the physical strength and the social status as is conventionally intended.

There is a lack of models for people with disability, as society's ideal of attractiveness as transmitted by the media, conveys negativity to people who do not fall into that idea of attractiveness and body image (Shuttleworth, 2000). McDonald, Keys & Balcazar (2007) affirm that men with disability felt that their disability prohibited them from living up to society's images about being a man, while social expectations made them feel twice as inferior (Shakespeare, 1999). Tepper (1999), who has a physical disability, explains that frustration, anger and sometimes hopelessness are common feelings experienced by men with learning disabilities, as their intentions are blocked before they are even voiced. This blockage comprises the latter's own comparative engagement with ideal images of masculinity and desirability

Although men with disability might want to have a sexual life, people supporting them might see their sexual life as a problem. Apart from not recognizing men with learning disabilities as sexual beings, people supporting them might fear the consequences of their procreation. Such are parents who convey negative messages to their children about the possibility of having a sexual life or getting married, often wanting to protect them from rejection and heartache (Shuttleworth, 2000). Aversive service responses are often generated towards men's sexual behaviour (Cambridge & Mellan, 2000), while the risk of HIV infection and of being perpetrators of abuse also adds to the concern (Thompson, 2001).

In his research with men with cerebral palsy Shuttleworth (2000) reports that many had experienced isolation from adolescent social contexts at the normal time sexual identities are being formed. They therefore also encountered socio-sexual isolation during their youth, which in turn affected their sexual intimacy coping skills as adults. Bourdieu (1977) as cited in Shuttleworth (2000) explains that men and women incorporate a gendered *habitus*, involving gender specific dispositions and bodily practices which are culturally constructed. There are, he concludes, female and male ways of being-in-the-world and of inhabiting the body. People with cerebral palsy typically cannot embody gender in some of these ways. In terms of trying to establish intimacy and sexual relationships, it can be seen how men feel their physical condition affects their sexual situation. Furthermore, in another study involving men with cerebral palsy, Thompson (2001) reports the general lack of knowledge that men with learning disability demonstrate with regards to women's bodies. Sex between men and women with learning disability is often initiated, controlled and meeting the needs of the men. Thompson (2001) brings this down to the lack of knowledge as well as a lack of communication between the two parties. He concludes that since women with learning disability are reported to read men's non-verbal signals (McCarthy, 1999) during sex, the lack of communication originates in the gender role rather than the learning disability. In fact it is reported that along with the peer pressure from other men with learning disability and from staff, these men tend to not exhibit their emotions and feelings relating to sex due the general reluctance of men to acknowledge these (Cambridge & Mellan, 2000). Yet Tepper (1999, pg.5) maintains that male sexuality goes way beyond the apparent issue of erectile function, and although everyone's experience may be different, *"society still tends to be andocentric, gender polarized and works to socially construct our gender"*.

Researchers have reported that sex between heterosexual women and men with learning disability did not reflect *"sexuality as an expression of a relationship, sensuality as a dimension of pleasure"*, and therefore was rather physical then emotional (Andron, 1983 as cited in Thompson, 2001, pg.4). Men with learning disability are also reported to not show much awareness of the risk of pregnancy, and as a result of not taking any responsibility of this issue (Thompson, 2001). Conahan, Robinson and Miller (1993) portray the case of a man with developmental disability, presenting the concern in addressing his legal status as an adult with regards to his own sexuality. Tepper (1999) attributes this to the lack of knowledge, education and training that medical staff are given in this area. On the other hand lack of sex education and counselling for people with disability who are going through these phases of growing up is also reported by Shuttleworth (2000) and Tepper (1999). Cambridge & Mellan (2000) also report a lack of social-sexual knowledge, amongst men with learning disability. Many men do not recognize acceptable and non-acceptable behaviour, and are lacking sexual negotiating skills such as seeking consent. Research portrays the need for sexuality work with men with learning disability and Cambridge & Mellan (2000) suggest that this is carried out by someone of the same sex. Yet there should be no rigid rules as there is evidence that men with learning disability who have been sexually abused by men would work better with women or request a woman to work with.

Shakespeare (1999) concludes that there is a significant lack of research about many aspects of men with learning disability, much of the present research revolves around the mechanism and biology of male sexuality rather then emotions and feelings involved in sexual relationships. He maintains that men with learning disability experience social exclusion, poverty, violence and abuse.

1.11 Men with Learning Disability as Victims and Perpetrators of Abuse

Sexual behaviour tends to be different in males and females. While a sexually active women with learning disability would be seen as promiscuous, such behaviour in a man with learning disability would be seen as appropriate masculine behaviour (Craft, 1994). Historically society has seen men with learning disability as sexual predators, while during the eugenics area they were thought to be particularly prone to commit crimes of abuse (Murphy 2007). Mellan (2001) and Sobsey (1994) maintain that sexual abuse among people with learning disability is known to be common. Furthermore research asserts that the sex of perpetrators of sexual abuse is gender related, with men forming the vast majority of abusers (McCarthy & Thompson, 1997). Men with disability can be victims as well as oppressors, and are at high risk of sexual and emotional exploitation (Shakespeare 1999; Cambridge 1996a). As is the case for men without disabilities, people with learning disability who have a history of sexual abuse as victims themselves are more likely to become perpetrators (Gilby *et al.,* 1989). Block (2000, pg 241) confirms that "*men and boys with cognitive disabilities who have experienced sexual aggression may, in turn begin to hurt others*". It is also reported that men and boys with learning disability are far more likely to experience sexual aggression than boys without disabilities.

Sex offenders with learning disability are more likely to have themselves been abused as children; they are reported to have low self-esteem, to be socially isolated, emotionally lonely and lacking social skills necessary to develop intimate relationships (Murphy, 2007). They also tend to come from a chaotic, violent and neglectful family with a criminal history; but differ little from non-disabled sex offenders whose victims are usually adults (though their victims are most commonly other people with learning disability and more frequently often males - Gilbey *et al.,* 1989). Sexual offenders with learning disability often show challenging behaviour, such as aggression and tend to have a history of mental health problems. Thompson (1997) suggests that they often commit the full range of sexual offences, re-offend and usually know their victims (Gilby *et al.,* 1989), just as in the general population.

Sobsey & Doe (1991) report 89% of perpetrators of sexual abuse against individuals with learning disability are men while Turk & Brown (1993) affirm that the figure goes up to 98%. McCarthy & Thompson (1996) also argue that research indicates that a good percentage of abuse is perpetrated by males against female service users, with 95% of perpetrators of sexual abuse also being known by their victims (Turk & Brown, 1993). Men with learning disability who are perpetrators of sexual abuse seem to lack appropriate ways of expressing their own sexuality (Wilcox, 2004). Recent research has focused significantly on the role of men with learning disability as abusers and in relation to homosexuality and HIV (Cambridge & Mellan, 2000). McCarthy & Thompson (1996) report male to male abuse, with more able men making up for the highest percentage of abusers (McCarthy & Thompson, 1996, Cambridge & Mellan, 2000). Hayes & Craddock (1992) in Murphy (2010) suggest that men with learning disability are less successful at keeping their abusive behaviours hidden and more likely to get their perpetrated abuse detected than other non-disabled men. They attribute this to the fact that men with learning disability have *"more supervision, fewer private spaces, less freedom to go out alone and have less advanced planning skills than other men"* (Murphy, 2010, pg. 2).

Feminists argue that the way that society and men in particular tolerate attitudes and behaviours associated with sexual offending, which include pornography and prostitution, is an important issue when considering abuse (McCarthy, 1999). However it is in fact reported that most services for people with learning disability restrict the use of pornography (Cambridge & Mellan, 2000). A few small scale studies suggest that men with learning disability who commit sexual abuse have much in common with non-disabled sex offenders, although men with learning disability often are rarely reported to the police, especially if the victim is another person with learning disability and are, moreover, rarely convicted in court (Thompson, 1997; Green, 2001). Yet it is not in the best interest of the offender to overlook or rationalize their sexual offending (Brown & Turk, 1991; Brown & Barrett, 1994). Having to go through the criminal justice system is a way to ensure that people with learning disability who have committed crimes of abuse, get the therapy or treatment they need to alter their offending behaviour (Murphy, 2007; Gardner, 1986). Research shows that there are many similarities between sexual offending in men with and those without learning disabilities and treatment also follows the model for non-disabled offenders. Although there has been much research in the area of men with learning disability and causes of sexual offending, many men with learning disability who have sexually abusive behaviours are not yet being offered treatment (Murphy, 2007). In the U.S. studies indicate that men with abusive histories are managed through close supervision. This simple measure of control cannot be removed since this would not decrease the risk of re-offending (Ward, Trigler & Pfeiffer, 2001).

During the 1980s theories which attempted to explain sexual offending of non-disabled men started to emerge. Wolf, (1988) cited in Murphy (2007), attempted to explain how low self-esteem and personal problems led to self-reinforcing fantasies which included sexual fantasies. This led to targeting a victim, getting to know him and planning the offence, whilst engaging in cognitive distortions to excuse or neutralise the actions. Following the sexual offence there would be a brief period of sexual satisfaction, again followed by guilt which lowered self-esteem, with the whole cycle repeating (Murphy, 2007). Another theory by Marshal *et al.* (1999) revolves around the social isolation of sexual offenders, the presence of attachment deficits and the role of empathy. The insecure attachments to parents as young boys, leading to fearful or avoidant attitudes to social intimacy with peers and resulting in loneliness, is one of these researchers hypothesis. Due to these social relationship difficulties, boys with insecure attachments begin to seek intimate experiences through sexual acts combined with feelings of anger, depression and resentment or under the influence of alcohol.

As a result of these theories, treatment for non-disabled men who had committed sex offences focused on cognitive and affective reasons for sexual offending (Murphy *et al.* 2010). Cognitive Behaviour Therapy (CBT) has become a large scale treatment, and rehabilitation programs have become mandatory for men convicted of sexual offences, with studies showing that it halves re-offending rates (Hanson, Gordon, Harris, Marques, *et al.,* 2002). CBT is usually offered as group therapy and run by one male and one female therapist. Most programs last one year and include; enhancing self-esteem, improving social and relationship skills, enhancing victim empathy, the role of fantasy and sexual preferences, the cognitive model and challenging of cognitive distortions and relapse prevention (Murphy, 2007). Murphy *et al.* (2010, pg.6) report that CBT treatment addresses human relations and sex education, thus providing;

> *"..a common knowledge base and understanding for human sexuality and relationships, including consent and legal issues.."*

Murphy *et al.* (2010) concludes that CBT takes;

> *"..a cognitive approach to changing sexually abusive behaviour, through changing the men's cognitive distortions...".*

Abusers may tend to be reluctant to attend a treatment program that forces them to confront their attitudes and behaviour and that lasts a whole year. Prior to CBT, treatment involved medicinal and behavioural methods. Medicinal treatment involved anti-androgens and anti-libidinal drugs or behavioural programs focused on correcting abnormal arousal either by punishment, such as aversive conditioning and covert sensitization or by reinforcement, as in orgasmic reconditioning (Quinsey, Cahplin & Carrigan, 1980; Marquis, 1970).

Very little is known about the sterilization of young men with intellectual disability, although there has been extensive public debate about the sterilization of young women with intellectual disability (Carlson, Taylor & Wilson, 2000; McCarthy, 2009). Recent reports throw light upon young boys and men with intellectual disability, some under the age of 9 years, who are being subjected to vasectomies and bilateral orchidectomies. These forms of surgery together with the use of drugs are used to alter sexual behaviour and forms of anti-social sexual behaviour, (Hamilton, 2010; Carlson, Taylor & Wilson, 2000). Cambridge & Mellan (2000) still report the use of medical models to treat sexual behaviours of men with learning disability, not necessarily due to abusive behaviour but also for homosexuality or transexuality.

Nowadays CBT is the treatment of choice and treatment manuals and training courses are available for therapists. Programmes for people with learning disability are simplified and almost always include an element of sex education, since this particular group is known to have lower sexual knowledge than non- disabled men (Murphy and O' Callaghan, 2004). CBT with men with learning disability also includes relapse prevention. The effectiveness of CBT in rehabilitating sex offenders with learning disability still needs to be established as few studies have yet been carried out (Murphy *et* *al.* 2010), although these have shown evidence of a change in behaviour, especially when treatment is carried out for one to two year periods (Lindsay *et al.*, 1998a & b).

1.12 Masturbation

> *'Masturbation is one of the most common and potentially harmless forms of sexual behaviour, enjoyed by women and men alike, sometimes solely, but more often as part of a wider sexual repertoire. Most people also masturbate throughout the majority of their lives".*
>
> Cambridge *et al.* (2003, pg. 251)

Walsh (2000) observes that masturbation is a normal and healthy human expression that occurs through the lifespan. It is known to be a key issue when supporting the sexuality of people with learning disability, despite receiving little attention in the academic and professional world (Cambridge, Carnaby & McCarthy, 2003). Cambridge *et al.* (2003) also maintain that masturbation is at times seen as problematic despite being a common and frequently occurring sexual behaviour in non-disabled and disabled people alike. Masturbation is seen at times as the only means of sexual expression people with learning disability, who often lack exposure to their own sexuality, have control over (Koller, 2000). Negative attitudes towards masturbation are bound to reflect misconceptions and anxiety held by people with learning disability with regards to masturbation (Katz, Bizman & Shemesh, 2000). Such negative attitudes are possibly the result of negative attitudes transmitted to people with learning disability by others who are responsible for their care (Poorman, 1988 cited in Katz *et al.* 2000). The emotional changes in young people with disability are often overlooked, although they would be going through the same hormonal and physical changes of any other young person. Cambridge *et al.* (2003) remind us that masturbation as well as body exposure and homosexual tendencies, were considered behaviour problems on the Adaptive Behaviour Scale. Furthermore researchers have admitted that few, if any of the major world religions look positively at masturbation (Cambridge *et al.,* 2003; Walsh, 2000).

Stoner (2007) argues that a wheelchair, a congenital or an acquired disability will result in obstacles in leading an active sex life. Kaufman, Silverberg & Odette (2006) comment on the fact that although there are many professionals whose aim is to teach self-help skills, teaching or facilitating masturbation is not known to be on the agenda, and to teach this physically is against the law. People referred for sex education support usually present issues with masturbation (McCarthy 1996a), most of these being men rather than women. Service users have reported negative interpretations and associated feelings of guilt and shame when discussing masturbation in individual or group sex education (Cambridge & McCarthy, 1997; McCarthy & Thompson, 1998). Cambridge *et al.* (2003) attribute this to decades of neglect with respect to sexuality, originating from a system which devalued people with learning disabilities, leaving them socially, economically and culturally marginalized. Little is known about women's experiences and feelings about masturbation, but it is known they find it extremely difficult and embarrassing to talk about (McCarthy, 1999). Apart from reporting that women referred to sex education have little or no knowledge about their body, McCarthy (2001, 2009) reports that women with learning disability seem not to consider masturbation as an acceptable activity and are less likely to engage in it than non-disabled women. Reasons range from social taboos to the stigma experienced by women in society in general. It is also possibly evidence of the negative feelings and lack of pride women with learning disability have of their own body image (McCarthy, 1998b).

Masturbation or rather inappropriate masturbation is one of the major and most common sexual behaviour concerns of staff working with people with learning disability (Mellan, 2001; Cambridge & McCarthy, 1997). It is usually seen as an inappropriate sexual behaviour carried out predominately by men (Cambridge & McCarthy, 1997) and is unfortunately often treated with insensitivity or ignored by care workers (Walsh, 2000). Downs and Craft (1997) report that masturbation often takes place during intimate and personal care (Cambridge & Carnaby, 2000) which often results in irrational and punitive response by care workers (Walsh, 2000). As Cambridge & Carnaby (2000a) maintain, the high incidence of masturbation during personal care may be due to the fact that this is the only time an individual has easy access to his sexual body parts. Masturbating in a public place, whether done or not done deliberately to offend or gain attention, is also a major issue, and requires private spaces which the person can be guided to although this is known to be a complicated issue (Cambridge & Mellan, 2000). Walsh (2000) affirms that rather than promoting appropriate masturbation, services often attempt to eliminate masturbation altogether. Carnaby, (1997; 1999) insists on the tendency to disrespect and disregard the privacy of people with learning disability, as well as desexualizing and deindividualizing them. Walsh (2000) and Cambridge *et al.* (2003) recommend private time, when an individual can have access to his own body and when he is being informed that his behaviour is allowed and valued.

The lack of interesting and enjoyable activities can also give way to self-involving behaviours in order to relieve frustration and boredom (Cambridge *et al.*, 2003). Baxter (1996) underlines that lack of privacy and lack of sex education, as well as not acknowledging different cultures and ethnicity, all add to the perceived problem of masturbation in people with disability. An example of such a situation highlighting the cultural and traditional boundaries entailed by religion is given by Malhotra & Mellan (1996) working with Jewish people with learning disability. Masturbation is considered an unacceptable activity for men generally in Judaism, but tolerated when performed by men with learning disability since masturbation is seen as a waste of seed, and men with learning disability are not expected to become parents. When masturbation is linked to challenging behaviour, particular procedures must be undertaken such as accurately observing the social and physical context of the behaviour to then help designing intervention. In these cases staff working with the people with disability need to reflect upon their own values and beliefs about sexuality (Cambridge *et al.*, 2003), as often carers' negative attitudes are internalized by the people with disability themselves, resulting in a sense of guilt and shame (Walsh, 2000). It is also likely that masturbation in men without learning disability is often the initial stage of a sequence of sexual behaviours which may lead to unsafe sex (Cambridge, 1999). Walsh (2000) recommends that the environment must reflect a positive attitude where the sexuality of people with disability is respected and accepted. Cambridge & McCarthy (1997) therefore recommend that services for people with learning disability follow a sexuality policy, while an individual educational intervention is set on the person's individual plan (Carnaby, 2002).

As Walsh (2000, pg.3) clearly states;

> *"Addressing inappropriate masturbation successfully relies on an understanding of what the behaviour communicates about that person, or what purpose the inappropriate masturbation may be serving for them. If this understanding is lacking, approaches tend to be oppressive and punitive".*

1.13 Homosexuality

Sexual orientation is another factor incorporated within this wider meaning of sexuality. Sexual orientation is described as *"an enduring emotional, romantic, sexual or affectional attraction to another person ... along a continuum that ranges from exclusive homosexuality to exclusive heterosexuality and includes various forms of bisexuality"* (National Disability Authority, NDA, 2005, pg.12). The terms homosexual and heterosexual can be used narrowly to describe the orientation of the sexual drive or the sexual gender a person is attracted to, in terms of eroticism or sexual behaviour. Homosexuality is found in most ancient and modern forms of human society, from China to Greece in the past, to Europe and North America nowadays. Homosexuality as a term derived from the Greek prefix 'homo' added to the Latin word 'sex', so as to indicate an attraction or sexual preference for the same sex, whereas the prefix hetero means other or different. Female homosexuality is known as Lesbianism and takes its name from the Greek island of Lesbos, where the Greek poet Sappho lived in a female community (Coleman, 1980). The views of ancient Greek philosophers, such as Plato, distinguished earthly and profane love, which originated from the body, from heavenly and sacred love which originated from the mind. Plato believed that profane love lowered men and women to the level of animals. Other ancient Greek writers such as Democritus and Epicurus believed physical love distracted humans from seeking higher spiritual levels. Such philosophies were influential amongst early Christian writers (McAnulty & Burnette, 2001).

Ancient Roman attitudes towards sex are known to have been decadent, with the fall of the Roman Empire partly attributed to their sexual mores. During the era of Roman Empire, Christianity rose steadily, and with the Empire's decline it was the leading religious, intellectual and political force in Western cultures that greatly influenced attitudes towards sexual behaviour. In the Medieval Period the Catholic Church, following interpretations of Christianity, established a rigid code for sexual morality, which saw homosexuality as a sin. St. Augustine's views, that sexual intercourse threatened spiritual growth, and could only be acceptable for procreation, became the official doctrine of the Catholic Church through the Middle Ages. Judeo Christian tradition therefore does not justify non-procreative sex, while the Old Testament overtly prohibits homosexual relations (McAnulty & Burnette, 2001).

Homophobia is a form of disapproval and discrimination, expressed towards people who are attracted towards others of their own sex. Homophobia can take the form of pity, scorn, rejection, legal prohibition and violence. Homophobia remains a deep-set attitude in today's society. The word homophobia describes the reaction of fear and dislike which the heterosexual majority tend to express to homosexual culture and people. According to Freidman (1989) homophobia sparks male hatred of women and fear of closeness to other people. Rigid sex role stereotypes prevent heterosexual males from establishing meaningful and intimate relationships with other men and women and set up male-female relationships based on male superiority that preclude the possibility of true intimacy (Neisen, 1990). Linn, Stein and Young (1992) report that homophobic name-calling is used to keep boys in line. Name-calling creates or reinforces hostility toward gay and lesbian people and it forces all children to follow strict sex role behaviours to avoid ridicule (Gordon 1983). Homophobia, seen as the fear of being perceived gay, is said to be perhaps the greatest pressure boys face while growing up (Friedman, 1989) and is considered the ultimate weapon in reinforcing rigid sex role conformity. The AIDS epidemic was closely associated with men who have sex with men, who as a consequence were thought to be more at risk of HIV infection and this created greater homophobic feeling towards gay men (Cambridge, 1997).

Sex is also a politically sensitive issue, which politicians often view as their responsibility to address (McAnulty & Burnette, 2001). In the Eighties, the U.K, at the time under a Conservative Government led by Prime Minister Thatcher (1979 to 1990), saw a controversial amendment to the Local Government Act 1986 which related specifically to homosexuality. Section 28 was a enacted by the Local Government Act on 24 May 1988 and repealed on 21 June 2000 in Scotland, and on 18 November 2003 in the rest of the UK. The amendment stated that a local authority "*shall not intentionally promote homosexuality or publish material with the intention of promoting homosexuality*" or even '*promote the teaching in any maintained school of the acceptability of homosexuality as a pretended family relationship*". Section 28 prohibited local councils from distributing any material that portrayed gay relationships as anything other than abnormal. Teachers and educational staff in some cases were afraid of discussing gay issues with students while a number of lesbian, gay, transgender, and bisexual student support groups in schools and colleges across Britain were closed for fear of breaching the Act.

Nowadays debate revolves around issues of homosexuality and equality, with movements lobbying for equal rights and against discrimination of the lesbian, gay and transsexual population. Amongst the issues recently being raised is the controversial acceptance of gay priests as clergy. This is something the Catholic Church is completely against, but other strands of the Church, such as the Anglican Church have accepted to allow homosexual couples to marry under the new civil partnerships law. Gay and lesbian clergy who wish to register their relationships will be able to benefit from tax and inheritance laws currently only applicable to heterosexual married couples. This stance does not come without conditions for clergy in gay relationships, who are required to give a guarantee to the diocesan bishop that they will abstain from sex. Conflicting ideas towards the heterosexual and homosexual meaning of marriage in the eyes of the Church are here clearly outlined, reinforcing a sense of stigma on sexual acts between gay or lesbian couples.

In Roman Catholic marriage, a marriage is null unless it is physically consummated (Matt 19:6), while in the Church of England, homosexual civil partnership, which still does not replace full marriage rights, condemns the physical consummation of such a union. Coward (2010) confirms that the majority of gay Christian clergy at the moment marry secretly as *"...it's a taboo subject but the church is now under huge pressure to change its stance and that pressure will only increase in the future"*. None the less blessing civil partnership in church is forbidden, even though Coward (2010) argues that the Church; *"can bless almost anything else; animals, bombs, battleships, armies going to war but gay couples"*.

This position is in line with the Roman Catholic Church who accepts homosexual orientation but condemns the sexual act. According to the teachings of the Roman Catholic Church, men and women with homosexual tendencies must be accepted with respect, compassion and sensitivity. Every sign of unjust discrimination in their regards should be avoided (Letter on the pastoral care of homosexual persons, 1986, No.10). Despite this declaration, the Congregation for the Doctrine of Faith (Catechism of the Catholic Church, No. 2357) resolves that there are absolutely no grounds for considering homosexual unions to be in any way similar or even remotely analogous to God's plan for marriage and family. Marriage is holy, while homosexual acts go against the natural moral law and under no circumstances can they be approved.

1.14 Homosexuality and Learning Disability

Opportunities to express sexual identity and in particular sexual orientation within the context of disability remain a relatively unexplored area (NDA, 2005). Noonan & Gomez (2010) attribute the lack of opportunity to choose a sexual identity to the absence of sexual experiences in the lives of people with learning disability. Additionally reports by the National Disability Authority such as Sexuality and Sexual Orientation (NDA, 2005) claim that same sex relationships have been at times treated as lacking in value and meaning (Noonan & Gomez, 2010). Similarly the report of the Commission on the Status of People with Disabilities (1996) refers to the 'desexualisation' of people with a disability, where the individual with learning disability is prevented, through a variety of factors, from having the opportunity to achieve the *"same degree of fulfilment through relationships and sexuality as anyone else"* (para 18.1). Key issues reported in the NDA's (2005) document, regarding sexual orientation and individuals with disability, who are lesbian, gay or bisexual and disabled, is their subjectivity to a complex array of prejudices (Sect.11). It claims that people with disability are individually and collectively subject to prejudices based on the 'normalising' principles of a non-disabled, largely heterosexual mainstream population.

> *"The combination of this misconception with societal and cultural prejudices towards persons who are lesbian, gay or bisexual creates a population within society who face a double prejudice for acceptance and equal rights - as people with disabilities, and as lesbian, gay or bisexual individuals"*.
>
> (NDA, 2005, pg 17)

Social interaction opportunities for lesbians, gay men or bisexuals with disability are reported to be virtually non-existent and the absence of specialised support services in this area is underlined. The NDA (2005) emphasises how paternalistic care is believed to undermine the rights of service users with learning disability. The latter's expression of a lesbian, gay or bisexual orientation to carers or personal assistants is often accompanied by the "*well-founded fear*" that such care providers will report back to the individual's parents 'for their own good'. The identification within disability services of considerable differences in staff attitudes towards sexuality and sexual expression is present across research (Garbutt, 2008 and Murray *et al.* 2001) . In the NDA (2005, pg. 24) service users report that;

> "*some staff may accept, others tolerate, while yet others can be very uncomfortable dealing with issues around sexuality*".

Disability research is also reported to be wedded to dominant heteronormative stances (Rembis, 2010). While expression of intimacy towards the same sex is ridiculed, homosexuality and bisexuality as sexual identities are considered an anathema or part of the development towards heterosexuality (Noonan & Gomez, 2010). As a consequence if a person with learning disability is sexual, then they are assumed to be heterosexual. Heterosexism is a form of discrimination, which assumes that the natural sexual desire is heterosexual (Clements *et al.*, 1995). Clements *et al.* 1995 maintain that within services heterosexism is prevalent but remains unchallenged. Clements *et al.* (1995) claim that heterosexuality among people with learning disability can possibly be associated with higher cognitive functioning and the ability to distinguish gender, while attraction to someone of the same sex would reflect lower developmental abilities. This is an example of heterosexism. Pharr (1993) as cited in Brown (1994) asserts that within services homosexuality is not discussed and is morally stigmatized, while Brown (1994) maintains that people with learning disability who chose same-sex relationships were not helped to build such an identity. Research in the field of lesbian or queer sexualities and disability also indicate a dominant heterosexual norm, both in the literature and in the actual lives of people with learning disability themselves (Rembis, 2010). Noonan & Gomez (2010) attribute this to lack of opportunities for people with learning disability to learn from sexual experiences and being informed when choosing their sexual identity.

Men with learning disability, living in both in community settings and institutions, are more likely to have sex with men than with women (McCarthy &Thompson, 1997). Thompson (2001) claims that men with learning disabilities in his study showed no strong gender preference to sexual partners, but rather took all opportunities for sex. This would explain why men who had sex with men also had sex with women with learning disability. Furthermore the needs of men with learning disability, who have sex with men, are not recognized because of social and legal implications (Cambridge, 1997a), with such behaviour more likely to be kept concealed than recognized as a positive choice (Brown, 1994). Mellan (2001) also reports that same sex relationships, especially those involving men with disability, are seen negatively by staff and carers. Public expression of intimacy between people with learning disability of the same sex is not considered acceptable and often ridiculed (Lofgren-Martenson, 2008; Noonan & Gomez, 2010).

Between 1983 and 1987 the early stages of the AIDS epidemic received wide attention and was associated with negative images of homosexuality (O'Toole & Bregante, 1992). Because homosexuality is often associated negatively with challenging or offensive behaviour it is further pathologised, with HIV reinforcing this stigma. Although not much is known about the epidemiology of HIV infection in people with learning disability (Simonds & Roger, 1992), there is evidence that they have been infected

(Marchetti *et al.*, 1990), as segregation in services and institutionalization have not been able to shield and protect anyone from HIV infection (Cambridge, 1997). Indeed Cambridge (1996a), argues that people with learning disability who are sexually active are at a high risk of HIV infection, especially in relation to sex with men without learning disability. Moreover Cambridge (1996c) highlights the high risk sexual behaviour of men with learning disability living in residential homes and attending day support services. He maintains that HIV risk assessment is necessary in services for people with learning disability, in order to manage risk and HIV transmission. Many men with learning disability are reported to be more vulnerable because of individual and/or environmental factors. They tend to hide their homosexual behaviour because they have been led into the belief that it is wrong (Cambridge, 1996c). Men with disability are known to have unsafe sex with different sexual partners in places such as public toilets, a practice which is known as *"cottaging"* (Cambridge 1997). Therefore they are more likely to have penetrative sex anally or orally by men from a high HIV risk group (Thompson, 1994). HIV testing for men with learning disability would involve the person giving informed consent and therefore knowing what the test involves and the consequences of knowing HIV status. Without informed consent from the individual, a legal judgement is left to a High Court decision (Cambridge, 2001). Cambridge (1997a) reports that although specialist counselling, sex education and therapeutic services in sexuality and HIV for people with learning disabilities have been established, support is still very limited. Only recently have sex education materials incorporated homosexual sexual relationships and HIV, although in such materials there continues to be unequal representation of homosexual behaviours when compared to heterosexual behaviours (Cambridge, 1997a). Cambridge & Mellan (2000) observe that men with learning disability are in fact most likely to receive only heterosexual sex education.

Women with a disability are known to engage in sexual behaviours later than non-disabled people. Furthermore, women with learning disability who have sex with women or identify as being lesbian is known to be an uncommon behaviour (McCarthy 1993). Whitney (2006) maintains that women with disability are more likely to face barriers when coming to terms with their sexual orientation. "*Identifying as both queer and disabled is a complex and multifaceted process*" (Whitney, 2006, pg. 46). Whitney (2006), McCarthy (1999) and O'Toole & Bregante (1992) all report that there is a particular lack of resource and research about lesbian women with learning disability. O'Toole and Bregante (1992) explain that in health services, workers presume that these women are asexual or else they focus just on birth control. Although support within lesbian communities is emerging there is still a lack of it, resulting in isolation and homophobia as is reported by women with disability who are themselves lesbian (Rembis, 2010).

1.15 Conclusion

This chapter has aimed to give a clear picture of the influences of culture and gender upon the sexuality of people with learning disability through the review of the international research and literature available. Sexual identities are explored separately according to gender and in relation to learning disability with similar themes such as abuse portrayed in both. Past perceptions and conduct towards people with learning disability and their sexuality undermine the opinions of today's society and are reflected in the changes in current ideologies and practices outlined in this chapter. Finally the chapter draws upon homosexuality as a third sexual identity and gives an account of the issues that emerge in the case of homosexuality in people with learning disability.

CHAPTER TWO

How disability is defined is of crucial importance.
The presuppositions informing
particular definitions can be offensive
and provide the basis of stereotyping
and stigmatisation.
Barton, L. (1993)

LEARNING DISABILITY
&
SEXUALITY

This chapter provides a current definition of learning disability, based on theories of the Social Model of Disability, and relates learning disability to sexuality. The history of the sexuality of people with learning disability across European countries sets the background to the early years and the Eugenics period between the 18th and 19th centuries. Deinstitutionalization and the influence of the normalisation are also examined in the context of changes in sexual norms in the late 20th century.

This chapter will consider how people with learning disability are still depicted through the stereotypical images which prevail in society, and which hinder the opportunities for people with learning disability to establish and maintain friendships and relationships. The value of social platforms for people with learning disability to establish friendships and relationships is then explored, with the difficulties encountered by people with learning disability at developing and establishing their sexuality discussed, including parental attitudes about the sexuality of young people with learning disability.

Issues of capacity to consent to medical treatment in children and adults introduce the debate on capacity to consent followed by criteria and approaches determined by to Capacity to Act Legislation, which includes capacity to consent to sexual relationships. Overviews of people with learning disability, sexuality and the law are contrasted across different countries and diverse legal jurisdiction including the U.K. and Malta.

The chapter concludes by looking into policy domains applicable to supporting people with learning disability and their environments. The policy domains involve Vulnerable Adult Abuse, Sexuality and Sexual Health.

2.1 Definition of Learning Disability

In the UK the term 'learning disability' replaced previous more medicalised terms, such as mental handicap, mental retardation and mental deficiency. The rejection and replacement of terms determined by the medical model resulted in terminology that reflects psychological and educational constructs (MacKay, 2008). New terminology emerged as the focus of the definition moved away from the medical deficits and disorders and moved towards "*learning styles, strengths and difficulties and educational needs*" MacKay (2008, pg 9). In the U.K. the term 'learning disabilities' was first officially used by the Minister of Health during a speech in 1991. Its use was reflected in educational circulars, reports and legislations, and with it came the move away from assessment of an individual in order to place the individual into known categories.

There is as yet no universally agreed terminology related to learning disability, as McKay (2008, pg. 11) regards it as "*an arena marked by a plethora of confusing and competing terminologies*". In the U.S. the term 'Intellectual Disability' has replaced the former term 'Mental Retardation' (MacKay, 2008), while 'Developmental Disabilities' is also commonly used (Emerson, Hatton, Felce, Murphy, 2001). In the U.K. 'Learning Disability' has over the years, replaced the formerly used term 'Mental Handicap'. The definition of 'Learning Disability' in the UK encompasses people with a broad range of disabilities, indicating the presence of:

- a significant intellectual impairment with reduced ability to understand new or complex information and to learn new skills.

- impaired social functioning or adaptive behaviour (Emerson *et al.*, 2001), resulting in decreased ability to cope independently as well as in significantly impaired social functioning (Carnaby, 2000). Significant impairment implies that a person needs significant support during daily living activities.

- These signs of impaired learning would become evident in the developmental period and have a lasting effect on development.

Organisations and service providers find that there needs to be a definition of 'Learning Disability' in order to make it clear who the services are targeting, (Emerson *et al.*, 2001). Yet many people object to the term 'Learning Disability' and other labels, as they tend to provoke stigma and discrimination.

Significant impairment of intelligence is defined by the World Health Organisation (WHO) as having an IQ (intelligence quotient) score of more than two standard deviations below that of the general population. This means an IQ below 70 on recognised IQ scales such as the Wechsler Adult Intelligence Scale. However a low intelligence quotient, for instance an IQ below 70, is not a sufficient reason for determining that an individual has a learning disability. An assessment of social functioning and communication skills also needs to be taken into consideration, as well as the developmental history of the person (see the definition above).

The World Health Organisation (WHO) subdivides significantly low IQ scores into four categories each describing a level of disability: mild (between 50-69), moderate (between 35-49), severe (between 20-34) and profound (below 20). People with profound and severe learning disabilities are those who need significant help with daily living, while people with mild to moderate learning disabilities will usually be able to live independently or with some support. Professionals argue that it is extremely difficult to measure a person's IQ, "*as IQ measures like all measures, are imprecise*", (Emerson *et al.*, 2001). Apart from the fact that a person's IQ score may vary across a range of tests and over time, it is also extremely difficult to measure IQ when a person has a severe or profound disability. Given all these different degrees and descriptors for people with disability, society has come to realise that people with disability are not a homogeneous group. Interests and needs differ as does the degree of disability, class, race, gender and age (Williams , 1992).

A learning disability can be congenital; therefore occurring before birth due to prenatal causes. Prenatal causes include genetic factors and anomalies as well as environmental factors such as malnutrition, drugs, alcohol or infections. Learning disability can also be due to perinatal causes, which occur during birth, such as infections to the womb, toxoplasmosis, asphyxiation, premature birth and difficulties during labour. Postnatal causes occurring after birth include epilepsy, meningitis or other environmental factors or traumas such as head injuries. Many of these causes prevent the brain from developing fully and therefore cause difficulties with cognitive and learning processes (Carnaby, 2002).

Many people with learning disability also tend to have physical and/or sensory impairments. The definition includes adults with autism who also have a learning disability, but not those with a higher functioning level in autistic spectrum disorder who may have IQ scores in the normal range (i.e. above 70), as for instance people with Asperger's Syndrome. 'Learning disability' does not include all those who have "Learning Difficulties", which is more broadly defined in education legislation and includes people with specific learning difficulties, such as dyslexia.

It is difficult to estimate the precise number of people with learning disability in any country in the world. In the U.K. it is estimated that there are between 230,000 and 350,000 people with severe learning disability, and between 580,000 and 1,750,000 people with mild learning disability (Emerson *et al.*, 2001). In the U.K. the prevalence of severe and profound learning disabilities is fairly uniformly distributed geographically and across socio economic groups, the prevalence being about 3 per 1,000 persons. Mild and moderate learning disabilities on the other hand are linked to poverty, material deprivation and to urban areas. It is estimated that the number of people with severe learning disability living in the U.K will increase by 1% per annum in the next 15 years due to extended life expectancy, rising numbers of school age children with autistic spectrum disorder and a greater prevalence of learning disabilities among minority ethnic populations of South Asian origin (Department of Health, 2001).

Some prevalence data have been collected in Malta but the four available statistics reporting prevalence rates of disability in Malta show a substantial difference between each other. Pace (2002) attributes these differences to the different methods of administration of studies.

> *"In Malta there is no legislation related to the registration of disabled persons with regards to their disability. This creates a difficulty in gathering accurate information about disability"*
>
> Pace (2002, pg. 7)

Published statistics in the National Commission for Persons with Learning Disability's Annual Report (2010, pg. 37);

Statistics according to Disability

	No. per year	**No. per year**	**No. per year**	**No. per year**	**No. per year**	% per year	% per year	Difference
	2010	2009	2008	2007	2006	2010	2009	
Physical	8470	8190	7801	6556	5953	70.94	70.16	0.78
Intellectual	2269	2234	2184	2052	1964	19.00	19.14	-0.13
Psychological	1214	1182	1166	1054	946	10.17	10.13	0.04
Visual	1138	1166	1236	1159	1129	9.53	9.99	-0.46
Hearing	1019	1060	1128	1062	1025	8.53	9.08	-0.55
More than one	2286	2292	2284	2022	1881	19.15	19.64	-0.49
Not Specified	886	903	1140	1279	1383	7.42	7.74	-0.32

Statistics according to Age and Gender (pg.39)

					%	Difference
Age	Fem	Male	Total	2010	2009	
0-4	49	60	109	0.91	0.89	0.02
5-9	94	157	251	2.10	2.07	0.03
10-14	137	220	357	2.99	3.27	-0.28
15-19	165	217	382	3.20	3.12	0.08
20-24	149	242	391	3.27	3.24	0.04
25-29	166	263	429	3.59	3.76	-0.07
30-34	190	273	463	3.88	3.87	0.01
35-39	199	257	456	3.82	3.86	-0.04
40-44	203	244	447	3.74	3.41	0.33
45-49	215	352	567	4.75	5.71	-0.43
50-54	319	447	766	6.42	6.31	0.11
55-59	358	514	872	7.30	7.37	-0.06
60-64	444	627	1071	8.97	8.72	0.25
65-69	416	548	964	8.07	7.80	0.27
70-74	510	574	1084	9.08	9.06	0.02
75-79	603	463	1066	8.93	9.06	-0.14
80-84	707	524	1231	10.31	10.27	0.04
> 85	612	368	980	8.21	8.17	0.03
Unknown			54	0.45	0.65	
Total	5539	6350	11940			

Statistics published in the annual report of 2010 by the National Commission for Persons with Disability (in Malta), indicates that the number of people with disability registered with the Commission, has more than tripled in eight years, increasing to 11,673 last year from 3,330 in 1994. According to commission chairman Joe Camilleri, limited services in the past failed to encourage people to register their disability. Moreover, a change in perception of disability means more people are prepared to be listed on the register because they are less afraid of stigma.

Many people with learning disabilities need additional support and services throughout their lives. As a consequence large amounts of public money are spent on learning disability services. In the U.K., health and social services provision only for adults with learning disability cost the country over £3 billion (£1.4 billion on health and £1.6 billion on social services) between 1999 and 2000, while £308 million and £177 million were spent over and above on social services and on supporting disabled children respectively. In Malta no such statistics have officially been issued so far.

2.2 The Social Model of Disability

People with disability have increasingly begun to reject stigmatizing ideas which suggest that a disability is an impairment, a common illness or a medical condition (Thomas, 1994). The social model of disability was founded in the 1970's when people with disability were reflecting on the effect of institutional experiences (Azzopardi, 2009). A text that has greatly influenced and acted as a launch pad for the social model of disability was the *Fundamental Principles of Disability* (UPIAS & The Disability Alliance, 1976). The text rejects the charity model that has dominated attitudes towards disability and proposes economic, political and social changes (Azzopardi, 2009). Movements made up of people with disability themselves, together with researchers and writers in disability studies have developed an insight on disability known as 'the social model of disability', providing the basis for understanding disability and the foundation for the liberation of disabled people (Swain & Cameron, 1999). As Crow (1996) confirms, the social model of disability has been the key to dismantling the traditional concept of impairment as a personal tragedy, challenging the oppression it creates. The social model does not see the disability as impairment or as being caused by impairment. In other words it is not the difficulty of functioning with a physical, sensory or intellectual impairment which creates the problem of a person with disability. According to the social model; *"disability is redefined as the outcome of social arrangements and practices which work to exclude and disadvantage people with impairments"* (Thomas, 1999, pg.1). How a person with disability can live and act is restricted by social barriers, making the disability a form of social oppression. Thus, as Crow (1996, pg.208) concludes, *"disability is the loss or limitation of opportunities resulting from direct and indirect discrimination"*, making social change the only solution to disadvantages encountered.

Lois (1996, pg.75) mentions the *"apparently minor, but actually very significant events"* in the lives of people with disability, what they mean and the effects these leave. By these events he is referring to *"the smiles, the patronising gesture, the questions, the stares, the rudeness and the rejection"* (Lois, 1996, pg.75), commonly experienced by persons with learning disability in everyday life. These events obscure the image held by this person while reinforcing a negative identity. Lois (1996) insists that the political progress achieved by people with disability is changing the meaning of these events and how they affect people with disability. Morris (1991) as cited in Shakespeare (1999) maintains that people with disability must avoid '*internalising*' these above '*values*' harboured by society, so as not to let these undermining messages become part of the way people with disability think or see themselves.

Shuttleworth & Mona (2000) recall that disability studies have focused on the critical analysis of our disabling society. They assert that a critique of social and cultural barriers is indispensable for the emancipation of people with disability. The emergence of the social model of disability has challenged other models of disability such as the charity model, the medical and the fixing model. Addlakha (2007) asserts that in India, a culture of charity and welfare opposed the empowerment of rights of people with disability. When referring to the charity model Lois (1996) explains that Charities create a culture of dependency where people with disability are expected to feel grateful for what they are given. On the same note Morris (1991) argues that charity is about making non-disabled people feel good about themselves while making people with disability grateful for social tolerance and for the material help provided. Crow (1996) reflects upon the medical model of disability, where a person's functional limitations are the basic cause of the disadvantages experienced, and curing or treating these disadvantages is the only way to overcome them. The social model has highlighted the need for societal change and a broader cultural thinking about disability (Thomas, 1999). Bartolo (2000) from a Maltese perspective claims;

> *'Inclusion is the continuation of deep and painful historical process over the centuries ...previously excluded and considered a threat to the mainstream, vilified and persecuted for a long time... have to struggle hard to start being accepted and included...To include disabled persons in a real way: we must move away from the charity model to the human rights model...The struggle continues".*

People with learning disability face more or less the same kind of difficulties all over the world. Williams (1992) confirms that the fact is now being acknowledged that people with learning disability constitute one of the most marginalized and oppressed groups in society. Their basic rights to integrate with others, to marry, to have a family, the right to vote, the right to freedom from harassment, violence and abuse have been seriously denied (Shuttleworth, 2002; Hamilton, 2010). While social inclusion presents major challenges to services (Forrester-Jones, Carpenter, Coolen-Schrijner, Cambridge, Tate, Beecham, Hallam, Knapp & Wooff, 2006), social exclusion is one of the major difficulties encountered by people with learning disability. Social exclusion may include elements of economic difficulty resulting from higher living costs faced by the families of children with learning disability as well as diminished employment possibilities. It also compromises the transition from school to adult life which is often an uncertain and unfruitful period for people with learning disabilities (Forrester-Jones *et al.*, 2006). Azzopardi (2009) concludes that oppressive behaviour is a "*human creation*" (Barnes; 1996), that can only be confronted by challenging the philosophy that has modelled such a repressive attitude. Education and media channels are recommended as ways to bring about a change in pejorative public attitudes and promote social inclusion (Forrester-Jones *et al.*, 2006).

People with learning disability have little say over their lives and the choices they make. Schwabenland (1999) asserts that certain activities which are considered part of everyone's life, such as socializing, having a relationship or being a parent, are not considered the norm for people with disability. Generally, individuals who are present in the lives of people with disability are, as a rule, being paid to provide physical support such as washing, feeding and cooking (Forrester-Jones, 2001). In the U.K. research showed that only 6% of people with learning disability lived with people of their choice, while 1% had a choice of who was to be their carer (Department of Health, 2001). As a result social isolation is very often experienced by people with learning disability, who usually only have other people with disability or family members or paid carers as company (Department of Health, 2001; Forrester-Jones, 2001).

People with disability have also lacked autonomy in their own financial issues. Direct payments are slowly taking off in the U.K. (*Valuing People,* 2001; *Valuing People Now,* 2009), while they are still unheard of in countries like Malta. Independent community living, a key to social inclusion, is limited and day services also still leave much to be desired in Malta. These day services frequently provide unproductive, non-stimulating environments with little individual support. Employment for people with disability includes only 10% of the population of people with learning disability in the U.K., a very small fraction of the available work force. In Malta figures state that 263 people with disability are seeking employment. Considering that 10% of the population has a disability of some kind, as indicated by the United Nations, than figures of people with disability in Malta who are seeking employment can be estimated at roughly around 790 (NCPD, 2003). In 1969, Malta issued a law that required that people with disability form 2% of the total workforce. This employment law helped some individuals to find employment, yet on a national level this legislation had little if any positive impact (NCPD, 2003). The National Commission for Persons with Disability (2003) asserts this kind of law rarely works if imposed on an employer.

Camilleri (1998, pg.845) asserts that *"what we call ourselves and what society calls us is fundamental to the way we are perceived, fundamental to our dignity as human beings and in some situations vital to our existence".* In their research McDonald *et a.l* (2007) introduced cultural narratives of disability, which compromised assumptions drawn from the culture that people with disability are "*pathological*" and "*incompetent*". These cultural narratives have been derived from analyzing discourse, policies and structures. Cultural narratives are communicated to individuals through *'socialization channels'* such as schools and the mass media. These cultural narratives reinforce segregation of people with disability. Mcdonald *et al.* (2007) maintain that people with an apparent physical disability and those with a learning disability encounter cultural narratives in a different manner. Camilleri (1998, pg. 845), who is himself disabled, confirms that most of his life he was influenced by media images amongst others and by "*the everyday negative responses …that made him see himself as lesser than anyone non- disabled*". While physical disability is more identifiable, people with learning disability encounter assumptions of incompetence and exclusion from social and community life, as well as omission from media images (Brown, 1994). McDonald *et al.* (2007, pg. 153) report people with disability found that there was a "*societal assumption that disability is synonymous with inability to perform global and/ or specific intellectual tasks such as quickly processing, learning or understanding material and reading*". McDonald *et al.* (2007) also maintain that persons with learning disability are seen as even less than fully human and are regarded as less worthy of attention, respect and inclusion in the community (Forrester-Jones *et al.* 2006).

The policy document known in the U.K. as the white paper *Valuing People* (2001) represents people with learning disability as people first. The focus is on what people can do, rather than what they cannot do. The paper asserts that people with disability have the right to education, to vote, to marry and have a family, to express their opinions and to be provided with help and support to do so. These civil rights can only be exercised if discrimination is eradicated from society. People with disability have the right to be included in society, to be treated with respect and dignity and to be protected by law where necessary (Department of Health, U.K., 2001). Williams (1992) reports that significant changes have been taking place including de-institutionalization and community care. Irrespective of the level of assistance required, people with disability are being encouraged to learn to meet their own basic needs independently, with the emphasis on the person choosing and living their own lifestyle. These challenges have also been the product of pressure groups, composed of people with disability themselves and their families. Advocacy and self-advocacy groups have also been an effective way of empowering people with disabilities to make choices regarding their lives (Williams, 1992).

2.3 History of People with Learning Disability and Sexuality

2.3.1 The Early Years

Carnaby (2002) reports that, in the UK, from medieval times to the late 19th century people with disability were known as *"idiots"*. *"Idiocy"* was used to describe people with learning disability seen to have been born with an unalterable condition. At this time it was the family who supported these persons. During the Victorian era (1837 to 1901) asylums were set up to house people with disabilities. They were intended to educate people with learning disability to their full potential, but because of overcrowding, people with learning disability were also being kept in workhouses together with patients with mental health problems. The Victorian era marked the height of the British Industrial Revolution when people with disability, who could not produce goods as fast as a non-disabled person could, were looked upon with scorn. Segregation in institutions therefore was also a result of a productive industrial society that saw people with disability as worthless. Medical professionals working in these institutions focused their work on diagnoses and classification rather than on social care and education. Sterilization and the repression of the sexuality of people with disability was a result of the values reflected in society at those times together with the concern that people with disability would procreate and multiply (Carnaby, 2002).

Walkowitz (1997) recounts the upholding of sexual respectability in the UK during the Edwardian era (1901 to 1910), the reign of King Edward VII, where social purity distinguished the elite from the bestiality of the poor labourer. Kempton & Kahn (1991), give us a view of the sexuality of people with disability from as late as the 18th century. Prior to this era homecare alongside almshouses and asylums were the options available for children with disabilities. With the 18th century came the beginnings of political democracy which somewhat promoted social responsibility towards the care of the less fortunate, while the influential ideas of philosophers like Locke and Rousseau, contributed to the first 'special education' programs for people with an array of disabilities. This era also gave rise to the charity model, the only option for rejected and unwanted individuals.

The 1913 Mental Deficiency Act in the U.K. was one of the first major pieces of state intervention for people with learning disability. This piece of legislation graded people with disability as *"mental deficient"*, *"idiots"*, *"imbeciles"* and *"feeble minded"*. It permitted the detention of these people in institutions, segregated from their families and from society, but above all segregated them from the opposite sex (Williams, 1992; Shakespeare *et al.*, 1996; Colins & Cozens, 1999; Valios, 2002;Garbutt 2008;).

2.3.2 The Eugenics Period (1880-1940)

Eugenics is the science of the genetic improvement of the human race. It was influenced by Darwin's theory of the importance of heredity in the evolutionary process (Block, 2000). Up till the early 20th century *"mental deficiency"* was attributed to genetic mutations, the unfortunate result of *"inappropriate breeding"* on the part of defective parents (Block, 2000). Eugenicist policies, which targeted a wide range of vulnerable adults, including those with learning disabilities and also those with mental health problems, are now considered outdated and above all discriminatory. . The infamous Eugenics movement period (1880-1940) proposed as a solution to society's problems, to improve the human race through selective breeding. This movement aimed at increasing the proportion of people with better than average hereditary endowments, by separating defective people from society and imposing mandatory sterilization. Eugenics intended controlling "*intellectual disability*" by eliminating the reproductive capacity (Sobsey, 1994).

> *"The feeble-minded are a parasitic, predatory class; never capable of self-support or of managing their own affairs...they cause unutterable sorrow at home and are a menace and danger to the community. Feebleminded women are almost invariably immoral, and if at large usually become carriers of venereal disease or give birth to children who are defective as themselves...every feeble-minded person, especially the high-grad imbecile, is a potential criminal...the unrecognized imbecile is a most dangerous element in the community".*
>
> Fernald (1912), lecture given to the Massachusetts Medical students,
> quoted in Abbott & Sapsford (1987) as citied in Williams (1992, pg.153)

Murphy & Claire (2003) assert how during this period the rights of people with disability were 'seriously violated'. McCarthy (1999) reaffirms how hundreds of men and women with leaning disabilities, then labelled 'feeble minded', were thought to be promiscuous, immoral and to reproduce extensively, producing children of a similar intelligence, and during this period underwent involuntary castrations and ovariectomies.

> *"Involuntary sterilization including hysterectomies was another means to avert sexual disaster. Laws permitting involuntary sterilization, variously defined to cover the mentally retarded, the mentally ill, epileptics, sexual perverts" and "habitual criminals".*
>
> Kempton & Kahn, (1991, pg. 94)

Torbhorn (1998) confirms that 63,000 persons were sterilized between 1935 and 1975 in Sweden, although Davies (1959) as citied in Kempton and Kahn (1991, pg. 94) claims that by 1925 research had proved that people with "*genetic mental retardation were infertile and/ or incapable of intercourse*". Yet mass sterilization was still performed for fear of an increasing number of people with disability. In their research, Kempton & Kahn, (1991), state that between 1907 and 1957, 60,000 people with disability were sterilized against their will in the U.S. Sterilization seems to have decreased during World War II, as a counter reaction of the Nazi's eugenic sterilization movement and overtly eugenic practices seem to have largely ceased (McCarthy, 2009a).

In Britain involuntary sterilization was not adopted but instead the trend was for institutionalization since this was seen as the other solution to avoid reproduction, with segregated sexes as well as segregation from the rest of the world, (Murphy & Clare 2004; McCarthy 1999; Brown 1994). In the 1940s when institutions housed a large number of persons with learning disability, attempts by people with learning disability to have heterosexual contact were severely punished, commonly by means of solitary confinement or the shaving of heads. This treatment emphasized the fact that people with learning disability "*were actually oppressed largely because of their sexuality*" (Kempton & Kahn, 1991, pg. 94).

Nowadays eugenics can take a different form. It is argued by people with learning disability themselves that in recent years genetic screening offered to pregnant mothers has become an instrument of population control itself (Williams, 1992). Genetic screening gives parents or mothers an opportunity to decide whether they feel able to care for a child with disabilities. Some mothers with disability have argued that it is assumed that parents want a perfect child; hence such screening serves to devalue people with disability.

> *"The development of genetic engineering raises fears of a new eugenics movement, which gives priority to improving the human or national gene pool....".*
>
> (Williams, 1992, pg. 157)

2.3.3 Deinstitutionalization & Normalisation

'Normalisation' philosophies supported social and community integration and saw a move from segregated institutions to the community (Drummond, 2006). The normalisation movement brought with it recognition of the human rights of people with disability and changes in legislation. The normalisation philosophy demanded that people with disability live a normal life and hold the right to form relationships and experience an acceptable standard of living (Carnaby, 2002; Craft, 1987). The way people looked at disability changed during this period both in terms of the opportunities offered, age appropriateness of services and quality of life. The right to have sexual relationships as well as sex education were all new issues (McCarthy 1999; Murphy & Clare 2004). Influential publications in the 1960s and 1970s emphasized the inadequate situation in institutions and helped build professional and public awareness (McCarthy 1999; Wolfensberger, 1972 cited in Grieveo *et al.* 2006). Some studies focused on the poor conditions, others gave a more in-depth reading of ill-treatment and atrocious living conditions (Carnaby, 2002). Wolfensberger (1972) was a pioneer in his philosophy that people with learning disability should be afforded the same rights of choice and opportunities as non-disabled people (Grieveo *et al.* 2006). Apart from the humanitarian concern to provide quality community care rather than segregated institutional care, financial matters were crucial in orchestrating this move (Korman & Glennerster 1990). It was believed at that time that community care would be more financially sustainable than big institutions, although research now shows that community care is in fact not more cost effective than hospital care (McCarthy 1999).

Kempton & Kahn (1991) criticize this transition from institutions to community care stating that it was done too rapidly and did not give the clients at the institutions the time and resources to learn adequate social coping skills. The researchers report that people in these situations were particularly unaware of social behaviour and laws concerning sexual behaviour. They even lacked information about procreation, birth control and sterilization. This may have resulted in people with learning disability committing offences such as child molestation, voyeurism and indecent exposure. Brown (1994) recalls that Scandinavian models of normalisation were based on the rights of people with learning disability. These rights are embedded in the United Nations Declaration of Human Rights (1971) and are often the basis of policies and statements adopted by services regarding sexual issues (Brown, 1994). Yet Brown (1994) claims that prejudice and isolation have kept people with learning disability from experiencing, engaging and sustaining satisfying partnerships, sexual relationships and family life.

2.3.4 Changing attitudes to sex

Prior to the 1960's Montebello (2010) reports a sharp gender divide in attitudes towards sex, with the female gender equating sex to love and perceiving sex as acceptable only in love relationships, while the male gender tended to have more permissive attitudes and predisposition to have casual sexual encounters. The 60's and 70's brought with it a 'sexual revolution' for the general population in Europe. There are nowadays more liberal attitudes towards pre-marital sex, although if in a long-term, monogamous and committed relationship it is regarded as more acceptable (Moore & Rosenthal, 2003).

Males in a study conducted in Malta (Abela, 1998) held more permissive attitudes towards pre-marital sex, sex between engaged couples and abortion then females. This development in attitudes in turn affected the population of people with learning disability (Lofgren-Marterson, 2004; Downs & Craft 1996). There was a general spread of the acceptance of people with disability as sexual beings, of their sexual rights and of the need for sex education (McCarthy 1999; Christian, Stinson & Dotson, 2002; Cuskelly & Bryde, 2004).

The 1980's saw a broadening and development of the topic of sexuality that had emerged in the 1970s. On the other hand the 1980's also witnessed the emergence of AIDS and the unmasking of sexual abuse. The reasons why these issues surfaced at this specific time may stem from the vulnerability of people with learning disability and a simultaneous increase in communication on the topic of sexuality (Downs & Craft, 1996). Kempton & Kahn (1991), recount that 80 to 95% of people with learning disabilities were victimized at some point in their lives, with 90% of the perpetrators being in care-giving positions. Later studies in the U.K. by Brown, Stein and Turk (1995), reported a minimum of 1400 new cases of sexual abuse against people with learning disability each year in the U.K. McCarthy and Thompson (1997) showed that an incidence of 61% of women and 25% of men referred for sex education had also experienced abuse. These figures made agencies and practices aware of this phenomenon and led services to opt towards the prevention of abuse and counselling of victims. Prevention through sex education was introduced in order to protect people with learning disability from abuse as well as to empower their sexual choice making (Murphy & O'Callaghan 2004).

Reproductive rights and contraception also became a significant topic within the literature during this decade (McCarthy 1999). Development of staff training packs and sex education material, especially designed for working with people with learning disability, was produced during the 1980's, amongst others by Craft & Craft (1979), Kempton (1988) and by Dixon (1986). McCarthy (1999) underlines the fact that these packs did not give much recognition to homosexual relationships and states that it was not until the 1990's that their content started to change. In the 1990's the sex education material produced, such as that of McCarthy & Thompson (1992); McCarthy & Cambridge (1996) and Cambridge (1996 & 1997), reflected equal opportunity perspectives and gave value to same sex relationships.

2.4 Stereotypes

> *"The misrepresentation of people with learning disabilities as innocent and childlike is as damaging to them as the more blatant charge of being 'oversexed' and menacing which fed the eugenics movement at the beginning of this century"*
>
> Craft (1994, pg. 51)

Stereotypes are difficult to challenge as they are not perceived by the general population as harmful, but rather as benign. Unfortunately people with disability tend to internalize these stereotypical attitudes towards them, resulting in barriers to self-expression (McCarthy, 1999; May & Stone, 2010). These myths evolved from the belief that people with disability are different and "less" than non-disabled people and resulted in an apparently justified basis of discrimination (Corbett & Bregante, 1992).

The denial of socio-sexual maturity increases the image of people with disability as being forever children thus influencing their sexual expression and behaviour (Rodgers, 2001). Concurrently with their lack of understanding of social norms, these issues could in turn lead to either being vulnerable to abuse or to acting in a sexually inappropriate way (Grieveo *et al.* 2006). Such issues are usually a consequence of not being educated about the seriousness of sexually inappropriate or abusive behaviour from another person and from not being allowed to develop a sense of responsibility and respect for others. Baxter (1994) affirms that people are generally influenced by the cultures of their families. People with learning disability, who in societies such as the Maltese one spend most of their lives in their family home, tend to be overprotected and unexposed to sexuality (Malhotra & Mellan, 1996).

An area of particular interest in this study is the historically stereotypical image of people with learning disability as an 'eternal child' (McCarthy 1999; Begum, 1996), as this phenomenon is still present in Malta. The stereotypical image of the 'eternal child' portrays people with learning disability as having limited intellectual ability and retaining permanently the understanding of a child, thus assuming that children are not sexual beings and that people with learning disability were simply overgrown children (McCarthy 1999; Murphy 2004). Williams (1992) also refers to the eternal child stereotype, describing it as creating an attitude that treats adults with learning disability as perpetual children, refers to them as having a "mental age" of a child and causes people with disability to not have their emotional maturity acknowledged, to be given pocket money instead of a wage and to being "*dressed in short white socks and sandals*" (Williams, 1992, pg.151).

Another term which is closely related to the picture of the eternal child, and is also used to describe the sexuality of people with learning disability or rather the lack of it, is 'asexual'. McAnulty & Burnett (2001), describe an asexual being as having no erotic or romantic inclinations. Niederbuhl & Morris (1993) and Whitney (2007) report that historically people with learning disability were often considered to be asexual. Contemporary researcher, Tom Shakespeare (1999, pg.53), himself a person with physical disability, describes asexuality as a third gender and interestingly compares it to a "*row of toilets; ladies; gentlemen; disabled people*".

Service models which encourage the stereotypical image of the eternal child are described by Clements *et al.* (1995) and Downer (2000). Such provision reflects an idealized and sanitized environment, where paternalistic staff attitudes are reflected in staff seeing their role as parents fostering 'family life'. This may result in a blurring of boundaries where the intimacy level acceptable for young children becomes acceptable for adults.

2.5 Friendships, Relationships and People with Learning Disability

People seek company, recognition and acceptance and therefore friendship is crucial. Shakespeare (2006) maintains that although sexuality is an important form of intimacy, friendship and acceptance are more essential than sex. While people get along without sex, '*individuals would be desolate without friendship*' (Shakespeare, 2007 pg. 169). There is an increased awareness that people with learning disability want and need friendships (Forrester-Jones, 2001), while developing friendships depends on the opportunity to meet people and develop skills to sustain friendships (Shakespeare, 2007). Different genders have different kinds of friendships, as men's friendships seems to be based on sharing activities and women's friendships are based on communication (Traustadottir, 1993). Schwier & Hingsburger (2000) highlight the need to develop values and instil good manners in children with learning disability as these are essential to cultivate a wide range of friendships and relationships. Friendships vary from the intimate friends with whom to share private and intimate experiences to the social friends who are there for company and sociability (Shakespeare, 2006). A vital aspect of society that we might not be aware of is the development of a wide range of social connections and friendships. Shakespeare (2006, pg.173) claims that "*a range of social, economic and demographic factors have reduced the strength of networks of kin, friendship and community*".

Community life as opposed to institutionalization, has given people with learning disability the opportunity to develop and maintain friendships, leading to a richer quality of life (Forrester-Jones, 2001; Heller 2002). Although friendships are important and enhance the quality of life, yet people with learning disability tend to experience greater isolation and loneliness than non-disabled people, even when they live in the community. Reasons for this isolation are various, ranging from not having anyone to identify with and being excluded from social settings, to attitudinal and accessibility barriers (Shakespeare, 2006). Sinason (1999) notes that it is known that family and carers in the life of people with learning disability become overprotective over people with learning disability to the extent that they prevent them from having friendships or relationships. Traustadottir (1993) concludes that many people with learning disability remain isolated, lonely and have few friends, even though they have been moved from institutions to community homes. Forrester-Jones (2001) reports on overlooked friendships within institutions that were broken when service users were returned to their borough of origin.

Shakespeare (2006) affirms that people with disability are living in the community in a time where the concept of community has been eroded. Families could possibly be socially excluding their children as their financial status does not allow time to support their children with friendships. Otherwise people who have adults to support them all the time find it difficult to infiltrate social groups as they are always accompanied by someone else (Shakespeare, 2006). Lack of appropriate support such as accessible transportation and personal assistance were found to induce isolation, loneliness and exclusion in the lives of young people with disability (Murray, 2002, Forrester-Jones, 2001).

Services and professionals tend to focus on physical care and the developing of life and independent skills training as a priority, rather then relationships (Murray,2002; Amado, 1993 quoted in Forrester-Jones, 2001). Yet Murray's (2002) respondents claimed that the life goal for young people with learning disability was friendship. O'Brien (1987) established the 5 Accomplishments for services for people with learning disability, which target vital aspects of human experiences, often a limited aspect of the life of people with learning disability. These 'Accomplishments for Normalisation' recognised the interdependence between the entities involved to form and maintain the variety of ties and connections that constitute community life (Brown & Benson, 1992). These 5 accomplishments included :

- The right to community presence by taking part in community life and spending leisure time with other members of the community.
- The right to experience valued relationships with non-disabled people. The right to make choices including choices about where to live and with whom.

- The right to learn new skills and participate in meaningful activities with adequate support.
- The right to respect and equality.

(O'Brien quoted in Brown & Benson, 1992)

Explanations for the isolation of people with disability range from the presence of environmental barriers to that of social barriers, including educational segregation, discrimination in employment and lack of accessibility and transportation (Shakespeare 2006, Forrester-Jones, 2001). Shakespeare (1996) in fact asserts that the prime barrier is the society that people with disability live in rather then their physical impairments. Attitudes and behaviours of non-disabled people can influence both the isolation or, on the other hand, the integration of people with disability. Through segregation non-disabled people and people with disability have never become familiar, this has resulted in fear, ignorance and prejudice, a situation which will not allow social networks to develop (Shakespeare, 2006). Yet Shakespeare asserts that there are many non-disabled people who are willing to build friendships with people with disability. In these cases of reciprocal friendship, Shakespeare claims that the salience of impairment diminishes and the person is accepted and 'delabelled'.

2.6 Sexuality and People with Learning Disability

"Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing – discrimination in employment, education, and housing then to talk about our exclusion from sexuality and reproduction".

Finger, (1992, pg. 136)

2.6.1 Society, Sexuality and People with Learning Disability

"Society constantly bombards us with outright and indirect messages that our lives are worthless, that we are helpless, hopeless cripples."

Ratzka (1998, pg.1)

When referring to sexuality in past times, McCarthy (1999) explains how any signs of sexual interest or arousal were potentially ignored and repressed (Clarke & Cropley, 2010). Malhotra & Mellan (1996), Kempton & Kahn (1991) and Whitney (2006) also underline how the sexuality of people with disability has been feared, ignored and grossly misunderstood since the beginning of time and how the aberrant sexual interest of people with disability was thought to need social controls (Niederbuhl & Morris, 1993). Sobsey (1994), points out how people with learning disability have been targets of intervention intended to increase compliance or eliminate undesirable behaviour, particularly sexual behaviour. Research reports that society perceives the sexuality of people with disability more negatively if the disability is a learning disability (Rodgers, 2001; Katz, Shemesh & Bizman, 2000). Society's fear of the unknown was one of the reasons put down by Wolfenberger (1983), to explain the high levels of control exercised over people with learning disability in comparison to people without disability. Still today Murray, MacDonald & Levenson (2001) recall stereotypical views of people with disability revolving around extremes of asexuality to hyper sexuality. While men with learning disability are often associated with sexual offending, women are associated with promiscuity. In her book *The Second Sex*, Beauvoir (1961) as cited by Waxman & Finger (1989) points out that people with disability represent the negative of sexuality, "*our role is the asexual, the sexually undesirable, and the sexual deviant*". Brown & Barrett (1994) point out that people with learning disabilities are often restricted in their sexual options by the prejudices and anxieties of carers, staff or the general public. Stereotypes lead to the sexual behaviour of people with disability to be judged in a different manner to how it would be judged if the person did not have a disability. Wheeler (2004, pg. 124) considers sexuality as an area in which people with disability are disabled by society itself. He attributes this handicap to societal attitudes, such as society seeing people with disability as being asexual and also to *"an unwillingness on the part of service providers to facilitate sexual relationships"*. Murphy (1987, pg. 90) states that;

> "*...a serious disability (i.e. impairment) inundates all other claims to social standing, relegating to secondary status all attainments of life, all other social roles, even sexuality. It is not a role, it is an identity, a dominant characteristic to which all social roles must be adjusted*".

Corbett & Bregante (1992) claim that unfortunately research on both women and men with disability assumes that gender, race, ethnicity, sexual orientation or social class are irrelevant, as having a disability removes the possibility of these social experiences. Yet others assert that the way society looks at the sexuality of people with disability has changed to become more positive and liberal since the 1990s (Murray, MacDonald & Levenson, 2001). Clements, Claire & Ezelle (1995) assert that the sexuality of people with learning disability may either be acknowledged or censored. Yet Brown (1994) implies that people with learning disability have to fight and surmount barriers imposed by society in every area of their sexual lives such as in asserting their preferences and making their choices. Craft (1987) maintains that "*sexuality is not an optional extra*" through which the non-disabled people can marginalize people with disability, according to whether their cognitive criteria are satisfactory. Craft (1987) argues that sexuality and sexual expression are not issues that can be allowed or suppressed according to how comfortable those in a position of authority feel about them. Hamilton (2009) adds that recent research in this area began to explore what people with learning disability want with regards to their sexuality and what they currently experience. The findings of this recent research suggest that powerful attitudinal suppositions compromise proactive support towards living a healthy sexual life.

2.6.2 People with Learning Disability developing the Sexual-Self

Research done by Kedee & Berlo (2006), on a more individualistic approach, holds that the age of onset of disability is an important factor in how sexual self-image and gender roles develop. Since sexual self-image and gender roles develop when children start to interact with their social surroundings, individuals with congenital and early onset disabilities are generally socialized into an asexual disabled role, due to a lack of privacy and overprotective parents or caregiver (Stoner, 2007). Cole's (1975) developmental model explains the relationship between sexuality, disability and self-esteem. This theory advocates how engaging in sexual encounters leads to higher self-esteem levels and will encourage an individual to engage further in these activities with increased self-esteem. McCabe and Taleporos (2003) demonstrated that people with severe physical disabilities experienced lower levels of sexual esteem and satisfaction than people with mild impairments. Shakespeare (2007) highlights that people with disability find it harder to experience everyday intimacies than non-disabled people. Some of the difficulties arise from a lack of communication due to speech impairment. Physical contact with others is also at times limited, especially when the person with disability is in pain, has lack of control over or restriction of movements or of environment. Their most frequent physical contact with another person would be through personal and intimate care in daily living situations.

Amongst the sexual theories available, is that of the hierarchy of attraction (Lofgren-Martenson, 2004). This proven phenomenon (McCarthy 1999), demonstrates that individuals with moderate learning disability prefer to be with someone who has a mild learning disability. In turn, an individual with a mild learning disability would prefer to be with a person without a learning disability. This could be a strategy used by people with disability to avoid stigmatization. Lofgren-Martenson's (2004) research results also indicates that similar levels of learning disability help two persons to have a deeper and closer relationship. Research (Cuskelly & Bryde, 2004; Esterele, Sastre & Mullet, 2008) also indicates that society finds it easier to accept relationships between people with learning disability who have higher degrees of autonomy. Young, heterosexual men with mild learning disability who can 'pass for being normal' are described by Hamilton (2010) as receiving better acceptance due to the values and behaviours of a euro-western masculine society. Moreover being part of the same generation is even more unifying in relation to sexuality, sexual attitudes and norms. While body language and / or communicating in the same way or at the same level increases the opportunity to find a partner.

Shakespeare (2000, pg. 159), himself a researcher with physical disability, gives a contemporary perspective of sexuality; *"in our culture sex is omnipresent, and bodily pleasures go hand in hand with consumer culture and consumption"*. He continues to describe sexuality for people with disability, as an area of distress, exclusion and self-doubt. Shakespeare argues that the barriers to sexual expression are primarily social. Some of the problems he mentions include the lack of sex education, lack of socializing and therefore the lack of opportunity of potentially meeting people with whom to develop friendships, partnerships and relationships. He also mentions financial barriers since, he affirms, self- image and socializing require monetary assets. He finally mentions what is fundamental for the personality; self-esteem, confidence and communication.

Lofgren-Martenson (2004) also brings to light the strict boundaries set around leisure time for people with learning disability. It transpires that most of the time it is other people who organize activities for people with learning disability leaving little opportunity for a private life which people with learning disability can spend together, in sexual exploration. Public policies play a crucial role in suppressing the sexuality of people with learning disability (Finger & Waxman, 1989). Amongst others Finger and Waxman (1989) mention the fact that the magazine Playboy was not converted to Braille by the Library of Congress. They condemn the illegality of so called "*unnatural*" sex acts which on the other hand they claim might suit people with physical disability. They also condemn policies and procedures that forbid people in institutions from having sexual relationships and exclude people with learning disability from receiving sex and safer-sex education whilst also discouraging parenthood. Clements *et al.* (1995) affirms that since the experience and expression of sexuality is censored, people with disability are not yet able to live their sexuality. By not acknowledging a persons' sexuality Clements *et al.* (1995) maintain, is prevented him from moving out of childhood and taking on an adult status.

2.6.3 Difficulties Encountered by People with Learning Disability in Establishing their Sexuality

It is apparent that there are different perspectives pursued by researchers in the area of sexuality. Researchers such as McCarthy & Thompson (1992) and Lofgren-Martenson (2004), report that on the grounds of sexuality, there are more similarities than differences between people with learning disability and the rest of the population. Yet

Waxman & Finger (1989) state that certain strategies such as sexual planning, which violates the myth of sexual spontaneity, can play an indispensable role in achieving good sex when people with physical disability are concerned. On the other hand they also state that even nowadays, expressing sexuality in a socially accepted way could prove to be a challenging task for the majority of people with disability, as their level of sex education and their overall knowledge about sex is limited.

McCabe (1999) also argues about the negative aspects of the sexuality of people with disability. Such aspects revolve around sexuality not being an "*integral part*" of the lives and experiences of people with either a learning or physical disability. Another aspect focused on by McCabe is the fact that people with learning disability had less sexual experiences than people with physical disability, who in turn experienced lower levels of sexual contact than the general population. Lack of communication and social skills, both of which establish negotiation and assertiveness, result in barriers to the sexual expression of people with disability (Murray, MacDonald & Levenson, 2001). It is a fact that from an early age people with learning disability are taught to do as they are told, and obey parents, staff and carers, without being given the right to choose or to say no (Grieveo *et al.* 2006). Van Dyke, McBrien & Sherbondy (1995) also put a spotlight on the prejudice instigated by society with regards to the sexuality of people with disability. From the point of view of a researcher, Clements *et al.* (1995) argued that in spite of the public's attitude towards the sexuality of people with learning disability, related staff training, sex education, policies and procedures have all been widely researched. Yet De Palma & Atkinson (2007) claim that lack of discussion about sexuality does not stem out of indifference but rather from a "*policed and defensive silence*". Such silence establishes codes of conduct that the targeted group are expected to adhere to (Lapinsky & Rimal, 2005). Clements *et al.* (1995, pg. 431) concludes that;

> *"The experience and expression of sexuality of persons with disability is still essentially censored and the lives of people with disability remain unchanged*".

Wheeler (2004) also observed that while everyone's sexuality is controlled by social mores and laws, the sexuality of the participants with learning disability in his research was controlled by further factors. Although the participants of his research asserted their sexual status, other non-disabled people were not necessarily of the same opinion. Wheeler attributes this to the non-disabled persons' view that the sexual expression of the participants in the research was dangerous or inappropriate. The participants felt constrained because of lack of privacy, limited finances, reliance on others for support and/or transport. They also found that parents and carers exerted control over whether they could have a sexual relationship at all and limited the form of sexual expression permitted. For instance sexual expression other than a limited form of heterosexuality would be considered more acceptable than a homosexual relationship by parents or carers.

Clements *et al.* (1995) maintain that the gender of people with learning disability is ignored by carers and services, often until there is an incident involving the person's sexuality. It is then considered a problem and all efforts are directed towards controlling it. When this happens the sexuality is then perceived as a problem and attempts are made to control these manifestations (Savarimuthu & Bunnell, 2003; Carson & Blyth, 2009). Exhibited sexual behaviour is often seen as inappropriate behaviour (Noonan & Gomez 2010), instead of genuine expressions of need for information or for a relationship. Such expression is regarded as potentially dangerous for the person himself and others, while expressing sexual behaviour in the form of challenging sexual behaviour stigmatizes the person with disability and causes harm to others (Brown, 1994). Intervention to deal with this problematic manifestation may involve limiting the sexual behaviour itself or its possible consequences. Women, for instance, are given birth control pills or implants while men sometimes undergo chemical castration. However Cambridge & Mellan (2000) claim that these sexual behaviours are the product of the social and physical environments constructed by services, together with the effects of society's perception of the sexuality of people with learning disability. Cambridge & Mellan (2000) report that the sexuality of people with disability is viewed and responded to negatively, due to segregation and social exclusion brought on by economic, social marginalization and dependency on services.

Brown (1994) highlighted that people with disability must prove themselves to have sufficient independent skills and financial autonomy to live as a couple. Both these qualities are often unattainable by people with learning disabilities. Although people with learning disability are supported in independent living, they are rarely supported in partnership or in family groups. Stoner (2007) writes about the problems encountered by people with disability in all areas of sexuality, starting from privacy, to motor difficulties. The issues between people with disability and carers are discussed at length and the two extreme sides of involvement in the sexual lives of people with disability by their carers are explored. It is possible that private sexual experiences are made public as people with disability tend to lack privacy in their lives, whether living at home with parents or supported by services. Reports claim that some carers completely refuse to help with sexual encounters, while others consent as long as it is kept confidential (Selina, 2008; Tepper, 2009; Hamilton, 2009). Sexual encounters mentioned range from hiring sex workers for a client, even though it is illegal to do so, ensuring their privacy and even helping out with payment afterwards, to positioning people in bed and putting on a condom.

Brown (1994, pg. 124) maintains that;

> *'When people with learning disability assert their rights to sexual lives they heighten their visibility rather than increase their chances of integration and acceptance".*

Waxman & Finger (1989) claim that the disability community has not politicized problems with sexuality as they have done for other issues such as accessibility. They maintain that sex must be approached with the same passion as other human rights issues. Language that describes sex is a powerful tool to use when forging a sexual identity. Words used in the context of people with disability and their sexuality focus on words such as 'impotence', 'sexual options', 'sexual adjustment' or 'rehabilitation' according to Foucault (1980). He asserts that these words need to be replaced by terms such as 'pleasure', 'passion', 'erotic', 'romance' and 'lust'. Rembis (2010, pg. 57) on the same note concludes that; "*disabled bodies must cease being the objects of abuse and neglect, or of pity and sorry, and charity, so that they might become the objects of desire and eroticism.*" Amongst other recommendations Waxman & Finger (1989) insist that people with disability should have on their agenda important issues such as access to reproductive health care, disability relevant sex education, health insurance that covers sexual counselling and therapy as well as a legalization of prostitution which allows direct payment of sexual surrogates. In return Cambridge, Carnaby & McCarthy (2003), confirm that recent literature about sexuality including HIV, homosexuality, men and sexuality, capacity to consent, women and sexuality, sexual health, menstruation and menopause, have shifted the idea of pathology and suppression which existed and moved to an ideal of human rights and of empowerment. Hahn (1981) reports that above historical, social and psychological influences that effect people with disability and their sexuality, the major difficulties facing sexuality and disability emerge from the tendency to view disability from a clinical or biological rather than from a social perspective and that these issues are considered within the context of particular physical impairments. Hahn (1981, pg. 220) refers to physical attractiveness as an example of social customs which regulate the formation of intimate relationships, many times found as a significant disadvantage to people with disability. Physical attractiveness reflects;

> *'Traditional values which were attached to physical strength and power as well as to physical beauty and grace, the contemporary significance of the whole body or the body beautiful, and the narcisstic anxiety aroused in people who are plagued by doubts about supposed flaws or defects in their own physical images".*
>
> Hahn (1981, pg.220)

2.6.4 Changing the Perception of Sexuality and People with Learning Disability

The medical model of disability portrays people with disability to be;

> *"...not only broken or damaged, but also incompetent, impotent, undesirable, or asexual. Their inability to perform gender and sexuality in a way that meets dominant societal expectations is seen as an intrinsic limitation, an unfortunate but unavoidable consequence of inhabiting a disabled body".*
>
> Rembis (2010, pg. 51)

Feminist disability scholars together with activists and other researchers who supported the social model of disability, began their battle at deconstructing dominant assumptions about the sexuality of people with disability in the beginning of the 1980s (Rembis, 2010). Amongst these researchers and activists Shakespeare (2000, pg. 163) challenged the idea of people with disability conforming to stereotypes of body image and suggested that people with disability *"demonstrate that sexual activity and sexual attraction can be whatever you want it to be"*. Shakespeare concludes that limitations created by impairment should create different options and not close down possibilities to sexual experiences. Yet as Rembis (2010, pg.52) puts it, the *"..power of normative gender presumptions are deeply rooted in dominant notions of ability"*. In his work Shakespeare (2006) explains that he tries to replace the medical model of disabled sexuality, merely erectile dysfunction and movement limitations, with a social model of *"disabled sexuality"*, where the negative attitudes and self-esteem are the accentuated barriers. Yet Rembis (2010, pg. 51) insists that the social model of disabled sexuality still remains limited although it offers a fundamental and vitally important critique of assumptions concerning the sexuality of people with disability.

Rembis (2010) insists that the complexity of the lives of people with disability remains largely unexplored and unintelligible to people without a disability. In an attempt to overcome this shortcoming, Gallery: Sexuality & Disability, (http://www.belindamason.com/), an internet site with sexually explicit photos of people with disability and their views about sexuality, gives modern perspectives of the way people with disability from different parts of the world perceive their sexuality. Matt Fraser a contributor to the site, and also an actor, musician and a writer with disability who performed in Malta in 2005 claims that;

> *"Disabled people's sexuality has been denied throughout history, especially in the media imaging of our society. This is a glorious chance to celebrate my own disabled sexuality with my partner Patou..."* (quote on site).

2.7 Opinions of Parents of People with Learning Disability upon Sexuality

Olshansky (1962) as cited in Bennett, Deluca, & Allen (1995), relates that families who have a child with disability, report distress as well as stigma. While recent research (Singer, Irvin, Irvin, Hawkins, Hegreness & Jackson 1993 cited in Bennett, Deluca & Allen, 1995) reports on the strengths that derive from having a child with disability, Summers *et al.* (1989) as cited in Bennett, Deluca & Allen (1995, pg. 301), maintain that the majority of families are able to accept the reality of their child's disability while having "*successful marriages and emotionally well adjusted children*". Bennett, Deluca and Allen (1995) imply that families who are adjusted to the situation early on are still faced with the challenges and stressors associated with raising their child over the family life span. The adolescent years have stressors associated specifically with this stage. The emergence of a sexual identity is often associated with this life cycle stage.

Murray, MacDonald & Levenson (2001) assert the importance of the family's views and behaviour towards the sexuality of people with learning disability. Apart from being overprotected by their carers or relatives, young people with disability tend to have parents who do not perceive their children as having sexual needs or as becoming sexually mature adults. Dealing with the sexuality of people with disability is a great dilemma for parents as well as for service providers and members of staff working with them. Here the individual's private and personal beliefs about sexuality play a significant role in the experience of the person with disability.

Often staff members or parents prefer encouraging friendship instead of a sexual relationship even if love is involved. Van Dyke *et al.* (1995) express their views about the anxiety parents encounter when their sons and daughters engage in sexual behaviours.

Van Dyke *et al.* (1995) relate this to the fear parents or caretakers have with regards to the vulnerability of people with disability, which is of course related to sexual abuse and exploitation, pregnancy and sexually transmitted disease. Much research has been done about people with disability and sexual abuse, and it is acknowledged that people with learning disability are particularly vulnerable to sexual abuse (Schwab 1992; Elvik *et al.*, 1987; Schor, 1987). Studies (Cuskelly & Bryde, 2004; Esterle, Sastre & Mullett, 2008; Hamilton, 2010) also suggest that older parents are less accepting of people with learning disability having relationships then parents from a younger generation. This relates to findings that caregivers who are younger, and have a higher level of education tend to hold more open attitudes to sexuality generally and for people with learning disability specifically (Drummond, 2006).

2.8 Learning Disability and the Law

The Capacity to Act legislation oversees decision-making on behalf of adults, both where they lose mental capacity at some point in their lives, for example as a result of dementia or brain injury, and where the capacity to make decisions has not been present since birth. This legislation covers a number of areas, two of which are key to sexuality and disability. Sometimes these two interrelate, for instance when a proposed medical treatment is sterilization. In general, different countries have adopted diverse capacity criteria. People with learning disability who are in contact with health services may need to exercise their capacity to consent to treatment. Although Lyden (2007) maintains that; capacity is a state and not a trait., it is often the case that assumptions are made about their capacity on the basis of their medical diagnoses.

2.8.1 Capacity to Act in the U.K.

Adults with learning disability across the U.K, have their own legal systems to tackle issues of capacity to consent; Scotland has its Adults with Incapacity Act (2000), England and Wales has the Mental Capacity Act (2005). Under U.K. law, as in most jurisdictions, the Mental Capacity Act (2005) starts from the premise that a person must be assumed to have capacity to make decisions unless it is established that they lack capacity. This presupposition may be queried when an individual's capacity might be compromised by a learning disability or mental health problems. The Mental Capacity Act (2005) also states that a person is not to be treated as unable to make a decision simply because they might have made an unwise decision. Thus people with learning disability are granted the right to make their own choices even if parents or professionals do not agree with their choices (Garbutt, 2008).

The Mental Capacity Act (2005) aimed to clarify a number of legal uncertainties and also to reform and update the previous laws. The Act covers decisions on such topics as: personal welfare, health and financial matters. It allows substitute decision-making by attorneys or court-appointed "deputies" and clarifies the position where no such formal process has been adopted. The Act also involves new rules to oversee research involving people with disability who lack capacity to consent. It deals with providing independent mental capacity advocates, to act in the best interest and to represent and provide support to such people in relation to certain decisions ((Stanfield, Holland & Clare, 2007; Garbutt, 2008). The Act provides recourse, where necessary and at the appropriate level, to a court with power to deal with all personal welfare, including health care and financial decisions on behalf of adults lacking capacity. However the Mental Capacity Act excludes decisions over family relationships (Article 27):-

(1) Nothing in this Act permits a decision on any of the following matters to be made on behalf of a person-

(a) Consenting to marriage or a civil partnership

(b) Consenting to have sexual relations

2.8.2 Medical Treatment in Children and Adults

"The fundamental principle, now long established, [is] that every person's body is inviolate"

Lord Goff, House of Lords, U.K

Re F. (Mental Patient: Sterilization) [1990] 2 A.C. 1, 72 E.

The principle of respect for the person, established in the Belmont report, incorporates respect for the autonomy of those who can make their own choices, but also includes an obligation to protect those who are not sufficiently autonomous to make such choices (Hunter & Pierscionek, 2006). Wong *et al.* (2000) asserts that standards for capacity to make health care decisions universally are still vague. Nowadays it is generally the functional approach that must be taken with respect to capacity to consent to treatment decisions. This means that a person must be able to understand what he or she is consenting to, must be able to remember the information and appreciate that it applies to him or her and weigh the information to arrive to a decision (Murphy & Clare, 2003). The way in which information is presented to the person, whether they have disability or not, must also be considered, as material is easier to understand when it is visually and linguistically simplified (Grisso & Appelbaum, 1995).

In the U.K. common law jurisdictions require clinicians to obtain consent before taking any health care intervention decisions. In Europe, Australia and the U.S. patients also are required to give informed consent to medical treatment, requiring knowledge of the information relevant to a decision for treatment, voluntarily exercising choice and having the capacity to make the decision. Patients over the age of 16 who are considered autonomous adults, are permitted to give consent to or to refuse treatment without parental involvement. Since patients under the age of 16 are not considered autonomous adults, decisions requiring consent are made by parents or guardians, unless the person is considered 'Gillick competent' (see below), (Hunter & Pierscionek, 2006). Consent to treat patients under the age of 16 who cannot give consent themselves is essentially given by the parents, although they do not have unrestrained power. If there is disagreement between the professionals and the parents, or between the two parents, the child will be made a ward of the court. Furthermore the courts require that doctors and healthcare professionals who make decisions for patients act in the best interest of patients (Grisso, 1986).

However in the case of someone aged under 16 but deemed mature enough to understand the nature and implications of a clinical treatment or procedure, a Gillick competency test is carried out. If the person under 16 successfully passes the test, his or her decisions will be seen as those of an autonomous adult. Yet subjectivity arises as the law leaves the decision as to whether a child is Gillick competent or not, to an individual practitioner. The clinician trained to administer the treatment and deal with adverse consequences is treated by law as able to decide on the maturity and competency of the child doing the test. Since there is always a risk associated with deciding whether a child is Gillick competent or not, medical practitioners can take recourse to the law and often it is the court who decides upon whether the treatment should be carried out or not (Hunter & Pierscionek, 2006).

Medical treatment of adults with particular reference to sterilization and abortion necessitates the consent of the adult person undergoing the treatment (Gunn, 1991), provided the person has sufficient understanding and knowledge to be capable of making a decision. However the choice to give or withhold consent cannot be considered valid unless an individual has the capacity to make that decision, (Wong, Clare, Holland, Watson & Gunn, 2000). The provision of medical treatment to an adult who cannot for various reasons give consent is a very controversial issue which has been researched widely (Niederbuhl & Morris 1993; Grisso & Appelbaum 1998). Consent to treatment requires understanding of the proposed treatment, its benefits and risks, the alternatives and the benefits and risks of those alternatives as well as choice making skills, (Mental Health Act Code of Practice ,1990).

U.K. legislation requires that when it has been determined that a person needs treatment but does not have capacity to consent, treatment can still be provided when this action is taken to preserve life, health or well being. This puts the person in an awkward position, as 'well being' clearly includes actions not designed to deal with health problems and consequently non-therapeutic sterilization can be permitted. The doctor may only act in the best interest of that person, but when this is not a simple decision, the professional can act in accordance with a responsible and competent body of relevant professional opinion (Gunn, 1991). It is required and expected that in some cases, the treatment provider would wish to seek the guidance of the court as whether the treatment is in the person's best interest (Gunn,1991).

Medical treatment of adults with particular reference to sterilization and abortion necessitates the consent of the adult person undergoing the treatment (Gunn, 1991). Sterilization of men or women, who are unable to give or withhold consent, has had a controversial history in many countries and has been researched widely (Niederbuhl & Morris 1993; Grisso & Appelbaum 1998). Stanfield, Holland & Clare (2007, pg.570) argue that special provision should take place when considering sterilization procedures as it is a "*significant and irreversible procedure in the context of which the best interest of the person may not be obvious*". The House of Lords ruled that a woman's right to reproduce is a basic right and sterilization cannot be carried out for eugenicist or social purposes. It is also clear that sterilization cannot be performed when the objective is simply to make the person more easily manageable (Gunn, 1991). In the U.K. and Wales a specific process needs to be enacted to allow a person with disability to undergo sterilization, if she or he does not possess capacity to consent to that decision (Stanfield, Holland and Clare, 2007). This process envisions a judge sitting in the Family Division of the High Court requiring evidence from a psychiatrist and a gynaecologist amongst other experts, in order to decide upon the lawfulness of this procedure.

2.8.3 Capacity to Consent to Sexual Relationships

Research exploring non-disabled people's attitudes towards the sexuality of people with learning disability confirms that there still is a "*deep sense of unease*" towards the idea of people with learning disability being sexually intimate, getting married and even more accentuated towards having children (Hamilton, 2010, pg. 4). Yet the Human Rights Act (1998), Article 8 states the "*right to respect for private and family life*", while Article 12 asserts that "*men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right*". The European Manifesto on Basic

Standards of Health Care for People with Intellectual Disabilities (2003, pg.13) furthermore outlines that; "*People with intellectual disabilities have the same human rights as other citizens*". Above all the United Nations Economic and Social Council (Rule No.9) declares that "*persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood*".

Many more studies have been carried out on consent concerning medical treatment rather than on consent to sexual relationships by people with disability. Yet establishing whether a person with learning disability has the capacity to consent to a sexual relationship has not been an easily agreed matter. Unlike consent for medical treatment, no-one can consent for another person to engage in a sexual activity (Stavis, 1991). In the UK capacity to consent to sexual relationships is defined in the Sexual Offences Act 2003. The criterion laid down in that Act is that a person must understand the nature of the act and the reasonably foreseeable consequences to be deemed capacious in relation to sexual matters. When capacity to consent concerns sexual relationships, Kennedy and Niederbuhl (2001) assert that there is a consensus among psychologists regarding criteria for sexual consent capacity. Whereas Lyden (2007) states that there is enough evidence to prove that there is no consensus concerning the definition of capacity. Futhermore he maintains that there is no universally accepted criterion to determine capacity to consent to sexual behaviour and that these criteria vary across different jurisdictions. Kaeser (1992), argues that standards to determine competency and capacity are too strict and, although he acknowledges the fact that balancing the need to protect people with disability from harm and promoting their right to express their sexuality is a difficult challenge, he finds that there is an inclination towards protection, rather than enhancement of the sexuality of people with disability.

According to Lyden (2007) sexual consent capacity is cognitive rather than behavioural. Decision making in general is the cause of continuous debate, though researchers believe that legal decision making should involve: understanding the nature of the choice to be made, making the decision and communicating the decision to others. Suggested criteria of knowledge required to engage in sexual relationships are similar to criteria set for the consent to medical treatment purposes. These are; understanding what sexual relationships are, understanding the risks, benefits and alternatives of such relationships and recognizing the fact that they have free choice on whether to engage in them, (Murphy & O'Callaghan, 2004). While Brown & Turk (1992) suggest that if a person does not know the significance of what a sexual act or abuse is, does not appreciate the value usually accorded to sexual acts, does not understand the consequences of sexual acts and does not appreciate who is socially inappropriate to have sexual encounters with, then that person is not able to give consent. Research seems to acknowledge one common theory; that capability to consent to sexual relationships is strongly associated with sexual knowledge (Niederbuhl & Morris, 1993; McCarthy, 1999; McCabe, 1999):

> "*One major issue in relation to the sexuality of people with intellectual disability is their capability to consent to sexual contact, Niederbahl and Morris (1993) found that this capability was largely related to their sexual knowledge scores, level of intellectual disability, adaptive behaviour, completion of a sex education program and capacity to consent to other issues. Sex knowledge plays an important role in capacity to consent to sexual activity...*".
>
> McCabe, (1999 pg.159)

When a person's capacity to consent to sexual relationships is in question they, although indirectly, have the right to access services to assess the capacity and support them in achieving capacity. The balance required by agencies to provide people with disability with their sexual rights and protecting them from abuse is surely a challenge to achieve. Kaeser (1992) reported that the number of residential services agencies which sanction sexual expression have steadily increased over the last ten years. However this sanction applied to people who had mild learning disability has decreased, while there prevails a greater reluctance to providing the same authorization for people with a more severe degree of learning disability. Kaeser (1992) also reports that literature gives little importance to the sexuality of people with severe learning disability, or even worse it suggests that the more severely disabled the person, the less interested they are in sexual activity.

People with learning disability sometimes have consented to sexual acts for a range of motives such as sexual gratification, fear, affection, dutifulness, money and material objects such as cigarettes and sweets (Murphy & Clare 2003; McCarthy 1999). England and Wales are amongst countries that have fortified their laws to protect people with severe learning disabilities from unwanted sexual encounters (*No Secrets*,2000; Sexual Offences Act, 2003). People with learning and/or physical disabilities are regarded as having an increased risk to sexual exploitation and/ or sex abuse, because of their social and / or cognitive level of ability (Murphy & Clare, 2003). Yet Kaeser (1992) argues that the laws designed to protect people with learning disability from abuse in the Sexual Offences Act (2003) are the same laws which work to exclude them from engaging in sexual relationships.

Lyden (2007) and Niederbuhl & Morris (1993), have questioned whether it is possible to have a '*limited sexual consent capacity*' or '*situational competency*', where for instance two people with learning disability may not have full capacity to consent to sexual relationships, but would want to engage in physical intimacy that does not require sexual intercourse. As some forms of sexual contact incur fewer risks and are less complex, consent capacity standards may be modified according to the situation. It is argued that this approach would strike a balance between self-expression and protection from abuse (Noonan & Gomez, 2010). Lyden (2007) suggests that these people could be allowed partial privacy in designated areas with periodic visual monitoring. Bonnie (1992) as cited in Neiderbuhl & Morris (1993), argues that consent capacity is highly contextual and a person may be competent in making one decision but not another. They make claims that 'situational competency' calls attention to the fact that a person may be capable of consenting to some forms of sexual contact with a particular individual in a specific setting, but not to other forms of sexual contact with the same, or other individuals in other settings. Stavis (1991, pg.2) on the same note affirms that capacity to consent *"cannot be determined in accordance with precise and inelastic standards"*, and that people with learning disability may have very different degrees of capacity or incapacity to consent to sexual activity.

The other issue arises from mobility barriers faced by people with physical disabilities, such as people with quadriplegia. Although capacity to consent to sexual relationships might be present, assistance to undress and for positioning in order to have sexual relations would be required. This would involve a person to physically assist them have sexual intercourse. These situations highlight the delicate balance between the protection of people with disabilities and their rights, and the protection of the person facilitating the act from false allegations of sexual abuse or exploitation (Lyden, 2007).

2.8.4 Criteria and Approaches that determine Capacity to Consent

In general in the U.K., people are required to be capable of understanding what is proposed and its implications and must be able to exercise choice in order to be judged able to consent (British Medical Association & The Law Society, 1995). There are three well known approaches worldwide which are used to determine if a person has capacity to act; the diagnostic, the outcome and the functional approach. The diagnostic approach focuses exclusively on the diagnosis of the person and it has been widely criticized by researchers (Grisso, 1986). Till some time ago the U.K. used to adopt a diagnostic criterion (minimum IQ) in order to determine a person's capacity to consent to sexual activity. Persons with severe intellectual disabilities, having an IQ below 50 (Lyden, 2007), were not considered able to consent in law, not only in a sexual consent context but more broadly. The outcome approach to capacity argues that when an individual makes a decision that is different to that of the general population, his capacity should be put into question. This approach in English law might in some circumstances contravene the Human Rights Act of 1998. These two approaches, the diagnostic and the outcome approaches, have not been supported in court cases recently in the UK and have been compared to the functional approach, which emphasizes that capacity reflects the interaction between a person's functional abilities and a given situation. This approach is based on establishing whether a person's functional abilities, his behaviours or capacities, what he understands, knows and believes, or can do, are directly relevant to the legal context at issue.

The functional approach to determine capacity requires the person to understand what he or she is consenting to and remember that information. It also requires the person to appreciate that the information about the situation applies to him or her and to be able to evaluate the information before making a decision (Murphy & Clare, 2003). Therefore, capacity to act can change over time and depending on the situation. A person with intellectual disability may be found unable to consent but later increase his knowledge, by means of educational training and counselling, and his capacity status may be changed. Therefore before declaring a person's incapacity, his current capacity and his possible improvement should be considered. A decision could be amended or simplified and a person could be offered education or support to improve his functional abilities and increase his capacity to make decisions. This functional approach is in turn preferred as a method of establishing capacity and has been up-held in recent U.K. legislation (Murphy & Clare, 2003).

2.8.5 Capacity to Act in Malta

In Malta the law regarding Capacity to Act is listed under the Maltese Civil Code (c.16), upon Interdiction and Incapacitation (189,1). This law has not been reviewed since 1889. It uses terms no longer acceptable when referring to persons with disability; such as "*imbecility*", "*mental infirmity*" and "*prodigal*". This legislation states that persons who are considered "*incapacitated from doing certain acts*" may be interdicted or incapacitated, therefore legally rendered incapable of making a legal decision. The Maltese Civil Code Legislation (190) is deemed automatically applicable to people who are "*congenitally deaf-mute or blind*" and in "*any such case no further proof shall be required that such person is incapable of managing his own affairs*".

The Code of Organisation and Civil Procedure continues to explain that a request for the "*interdiction or incapacitation of persons who are habitual idiots, insane, frenzied or prodigal*" 520 (1) is made by a request application to the Court of voluntary jurisdiction. The court reserves the right to employ one or more experts (although no specified criteria of expertise are listed), to examine and question the person whose interdiction is being reviewed, **522.**

It is worth mentioning that even though for a long period such terminology was used in legal systems, it is nowadays seen as demeaning and inappropriate, even since it is used to insult rather then being a serious descriptor (MacKay, 2008). Nonetheless there seems to be no mention of the capacity to consent to sexual activity in Maltese law, albeit on the 30th March 2006, Malta together with another 80 countries, signed the United Nations Convention on the Rights of Persons with Disabilities. The European Union, of which Malta has been a member state since May 2004, also signed this international treaty. Article 12 of the Convention speaks about equal recognition before the law, including the exercise of their legal capacity. In cases of people with learning disability the article allows the necessary but adequate and individualized measures to prevent abuse, but insists on these being for the shortest time possible and subject to regular review. Article 23, Respect for Home and the Family, proclaims that state parties shall take effective and appropriate measures to eliminate discrimination against people with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others.

The article requires that;

(a) People with disabilities who are of marriageable age have the right to marry and to found a family on the basis that free and full consent of the intending spouses is recognized. It foresees the rights of people with disabilities.

(b) To decide freely and responsibly on the number and spacing of their children while it advocates for sex education, requesting access to age-appropriate information, reproductive and family planning education and the means necessary to enable them to exercise these rights.

The convention will bind the particular states who have signed, after it is ratified and after it enters into force on an international level. The convention needs at least 20 countries to ratify it. Till now in Malta the law does not conform to the provision of the United Nations Convention on the Rights of Persons with Disabilities, as a person declared by Maltese law courts as not having the legal capacity to act, loses all his or her civil rights and is assigned a legal guardian to act on his behalf. Therefore the measures are neither individualized nor proportional. The National Commission for Persons with Disabilities has already put forward legislative proposals to change this legislation (The Times of Malta, 2007).

2.9 Policies

Policies and procedures provide ground rules for effective interaction; they are used widely in high-risk areas to guide and inform practice (Murray, MacDonald & Levenson, 2001; Cambridge, 1997). Policies provide a framework for establishing general principles (Cambridge, 2006) and are used to coordinate responsibilities for care processes, for preventing and solving problems and to inform decision-making. They provide standards for assessing performance by identifying the roles and responsibilities of various individuals, while helping to identify potential obstacles to efficient and consistent performance. Policies and procedures have generally been developed for each major area of management of practice, but should ideally be tailored to the individual setting. As policies and procedures will direct the activities of diverse providers and service users, it is advantageous to include a multidisciplinary involvement in defining issues and drafting documents (Cambridge, 2006).

The first step in developing policies and procedures is to define issues relevant to the provision of the particular service including; goals and objectives, care processes, roles and responsibilities of staff, existing regulations, standards and guidelines (Cambridge & McCarthy, 1997). It is recommended that staff training to introduce staff to policies and procedures and reinforce their importance is incorporated into employee training (Levenson *et al.,* 2001). The effectiveness of polices and procedures needs to be evaluated. Evaluation activities should begin prior to implementation to serve as a basis for comparison after implementation. Process measures can be collected during implementation to ensure that policies and procedures are being followed as intended (Cambridge, 2009). Furthermore outcome measures should be collected to find out whether desired outcomes are achieved when policies and procedures are followed, while findings can be used to provide feedback to staff members and make modifications if necessary (Centre for Advanced Palliative Care Manual, 2008). Cambridge (1997) concludes that without policy development and consistency of service responses, the lives of people with learning disability remain undervalued and their opportunities for sexual expression restricted.

2.9.1 UK Policies

This study is located in an understanding of relevant policies relating to learning disability and service philosophies, with a vast amount of material being drawn from the U.K. thus various documents issued by the Department of Health as well as standing U.K. policies are referred to throughout the research. Reference is made to the documents such as *Valuing People* (Department of Health, 2001), and *Valuing People*

Now (Department of Health, 2009), *No Secrets* (Department of Health , 2000) and *Raising our Sights* (2010). A brief account of the relevance of these document follows.

Valuing People (2001) and *Valuing People* Now (2009); outline the rights of people with learning disability, such as the right to choices and the right to inclusion in society. Rights to expressing sexuality and the right to education in order to make informed choices are promoted in this document. *Valuing People* Now (2009) promotes well-being for people with learning disabilities, it emphasises the importance of access to the full range of healthcare services , including sexual health that is essential in ensuring that people with learning disabilities can take greater control of their health and well-being. This conforms with the Disability Discrimination Act (1995) that gives people with learning disability, amongst other impairments, the right to equal treatment in terms of accessing goods and services, including services such as family planning clinics and advice centres (Garbutt, 2008).

There is evidence that people with learning disability have limited opportunities to build and maintain social networks and friendships. Thus these two strategies emphasises the importance of enabling people with learning disability to meet new people, form all kinds of relationships, and to lead a fulfilling life with access to a diverse range of social and leisure activities. The document refers to person centred planning in particular, as a system which should include and respond to people's choices about relationships. One of the objectives in the national policy, *Valuing People Now* (2009), is related to relationships and having a family. The objective states that; *'people with learning disability have the choice to have relationships, become parents and continue to be parents, and are supported to do so"* (Sect. 33, 7, pg.21) It states that people with learning disability are claiming that both friendships and relationships of a personal and sexual nature are important to them (Sect.3.52). Yet it underlines that there is evidence that people with learning disabilities are often lonely, have very few relationships and limited opportunities to form or sustain them. The document asserts that one of the reasons for this is their exclusion from the kinds of places where other people form and maintain relationships, such as work, college, clubs, places of worship, leisure centres, etc. Other reasons set by the document are mostly based on assumptions about people with learning disability by wider society. The document claims that local systems should enable practice that supports the individual's choice with regard to forming and sustaining relationships. It concludes that supporting peoples' rights to have relationships is mostly about challenging stereotypes and changing attitudes (Sec.3.54).

Section 3.53 makes reference to discuss the right of people with learning disability to marry or have a civil partnership, as both a civil and a human right, as in Article 8 of the Human Rights Act (1998). It also emphasises their right to become parents and the need for adequate support to sustain the family unit. It emphasises the fact that parents with a learning disability do not get sufficient access to support, putting families at risk of enforced separation (No. 18, pg. 16).

Valuing People Now (2009) makes recommendations on a local and regional basis which in turn will enable people with learning disability to build and sustain relationships. It also recommends the generation of tools for health and social care professionals that promote safe relationships within the laws of safeguarding and human rights. On a National level it recommends action from governmental departments to develop and sustain relationships, including sexual relationships. The document suggests an increased access to mainstream leisure and recreational services, thus supporting people to keep in contact with their friends and family.

No Secrets (Department of Health, 2000) provided the framework for a national policy in adult protection, to be taken forward by local authorities as lead agencies, and included reference to sexual abuse. This document includes reference to protection from abuse in general and sexual abuse in particular. It underlines the significance of sex education and the importance of raising awareness and information about sexual abuse. Consultation documents for *No Secrets*, claims that the nature of abuse in relation to adults with learning disability is different and wider than most common forms of abuse. *No Secrets* refers to abuse as "*a violation of an individual's human and civil rights by any other person or persons*" (*No Secrets*, 2000, pg.9). The document recommends that there are further actions taken upon the current framework, to implement equal opportunity policies and anti-discriminatory training with regard to issues of race, ethnicity, religion, gender, sexuality, age, disadvantage and disability (Sect. 3.6, pg. 15). It suggests that service providing agencies produce a set of internal guidelines for their staff, which relate clearly to the multi-agency policy and which set out the responsibilities of all staff to operate within it. Such guidelines are recommended to include guidance on sexuality (pg.35).

Relevant reports to U.K. policy include those by Mansell such as Mansell's (2007) report which provides recommendations for services addressing challenging behaviour and mental health issues, as well as Raising Our Sights (Mansell, 2010) which is aimed at individualised services for people with profound and multiple learning disability. The latter report underlines that:

> *"Despite such serious impairments, people with profound intellectual and multiple disabilities can form relationships, make choices and enjoy activities"*.
>
> (Raising Our Sights, pg.4)

Raising Our Sights (2010) also addresses situations where conventional approaches to sex education may not work, for reasons that range from communication difficulties to general social care policy agenda. It emphasises the personalisation discourse, promoting the need to give people with learning disability more control and choice making opportunities in their lives. This in turn reflects on the empowerment in sexual and personal relationships through education and social policy agenda. Mansell (2007) recommends that commissioners have a detailed understanding of the specific social care and health needs of adults within the population of people with learning disability, who have complex needs and whose behaviour presents a challenge to services (2.2). This understanding includes the detail of how to support people to express their needs and how to support their lifestyle, including their sexual orientation.

2.9.2 Sexuality Policy

It is clear that professionals and service providers working with people with learning disability have difficulty addressing issues of sexuality whilst establishing policy with regards to sexual expression is considered challenging (Conahan, Robinson & Miller 1993). Policies are meant to formally guide service providers towards managing the complex issues of sexuality (Cambridge & Mellan, 2000). Historically, service providers and staff have not been given clear instructions about their roles and responsibilities in regard to the sexual life of people with learning disability (Conahan *et al.*, 1993). Disability services are known for lacking policies facilitating sexual experiences and staff training on sexuality (Noonan & Gomez, 2010). This lack of direction in developing guidelines may be due to the absence of consensus on this issue by professionals facing the challenging task of establishing policy regarding sexual expression. Sexual expression for people with learning disability often regulates boundaries for intimacy and social contact. For instance some regulations might stipulate whether a person is allowed privacy and can associate with others inside and outside a facility.

Sexuality Policies can work hand in hand with other policies such as an Equality and Diversity Policy or Gender Policy. They can tackle issues of homophobia, assumptions of heterosexuality and prejudice on the grounds of sexuality (Whitefrairs Housing Group, 2008). Many service providers for people with disability issue their own Sexuality Policy specifically for people with learning disability. Human Rights are often the basis of policies and statements adopted by services regarding sexual issues (Brown, 1994). In most cases a Sexuality Policy would promote the rights and ensure that people with learning disability are supported to experience and express their sexuality (British Columbia Association for Community Living, 2008; Missouri Alliance for Individuals with Developmental Disabilities, 2008). Sexuality Policies should acknowledge that people with learning disability have rights in relation to sexuality and provide a framework for the development of interventions to promote healthy relationships, sexual health and wellbeing. Such policies underline the need for sex education, the right to establish a relationship, marry or live with a partner, have children and chose one's own sexual orientation. Sexuality Policies also need to ensure the physical and emotional safety of people with learning disability. Conahan *et al.* (1993, pg.318) conclude that:

> *"the question is not whether the person understands sexuality or is sexual, but rather, how the provider ensures his right to pursue his interest safely and with regard to the rights of other in treatment*".

Amongst policies that relate to sexuality are Sexual Health Policies, which acknowledge that young people have rights in relation to the development of healthy relationships and sexual health and wellbeing. A Policy Statement reflecting this position is held by the Spastic Centre, Australia;

> *"The Spastic Centre is committed to actively assisting adult service users to access healthcare and information aimed at maintaining and promoting safe/healthy sexual activity".*

Sexual Health Policies also aim to provide a framework that defines the roles and responsibilities, for everyone who works in such environments whilst supporting the access of people with learning disability to sexual health services (Spastic Centre 2001).

Malta published its National Sexual Health Policy in 2011 after it had been in gestation for eleven years. The policy aims at providing the framework and overall direction of where Malta should be going on sexual health. Unfortunately the policy makes no specific reference to people with physical or learning disability.

Policies aim at providing a framework that defines the roles and responsibilities, for everyone who works with these people. They can act as a guideline to staff working in services for people with disability, it elaborates on managerial responsibilities, including staff training and support. They also set guidelines for good working practice and decision making for staff involved (McCarthy, Brown, Cambridge, Clare and Murphy, 1995). Such procedures and policies are successful only if services and service providers have positive attitudes towards sexual expression by clients (Cambridge, 2006; Murray, MacDonald, Levenson 2001). Sexuality Policies report on the need for confidentiality and privacy as well as professional behaviour (Powell & Harwood, 2005). Policies provide guidance for staff with respect to the recognition and reporting of sexual abuse. Others go into more detail and advice on how to support service users on topics such as friendships and relationships, physical contact, courting, personal hygiene, marriage and cohabitation, parenting, birth control and sexual relationship issues such as consent and abuse (Murphy, 1996).

Many Sexuality Policies for people with learning disability include a Sexual Abuse Policy, possibly due to the fact that people with learning disability are more vulnerable to abuse and need to be protected from such circumstances (Beadle-Brown, Mansell, Cambridge, Milne & Whelton, 2010, pg.104).

2.9.3 Adult Protection Policy

The national policy issued by the Department of Health (2000), *No Secrets*, guides adult protection policy and practice in the U.K. (Cambridge, Beadle-Brown, Milne, Mansell & Whelton, 2010). It requires local authority adult social services and departments to lead the development of local multi-agency adult protection policies and procedures (Cambridge *et al.* 2010). The guidance proved somewhat significant in the U.K. and influenced parallel policies in Wales and Scotland (Cambridge *et al.* 2010). Adult protection policy and practice systems in the U.K. share parallels internationally with Australia, North America and Europe. The protection of adults and children with disability has become a priority of international organisations such as the World Health Organisation and the Council of Europe, who in 2005 directed its focus on the protection of these strands of people. (Cambridge *et al.* 2010).

Sexuality Policies for people with learning disability often include a Sexual Abuse Policy, possibly due to the extent of abuse endured by people with learning disability (Turk & Brown, 1993; Brown *et al.* 1995; McCarthy & Thompson, 1997; McCarthy, 1999). It is acknowledged that the prevalence of sexual abuse perpetrated towards people with learning disability is higher than for the general population (Beadle-Brown *et al.* 2010). This incidence is attributed to "*management failure, closed and inward looking organizations and the isolation of staff and services*" (Cambridge *et al.* 2010, pg.574). On the part of people with learning disability abuse is a result of poor communication skills, over protection from family and carers as well as issues of powerlessness (Cambridge & Carnaby, 2000, Cambridge *et al.* 2010). Together with these pitfalls the need "*for detection, intervention and monitoring*" (Beadle-Brown, Mansell, Cambridge, Milne & Whelton, 2010, pg.104) of such abuse has been identified (Turk & Brown, 1993; Brown *et al.* 1995; McCarthy & Thompson, 1997; McCarthy, 1999).

Policies such as Vulnerable Adults and Child Protection Policies deal with various areas of abuse including physical, sexual and emotional abuse as well as neglect, others include financial and material abuse as well as discriminatory abuse. Amongst other more detailed definitions, the Lord Chancellors Department (1999) defines a "*Vulnerable Adult*" as;

> "*someone over 16 who is or may be in need of community care services by reason of mental or other disability, age or illness and who is or may be unable to take care of him/herself or unable to protect him/herself against significant harm or exploitation*".

Abuse is further defined by the Centre for Policy on Ageing (1996, no.9.2) as;

> "*The harming of another individual usually by someone who is in a position of power, trust or authority over that individual. The harm may be physical, psychological or emotional or it may be directed at exploiting the vulnerability of the victim in more subtle ways. The threat or use of punishment is also a form of abuse…*".

Abuse and Vulnerability Policies set guidelines for good working practice and decision making for staff involved with people with learning disability (McCarthy, Brown, Cambridge, Clare & Murphy, 1995). Vulnerable Adult policies name staff members who are designated as responsible for the protection of individuals; e.g. procedures when dealing with disclosure of abuse and reporting concerns (Canterbury College Child Protection Policy, 2008). In the U.K. social services departments are required to have Vulnerable Adults and Child Protection Policies which would be relevant to children and adults with and without disabilities. As emphasised in Safeguarding Adults: A National framework of standards for good practice and outcomes in adult protection work (ADASS, 2005), strategies for reducing risk of abuse and neglect across a variety of settings, include care and community settings (Elvidge & MacPhail, 2009). Review of policies and procedures is recommended as Brown (2009) concludes that safety standards require ongoing quality assurance while safeguarding systems need continual organisational change.

Sex Education Policy is discussed in detail in Chapter three.

2.10 Conclusion

This chapter focuses on learning disability, by defining this condition, portraying stereotypical beliefs and later delineating the structure of the social model of disability. The sexuality of people with learning disability is then traced through history, from the eugenics period to recent years while friendships and relationships are explored in a social context. The difficulties encountered by people with learning disability at establishing their sexuality and developing their sexual-self are examined together with societal perceptions and parental opinions upon sexuality and people with learning disability. Capacity to consent to medical treatment and sexual relationships are explored in this chapter through legislation in countries such as the U.K. Finally the chapter concludes by giving an account of policies associated with sexuality that make particular reference to people with learning disability.

CHAPTER THREE

> ***"We educate children about sex within a society which is both sexualized and yet deeply confused about how it understands childhood an its sexuality".***
> Archard (2000)

Sex Education

Sex education as discussed in this chapter, aims to cultivate education on topics related to relationships and sex. It tackles issues of morality encountered by both parents and professionals working with people with learning disability in this area, and examines the controversial discourse on the provision and content of sex education. This chapter explores sex education in both school based and adult environments, and highlights the relation between sex education and sexual abuse. Homosexuality is given specific importance in this chapter, and resources as well as attitudes surrounding this sexual identity are investigated through current literature. Finally this chapter investigates staff attitudes towards the sexuality of people with learning disability whilst policies framing sexuality and sex education are reviewed.

3.1 The Aims of Sex & Relationship Education

There is widespread disagreement about the aims of sex education (Reiss, 1995). In the past, before the Second World War, sex education aimed at reducing pre-marital pregnancies and sexually transmitted disease and these aims, amongst others, still remain today. On top of this Reiss (1995) confirms that apart from the knowledge about human development, sex education seeks to enable students to develop decision making skills and assertiveness.

Sex education for people with learning disability requires a specific design, layout and delivery (Garbutt, 2008). Research literature has proven that sex education reduces vulnerability and the risk of sexual abuse resulting from ignorance and fear (Murphy 2007). For sex education to be effective it is believed that it has to be delivered in according to the individual needs of the person and for the lenght of time required by that person not on a one-off basis. Sex Education for adults with learning disability across services is aimed at giving knowledge about the persons' rights and responsibilities. Sex education and corresponding material should ideally comprise information on all kinds of relationships possible, in terms of hetero and homo sexual relationships and sexual acts.

The World Health Organization (1993) declared that, contrary to common belief, there was no evidence that sex education encouraged sexual experimentation and they also affirmed that it postponed initiation of sexual intercourse and supported the effective use of contraceptives. Wellings *et al.* (1995) similarly stated that there is no evidence to show that the provision of sex education hastens the onset of sexual activity, while research (Archard, 2000) demonstrates that such an education can in fact delay the first intimate relations of young people. Also taking this standpoint Reiss (1995) argues that valid sex education promotes rational sexual autonomy and encourages pupils to consider the needs of others.

Archard (2000, pg.13) insists that;

> *"Sex education must work with, and not against the grain of the social realities in which young persons find themselves. If it does not, it will not be taken seriously by the children themselves.*

> *It will simply cause confusion by sending out mixed messages none of which are effective or by appearing to betray an adult hypocrisy which undermines the authority of the educator".*

3.2 Sex Education and Morality

All the major religions have something to say about human sexuality. What they actually say generally derives from a literal interpretation of scriptures, or as interpretation by religious leaders, in relation to the ongoing worshipful life of believers (Reiss, 1995). This leads to there being no universal consensus about adopting a particular moral framework in the area of sex education.

From a philosophical point of view, Archard (2000, pg.19) asserts that sexual morality has two views.

> *"One end is the view that anything sexual goes so long as it is done with the consent of those who are capable of giving their consent. On the other extreme is the view that some kinds of sexual behaviour are immoral and they are so because of their sexual content. The view is associated with religious doctrines. The view will appeal to the true nature or ends of sex which may be discerned by the exercise of human reason and need not only be revealed by religion. These ends are normally defined as the conjunction of the expression of conjugal love and procreation".*

Speaking from a religious point Genovesi (1996) explains that sex education is aimed at giving people with disability information, helping them develop skills, modifying their behaviour if necessary and protecting them from abuse and from sexually transmitted diseases. Within the context of Christianity it makes eminent sense, therefore, to suggest that the highest goal of any sex education is *"to introduce human beings to a knowledge and exercise of truly responsible and partner oriented behaviour"* (Genovesi, 1996, pg

89). Reiss (1995) affirms that a possible way forward is seen in the creation of a moral framework, both in schools and in society in general, capable of dealing with diversity of moral views. Some sex education resources, such as Thompsons' (1993), take into consideration individuals coming from different ethnic and cultural backgrounds and religious beliefs. Cultural and religious issues are now being taken into consideration, so that professional practice matches the individual needs of people with learning disability.

3.3 Sex Education and People with Learning Disability

The history of sex education for people with learning disability is reported to have been characterized by neglect, distortion and toleration (Cambridge & Mellan, 2000). Shakespeare *et al.* (1996, pg. 25) suggests that;

> *"People with learning difficulties face some of the biggest restrictions in terms of availability to sex education".*

The neglect of the topic of sexuality of people with learning disability was challenged by the pioneering work of Craft (1983; 1987) and Brown (1980; 1987), whose work focused on bringing sexuality issues closer to disability services. However Malhotra & Mellan (1996) assert that till the end of the 1980's there was only a limited amount of direct sexuality work with people with learning disability in services. In the early years of the HIV/AIDS epidemic in the 1990s, it was recognized that people with learning disability were potentially vulnerable (Cambridge, 1997a), and yet there was little or no education about protection from this infection (Grieveo *et al.* 2006). The necessity to fight this epidemic led to safer-sex education work, including HIV prevention work among people with learning disability (Cambridge, 1997a). Johnson *et al.* (2002) still report a lack of accurate information about sexuality available to people with learning disability in recent times, despite some specialist resource in this area (Cambridge, 1997b).

Garbutt (2008) reiterates the use of internet and watching television, particularly watching soap operas as an identified source of information in her research.

Brown (1994) asserts that a new approach to sex education is based on self-advocacy. Thus people with disability are beginning to define themselves as a group with a distinct social identity; this can be seen as a prerequisite to developing an individual sexual identity. Providing comprehensive sexuality education to children and youths with learning disability is particularly important and challenging due to their unique needs. Davies (1996) as cited in Guest (2000) affirms that young people with learning disability need to be given sex education as they too have to cope with the physical changes in puberty, with menstruation and wet dreams, and with emotional changes. Although young people with learning disability experience puberty around the same time as their typically developing peers, they are likely to be delayed in the social and emotional maturity that typically accompanies this new stage of growth. This dissonance between biological maturity and social/emotional maturity often requires additional attention (Walker-Hirsch, 2007). Because puberty is the bridge between childhood and adulthood, it highlights rather than ignores sex differences, therefore young people with learning disability will need reassurance, as they are likely to have anxieties about the form of relationships they can have.

Guest (2000) maintains that well balanced and comprehensive sex education influences interpersonal relations and self-assurance. It is also an essential part of the character formation of people with learning disability. People with learning disability often have fewer opportunities to acquire information from their peers, have fewer chances to observe, develop, and practice appropriate social and sexual behaviour (Murphy & O'Callaghan, 2004; Jahoda & Pownall, 2010). They may not have reading levels that allow them access to information and may require special materials that explain sexuality in ways they can understand. They may also need more time and repetition in order to understand the concepts presented to them (NICHCY, New Digest, 1992). Cole & Cole (1993) discuss the importance of teaching children with learning disability the correct words so that they can express themselves appropriately regarding sexual matters. Since children with learning disability are particularly vulnerable to sexual perpetrators, Cole & Cole (1993) insist sex education can help a child recognize inappropriate behaviour, abuse and violence. McCarthy & Thompson (1992) discuss the process for sex education and insist on the importance of using visual material such as pictures both to enhance understanding and to enable discussion.

During a survey, (Wheatley, 2005, pg.195) young people with learning disability, were asked what they wanted to do as they grew up, their answers included; '*have girlfriends and boyfriends*'. Wheatley (2005) insists that in order to achieve this they require correct information about sexuality, sex and relationships. It is recommend that sex education is tailored to a person's cognitive capacity and known sexual experiences (Cambridge, Carnaby & McCarthy, 2003). While safer-sex practice needs to be essentially interwoven into this education (Cambridge, 1997a, Cambridge, 1997b).

Guest (2000, pg.141), a person with disability, introduces a very authentic aspect of sex education - the difficulty of the task of letting the person with disability know "*how the extent of their disability could restrict their physical sexual activity and the compromises they would be likely to have to adopt*". McCarthy (2001) recommends that sex education for both men and women targets mutually experiencing sexual pleasure, as this seems to be greatly lacking in women's experiences of sexuality. McCarthy (1996) reports that men with learning disability are referred to sex education twice as much as women. She puts this down to the fact that men are more often perpetrators of sexual abuse than women. In addition McCarthy (1996b) reports that female staff working with people with learning disability may feel uncomfortable addressing sexual issues with male clients, therefore preferring to refer them on.

3.4 Parents, Professionals and Sex Education

School curriculum inevitably should encompass sex education, however content and delivery is often marred by issues of morality and its' contents are often at the discretion of educators and the parents. Schwier & Hingsburger (2001) assert that from the very beginning parents need to play a key role in ensuring that their children with learning disability develop healthy attitudes towards their sexuality and their relationships. On the other hand societal attitudes may influence the opportunity of people with learning disability to receive sex education, as assumptions may be made that these issues do not need to be addressed (Wheatley, 2005). Research reports that some parents might feel that their children have enough to cope with and that to raise the subject of sex is unnecessary and unkind (Guest 2000; Brown, Stein & Turk, 1995). Parents may think that sexual activity will not happen, if it is not discussed, or that knowledge of sexuality and reproduction may present their disabled child with false hopes and expectations. The continued dependence of people with learning disability on the parents keeps the relationship between parents and their children literally childlike, making it more difficult for parents to tackle adult topics such as sex (Jahoda & Pownall, 2010). Yet again it is known (Jahoda & Pownall, 2010) that mothers tend to discuss sexual issues with their female children with learning disability earlier than if they were male, due to their visibly prominent sexual development. Parents and support workers are often concerned that giving knowledge about sexuality to a person or young adult with learning disability will increase the likelihood of that person displaying inappropriate behaviour (Page, 1991;

Jahoda & Pownal, 2010). Robinault (1978) as cited in Walter, Nosek & Langdon (2001) also found that parents of people with disability, who are typically pressed for time and moreover face financial burdens, did not find sex education to be a parental priority. Likewise, Squire (1989) cited by Griffin, Carlson, Taylor & Wilson (1996) reports that parents and staff give aspects such as appearance, hygiene, health and social behaviour more importance that sexuality and personal issues. Similarly Walter *et al.* (2001), affirms that sexuality is not a topic discussed in family conversation and therefore parents need to be informed about the value of discussing sex at home and also need to be taught how to approach the subject with their children. In fact talk about sexuality tended to be "*reactive rather than proactive*" (Jahoda & Pownal, 2010, pg.2), due to lack of confidence and discomfort at facing the topic. Jahoda & Pownall (2010) insist that mothers should be helped to understand that providing sex education to people with learning disability can help them stay safe and reduce their vulnerability to abuse. Other research (Wheatley, 2005) reports that professionals and parents working with people with learning disability felt uncertain about how to address these issues (Cambridge & Mellan, 2000), as they feared for the children's vulnerability and the risk they ran of being sexually abused, so that with the intention of protecting people with learning disability these fears led to not discussing sexuality and instead associating sex with negative issues.

3.5 The Provision of Sex Education

There are widely varying views about sex education. McCarthy and Thompson (1993) underline that although sex education is more common than it used to be; staff training in the area of sexuality and people with learning disability is still relatively rare. Baxter (1996) affirms that whoever is delivering sex education or counselling to people with learning disability must be aware of his own attitudes, beliefs and practices regarding sexuality. Reiss (1995) finds that one of the philosophical positions maintained with regard to sex education is that it is the responsibility of the parents and it should not be tackled at school. Masters (1992) as cited in Reiss (1995) for instance, accuses teaching professionals of having become seducers, who corrupt innocent young people, leading them to forbidden sexual experiences that guide towards teenage pregnancy, abortion, sexual disease and mental and emotional problems. Furthermore teachers may not have the skills needed to teach sex education and might have different values and beliefs from those held by parents. Reluctance to be involved in sex education is reported to stem from conflicting moral beliefs and attitudes towards sexuality, lack of confidence in the abilities to provide adequate sex education and the lack of availability of sex education material (Garbutt, 2008). Guest (2000) maintains a central position as he sees parents as the principal source of sex education information and professionals as valuable collaborators providing complementary resources. Stewart (1996) cited in Cambridge (1997), in fact proposes that in special schools sex education for people with learning disability is carried out in parallel to sex education training for staff and parents (Jahoda & Pownall, 2010). Parents often report that they are not aware of what their sons and daughters with learning disability are being taught at school in terms of sex education and that schools have not consulted them on this topic (Garbutt, 2008).

Independently of the opinions discussed above there are reasons to think schools are the best place to supply this kind of education, while on the contrary to what for instance Masters (1992) as cited in Reiss (1995) believed, other researchers claim that the vast majority of parents and children look to schools to provide the education (Wellings, Wadsworth, Johnson, Field, Whitaker & Field, 1995). Archard (2000) claims that the default alternative (leaving it up to the parents) risks leaving children with inadequate information about sex or even none at all. He states that many parents will confess to the unwillingness to talk to their children about the subject, and tended to leave it up to the school to talk about these issues (Jahoda & Pownall, 2010). Moreover schools have the resources, the training, and the commitment to a common curriculum, which the home lacks. On the other hand Jahoda & Pownall (2010) highlight the need for information to also be readily available for parents who very often find it a sensitive topic to ask about.

McCarthy and Thompson (1993) bring up the issue of gender and the provision of sex education. They assert that on almost all sex education training courses for staff working with people who have learning disability, a significant majority of participants will be female. They claim that since all sex education will include discussion about women's bodies and sexuality it is advisable to have at least one woman as a trainer to make female participants feel more at ease.

3.6 Sex Education and Adults with Learning Disability

When sex education concerns adults with learning disability, research takes up different aspects of sex education. McCarthy & Thompson (1992) affirm that in an adult population, involving community based homes or institutions, service providers should carry the responsibility to see to their clients' right to sex education.

While sex education has been available to the general population it has not been part of the education of people with learning disability.

> *"There is considerable evidence that people with learning disability have lower levels of sexual knowledge and poorer self-protection skills than people from the general population."*
>
> Murphy (1996, pg. 844)

Murphy & O'Callaghan (2004) demonstrated that adults with learning disability often lacked knowledge in a number of key areas, including pregnancy, masturbation, contraception, birth control, sexually transmitted infections, types of sexual relationships, and legal aspects of sex. Reasons for having lower levels of sexual knowledge are numerous. Among these reasons are sources of informal sex education, less information from parents, friends and media sources and ultimately having had fewer sexual experiences and relationships than other young people without a learning disability. For instance Walter, Nosek & Langdon (2001), confirm that the women with learning disability participating in their research were more likely to learn about sexual intercourse from college courses than from parents. McCarthy (1999) agrees that previous sex education did make a difference to the lives and relationships to numerous people with learning disability. She asserts that sex education was associated with higher levels of knowledge and lower levels of vulnerability amongst people with learning disability, as also reported by Murphy & O'Callaghan (2004). Archard (2000) also reports there is agreement amongst those involved with people with learning disability, that the amount of sexual knowledge a person has indicates his capacity to consent to sexual relationships. Moreover, the fact that a better provision of sex education incorporates an on-going model of sex education and not the "*single inoculation*" model is underlined by Murphy & O'Callaghan (2004). They insist that this will allow people with learning disability to exercise their sexual rights, while at the same time protecting themselves form abuse. Hingsburger (1995) insists that a positive sexual identity and sense of self-worth, together with an understanding of rights, reduces the risks of sex abuse.

Nowadays, day service settings in the U.K. provide '*keeping safe programmes*' for adults with learning disability. There are various packages available to aid the teaching of sex education. Packages include slides, pictures and video. They target recognizing abuse, the right to say 'no' and how to report abuse to staff and/or the police. Research has shown that people with learning disability who have received sex education have shown better sexual knowledge and understanding of abuse (Murphy and O'Callaghan, 2004). Some researchers have argued that sex education needs to employ behavioural training methods such as role play and likely scenarios as well as decision making skills and abilities in order to help people keep themselves safe (Kemkha 2000; Miltenberg *et al.* 1999).

3.7 Sexual Abuse and Sex Education

Sobsey (1994, pg.28) observes that;

> "*The abuse of people with learning disability is a product of disempowered personal relationships, their living environments and cultural attitudes towards both people with learning disability and abuse*".

Segregation, lack of sex education, limited opportunities for decision making and barriers to appropriate sexual expressions all increase vulnerability to abuse (Hingsburger,1995; Craft, 1983). This is amplified by the lack of understanding of social mores or laws in relation to sexual behaviour (Caffrey, 1992 in Drummond, 2006; Craft, 1983).

Evidence claims that people with learning disability are more likely to be victims rather than perpetrators of sexual assault, possibly due to their lack of skills in judging people's intentions and motivations (Sobsey,1994; Craft, 1983). Murphy (1996) observes that there is often an unjustified toleration of inappropriate sexual behaviour in services, with insufficient reporting of sexual offences to the police and a tendency to simply migrate male sexual abusers to different residential setting. The criminal justice system tends to fail the victims with learning disability and make it more likely for sexual abusers to re-offend. In fact Brown (1999) also calls upon services to be more explicit and open about abuse. Male service users and family members have been reported to be commonly the perpetrators of sexual abuse (Beadle-Brown *et al.* 2010), while residential and day service settings were more likely to be settings were abuse was committed compared to private home settings (Beadle-Brown *et al.* 2010).

Cambridge (1997) comments that educational videos and photographic images designed to address sexual behaviour in men with learning disability who have sex with men are lacking; as is educational material that deals with men with learning disability who sexually abuse. Shakespeare (2006) maintains that services might be so concerned about protection that they fear that exposing clients to unstructured contact and exploring their sexuality might make them vulnerable to abuse and exploitation. McCarthy (1999) and McCarthy and Thompson (1996) both argue that for the prevention of sexual abuse and the improvement of services for people with learning disability, it is necessary to start with closing down institutions which accommodate both men and women with learning disability. These institutions tend to have predatory men who take advantage of lack of close supervision and the vastness of the premises to commit abuse. It has been suggested that service users should be segregated by gender to diminish the amount of abuse, but this is seen as an extreme step which still would not protect men with learning disability from abuse.

3.8 Sex Education and Homosexuality

In the U.K., the government's guidance on SRE (DfEE 2000, pg. 7) warns teachers that *"There should be no direct promotion of sexual orientation"*, (DfEE 2000 pg. 15), and that sex education *"is not about promotion of sexual orientation"* (DfEE 2000). The Guidance admits that teaching about sexual orientation needs to be done in close collaboration with parents. It also states that schools need to be able to deal with homophobic bullying.

Thompson (1994) & Cambridge (1997a) recall that men are most likely to receive sex education within a heterosexual context, despite a high incidence of reported homosexual behaviour. They also report an under representation of same sex relationships in sex education literature. This absence of relevant literature is reflected in the social sexual knowledge and appropriate language and skills of people with disability. Although *Valuing People* (2009) states that same-sex relationships should be supported, issues arise when a person with learning disability wishes to engage in a same sex relationship within a culture that disapproves of this kind of relationship. Conflicts also arise among staff working with the individual with learning disability in question, as many assume that people with learning disability are heterosexual (Carson & Blyth, 2009). Since the best interest of people with learning disability cannot be achieved either by ignoring or by giving a negative response, it is recommended that organizations issue clear guidelines for staff outlining their responsibilities to respond in the best interest of the clients (Malhotra & Mellan 1996).

Malhotra & Mellan (1996) report a disproportionate representation of gay men in sexuality work, attributable to the fact that gay men were a group of people greatly affected by HIV/AIDS who also experienced sexual exclusion and sexual oppression.

Malhotra & Mellan (1996) state that the earlier sex-education material was biased and reflected white, heterosexual sexual orientation which did not reflect the reality of persons with disability. The authors however assert that the gay community has successfully challenged this notion and recent educational resources do include same-sex relationships in *'positive and realistic'* ways. For example, research on HIV and learning disability such as Cambridge (1996), helped make the issue visible. However, work remains to be done to address the relative lack of information and images in learning disability relating to lesbian and gay identity and sexuality, how homosexuality is presented positively in sex edcuation and how cultural differences are more generally portrayed and celebrated.

3.9 Staff attitudes to Sexuality and People with Learning Disability

Research has proven that women play a greater role than men when providing social support to people with learning disability (Traustadottir 1993). Men on the other hand might find difficulty in providing assistance and are often not at ease with emotional intimacy in general (Shakespeare 2006). Even when discussing sex education Malhotra & Mellan (1996) argue that women's traditional role as carers has led them to become the prevalent gender in the caring field also predominantly present as support staff for people with learning disability. They are known to be over represented in social networks of people with learning disability (Forrester-Jones, 2002) as they are more tolerant and accepting than men. Brown (1994) argues that because women have to confront sexual oppression related to their sexuality, they are very conscious of these matters and therefore tend to be overrepresented amongst those working in sexuality issues with people with learning disability. Women, who tend to experience discrimination in their everyday life, are seen to be more aware of the vulnerability of women with learning disability to abuse and exploitation. Other reasons for their over-representation is that they tend to be more at ease and sensitive in discussions related to sexual matters, emotions and inter-personal relationships. Again women pursue sexuality training more than men who find sexuality in services difficult to confront (Brown 1994). It is reported Cambridge & Carnaby (2000) that same gender intimate and personal care policies are nowadays adopted to protect women from sexual abuse by male staff and carers. Yet Thompson *et al.* (1997) recounts that female staff is potentially exposed to the sexualized or sexually inappropriate behaviour of men with learning disability. Furthermore gay and lesbian identified staff are likely to observe that same gender care involves heterosexist assumptions (Cambridge & Carnaby 2000).

Brown (1994) implies that staff working in the area of sexuality respond to and empathize with people with learning disability in different ways according to their gender. It is imperative to be responsive to cultural and religious based needs apart from gender needs when carers are working with people with learning disability (Malhotra & Mellan, 1996). Malhotra & Mellan (1996) discuss the cultural background and the gender of workers in the area of disability and assert that there needs to be more sensitivity towards people with learning disability and these cultural and religious issues. Unfortunately it is stated that staff working with people with learning disability often impose their values rather than respecting and enhancing the cultural, ethnic and religious diversity of the person with a disability (Malhotra & Mellan 1996; Garbutt, 2008).

Negative attitudes towards the sexuality of people with learning disability are often maintained by staff working with them (Garbutt, 2008; Carson & Blyth, 2009). Brown

(1994) suggests that services often assume that people with learning disability are going to lead an asexual life. Therefore, the sexual expression of people with learning disability is seen as either inappropriate or tolerated to a limited sexual expression such as kissing or holding hands (NDA, 2005; Noonan & Gomez, 2010). Staff needs to be more supportive when people with learning disability are forming relationships (Carson & Blyth, 2009). The maintenance of the right to sexual expression strongly relies on the views and beliefs of staff working with people with learning disability, as they affect their daily behaviour (Murray, MacDonald & Levenson 2001). Downs & Craft (1996) assert that the views and attitudes of different members of staff might send conflicting messages to service users. Malhotra & Mellan (1996) recommend that individuals working with people with learning disability must be aware of the messages that they give to the people they work with. Staff may need to accept that societal norms may not be appropriate for everyone, making sure "*that people with learning disability are informed about the true diversity of human relationships*" (Malhotra & Mellan, 1996, pg. 7). Staff working with people with learning disability might feel unsupported when sexuality policies or guidelines are ambiguous (Cambridge & McCarthy, 1997). This ambiguity will in turn reflect on the client's sexuality and associated situations such as those of abuse (Downs & Craft, 1996). As Clements *et al.* (1995, pg. 427) suggest that staff might for instance believe that they need to adopt a parental role and *"seek to foster the notion of 'family life' where the people who live there are thus somehow like the staff's children"*. Clements *et al.* (1995, pg.427) argue that this role play might lead to "*serious blurring of boundaries as the level of intimacy appropriate for young children becomes acceptable for relating to adult 'strangers*".

Murray, MacDonald & Levenson (2001) report that through the support given to clients, a more constructive acceptance of the sexuality of people with learning disability is created when it comes to making practical informed choices about their sexual behaviours. This does not imply that staff impose their views on clients but rather that they have the knowledge and skills to help clients develop and practice appropriate social sexual skills in a safe environment. Untrained support and care staff might not feel confident providing this kind of education to people with learning disability, therefore it is also evident that staff in services needs support and training in order to educate, recognize and deal with sexual abuse. Nowadays in the U.K. and the U.S. as well as in many other countries, staff employed in services have to undergo a criminal record check before being employed to work in this area (Murphy 1996), providing some protection to people with learning disabilities in their care.

3.10 Sexuality and Sex Education Policies

Malhotra & Mellan (1996) observe that when the emotive and often taboo topic of sexuality is tackled, conflict between or within cultures or individuals, often emerge - one of the reasons that policies relating to sexuality, sexual expression and sex education have been developed (Downs & Craft, 1996). Azzopardi (2009, pg 19) asserts that apart from being socially and politically constructed, *"policy is the culmination of a political discourse discussing issues that touch a disabled person's life"*. The existence of a policy implies that discussion has taken place regarding the philosophy of the setting and the approach to be taken. Downs & Craft (1996) however argue that policies are sometimes vague and unclear (Johnson *et al.,* 2002), purposely to accommodate all eventualities, leaving interpretation to the discretion of individual workers. McCarthy (1998a) maintains that services for people with learning disability are responsible for providing proactive sex education and support for their clients, as well as providing privacy and respect towards their sexuality. Yet the responsibilities of service providers and the rights of service users in the areas of masturbation, condom use, HIV risk and testing, consent, abuse and confidentiality and policy development are still being debated.

In the U.K. education providers have a legal responsibility to establish an SRE policy, while local authorities must determine, publish and maintain under review their policy for secular education including SRE (other than religious education). Contrarily, adult services for people with learning disability have no such obligation, although best practice would suggest the need for such a policy (Cambridge & McCarthy, 1997). Policy guidelines for governing bodies are issued by DfES, placing guidance in a legal framework. The sex education policy discusses the age of the students receiving SRE, the parental involvement as well as the moral values involved (Norfolk County Council, 2008). Malta so far does not hold a SRE Policy.

Policy in the area of Sex Education usually entails a rationale, aims and a framework. It includes details on how SRE is provided and by whom, monitoring and evaluation, lesson aims and objectives; specific issues. In most schools for students with learning disability in the U.K., this policy is revised periodically every few years and is made available to parents (Westgate School Policy Paper, 2004). Cambridge (1997b) recommends that policy developed on sexuality includes HIV, STIs and safer-sex. SRE policies are essentially formulated by teachers, school-governing bodies and to a lesser extent parents (Harris, 1996). The Sex and Relationship Education Guidance, issued by the DFEE (2000) in the U.K., advises governing bodies and head teachers, to consult with parents when developing sex and relationship education policy in order to make sure that the policy developed reflects parent's wishes and the culture of the community they serve. When developing a school's SRE policy, materials used during delivery of lessons should also be discussed with parents. The policy also refers to giving staff appropriate training and support while on the other hand ensuring that the students' views are listened to.

Professionals working with people with learning disability such as physiotherapists, nurses and carers as well as teachers, should follow the school's sex and relationship education policy when working with students with learning disability. Teachers are in turn expected to be more explicit and plan work in different ways in order to meet the individual needs of students with learning disability.

It is clear that professionals and service providers working with people with learning disability have difficulty addressing the issue of sexuality and face dilemmas when establishing policy with regards to sexual expression (Conhan, Robinsona & Miller 1993). Policies are meant to formally guide service providers towards managing the complex issues of sexuality (Cambridge & Mellan, 2000). Historically, service providers and staff have not been given clear instructions about their roles and responsibilities in regard to the sexual life of people with learning disability (Conhan, Robinsona & Miller, 1993). This lack of direction in developing guidelines may be due to the absence of consensus on this issue by professionals facing the challenging task of establishing policy regarding sexual expression. The sexual expression of people with learning disability is often regulated by boundaries associated with intimacy, social contact, and contact associated with care responsibilities (Cambridge, 2006). For instance some regulations might stipulate whether a person is allowed privacy and can associate with others inside and outside a facility or when they might be left in a safe place to masturbate (Cambridge, 2006). When clients are married some regulations provide them with a room to share inside the facility. These examples somehow show that the person with learning disability continues to be viewed and treated like a child whose decisions must be sanctioned by adults who know better. Clements *et al* (1995) argues that not to acknowledge the sexual personality of people with learning disability is to prevent them from stepping out of childhood and establishing themselves as adults.

It is recommend that service providers invest in staff education and policy development (Murray *et al.* 2001). Murphy (1996) reports that most services now have sexuality policies while Gust *et al.* (2003) calculates that 61% of services now have these policies. Some of these polices provide guidance for staff with respect to the recognition and reporting of sexual abuse. Others go into more detail and advise on how to support service users on topics such as friendships and relationships, physical contact, courting, personal hygiene, marriage and cohabitation, parenting, birth control and sexual relationship issues such as consent and abuse (Murphy, 1996). Cambridge (1997b) concludes that the lives and experiences of people with learning disability in services will continue to be undervalued while their opportunities for sexual expression will remain restricted unless services provide sexuality policies, sex education programs as well as staff training in the area. Yet staff confirms that writing policies without supporting staff is unlikely to have an effect on attitudes and behaviour (Cambridge & Mellan, 2000). Murray *et al.* (2001) report that there is a complicated interrelationship between policies, beliefs and practice. They maintain that policies are filtered through staff beliefs. Their findings reveal that policy guidelines do not influence the staff's interactions with clients. Cambridge (1997b) has also reported a considerable difference between written policies and the practical strategies employed by staff.

Emphasis on human rights has resulted in services working at understanding the behaviour and lifestyle of people with learning disability rather than trying to change it (Baxter, 1996). Baxter (1996) also reports that services are making necessary changes to meet the cultural needs of their clients. Cambridge & Mellan (2000) claim that this shift from a culture of protection to one of inclusion and empowerment is a long term solution to sexuality and sexual abuse. In the United States for instance, individuals over 21 living in federally funded facilities, must be afforded all the same rights as any adult citizen of the U.S. (Conahan, Robinson & Miller, 1993). Conahan *et al.* (1993, pg.318) conclude that; *"the question is not whether the person understands sexuality or is sexual, but rather, how the provider ensures his right to pursue his interest safely and with regard to the rights of other in treatment"*. Agencies are obliged to facilitate the adult's free exercise of his rights by providing on-going education about what these rights entail. This education should be aimed at empowerment so that he can enjoy authentic exercise of his rights. The person with learning disability has the right to make choices, develop his potential to the fullest, be informed, be sexually expressive, marry and reproduce (*Conahan et al.*, 1993).

3.11 Conclusion

Discussion about the aims and provision of sex education is one of the issues dealt with in this chapter. Sex education is outlined in the context of school and adult services, highlighting the importance of guidelines and policies to act as a framework to the educational programme. This chapter acknowledges the diversity of sexual identities that sex education is meant to address as best practice provision. The vulnerability of people with learning disability is again stressed in this chapter and related to the significant importance to sex education in relation to abuse.

CHAPTER FOUR

> ***" It's amazing how sex***
> ***...be it theory or practice...***
> ***is many times, very close***
> ***to people who swore chastity for life!"***
> ***Isabelle Bonnici***

Disability, Sexuality and Christianity

The first part of this chapter addresses the impact of culture and religion on people with learning disability in today's society, particularly appraising the influence of Maltese culture on people with learning disability. The history of Christianity is set as background to current Christian beliefs and its' direct influences on people with learning disability. Religion is not only explored in terms of Christianity but the role of spirituality in the lives of people with learning disability is also investigated. Religion is therefore perceived as an important element for the whole family in terms of values and support.

The second part of the chapter investigates the role of Christianity in the sphere of sexuality and gives further significance to the position of Christian beliefs towards the sexuality of people with learning disability. The dispute over the exploration and expression of sexuality of people with learning disability in Malta, being a predominantly Catholic country, is researched, giving rise to discussion of stigmatized topics such as homosexuality and marriage for people with learning disability. Finally Christianity based services for people with learning disability in Malta are reviewed vis-à-vis the rights of sexual expression of service users.

4.1 Culture, Community, Religion and Disability

Culture generally refers to patterns of human activity and the symbolic structures that give such activities significance and importance. Different definitions of 'culture' reflect dissimilar theoretical bases for understanding, or criteria for evaluating, human activity. Culture is defined as being the way of life found in a particular society. Jencks (1993, pg. 75) refers to culture as *"all which is symbolic: the learned...aspects of human society"*.

The meaning of the term culture is often confused with that of religion or ethnicity (Malhotra and Mellan, 1997). Within some cultures, religion can be said to give a purpose to a families' experience of disability (Haworth, Hill & Glidden, 1996). Within specific cultures, religion can be seen as a tool that provides meaning to events. For instance a child's disability can be seen as an opportunity given by God rather than a burden (Bennet *et al.,* 1995, Weisner, 1991). In certain cultures such as Latino culture families rely on religious practices and beliefs such as prayers, pilgrimages to holy sites and religious vows to cure or ameliorate symptoms of disease or disability (Guarnaccia, Parra, Deschamps, Milstein & Argiles, 1992). This perception is also valid for Maltese culture, as Maltese families visit holy sites such as Lourdes and make vows during Good Friday processions. Although culture may help families cope with disability it may also give rise to conflict over the sensitive nature of sexuality, including issues such as homosexuality and contraception.

Heller (1989) defines the relationships within a community as the social forces that draw people together, on the basis of common interest rather than vicinity (McNair & Smith 1998). Fawcett *et al.* (1994) as cited in McNair & Smith (1998) observed that families of children with disability within communities found support from family members, friends, voluntary associations and religious groups. This is also easily observed within Maltese communities where the above are all actively involved in the lives of people and families of people with learning disability. Community presence and competence, (O'Brien, 1987) are recommended as presence in the community and the involvement in function and meaningful activities are deemed essential in the lives of people with learning disability. According to Heller (1998):-

> "*Sense of community develops among group members who have a common story, share common experiences, develop emotional closeness, and whose group membership conveys a recognition of common identity and destiny*".
>
> (Heller, 1989, pg. 6)

McNair and Smith (1998) support the notion that the Church offers opportunities to adults with disabilities, to become integrated into the community since religion provides a place to belong, to be accepted, to be comforted and to share values (McNair and Smith,1998 ; Riordan & Vasa;1991). This support is reiterated by O'Brien's (1987) as accomplishment recommended in the form of community participation and respect.

4.2 Maltese Culture and People with Learning Disability

Camilleri (2000) recalls events in Maltese history, such as the Great Siege of 1565 and the Second World War (1940-42) when portraying the great sacrifices our country has made in order *"to live in a more just society"* (pg. 1). Yet he insists that still nowadays there are local minorities within our society who are being oppressed, being denied quality of life, denied choices and denied equal opportunities. Camilleri (2000) maintains that these local minorities tend to have to face negative attitudes and social isolation. Camilleri (2000) feels that people with disability are amongst these minorities. He recommends that minority groups can only overcome this oppression if society recognizes its faults and looks forward to change. Bartolo (2000) claims that in a society that values compassion and benevolence highly, the process of becoming effective citizens is arduous. Locally Azzopardi (2009, pg. 37) claims that unfortunately the mentality finds the "*charitable attitude an excellent opportunity to drive home the value of solidarity*".

Yilmaz (2002), a person with disability, who visited the island of Gozo, one of the islands of the Maltese archipelago, on a European Voluntary Service project, with the aim to increase awareness on the abilities of people with disability, reported that the people in "*Gozitans were very kind but they tend to perceive people with disability as being helpless*". This view was possibly influenced by his experience locally, where a shopkeeper refused to sell him a bottle of whiskey for no apparent reason (Massa, 2002 pg. 16).

One of the barriers faced by people with disability in Malta is surely accessibility. This reality is still a prime barrier to people with disability, who as a consequence are confined indoors and denied a range of opportunities. Camilleri (1995a) asserts that on a national level there is not enough appeal for the rights of people with disability by people with disability themselves, unlike in USA or UK for example. Camilleri (2000, pg.2) maintains that although considerable improvements have been made in the areas of education and employment, '*prejudice and ignorance are not always won over with kind words and deeds*'. Azzopardi (2009) reflects on the same line of thought, confirming that in a society immersed in the medical model, change can only be achieved through appropriate legislation with concern for human rights. Nevertheless the year 2000 saw the introduction of an anti-discriminatory legislation known as 'The Equal Opportunities Act'. Malhotra & Mellan (1997) confirm that addressing issues within an equal opportunity framework may give rise to conflicts due to cultural and political beliefs; in fact they suggest that clear guidelines are issued in the best interest of people with disability. Camilleri asserts that from personal experiences it is clear that;

> *"Many individuals from every level of our society can live comfortably with minorities that are passive, weak and silent, but feel overtly threatened by minorities which are active, assertive, strong and ready to speak out".*
>
> (Camilleri, 2000, pg. 2)

4.3 The History of Christianity and Learning Disability

The discourse relating to Christianity and disability goes back centuries although Potter (1993) reports that the Christian response towards people with learning disabilities has been at a low level throughout history. Potter (1993) cites Pope Leo X (1531 – 1521) who supported the practice of using people with learning disability as clowns for entertainment for the wealthy. Medieval beliefs regarded people with learning disability as a punishment for sin and this idea unfortunately still survives in certain cultures (Camilleri, 1998). Maridos *et al.* (1989) recalls the participants of their research, who were of Latino heritage, to have been portrayed in earlier literature as viewing disability as either a punishment or a blessing from God. The charity model is exceptionally apparent in religious traditions, where disability is the result of sin, disobedience or the wrath of God (Azzopardi, 2009). Camilleri (2000) confirms that in Malta disability was considered a result of sin, because people lived in small communities and were afraid that the rest of the communities would accuse them of incestual relationships.

In many cultures there were predominantly two opposing views of people with learning disability. An early Christian belief saw '*fools*', as they were at that time referred to, as being closer to God than ordinary people. Due to their simplicity of mind and uncorrupted nature, they were referred to as "*holy innocents*" (McCarthy, 1999). This is still the idea that many in Malta, a country with a population which was predominantly Catholic since 60A.D, have of people with learning disability. In the Maltese context the representation of people with learning disability being an image of innocence also relates to and explains the phenomenon of the 'eternal child'; the forever asexual being (Clarke & Cropley, 2010). The state of innocence is assumed to be a result of an undeveloped intellect accompanied by a sheltered life without exposure to such experiences. The angelic image of people with learning disability contrasted strongly with another early Christian belief that '*fools*' were possessed by the devil. They were therefore dangerous and unable to control themselves; this was another stereotypical image of people with learning disability then. These two portraits of people with learning disability and also other cultural issues, contributed to the fact that people with learning disability were hidden from society from early childhood, either to be protected from society or to save the family from embarrassment.

Yet Brown (1994, pg. 126) asserts that "*the shift from the protection of holy innocents from the public, to the protection of the public from 'degenerates and perverts' took place within the space of one century*". Both these models still nowadays linger on and influence current thinking and the way people with disability are perceived.

> *"Images of people with learning disability have oscillated between that of child-like spiritual 'innocents' who can redeem others and that of animals with little control over their sexual desires – potential polluters of the moral order".*
>
> Clements, Clare and Ezelle (1995, pg.425)

4.4 Christianity and People with Learning Disability

Because of its association with physical and mental health (Idler & Kasl, 1997), religion has become a topic of scientific inquiry in research. As a result of community care for people with disabilities (Swinton, 1997), the Catholic Church is experiencing new challenges in dealing with its followers. McNair and Smith (1998) observe that one barrier to the integration of individuals with disabilities in the Church can easily be the Church itself. One of the challenges deals with the way the gospel could be communicated to people with learning disability (Swinton 1997). Potter (2002) brings to our attention the fact that since church practice relies greatly on what he calls book culture or visual texts, it becomes an inaccessible medium to people with learning disabilities who cannot read or are non-verbal. The abstract concepts and symbolic interpretation of ideas which require a higher level of understanding also limit participation, together with concentrations skills needed to follow what is being said and performed during a religious service. Webb-Mitchell (1996) cited in Swinton (2002a) confirms that there is evidence that people with learning disability have been prevented from participating in important religious rituals such as the sacraments because of their disability.

> *"The person with a severe mental handicap is in need of particular understanding. While some may be too limited to understand this sacrament, by the same token it cannot be presumed that they are too lacking in conscious decision to be in need of the sacrament".*
>
> F. Martin (1996, pg. 17)

Swinton (2002a) affirms that the spiritual needs of people with learning disabilities are often overlooked by their carers who support them. While Johnson and Mullins (1990) assert that religious organizations can provide meaning and motivation to the lives of individuals with disabilities, Swinton (2002a, pg. 33) maintains that "*religious communities can be as exclusive and excluding as society in general*" since they have the same fears and prejudices.

Potter (2002) on the other hand asserts that the church has little if any contact with people with learning disabilities and when they do have contact they lack the skills in conveying support. Potter (1993) concludes that until recently no major religion including Christianity had seriously attempted to bring faith to people with learning disability. Potter recounts that churches admit people with learning disability upon conditions either of catechesis or testimony of faith, which will only allow a small number of people with learning disability to participate. On the other hand others foresee people with learning disability as absolutely innocent and therefore, in some ways, this renders the role of the church unimportant in their lives (Potter 2002).

Preistly (1999) claims that;

> "*Religious and private philanthropy are part of a long-standing cultured response to the dependency of people with perceived impairments....a response based on maintaining them within that state of dependency rather than challenging its social causes*".
>
> (Priestly, 1999, pg.507)

Camilleri (1998) refers to religious attitudes as one of the key elements which have greatly contributed to the devaluing of people with disability. As a person with disability he maintains that religious instruction contributed to his having low self-esteem. He also asserts that in Maltese society where religion has long been the nucleus of daily life, literal interpretations of the scriptures have tended to equate disability with the presence of sin (Camilleri, 1998; Swinton, 1997). Yet it is not uncommon to hear people with disability being referred to as angels, especially during certain charity events. Such references specifically aimed to play on people's emotions are usually accompanied by images of people with physical disability.

> *'Nonetheless, being presented as objects of charity effectively robbed disabled people of the claim to individuality and full human status. Consequently, they became the perfect vehicle of the overt sentimentality and benevolence of others – usually the priesthood, the great and the good".*
>
> Barnes & Mercer (1997, pg. 13)

4.5 Spirituality and People with Learning Disability

Spirituality is seen as a basic human need, some argue that it is also a human right (Swinton, 2002a, Foster, 2000, Curtis, 2001), and it is increasingly being seen as an important part of holistic practice and person centered care. Although Helminiak (1998) recounts that the greatest difficulty is to define spirituality, typically it is defined by its association with religious faith and a person's relationship with God (Helminiak, 1998). Faith, religious practices and church affiliation are all indicators of a person's spirituality or religiosity. Studies (Skinner *et al.*,1999) of individuals going through stressful situations have shown positive responses to religious expression such as general enhancement of well being.

People with learning disability can be excluded from this dimension of spirituality not because they are not spiritual but because spirituality is defined in a way that excludes them (Swinton, 2002b). There is evidence that through the inclusion of that person within a religious or spiritual community the spirituality of people with learning disability "*can be a powerful source of social and psychological support…friendship … acceptance and self-worth*", Swinton (2002a, pg. 30). It is also seen as related in overcoming stigma, social isolation, low self-esteem, hopelessness and loneliness, as these are known to be significant aspects in the life of people with learning disability (Stiemke, 1994; Swinton 2002a). Although it is thought to benefit people with learning disability (McNair & Smith, 1998), Swinton asserts that "*spirituality of people with learning disability is under researched and misunderstood.... overlooked and considered irrelevant*" (Swinton, 2002a, pg.29). Swinton (2002a) maintains that service providers are unaware that the neglect of this domain has significant moral, legal and interpersonal consequences. He asserts that although service providers might not share the spiritual beliefs of another person it is important that they acknowledge and respect these beliefs. Spirituality or faith is known to give individuals strength, patience, and a sense of God as a supportive partner in daily life and stressful times (Skinner *et al.* 2001).

The integration of spirituality and sexuality has been a recurrent topic of recent interest (Chaves-Garcia& Helminiak, 1985). Helminiak(1998) asserts that the integration of the two is simply the integration of the human being. Helminiak (1998) observes that sexuality is thought to encourage or deter spiritual growth according to the religious beliefs and ethical requirements of the person involved. Underwood-Gordon (1995) supports the idea that spiritual roles and religious practice contribute towards functionalism, self- sufficiency, alleviation of suffering and provision of resources, which some would argue in turn assist in the integration into communities.

4.6 Religion and Families of People with Learning Disability

Early research attributes religious beliefs to the role of supporting families who have children with disabilities and helping them through the initial difficulties with accepting and dealing with their child's condition (Crnic, Freidrich & Greenberg 1983; Frey, Fewel & Vadasy, 1988; Skinner, Rodriguew & Bailey 1999). Researchers (Skinner, Rodrigues, & Bailey, 1999; Skinner & Bailey, 2001) specify that parents found both the Church and faith to be supportive, religious rituals have been said to be "*comforting and meaningful*" (Skinner & Bailey, 2001 pg. 298) to the family. While practical support such as community support services and spiritual support have also been of benefit (Fewell, 1986), Fewell (1986) and Roger-Dulan (1998) still affirm that faith and formal religion should be considered separately as faith is found to be more supportive. Other recent literature views religion as a resource focused on coping with the situation of having a child with disability (Freidrich, Cohen & Wilturner, 1988). Although there is research (Weisner, Beizer & Stolz, (1991) that affirms that there is no difference in the measure of peace of mind and emotional adjustment between religious and non-religious families, some research (Bennett, DeLuca & Allen; 1995) confirms that religion is a strong source of perceived support for some families. Rodgerss-Dulan (1995) suggests that there is a need for more research to be conducted in this area to determine the role of religion for families of children with disabilities, where families have different characteristics, such as marital status, gender, level of education, parents' age and the kind of disability involved, as this may explain the contradictory results of important research. Skinner (2001, pg. 306) concludes that his interviewees confirmed that in its institutional form the church provided them with "*a place to pray and hear the word of God ... and renew their faith*", while the church community "*provided socio emotional support*" and at times "*practical aid*". The church also at times provided religious education and rites for the child with disability.

Heller, Markwardt, Rowitz & Farber (1994) also assert that religiosity increases after families have a child with disability. Parents interviewed by Skinner *et al.* (2001) asserted that churches varied in their ability and willingness to include people with disability and their families in activities organized by them. Lack of participation in activities was attributed to the scarcity of special programmes and activities for children with disability, dearth of facilities and of trained personnel. Time constraints from the parents' side was also an issue. Some parents in Skinner *et al.*'s (2001) research noted that catechism classes were not adequate for children with learning disabilities, teachers were not trained and adequate material was not available. This situation is similarly experienced in Malta. Malta also demonstrates several instances of physical inaccessibility in churches. Skinner *et al.* (2001) concludes that there is more need for research on the interaction between disability, ethnicity and religion.

4.7 Christianity and Sexuality

Blenkinsopp (1969) claims that the church's negative attitude to sexuality comes from seeing only its procreative purposes, embraced by ethical norms and marriage, therefore contributing to the isolation and the separation of love and sex in our culture. He reports that the church has for a long time seen as its task the issue of guidelines for sexual conduct, defining what is and what is not compatible with Christianity. The Christian view implies that the further removed from anything sexual, the more perfect love is (Blenkinsopp, 1969). Nelson (1987) explains that in the last two decades Christian writers on sexuality referred to what Christianity and its ecclesiastical authority had to say about sexuality. Nowadays he maintains that we are also asking how our experience of human sexuality affect our perceptions of faith, how we experience God and our interpretation of the Scripture.

Love between man and woman was known to the ancient Greeks as *Eros.* This word is mentioned only twice in the Greek Old Testament, though it is represented as a divine power, while it never occurs in the New Testament. In the pre Christian world, the Greeks and other cultures at that time, saw *Eros* as an intoxicating experience of divine power, overwhelming reason and resulting in divine madness, in order to experience supreme happiness. Blenkinsopp (1969, pg.102) explains that *'Eros and fun are closely allied in that both spring from the sense of joy which is spoilt by any thought of purpose'*. This approach towards love, or *Eros,* gave rise to fertility cults that embraced sacred prostitution in their temples. Other words to describe love in the ancient Greek language were *Philia*; the love of friendship, and *Agape.* This last word is not commonly found in the Greek Old Testament but more often represented love in the New Testament. This clearly indicated the attempt to change the vision of love from *Eros* to a newer understanding of love, *Agape.* Blenkinsopp (1969) explains this by saying that *Agape* stood for a different kind of love from *Eros,* a love which is removed from any sexual connotation and is specifically Christian.

Critics such as Nietzche (1949) claimed that Christianity had poisoned *Eros; "Christianity gave Eros poison to drink. He didn't die, but became vice"*, while others like Goldbrunner quoted in Genovesi (1992 pg. 115) observed that "*Christianity changed from a religion of love to a religion of chastity*". Genovesi (1992) recounts how sexuality was presented as demonic or animalistic and how sexual sins were regarded as of the worst kind. The so called impulse of the flesh was perceived as evil and in need to be kept under restraint. Pope Benedict XVI (2007) admits that Christianity of the past is often criticized as having been opposed to the body. Petras (1973) also recounts how Western Judeo Christian tradition set a division between the body; source of physical lust and dishonesty, and the mind, the essence of purity and spirituality. In the Encyclical Letter called God is Love, (2007), Pontiff Benedict XVI explains how religion in the Old Testament did not oppose *Eros*, but rather resisted the distorted form of it, as it had dehumanized its original meaning. In this light, rather than ascending to ecstasy through supreme happiness, mankind had descended to its degradation.

In Christianity, sexuality is seen as a God-given gift meant to be enjoyed as an expression of love, and not of pure pleasure, therefore ways of living and certain actions distort the meaning of sexuality and offend human dignity. Christianity sees the deceitful ways in which nowadays *Eros*, or love, has been reduced to pure physical sex, and how it has become simply a pleasurable and consumable commodity. Throughout Christian history physical sexuality was permissible, meaning that it would not be considered sinful, under certain specific conditions and for specific reasons. In his task to re establish the true meaning of *Eros* once again, Pope Benedict XVI explains that *Eros* needs to be based on exclusive and definitive love, and direct man towards a monotheistic God and a monogamous marriage. In his writings about Catholic morality and human sexuality, Genovesi (1992), gives a detailed description of what the moral norm for genital sexuality is meant to be. He explains that to make a sexual act righteous in the eyes of the Church, it must be the fruit of a truly loving relationship that has invested in lifelong commitment. Therefore, physical or sexual attraction, otherwise infatuation, does not morally justify engagement in sexual intercourse.

Ratzinger & Amato state that;

> *"Sexuality is something that pertains to the physical-biological realm and has also been raised to a new level – the personal level – where nature and spirit are united".*
>
> (Raztinger and Amato, 2003, pg. 1)

Leeming (2003) asserts that as from the beginning of the history of humanity, religion and sexuality have shared certain characteristics. These characteristics included emotional, psychological and physical goals, yet patriarchal fear which fuelled certain religions tore these characteristics apart. Kazantzakis asserts that;

> *"Christianity soiled the union of man and woman by stigmatizing it as a sin. Whereas formerly it was a holy act, a joyous submission to God's will in the Christian's terror-shaken soul it degenerated into a transgression"*
>
> (Kazantzakis cited in Blenkinsopp, 1969, pg. 84)

Nelson (1987) asserts that Christians have inherited a disembodied idea of salvation, referring to the release from a lower and therefore physical plane to what is considered a higher one embodied in spiritual life. Leeming (2003) explains how the depiction of Jesus in the canonical gospel metaphorically represses sexuality. The asexuality portrayed in Jesus is seen as the denial of the sacredness of sexuality, according to Leeming (2003) it also contrasts other holy men in religion, such as Moses and undermines the idea that Jesus, who he refers to as God, truly shared our human nature. Blenkinsopp (1969, pg. 81) also refers to "*the silence of the Gospels on any sexual experience or temptation of Jesus*" and he continues by claiming that although the Gospel speaks of the anger, tenderness and compassion of Jesus, Christian theology has never found a satisfactory way of presenting the humanity of Jesus. He maintains that Jesus is presented as untouched by sexual desire in a way that conclude that in Christianity God looks unfavourably on human sexuality and sexual activity. Yet again reported incidents in the bible such as with the prostitute who washes his feet and the unfaithful wife, propose that Jesus was ready to forgive those who had loved in a human way although not wisely, without condoning prostitution or infidelity. Other saints are also typically depicted as asexual beings, "*without sexual needs and desires and sometimes even without genitalia*" (Nelson, 1987, pg. 2).

As maintained by McCarthy (1999, pg.17), the Western traditional perspective of sexuality, saw sexuality as an "*impulse of the flesh*" which resulted in "*humanity's fall from grace*" as described in the first three chapters of the Genesis. Although not a feminist writer Leeming (2003) maintains that the divide between sexuality and religion has been especially evident in women's repression. In Abrahamic religions, Leeming (2003, pg.106) asserts that due to the representation of sexuality as impure, women are made to seem inferior; "*as valuable property for men, controlled vehicles for pleasure under certain circumstances and reproduction*". Jochle (2007) also underlines the strained relationship between patriarchal religions and female sexuality.

McCarthy(1999) argues that religion has lost authority within many Western countries. Genovesi (1992) agrees with her views claiming that religion is having less impact upon people's everyday life, and the number of those who regard the teachings of the Church as relevant to their sexual activity has declined considerably. Leeming (2003, pg. 101) concludes that there has been a lack of investigation of "*the effect on current attitudes and events of the deep seated antipathy in our culture between sexuality and religion*".

4.8 Christianity and the Sexuality of People with Disability

> "..... *restricted experience of their condition may cause a priest to misread the situation. Parents and others who have been closely associated with a mentally handicapped person testify to the sense of right and wrong which can develop. The automatic labeling of the mentally handicapped person as incapable, of willful fault does not fit the facts. There is frequently an intuitive ability to understand wrong and a sorry which can be recognized in the explicit joy which may follow forgiveness. Mentally handicapped people are not just innocent children: they may become adults and capable of guilt, and will tell you this themselves*".
>
> F. Martin, (1996, pg. 167)

Jochle (2007) underlines the problems religions have with the expression of sexuality and homosexual sexuality. Marrying the prevailing Catholic ethos to the rights of people with learning disability to express their sexual identity is reported to be a burning issue for countries such as Ireland (Drummond, 2006). Christianity's theological reflections on physical sexuality have been directed towards marriage; the "*proper place for genital expression of love is marriage*" (Genovesi, 1992, pg 161). This is still reflected in the teachings of Pope Benedict XVI (2007, Ency. no.11), who emphasizes in his last Encyclical that love or "*Eros directs man towards marriage...*". Thus since sexual acts are to be related to life long committing relationships such as marriage, sexual relationships outside those boundaries are not approved of. There is no distinction made, when it comes to discussing these matters, between people with and people without learning disability. What stands for people with learning disability, stands for people without learning disability. Therefore it can be argued that a person with learning disability may not have reached the intellectual capacity to understand the meaning of marriage, but at the same time still feels and needs to express sexual urges. This leaves many unanswered questions in the field of people with learning disability and sexuality. Does Catholic morality that dictates that sex is only legitimate when it takes place within marriage, embrace the belief that the way to address the sexuality of people with learning disability is to repress it (Fairbairn, 2002)? Should therefore the sexuality of people with learning disability be repressed since they might not ever be ready for marriage, or might not have the will to marry? Brown (1994) concludes that communities still nowadays are run on religious lines and philosophies which are incompatible with sexual rights and relationships. Similarly Drummond's (2006) findings set in an Irish context outline the relationship found between attitudes and religious attendance, where more open attitudes were associated with lower levels of religious attendance.

4.9 Homosexuality and Christianity

> *'Traditional Christian teaching has been that homosexual people must remain physically inactive, or celibate, on the ground that the only form of legitimate sexual behaviour is between heterosexual couples married to each other...the basis of this teaching is to be found in the interpretation given to certain biblical texts and the undeviating tradition of the Christian Church....".*
>
> Coleman (1980, pg. 224)

Coleman (1980) reports that references to homosexuality in the Bible are neither common nor easy to identify. In the Old Testament there is a clear condemnation of male homosexual behaviour in the Holiness Code of Leviticus Chapter 18 and 20, in the story of Sodom found in the Genesis 18.16 – 19.29 and the story of Gibeah in the

Book of Judges. The Sodom narrative is regarded as the earliest indication of hostility to homosexual behaviour in the Old Testament (Coleman, 1980).

> *"You shall not lie with a man as with a woman: that is an abomination"*.
>
> (Leviticus 18.22)

> *"If a man has intercourse with a man as with a woman, they both commit abomination. They shall both be put to death; their blood shall be on their own heads"*.
>
> (Leviticus 20.13)

From a feminist point of view in both stories the acts of homosexuality are bargained against by heterosexual acts with virgin daughters of both hosts in the story. The women placed as virgin offered in these stories are always rejected but the point remains that while homosexual acts were deplored there is no mention of the deplorable heterosexual acts possibly in this case without consent of the women.

Within the New Testament, the Gospels do not mention homosexuality, but male and female homosexual behaviour is condemned in St. Paul's Epistles to Corinthians (1Cor 6.9 -10), Romans (Rom 1.26-27) and Timothy (1 Tim 1.8-11). In the Epistle to the Romans, St Paul denounces homosexual behaviour and refers to it as a feature of paganism. In his Epistle to the Corinthians he warns Christians that this activity would prevent them from entering the Kingdom of God. The shipwreck of St. Paul in 60 AD is recorded in some detail in the Acts of the Apostles, and a Pauline tradition of long standing supported by archaeological excavations carried out at San Pawl Milqghi prove beyond doubt that his arrival in Malta is a historical fact and it is also a fact that during his three-month stay on the island he sowed the first seeds of the Christian Religion to which Maltese people overwhelmingly belong, but inevitably, a number of legends have grown up over the centuries, some verging on the impossible, but others not without a grain of truth. The Apostle Paul was, at this time, being conducted to Rome under arrest to be judged before Caesar as was his right as a Roman Citizen. Amongst the other prisoners was the physician St. Luke who recorded the account of that eventful journey.

Following his shipwreck on the shores of Malta in 60AD, St. Paul preached the Gospel during his three-month stay on the Island. He converted many Maltese to Christianity during his stay, one of them being Publius. Publius was later appointed Bishop of Malta. The conversion of the Maltese to Christianity was quite slow. However, it is evident that by the 3rd Century A.D., Christianity became the accepted religion among the majority of the population.

Coleman (1980) asserts that since the time of St. Paul till half way through this century, Christian attitudes towards homosexual behaviour remained unchanged and were not often questioned. The Encyclical Letter, God is Love (Benedict P.P., 2005), and in other literature (Genovesi, 1992; Ratzinger& Amato, 2003), two people who engage in a relationship are always referred to as a man and a woman. Earlier in his role of Cardinal, Ratzinger (1986) addresses a letter to the Bishops of the Catholic Church on the pastoral care of homosexual people, then in 2003 Ratzinger and Amato issued the 'Consideration regarding proposals to give legal recognition to unions between homosexual people'. In these documents we find theological explanations of creation as found in the Genesis (Gen 1:27). These summarize the creation of mankind, as male and female, in the complementarity's's of the sexes, created in the image of God himself. Ratzinger also refers to the writings of the Leviticus (18:22 and 20:13) describing the necessary conditions for belonging to the "*Chosen People*" and excluding from the "*People of God*" those who behave in a homosexual fashion. Along with these are also the writings of the Corinthians (6:9) that imply that those who act in a homosexual fashion will not enter the Kingdom of God. Ratzinger specifies that only by the sacrament of marriage between man and woman, can sexual faculty be morally good, and therefore concludes that homosexual behaviour is not approved of and is on the contrary immoral (Ratzinger, 1986; Ratzinger & Amato, 2003).

Within the issue of homosexuality, disability is no longer a prime concern, as gender issues of homosexuality here overshadow disability completely. It is therefore argued that homosexual activity either of people with or of people without learning disability is not approved of by the Church. Malta, a predominantly Catholic country and its acting religious authorities oppose this minority group. This will therefore be the starting point that service providers, under the Malta Catholic Action, who are running institutions for people with learning disability will inevitably be taking. This is not because homosexuality is illegal but because sexual acts are only permissible within the institution of marriage as stated in Roman Catholic religion. Chetchuti (2009, pg. 158), a Maltese controversial author, who identifies as homosexual concludes;

> *'Roman Catholic theology continues to be grounded in a past that is no long with us, and Roman Catholic theologians continue to draw on a past that arguably has little relevance to modern society. From a Roman Catholic standpoint, much of the moral fibre of society hangs on marriage and human sexuality. The Church's anxiety is with every willed sexual pleasure – outside and inside the bounds of matrimony – not aimed at procreation".*

4.10 Sexuality and People with Learning Disability in Malta

Shakespeare (2006, pg. 174) asserts that the barriers to the sexual expression of disabled people are primarily to do with the society in which they live, "*not the bodies with which they are endowed*". McCarthy argues that "*nowadays contemporary perspectives upon sexuality have changed, and that it would be unusual to find many people….who would deny that people with disability have sexual feelings or rights*" (McCarthy, 1999, pg.55). This is not the predominant view in Malta, as when speaking to many Maltese people, of different age groups and educational backgrounds, about this the topic of research many expressed pity towards the lives of people with learning disability. Others embraced what McCarthy (1999) refers to as the 'ignorance is bliss philosophy', holding a 'what you don't know doesn't hurt you' view. Some underlined the limitations of people with learning disability, or else disagreed with their rights for sexual identity because of their religious beliefs - a reminder that Christian marriage is witnessed by the church but the sacrament is fulfilled by husband and wife in the act of sexual intercourse (Gotz, 2007).

Some Maltese people commented on the fact that people with learning disability do not really understand concepts of sexuality and that sexuality comes with responsibilities which, in their point of view, are alien to people with learning disability. Similar findings by Katz, Shemesh & Bizman (2000) reflected beliefs that people with learning disability "*lacked the necessary appropriate judgment to be responsible for their sexual behaviour*" (Katz, Shemesh & Bizman, 2000, pg.303). Others simply opposed the fact that people with learning disability could have an active sexual life and therefore procreate, or raise a child, disregarding the possibility of effective contraception. As for people with learning disability in the role of parents able to raise a child, some views revolved around the stigma and the difficulty the child would encounter by the rest of society. The exact same stance would be taken in another unconventional situation, such as having gay parents. To contextualize such views, it needs to be remembered that up to ten years ago children with learning disability here in Malta were not included in mainstream schools due to beliefs similar to those described above. Camilleri (2006) reflects on the paternalistic aspect of strong family structures in Malta and reports that these have had a negative effect on the aspirations of people with disability. However he underlines that where these structures have had been used positively they have ensured a better quality of life to individuals with disability. Similarly Drummond (2006) suggests that human sexuality must be managed within the context of family in a way that it is enriching to an individual's development, in a setting such as Ireland.

Polish attitudes towards the sexuality of people with learning disability seem to conform with Maltese attitudes and beliefs. Fairbrair (2002) reports that response to sexuality of people with learning disability was greatly influenced by the Catholic church in Poland. This stance conflicted with the approach the UK has about finding ways to support people with learning disability to have positive sexual relationships (Fairbrair, 2002). Lofgren-Martenson (2004) also reports that Swedish attitudes towards sexual activity are generally more permissive than those in Malta. This difference contributed to reports that young Swedish people with intellectual disability describe positive personal experiences and encounters concerning sexuality. In Malta some parents, usually younger in age or with foreign background or influences, seem more inclined to accept the sexual identity of their sons and daughters, while others have a tendency to shelve it, joke about it or completely refuse to recognize it. In many instances this is done with the intent to protect the person with disability from any harm that might come with being sexual.

4.11 Marriage and People with Learning Disability

> "*Regardless of a person's physical limitations and regardless of how his or her outward appearance is affected, the ability to love, and be loved remains unaffected...all human beings are born with the desire for meaningful connection with others*"
>
> Kroll & Levy-Klein (1992, pg. 14)

Miller & Morgan state that "*marriage is not the same as expression of sexuality; neither is sex necessarily the most important or interesting aspect of marriage*" (Miller & Morgan, 1980, pg. 2005). While there are significant similarities in the difficulties faced by men and women with and without learning disability, those with learning disability are often confronted with "*distinctive obstacles in their efforts to form satisfactory marital or sexual relationships*" (Hanh, 1981, pg. 221). While many people might regard not finding a companion as a threat to their natural instinct, Hahn maintains that most studies reveal that people with disability are less likely to marry than non-disabled individuals, asserting that; "*very few people with disability seek sexual conquests many are interested in securing the companionship and love enjoyed by most other members of society*" (Hahn, 1981, pg. 227). Reasons for this stance could be related to economic loss incurred by people with learning disability, who find barriers to employment which as a result may prevent them from supporting a family. Goffmann theorises that visible physical disability possibly reduces opportunities to achieve a marital or sexual relationship. He concludes that "*the effects of stigmatization maybe so powerful that they may pose a seemingly insurmountable obstacle to love or marriage*" (Goffmann, 1963, pg 223). Miller & Morgan (1980) report that many parents of people with learning disability did not approve of their marriage.

Schwabenland (1999) reminds us that the social lives of people with learning disabilities are usually characterised by relationships with people who are paid to provide daily living and care support (Forrester-Jones, 2001). She asserts that while everyone notices when people with learning disabilities do things within society regarded as ordinary and unremarkable, such as socialising with friends and partners, having a sexual relationship or children are still outside the norm. Camilleri (2006) comments on a Maltese couple who are married and whose situation was regarded as exceptional, as they both live with Muscular Dystrophy, by saying that "*….and….'s decision to get married and live independently is inspirational, but should not be perceived as heroic*" (personal communication).

Miller & Morgan (1980, pg. 203) assert that back in the 1960s when two people with disability married "*it was often in the face of great opposition*", as marriage, sexual relationships or activity were not considered the norm. They go on to affirm that people with learning disability, in this case with Cerebral Palsy, "*were conditioned from an early age to accept non-sexual role in life*" (Miller & Morgan, 1980, pg. 204). These ideologies are still relevant in Malta 40 years later. Figures from research quoted by Hahn (1981) reveal that even in countries that strongly support the institution of marriage and family, more than 85% of women and 69% of men with disability are single. Hahn (1981) concludes that decisions to remain celibate are based on various factors but also reflect barriers imposed upon them by society. Miller & Morgan suggest that people with disability would want to get married partly due to the need to be like the rest of society, and partly due to "*the need for the security of a long-term and mutually supportive relationship with another person*" (Miller & Morgan, 1980, pg. 204) .

People with learning disability are often regarded as asexual beings and unacceptable candidates for marriage. Very interestingly, studies utilizing social distance measures (Shim & Dole, 1967) cited in Hahn (1981) revealed an unwillingness to accept visibly disabled partners in a close personal or intimate relationship. Safilios-Rothschild (1970) cited in Hanh (1981) concludes that while people without disability accept and cooperate within the occupational parameters of disability, they tend to ignore attempts by people with disability to gain social acceptance that overcomes taboos that impede intimate relationships and marriage eligibility. When asked about the biggest obstacles encountered during their wedding preparations, a Maltese couple with physical disabilities in an interview claimed that accessibility was a problem as;

> *‘Many establishments simply did not acknowledge the possibility that disabled people might require their services. We actually had to use our own ramp for the wedding!* ”
>
> Vella (2006, pg. 42).

Miller & Morgan (1980) conclude that people who care for people with learning disability need to respect their relationships by offering an open social environment in which physical sexual difficulties can be dealt with and also by not imposing standards of sexual expression. Examples of such circumstances include allowing emotional privacy. Kroll & Levy-Klein assert that:

> *“Every person has the right to sexual expression and there is no one who is too disabled to have some pleasure from his or her sexuality – with a partner is possible, alone if necessary*”.
>
> (Kroll & Levy-Klein, 1992, pg. 33)

When addressing issues of procreation and contraception different literature offers different perspective and conclusions. Yilmaz (2002), a person with physical disability explains that one of the dreams he shares with his partner, also living with physical disabilities, is to have a child. However Yilmaz quoted in Massa (2002) explains that *"we discussed the issue with our care workers and know that although it is physically possible to have a child, we will not be able to care for one".* Then again Miller & Morgan (1980) assert that the presence of a child may upset the delicate balance of a relationship, while residential centres may not be an ideal place to bring up a child. While people with learning disability feel that attitudes towards parents with learning disability are often very negative, parents of people with learning disability often express great concern when the possibility of parenthood by disabled partners is discussed (Miller & Morgan, 1980).

4.12 Sex abuse scandals and the Catholic Church

A series of scandals has in recent years rocked the Catholic Church around the world. The Catholic Church has faced a raft of allegations of child sex abuse by priests and the inadequate response to these matters by bishops. Countries involved in the sex abuse scandals involve Belgium, where 300 cases of alleged sexual abuse by Belgian clergy have been reported, 13 of the alleged abused have committed suicide. In Ireland two major reports into allegations of paedophilia among Irish clergy revealed a shocking extent of abuse involving thousands of victims that took place between 1975 to 2004, following the abuse were cover-ups and hierarchical failings. The Dublin archdiocese is reported to have operated in a culture of concealment, placing the integrity of its institutions above the welfare of the children in its care. Another similar report documented six decades of physical, sexual and emotional abuse at residential institutions run by 18 religious orders in Ireland. It was also reported that in 1975 the abused children signed vows of silence over complaints against a paedophile priest.

The Roman Catholic Church in the United States has also been embroiled in a series of child sex scandals and cover ups for the past two decades. A report commissioned by the Church declares that more than 4,000 U.S. Roman Catholic priests had faced sexual abuse allegations in the last 50 years, in cases involving more than 10,000 children, mostly boys. Sexual abuse was also reported in Wisconsin, between 1950 and 1974, at St John's School for the Deaf. In March 2010 documents emerged, suggesting that Cardinal Joseph Ratzinger, before he became Pope, failed to respond to letters from U.S. clergy about the latter cases of alleged child sex abuse in Wisconsin.

In Germany since the start of 2010, at least 300 people have made allegations of sexual or physical abuse by priests. Claims are being investigated in 18 of Germany's 27 Roman Catholic dioceses. In Italy in June 2010 a high-profile former priest was charged with sexual abuse. In the mean time in one reported case earlier last year, the Associated Press news agency obtained a written statement from 67 former pupils of a school for the Deaf, naming 24 priests, brothers and lay religious men who they accused of sexual abuse, paedophilia and corporal punishment. In the Netherlands more than 200 allegations of sexual abuse of children by priests, dating from 1950 to 1970 have been uncovered. Spain, Austria and Switzerland have also received a series of claims of sexual abuse by priests spanning over centuries (B.B.C.,2010).

In Malta allegations of abuse at the St Joseph Home, a Church run 'home' for children and young people, came to public attention in 2003 after the victims broke more than 20 years of silence. Four priests, Fr Sciberras, Fr Carmelo Pulis, Fr Francesco Scerri and Bro. Joseph Bonett, were investigated by the Church Response Team. Police initiated criminal proceedings against the latter three, accused of sexually abusing 10 orphan children in Malta during the 1980s and 1990s. Following an eight-year-long court case, in August 2011, Mr Pulis (since defrocked) and Fr Scerri were found guilty by the Magistrates' Court, which sentenced them to six and five years in jail respectively. They have since appealed (Calleja, 2011a). Bro. Bonett died in January, aged 63. The Vatican has since then declared Fr Conrad Sciberras not guilty of sexual abuse claims for lack of corroborative evidence. Yet Fr Sciberras had his Sacred Ministry restricted to be with persons of adult age (Johnston, 2011; Times of Malta, 2011).

In 2010 Maltese child protection experts worked on putting together a draft national policy aimed at improving the services offered to children. Once completed, following a series of workshops involving the major stakeholders, including children, the draft policy containing recommendations to improve child protection services and identifying key issues that ought to be tackled, was presented to the government. The draft policy formed part of a project commissioned and funded by the Commonwealth Secretariat in collaboration with a government's social support agency. Children whose parents have addiction or mental health conditions, and children who have to appear in law courts were mentioned amongst the vulnerable. However the individualistic situations children with disability encounter was not referred to and no specific consultation with services for children with disability has been reported so far (Calleja,2011b).

Hundreds of people with disability in Malta and Gozo, including children, reside in charity funded, Church run, respite institutions and community houses. Yet no legal frameworks support sexual abuse implications for children with disability in such environments so far.

Nonetheless, the Times of Malta (2011), reminds its readers that:

> *"...those who have taken questionable pleasure from jumping on the bandwagon and slamming all priests in the wake of this episode have lost sight of a very important and salient fact: that is, while two have been convicted of terrible breaches of trust against children, hundreds of others are dedicated to working in communities both in Malta and abroad....They give up their time, their energy and at times even their health to make a difference to people's lives. In everyday matters as well as in major crises. The Church has many unsung heroes and remains an important part of society. The vast majority of clergymen are dedicated to helping other.*

As yet there does not seem to be a climate of tension surrounding the issues of sex abuse, children and the Catholic Church in the general public, as witnessed by the 4,000 applications for admissions for children in kindergarten Church Schools (non-governmental) in 2011 (Archdiocese of Malta).

4.13 Christianity based services for people with learning disability in Malta

Malhotra & Mellan (1997) observe that many services for people with learning disabilities tend to be culturally biased. This might be evident in the service's intent which would reflect a particular religious view. Services provided by religious congregations could heavily influence the moral, doctrine and philosophies of that service (Drummond, 2006). Religious inclination can work in favour of the integration of people who identify with these views but can also alienate those who do not share these views. In Malta the first well established charitable institutions opened their doors in the 1890s. They had a strong religious bias and focused exclusively on people with social problems and with an accent on moral regeneration. The founders of this institution aimed at improving the lives of people born with impairments, both mental and physical, and aimed at considerably easing the burden that their families were carrying. Adopting an idea being used by the Vatican at the time - that of broadcasting a radio program aimed at the sick and infirm - the founders took every opportunity to get the message concerning the needs of the disabled across to as many people as possible. On the other hand, Camilleri (1998) explains that institutionalised life was advocated as a utopian state, where special needs would be taken care of by highly trained professionals. Oliver (1990) insists that dependency is created through the delivery of professionalized services and institutional regimes while Camilleri (1998) maintains that this situation lives on in Malta still today. Indeed this is still an issue today as NGO and services for people with learning disability seem to survive on the charity model. In response to the latest charity event Camilleri (2008) asserts;

> *'I am very disappointed at NGOs that continue to raise funds by focusing on projecting negative images of us. Can you imagine the damage this sort of imagery does to young disabled people when they come to look for jobs? No wonder employers won't employ us, if even disability NGOs insists on portraying us as feeble, passive and unable. It's also insulting to give the impression that we only begin to enjoy a good quality of life if we make use of their services. This is deeply insulting to all those of us who have struggled and continue to struggle to be independent and productive members of society".*
>
> (personal communication)

4.14 Conclusion

In summary this chapter gives an account of the impact of culture and religion on the lives of people with disability, with a focus on Maltese cultural perspectives. The history of Christianity and its influence on learning disability outlines the framework for further literature on the impact of Christianity on sexuality. The chapter again locates people with learning disability at centre of the discourse and investigates the role of Christianity in relation to the sexuality of people with learning disability. Controversial topics in the light of Christianity, such as homosexuality and marriage for people with learning disability are explored. Spirituality and people with Learning Disability and religion as a supporting figure in family life is discussed. Particular reference is made to Christianity in the Maltese context due to the country's religious inclinations.

CHAPTER FIVE

> ***"A key result of the validity of a piece of research is whether it actually tells us anything useful or important or makes any difference"***
> **Yardley (2000)**

Methodology

Brunskell (2000) argues that within social science research, the choice of which aspects of the social world to research, the method of data collection and the ways to interpret that data is informed by the broad theoretically informed framework within which the research is carried out. *'The combination of these aspects constitute methodology'* (Brunskell, 2000). This chapter focuses on the methodology used for the research study, and commences by conceding the implications of researching sexuality whilst considering the role of the researcher in this field. It then continues to explore different methods of research including; qualitative, quantitative and the mixed methods approaches, which are outlined and reviewed. Finally, methods and theoretical frameworks relevant to the research are examined, with the feminist model and disability politics approach being reviewed in an international context.

As part of the process of undergoing qualitative research, different qualitative analysis methods are explored, including: Grounded Theory, Interpretative Phenomenological Analysis and Ethnographic Research. The key research instruments used in the study are also justified and discussed, including: interviews, focus groups and participant observation.

Ethical considerations and procedures concerning the participants involved in the study and the research topics are evaluated, with the chapter concluding with a framework outlining the involvement of participants in the data collection.

5.1 Research Aims

The research has five key aims:

1. Identify and interpret the opportunities and problems experienced by young people with learning disability in expressing their sexuality in the form of personal and sexual relationships from a range of perspectives in Maltese society.
2. Identify parental attitudes and perceived responsibilities relating to the sexuality of their adult children with learning disabilities.
3. Identify how parental attitudes in-turn influence the sexual identity and behaviour of their children with learning disability.
4. Identify how service managers and staff working with people with learning disability perceive the sexuality of their clients and how they influence the sexual identity of this client group.
5. Develop a culturally appropriate pilot educational intervention on personal relationships and sexuality in relation to the above.

5.2 Researching Sexuality

> *"Sex research has an irregular history. Much of this is due to the fact that sex has been a stigmatized subject. Proper people simply do not talk or write about it, and, especially, they did not do research about it during the 19th and the first part of the 20th centuries."*
>
> Bullouch (1985, pg. 375)

It has been argued that certain areas of life are too private and sensitive to be researched and therefore shouldn't be (MacIntyre, 1982). Field, Johnson, Wadsworth & Hargreaves & Welling (2004, pg. 48) claim that *"despite the apparent trend towards greater openness in sexual matters"* the topic of sexuality *"remains one of the most underdeveloped fields in the human sciences"*. There are arguments that sustain the idea that certain topics should be avoided when doing research, because of their potential negative effects on the participants. Yet with reference to the topic of sexuality, McCarthy (1999, pg. 94) insists that; *"it would be all very well if everything that happens under the cloak of intimacy is positive, lawful and healthy"*. For instance, feminist research has in fact exposed and been devoted to uncovering the exploitation and affliction of women in their own homes (McCarthy, 1999). The latter argument overlooks the need for and the potential positive effect that researching sensitive topics might have (McCarthy, 1998). McCarthy (1998) discusses how choosing the appropriate method of research is in itself an ethical issue. Research carried out within a disability rights perspective has the potential of identifying that it is the non-disabled world which denies opportunities to and oppresses disabled people (McCarthy, 1999). Not researching people because of their vulnerability means that they could be rendered even more vulnerable as there will be ignorance about their circumstances and how they are treated (McCarthy, 1999). Participants' vulnerability can be protected by use of anonymity and confidentiality and by the researcher being sensitive to people's dignity and the rights to privacy of those involved (McCarthy,1999). Yet again Ratzka (1998) implies that researching other people's sex life is related to their deep personal problems in this area. He adds that experts on disabled peoples' sexuality are mainly concerned with topics such as "*erections and ejaculatory capability, positions or sexual technical aids*" (Ratzka, 1998, pg. 1). He considers that knowledge of the everyday life and sexual needs of people with disability is far from these practical sexual issues.

5.3 The Researcher researching Sexuality

Ratzka (1998, pg.1) outlines the strong social taboos that "*surround talking about and researching in the area of sexuality and intellectual disability support*". Troiden (1987) reports personal and professional risks and benefits associated with careers in sexuality education and research. The reports also extend from the reactions of sexuality experts to the stigmatization they encounter. Field *et al.* (2004, pg.48) assert that "*researchers who have ventured into this area have rarely avoided suspicion and constraint*". Troiden (1987) found that 32% of the participants in his study, 1000 members of the Society for the Scientific Study of Sexuality (SSSS), had experienced occupationally related discrimination. Troiden (1987) concludes that human sexuality is a stigmatizing line of work as occupational stigma makes sexuality educators or researchers "*socially marked*". Social and personal variables seem to affect the level of stigmatization encountered. In the author's case, as Troiden (1987, pg. 244) claims, "*younger, attractive women, seem to be stigmatized more readily than men*", while a sexuality expert who is homosexual or bisexual will be at greater risk of being stigmatized than an expert who is heterosexual (Troiden, 1987).

Sexuality specialists are seen as violating a norm that almost everyone follows, in questioning about sexuality. Uncertainty about the professional's work and an insecure attitude towards sexuality are reflected in the general public's response to these professionals. Other types of stigma render sexuality educators "*sexually suspect*" of "*developmental flaws, such as obsessive interest in or fear of sex*" Troiden (1987, pg243). Another stereotypical stigmatization model mentioned by Troiden (1987) is that sexuality experts occupy sexual extremes, extreme sexual desire, extreme sexual expertise, or vast sexual experience. Sexual experts might in some instances be the objects of disbelief, being refused professional claims at being researchers or educators, assuming that sexual knowledge is acquired naturally (Troiden, 1987). Troiden (1987) maintains how sexuality professionals could be seen as "*sources of peril*", especially by conservative religious groups, who see them as "*godless secular humanists*", intending to harm cherished family values. Sexuality educators are often charged with trying to sabotage traditional family values, by influencing students and exposing them to harmful, liberal attitudes towards sexuality.

> *"In the popular mind, the scientific study of sexuality is faintly immoral, even unnatural. By extension, students of sexuality are looked upon as unnaturally interested in sex, and thus sexually suspect".*
>
> Troiden (1987, pg 241)

There is also the presumption that researchers in the area of sexuality advocate and practice the sexual pattern they investigate (Troiden, 1987). For instance a researcher who is investigating homosexuality is presumed to be homosexual. One of the reactions to occupational stigmatization experienced by the author is described by Toriden (1987) as a response involving selective self-disclosure. Troiden explains that this is a general unwillingness to broadcast topics of research or teaching with non-intimates.

On a more positive note Troiden (1987) asserts that the stigmatizing features of a career in sexuality may be viewed alternatively as constructively developing a person's self-awareness, strength of character and sexual integration. None the less Troiden (1987, pg.248) adds that professionals remain in this field because the subject matter is interesting and fascinating, while teaching sexuality is an "*opportunity to dispel sexual misinformation*", not to mention sexual behaviour and abuse. Troiden (1987) concludes that teaching and researching human sexuality can also manifest itself in a liberating experience, as the person involved has to overcome his/her own inhibitions to be comfortable to discuss such sensitive topics. In conclusion the researcher needs to internalise that it is the general population that possesses the sexual problem not the sexuality specialists.

5.4 Theoretical Frameworks

5.4.1 Disability Politics

Oliver (1990) claims that disability politics finds a philosophical relationship with feminism and minorities that have experienced discrimination and oppression, including black people and lesbian and gay people. People with disability experience discrimination in many areas of their daily life, including education, employment, accessibility and basic human rights (No Secrets, 2000, Equal Opportunity Act, 2000). In response people with disability have formed social and political movements to fight their oppression and campaign for equality (McCarthy, 1997). These social and political movements have come to embrace a model of disability which sees society as the disabling agent for people with impairments; this model is known as the social model of disability (discussed at further length in Chapter 2). According to Cambell (1997) the key to unlock some of the fundamental principles of the Social Model of Disability was simply to break away from those who spoke on the behalf of people with disability, and ask why people with disability are excluded from society, and how can they reinsert themselves.

The development of disability research has reflected the changing realities of a minority that has been disregarded by an oppressive society for as long as "*civilization*" has existed (Campbell & Oliver, 1996; Barnes, 1997, Azzopardi, 2009). Researchers and writers with disability such as Mike Oliver and Tom Shakespeare amongst others have in recent years challenged research on people with disability. Oliver (2002, pg.11) raises an important question when he states that he does not deny "*the value of research which gives voice to those previously denied it, but to question whether, by itself, giving voice can ever be enough*". Azzopardi (2009) claims that a contentious argument in disability research is whether it will actually bring about the desired change and what hinders it. McCarthy (1997) lists some of the challenges of carrying out research in this area such as; the actual lack of research, the uselessness of this research to the person with disability and the fact that it is non-disabled people researching disabled people. Oliver (2002) has argued that research has failed people with disability in many ways. He recalls ways in which research has failed "*to accurately capture and reflect the experience of disability from the perspective of disabled people themselves*" Oliver (2002, pg.11). He also claims that research has been unsuccessful in improving the conditions and the policies which influence the lives of people with disability. Oliver (2002, pg.11) states that research has not been able to portray disability as a political issue rather than a medical and welfare issue and finally it has failed to "*acknowledge the struggles of disabled people themselves*"

Oliver (2002, pg.5) comments on the power and control issues which emerge during a research project; "*whether we like it or not, failing to give disabled people through their own representative organisations complete control over research resources and agendas inevitably positions disabled people as inferior to those who are in control*". Research which is carried out by a non-disabled person, can be regarded as McCarthy (1999, pg.90) suggests, '*where able-bodied people have invited themselves into the lives of disabled people, asking all manner of questions*'. Oliver (2002, pg.11) underlines the need for giving participants control over the research, and claims that if "*such research is ever to be useful, it must not only faithfully capture the experience of the group being researched but also be available and accessible to them in their struggles to improve the conditions of their existence*". Priestley (1998) is one researcher who took to heart the criticisms by disabled people that there needed to be a fundamental shift in the social relations of research production. His research for instance was conducted within an emancipatory paradigm, which involved disabled people controlling the agenda. Selener (2001, pg.1) claims that;

> "*Participatory research is a process through which members of an oppressed group or community identify a problem, collect and analyse information, and act upon the problem in order to solutions and to promote social and political transformation*".

Oliver (1992, pg. 11) refers to this as the '*changing of the social relations of research production*', which translates into putting the researcher's knowledge and skills in the hands of research participants themselves. The goal of participatory research according to Brayton (1997) is of the inclusion of the participant's perspective and voice in all aspects of the research process. Participatory research aims for accurate and objective representation of the reality being investigated, as by involving the participants in the process, data will be unbiased and genuine in its representation (Brayton, 1997).

Smith & O'Flynn (2000, pg.515) underline that;

> *"In disability research, the role of the researcher and balance of the relationship between researcher and researched have correspondingly shifted toward greater partnership and equality in the research process, culminating in research that is used to change the relationship in favour of disabled people and their organizations".*

Yet Oliver (1997, pg. 2) maintains that Participatory and Action Research approaches *"share a limited vision of the possible"* as these approaches are concerned to allow previously excluded groups to be included in the research. While on the other hand he claims that emancipatory strategies are concerned about both conceptualising and creating a different kind of research, where no one is excluded in the first place. Although Participant Research fails to transfer the research agenda to people with disability it does give them a voice, and although it operates outside an explicit political agenda it is soundly in line with the social model of disability (Smith & O'Flynn, 2001). Smith & O'Flynn (2001) claim that these characteristics are cited as limitations of Participant Research when compared with an Emancipatory Approach in disability research. Participant Research presents a number of methodological challenges particularly when the area of interest to the research involves a disadvantageous experience (Smith & O'Flynn, 2001).

As Oliver (2002, pg.16) later states, the real challenge for today's research and researchers is to carry out a project that;

> *"..exposes the real oppression and discrimination that people experience in their everyday lives without merely contributing to the classification and control of marginalised groups who seek nothing more than their full inclusion into the societies in which they live".*
>
> Oliver (2002, pg.16)

Research must aim at meeting criteria of for good disability research principles, that of giving people with disability and in this case even their parents, an opportunity to voice their experiences and opinions (McCarthy, 1997). Unfortunately other studies and researchers even those with disability tend to disregard the experiences of men and women with learning disability as argued by Wheeler (2004). Sexuality is without the shadow of doubt an:

> *"area in which people with impairments are disabled by society...often as a result of societal attitudes and beliefs, such as people with disability are asexual or because of an unwillingness on the part of service providers to facilitate sexual relationships"*
>
> Wheeler, (2004, pg.54)

One research method which favours the above discourse is Action Research. Smith & O'Flynn (2001) recall that with the development of qualitative research approaches, Action Research became more interpretive, claiming that Action Research has emerged as New Paradigm research in both education and nursing research and is used in a variety of research studies. The specialists in these fields are being encouraged to act as researchers through reflecting on their own everyday practices (Smith & O'Flynn, 2001). The use of Action Research to promote participative Emancipatory Research is well documented by Reason & Bradbury (2001). They state that a principle of Action Research is to produce *"practical knowledge"* that is useful to people in the everyday conduct of their lives. A long term purpose of Action Research is to use this *"practical knowledge"* to improve the well-being of people and communities. The findings that are derived out of Action Research allegedly reflect the real needs and not assumptions about needs of the researched, and therefore have validity to influence policy and professional practice.

5.4.2 The Feminist Approach

Issues of gender equality and masculine dominance within society that came to a peak in the 1970s gave rise to feminist methodology within social science research. Feminist researchers Stanley and Wise (1983, pg. 17), define feminist social research as research "*on, by and for women*". Feminist methodology does not indicate any particular choice of method of collecting and analysing data over another (Brunskell, 2000). Yet the topic of investigation focuses on the lives of women, and data collection and analysis will be informed by feminist theory. Feminist theorizing in sociology has achieved a significant status, especially in the field of sexuality (Jackson & Scott, 2010). Feminists have argued that research models, being qualitative or quantitative, are biased because they reflect a white male, middle class and heterosexual orientation (Brayton, 1997, pg.2). Feminism challenges traditional social science research, and claims that "*patriarchal values and beliefs in our social world shape both the construction and definition of how research is done and how knowledge is determined*" Brayton (1997). Feminists hold diverse views about what women's oppression entails and its sources (Wadsworth & Hargreaves, 2001). A shared belief by all types of feminists is that women are oppressed and feminism arises from the acceptance that there is indeed a problem (Stanley & Wise, 1983). Brayton (1997) claims that what makes feminist research uniquely feminist are the motives, concerns and knowledge that act as a guiding framework to the research process. She underlines that at a basic level feminism recognizes the organizing of the social world by gender. Mcguire (1987) explains feminism as:

a) a belief that women universally face some form of oppression or exploitation;

b) a commitment to uncover and understand what causes and sustains oppression, in all its forms.

c) a commitment to work individually and collectively in everyday life to end all forms of oppression.

Feminism consequently seeks to eliminate the subordination, oppression, inequalities and injustices women suffer because of their sex (Wadsworth & Hargreaves, 2001; Porter, 1991). Feminists believe that women suffer discrimination because of their sex, that their needs remain neglected and that it would take a radical change in the social, economic and political order to fulfil these requirements (Delmar, 1986). Feminist knowledge therefore is not there for its own sake, but rather to bring change to women's situation; it is not merely research about women but for and by women (Wadsworth & Hargreaves, 2001). Stanko (1994) asserts that researching women's lives forces her to question men's lives and to challenge masculinity. Topics of study researched by feminists include; images of women in the media, mental health services, the culture of violence, men as perpetrators of violence, the relationship between sex and power and the nature of male dominated knowledge, such as; art, science, religion, architecture, literature and technology amongst others (Wadsworth & Hargreaves, 2001).

Women who undertake feminist research bring their own experiences and history to inform the research process and interpretation of evidence, while trying to understand these experiences as women in a patriarchal culture (Wadsworth & Hargreaves, 2001). A feminist researcher can be an "*insider*" to the environment of the research topic with a stronger understanding of the situation under investigation (Brayton, 1997).

> "*The issue of inequality may be overcome through the affiliation of the researcher with the context, where participants may feel more comfortable in sharing information with someone who is within the situation*".
>
> (Mansumoto, 1996, pg.156 as cited in Brayton, 1997 pg.2).

Conversely, as an "*outsider*" living outside the situation being examined, the researcher is able to give the women participating in the research, space to examine the reality of their own lives, the community or situation they live in. Feminist research is different to other research models as it seeks to remove the power imbalance between research and subject, it is politically motivated, seeking to change social inequality, and takes a starting point from the experiences of women (Brayton, 1997). To overcome power imbalances, the feminist researcher seeks to remove the hierarchical relationship between the researcher and the participant, therefore to validate the perspective of the participant in the research. Brayton (1997) states that an important factor that needs attention is terminology, which needs to address equality. McCarthy (1997) claims that another essential principle of feminist methodology is rejecting the bias that assumes that women's experiences are the same as men's, therefore using generic terms to describe research participants and their actions. Whilst recognising participants as the experts and owners of their lived experiences, feminist research is concerned with ensuring accuracy in depicting these. Brayton (1997) suggests that feminist research takes back the finalized information to the participants for verification.

It is evident that what makes feminist research uniquely feminist are the motives, concerns and knowledge brought to the research process. There are claims that quantitative research which focuses on numerical data is essentially masculine, and that qualitative data which focuses on meaning, definitions and experiences is therefore more feminine. Yet Brayton (1997) maintains that these kinds of claims simply reinforce traditional gender stereo-types, and that combining research methods to obtain the widest and most accurate representation of reality is one of the potentials of feminist research. Wadsworth & Hargreaves (2001) maintain that research tools in feminist research involve; conversation, group discussions, storytelling and participant observation. More artificial ways of collecting data such as questionnaires, interviews and secondary material analysis are only used if they appear to empower the women participants and are recognized as the best way to investigate a particular research question. It is believed that feminist researchers should try to use a multiplicity of techniques to reflect the multidimensional nature of women's experiences (Wadsworth & Hargreaves, 2001).

McCarthy (1999) puts forward a reality which is often taken for granted, that people with learning disability are rarely referred to as women or men with disability when addressed by services or in literature even though their needs and experiences are "*potentially conflicting*". Other forms of biases include ignoring or underestimating women's experiences, giving preference to men's interest above women's and blaming women for men's behaviour. McCarthy (1999) also comments on the rejection of women's matters as private and trivial, since feminist research methodology takes from feminist activism the belief that the personal is political, thus seeing the private as public.

5.5 Methods of Research

Disability research can be divided in two distinctive ways, participant research and Emancipatory Research. These two approaches have been described as complementary approaches although they have different philosophical roots and research objectives. They are said to have emerged from the way the flaws in traditional disability research were addressed. Participatory approaches have developed from qualitative research methodologies while Emancipatory Research has its roots embedded in the development of a social model of disability (Azzopardi, 2009), and the growth of the disability movement (Smith & O'Flynn, 2000).

5.5.1 Quantitative Approach

Quantitative research differs completely to qualitative research in the way data is analysed. Quantitative research reduces the phenomena investigated to numerical values so as to allow statistical analyses of this phenomenon. Even though data would have initially been verbal, quantitative research requires it to be changed into numerical information, *"counting occurrences, volumes or the size of associations between entities"* Smith & Osborn (2006, pg. 604). Yet Smith & Osborn (2006) insist that quantitative research always involves interpretation of data by the researcher, and this remains essentially a qualitative process.

Researchers who employed quantitative methods in the area of sexuality and learning disability include Kedde & Berlo (2006), McCabe (1999), Murray, McDonald & Levenson (2001), Karellou (2003), Gail & Biza Stenfert (2005) and Torices Rodarte & Bonilla Munoz (2004). Kedde & Berlo (2006, pg.53) used a quantitative method to measure the "*Sexual satisfaction and the sexual self-images of people with learning disabilities in the Netherlands*". Their figures are assessed in five different areas by five different scales and subscales, some of which were self-constructed. Results were issued in tables and later discussed by the authors. McCabe (1999) also used a quantitative research method to examine the sexual knowledge, experience, feelings and needs of people with learning and physical disability and compare them to respondents from the general population. McCabe (1999) used the Sex Knowledge, Experience and Needs Scale for People with Intellectual Disability (SexKen-ID); while for people with physical disability McCabe utilized the SexKen-PD and the SexKen-GP for the general population. McCabe (1999) also produced tables to illustrate results which were later discussed.

Murray, McDonald & Levenson (2001) conducted three empirical studies investigating staff attitudes towards client sexuality, giving special consideration to issues surrounding HIV infection. Murray *et al.* (2001) employed three identical survey-style questionnaires, amongst which were the Sexuality and Intellectual Disabilities Attitude Inventory – SIDAI and the Staff Attitudes towards Persons with Learning Disabilities and HIV Scale (LDHIVS). Similarly Karellou (2003) conducted her research to examine the attitudes of Greek public towards the sexuality of people with learning disability. A quantitative method was used by means of the Greek Sexuality Attitudes Questionnaire -Learning Disabilities (GSAQ-LD), this questionnaire incorporates four scales to measure; Human Sexuality, Acknowledgement, Discrimination and attitudes towards Homosexuality in the context of learning disability.

Other researchers such as Gail & Biza Stenfert (2005) used interviews and questionnaires to collect data from people with and without learning disability about the reactions of students with mild learning disability, participating in quantitative sexuality research. Another example of quantitative measures was used by Torices Rodarte & Bonilla Munoz (2004), who aimed their investigation at constructing and validating the properties of three scales which identify the experiences that compromise part of the study subjects' human sexual response. Their results were processed through statistical package SPSS, which analysed frequencies, variances and reliability amongst others.

5.5.2 Qualitative Approach

'For most qualitative researchers, this approach is consistent with a theoretical commitment to the importance of language as a fundamental property of human communication, interpretation and understanding".

Smith & Osborn (2006, pg. 2)

Smith & Osborn (2006) maintain that qualitative and quantitative research approaches differ in the way data is analyzed. The specific questions asked and answered in qualitative research also differ from those asked in quantitative research. Qualitative data is at times seen as more valid than quantitative data, while at times it is often dismissed as too subjective as assessment is not made in a standardized manner (Dey, 2004). Kvale (1996) attributes the growing acceptance of qualitative methods of research to the change from an economy primarily concerned with production, to one predominantly concerned with consumption and communication, or as Flick (2002, pg.12) suggests "*the result of rapid social change*". Qualitative assessment in psychological or social contexts is used when concepts cannot be measured in quantitative terms (Dey, 2004), "*where as quantitative data deals with numbers, qualitative data deals with meanings…mediated mainly through language and action*" (Dey, 2004 pg. 148). Qualitative analysis describes the essential components of the entity whilst determining how much of the entity there is, providing a rich descriptive account of the phenomenon under investigation (Smith, 2006). Elliott (1999) describes qualitative research as lending itself to understanding the participants' perspective. It is thought to value subjective, personal meaning and definition, commonalities and it is also known as giving voices to the oppressed (Brayton, 1997). Qualitative approaches are usually involved in exploring, describing and interpreting the personal and social experiences of a small group of people and their view of the world. Elliott, Fischer & Rennie (1999, pg.2) explain that "*the aim of qualitative research is to understand and represent the experiences and actions of people as they encounter, engage and live through situations*". Furthermore Devine (2002) concludes that the advantages of qualitative research are clear where the goal of a piece of research is to explore people's experiences, practices, values and attitudes in depth and to establish their meaning for those concerned. Flick (2002) reports that qualitative methods are more suitable for intricate subjects such as sexuality which are difficult to quantify.

Qualitative research is nowadays seen as research emerging from methods of collection such as: participant and non-participant observation, unstructured interviewing; group interviews collection of documentary material and such. Data produced from such methods include; field notes, interview transcripts, documents, photographs, sketches, video and tape recordings amongst others. Detailed description and in-depth quotations are the essential qualities of qualitative accounts (Genzuk, 2007). With a qualitative approach, the data collection usually takes the form of verbal reports, such as interview transcripts, while the analysis is contextual; "*thus, the concern is with interpreting what a piece of text means rather than finding the numerical properties of it*" (Smith, 2006, pg. 288). Elliott *et al.* (1999, pg.216) also refer to the role of the researcher, which they describe as "*attempting to develop understandings of the phenomena under study, based as much as possible on the perspective of those being studied*".

Lofgren-Martenson (2004) employed a qualitative approach in her research aimed at identifying, describing and understanding, the opportunities and hindrances for young people with learning disability in forming relationships and expressing sexuality and love. The nature of the study by Lofgren-Martenson (2004) encompasses ethnographical and empirical data collection. The approach was based on participant observation and interviews. Aguilera (2000) also used first hand accounts of people with learning disability and their "*devotees*" to investigate if the attraction of devotees is exploitative or empowering to people with phsyical disability. Similarly, staff attitudes towards the sexuality of adults with learning disability within a medium-secure hospital in the U.K. were examined by Yool, Langdon & Garne (2003), using a qualitative method. The researchers utilized interviews with staff members as their data collection technique, which were then transcribed and analyzed using a method adapted from Worthen & McNeill (1996).

In much of their work researching the lives of people with learning disability, McCarthy (1993; 1996), Thompson (1997) and McCarthy & Thompson (1997) use interviews or information derived from questionnaires and one to one sex education work as data. Booth & Booth (2001) have also used a variety of techniques and had interview transcripts, case records, observational notes, documentary evidence and research logs as primary data sources. Bennet, Deluca & Allen (1995) researched the link between "*Religion and Children with Disabilities*", by carrying out interviews which were tape recorded then transcribed for analysis. Several major themes which were then discussed emerged from the analysis of the data. Similarly Whitney (2006) in "*Intersections in Identity – Identity Development among Queer Women with Disabilities*" used semi-structured interviews which were transcribed then analyzed using the programme 'Atlas', in multiple steps to generate a list of important interview themes which were later discussed.

McCarthy (1998) concludes that through qualitative research, people with learning disability are consulted, they are asked for opinions and experiences, where before these were discredited as they were not consulted. Through the growing inclusive practices of empowerment and self-advocacy, people with learning disability are recognised as valuable and primary sources for research. On the other hand the researcher must apply good practice, building on the strengths of persons with disability without overlooking the subjects' and the own researchers' limitations.

Smith & Osborn (2006) claim that there is considerable discussion among qualitative psychologists about how to assess the quality of qualitative research. What is imperative, state Smith & Osborn (2006), is that qualitative research is judged by criteria which are appropriate to it. Brayton (1997) maintains that for the researcher to achieve neutrality the distance between the researcher and his participants needs to be removed, so as to enable the participants to confirm the validity of the depiction of their experiences. Devine (2002) claims that while quantitative research is expected to be reliable, qualitative research tends to be valid. Yardley (2000) draws an important point here, stating that: a key test of the validity of a piece of research is whether it actually tells us anything useful or important or makes any difference.

> *'Given that we tend to make sense of our social world and express that sense-making to ourselves and others linguistically, qualitative researchers emphasize the value of analytic strategies that remain as close as possible to the symbolic system in which that sense-making occurs."*
>
> Smith & Osborne (2006, pg.2)

5.5.2.1 Reliability and Validity as Qualitative Measures

Although 'reliability' is a concept used for testing or evaluating quantitative research, this concept is often also used in qualitative research. Berg (2004) defines reliability as the process of determining the accuracy of meaning in the material collected. In the case of this research and with respect to reliability, the research methods chosen here might be criticized for lacking in terms of the measurement procedures, and can be said to generate the same answers in any situation they are carried out in (Kirk and Miller, 1986). Similar criticisms can be put forward in terms of the work being subjective and based on the researcher's theoretical background and area of interest, whereas other researchers could have given different analysis and interpretations of the data collected. Yet Yardley (2000) implies that most qualitative researchers believe that human knowledge and the way the world is experienced cannot comply with an objective reality, due to reality being subjectively interpreted by experiences and accounts of the researcher (Yardley, 2000; Grigoriou, 2004). Researchers maintain that this argument calls for the use of different criteria in order to evaluate qualitative research (Grigoriou, 2004). Furthermore Lincoln and Guba (1985, pg. 316) maintain that there is a congruence between reliability and validity in qualitative research, thus: "*since there can be no validity without reliability, a demonstration of the former [validity] is sufficient to establish the latter [reliability;]*". This stance is echoed by Patton (2001) who claims that reliability is a consequence of the validity in a study.

Validity is defined by Creswell (2002, pg. 651), as the ability of the researcher to "*draw meaningful and justifiable inferences from scores about the sample or population*". It is also seen as: "*the extent to which an account accurately represents the social phenomenon to which it* *refers*" (Hammersley, 1990, pg. 57). Validity can be criticized in this research on the premise of its context of power relations which can possibly influence the narratives of interviewees participating in the research (Kohler Riessman, 1993).

Newman (2003, pg. 225) defines one category of validity, which was of interest to this study, known as external validity; "*the ability to generalize experimental findings to events and settings outside the experiment itself*". External validity is threatened by issues that affect the ability to draw correct inference from the collected data and to apply the findings to other persons, contexts and situations. Employing expert advice upon the subject investigated can assist in promoting external validity, as expertise and agreement can support and reduce the challenges to external validity (Newman, 2003). For this reason, the expertise of my supervisors were sought when undergoing the current research, and establishing data collection techniques, key research methods, and analysis of the actual data in order for the research to undergo a credibility check (Elliot *et al.*, 1999).

Priest (2002) maintains that the collection of data from participants in a variety of diverse settings can assist in establishing external validity of the research in place. In this research data was collected from 3 groups of participants, each group having several characteristics that differ from those of the others, although ultimately with a common interest in learning disability. Within each group, participants also differed to one another. Group 1 which compromised participants with learning disability differed by gender, age, ability and common interest. Group 2, made up of parents of people with disability, differed by gender, cultural background, nationality, education, social status, and settings their children with learning disability frequented. For instance some parents had children who still attended a mainstream higher secondary, some parents had children who were beyond school age but who stayed at home, while some parents had children who were in paid employment. Finally the 3rd Group consisted of Service Providers from different settings, including educational and residential settings for people with learning disability.

Qualitative research is often criticised, using concepts of validity and reliability through which it is often assessed, on the small sample size used, the generalisability and subjectivity of results. Having a small sample size is often criticised in qualitative research therefore achieving data saturation can possibly justify the sample size (Hale *et al.,* 2008). Data saturation here implies that the researcher found all they possibly could on the topic, giving the researcher a sense of saturation. Hale *et al.* (2008) point out that data saturation can be applied as a measure of the validity for qualitative research, even though it can be argued that data saturation is not a goal set for an IPA approach. Moreover Hale *et al.* (2008) maintain that by nature qualitative methods seek to distance themselves from what is called 'strictures of measurement'. Furthermore generalizability of results in qualitative research should not depend on whether the sample size used was large enough to be 'representative' as in qualitative enquiry, such as IPA, concepts or themes may in themselves be applicable elsewhere and in other situations (Hale *et al.* 2008). Hale *et al.* (2008) conclude that by focusing only upon generalizability actually limits the scope of scientific enquiry. On Hale *et al.*'s (2008) premise, this research study, using IPA as a key method of interpretation, does not flaunt a large sample group yet it can be said that the individual experiences of the participants can be applied to other people with learning disability in a Maltese context for reasons including the size of the population, the general attitude of society, the influence by the Catholic Church and the still influential medical model of disability.

research report, then confirming trustworthiness establishes confidence in the findings. They conclude that in essence measures such as reliability, validity, trustworthiness, quality or rigor are in place to identify good from bad research.

5.5.2.2 Alternative Measures to Validity & Reliability

Yet qualitative psychologists argue that although there is consensus that qualitative research must be judged by criteria which are appropriate to it, there is discussion about how to assess this quality. Hale *et al.* (2008) assert that how rigorously qualitative research has been conducted is often assessed through the same premises associated with quantitative research, usually by people who do not understand the fundamental nature of qualitative enquiry. Some (Yardley, 2000; Elliott, 2000) argue that there are a number of ways of doing this using broad measures rather then imposing ways in which such criteria should be met. Reliability and validity, particularly from a qualitative point of view, have to be redefined in order to reflect the multiple ways of establishing truth in qualitative research (Golafshani; 2003) Yardley (2000) presents three relevant principles that can be seen as criteria. A number of Yardley's (2000) principles were used during this research as alternative measures to and on top of the regular reliability and validity measures already discussed. The first of Yardley's principles is researcher's sensitivity to the context in which the study is situated. Sensitivity to context can be demonstrated in several ways according to Yardley (2000), such as showing an awareness of the existing literature as well as the degree to which the study is sensitive to the data itself. Such criteria can be said to have been fulfilled in this research, through an extensive literature review focusing of the most relevant topics that inform the subject researched. Yardly (2000) implies that

In terms of subjectivity, my interpretations of the accounts given by the 3 groups of participants were examined by and discussed with my supervisors, who verified that interpretations, themes and sub-themes, were grounded in the data (Elliot *et al.*, 1999; Grigoriou, 2004). Extracts from the transcripts found in the Findings chapters (Chapter 6, 7 & 8) also allow readers to assess the consistency between the data and my interpretation, found later on in the Discussion chapter (Elliot *et al.*, 1999; Grigoriou, 2004).

Patton (2001) asserts that validity and reliability are two factors which any qualitative researcher should be concerned about while designing a study, analysing results and judging the quality of a study, yet researchers' opinions conflict on this issue. Healy and Perry (2000) for instance claim that the quality of a study in each paradigm should be judged by its own paradigm's terms. They maintain that while the concepts of reliability and validity are essential criterion for quality in quantitative paradigms, qualitative paradigms should rely on criteria based on concepts of credibility, neutrality or conformability, consistency or dependability and applicability or transferability (Lincoln & Guba, 1985). Other qualitative researchers (Creswell & Miller, 2000) argue that the term validity is not applicable to qualitative research, although at the same time, they confirm the need for suitable measures for such research. Creswell & Miller (2000) suggest that validity is affected by the researcher's perception of validity in the study and the researchers own choice of paradigm assumption. As a result, many researchers have developed their own concepts of validity and have often generated or adopted more appropriate terms instead of validity such as quality, rigor and trustworthiness (Davies & Dodd, 2002; Lincoln & Guba, 1985; 2000; Seale, 1999; Stenbacka, 2001). Moreover, Lincoln & Guba (1985) maintain that since measures of validity and reliability depend on trustworthiness in a sensitivity to data is recognised as; the use of detailed extracts from the participants in the study which in turn provide evidence for the interpretation being offered. Extensive use of extracts from participants is distributed along 3 chapters of findings and can later be related to the emerging themes discussed in the Discussion chapter. Furthermore the researcher can demonstrate sensitivity to context by attending to how the socio-cultural background the research study is situated in may have influenced its conduct and outcome (Smith & Osborn, 2006; Yardley, 2000). Here the researcher makes broad connections to Maltese cultural attitudes, traditions, religious beliefs and legislation that were subjective to the way in which the research was carried out and the interpretations that were derived from the data. Finally Yardley (2000) refers to the relationship between the researcher and participants itself, as a further context to which sensitivity can be related to. To adhere to this principle the researcher made sure that participants in the current study were made to feel as comfortable as was possible, given the nature of the subject. Their anonymity and confidentiality was guaranteed unless otherwise agreed. Participants were also informed of their right not to answer to questions, to terminate the interview or to leave the focus group without further explanation required. A number of participants had also agreed to have follow up interviews, after participating in focus groups. Thus it can be concluded that overall participants had a good relationship with the researcher.

Yardley's (2000) second principle refers to 'commitment, rigour, transparency and coherence'. She argues that commitment is demonstrated by the degree of engagement by the researcher in a number of domains, such as extensive knowledge of the field of research. This can be said to have been demonstrated in the literature review where the researcher investigated issues relating to sexuality and learning disability and the context in which the research was set. Rigour is seen as the thoroughness of the study in terms of appropriateness of the sample to the question in hand and the completeness of the analysis undertaken (Smith, 2004; Yardley, 2000). The sample in the research was as varied as possible so as to adhere to the appropriateness. Participants derived from a spectrum of the population with learning disability and their parents, including participants from different age groups and gender, different socio economic status and educational background. The non-disabled participants who offered services also covered the not so extensive range of local services offered to people with disability, including respite and educational settings.

Yardley underlines the relation of transparency and coherence with how clearly the stages of the research process are outlined in the study. Coherence can also refer according to Yardley (2000) to the connection between the research carried out and the underlying philosophical assumptions, thus in this research referring to the social model of disability, as of the theoretical approach being followed. In relation to the theory of the social model of disability being adhered to in this research study, the researcher underlines the importance of looking at the sexuality of people with learning disability as no different to the sexuality of non-disabled people, thus upholding equality and Human Rights Acts (8, 12), which support these notions of sexuality and equality.

Finally Yardley's (2000) third principle; the impact and importance, argues on whether the research itself communicates useful or important messages that will make any difference to its readers or equally important its validity in the contribution towards social change or practice (Smith, 2004). It can strongly be concluded that this research reports on the quality of life people with learning disability and their parents are currently experiencing in relation to sexuality, sexual experiences and sex education. It aims at suggesting constructive changes in policy and practice to ameliorate the lives of people with learning disability in a functional way, through awareness, information and education of all those involved.

5.5.3 Mixed Methods Approach

The use of both qualitative and quantitative techniques within research has an established history, although the concept of merging qualitative and quantitative methods has become increasingly popular, particularly in areas of applied research (Tashakkori & Teddlie, 2003). The mixed methods approach is particularly valuable for obtaining the best results of both quantitative and qualitative approaches. Brayton (1997) claims that both methods seek to uncover the richest possible data for the research being carried out. This is a result of social sciences having a general goal; that of capturing and accurately conveying the reality of an event or an experience or facts about people (Brayton, 1997). Researchers in social and human sciences are therefore increasingly adopting mixed methods approaches which employ strategies to collect and analyze both qualitative and quantitative data (Ju & Kwon, 2009).

A mixed methods approach has the potential strength of utilizing triangulation as a means of searching for unification between data and findings. Rationales for using mixed method approach might also be related to the questions directing the research which require both quantitative and qualitative analysis and findings. Qualitative and quantitative methods also have the capacity to provide different perspectives to the same question. Ju & Kwon (2009, pg.1) confirm that "*it is important to approach the phenomenon under inquiry from diverse angles and to integrate diverse explanation resulting from* *diverse methods*". A mixed method approach gives the researcher the possibility of a reliable explanation, as it is possible to increase the reliability by cross-checking whether explanations from diverse methods converge (Ju & Kwon, 2009). One of the challenges of using mixed methods is that it may lead to the development of a conflicting interpretation of data, possibly due to distinctive experiences and manifold views. Ju & Kwon (2009, pg.3) describe the emergence of conflicting interpretation as;

> *"a critical learning experience in the regard that it provides an opportunity for a research to witness the intricateness of a phenomenon under inquiry and to develop a richer description and explanation through cross checking and reflection".*
>
> Ju & Kwon (2009, pg.3)

Researchers that employed mixed methods include; Skinner, Correa, Skinner & Bailey (2001), who collected both quantitative and qualitative data that addressed their four research question aimed at providing a comprehensive view of the role of religious beliefs and practices in the lives of Latino parents of young children with disability. Data was collected through interviews that combined scales and open ended questions (e.g. Fewell Religion Scale, 1996). Qualitative data analysis examined all narrative data that was transcribed and analysed using a thematic approach.

5.6 Different Qualitative Methods

5.6.1 Grounded Theory

Grounded Theory emphasises the generation of theory from the data being collected whilst the researcher is still in the process of conducting research. Grounded Theory methods are said to address studies of personal experience, emotions and attraction (Charmaz, 2006). This method of research works completely in an opposite way from traditional research. While in traditional research the researcher chooses a theoretical framework then applies its model to the studied phenomenon, in Grounded Theory the initial step is to apply a variety of data collection methods to study the phenomenon. From the data collected from this first step, key points are indicated with a series of codes, which are extracted from the text. Codes are then grouped into similar concepts. From these concepts, categories are then formed, which form hypothesis or propositions that in turn become the basis for the creation of theory.

The primary objective of Grounded Theory then is to expand upon an explanation of a phenomenon by identifying the key elements of that phenomenon, and then categorizing the relationships of those elements to the context and process of the experiment. The focus of the analysis is on organising ideas which have emerged from analysis of data (Strauss, 1994). Grounded Theory requires detailed and systematic procedures for data collection, analysis and theorizing, and is also concerned with the quality of emergent theory. It requires that data is comprehensive, that it should provide generality, in that the theory includes extensive variation and is abstract enough to be applicable to a wide variety of contexts. Yet quantitative methodologists tend to criticise Grounded Theory on precisely these grounds, since they question how a typically small sample size can be adapted to be comprehensive enough and applied so widely.

In the case of this research study since it limits its data collection and results to a particular context, Grounded Theory did not seem applicable. Grounded Theory also requires precision as a method of study therefore it necessitates high levels of both experience and insight on the part of the researcher. For this reason, even though numerous Ph.D. students use Grounded Theory, as a novice large scale researcher, this method of study was avoided as a consequence of not being sure that as researcher I have the required qualities to effectively implement this approach.

5.6.2 Ethnographic Research

> *"Ethnography literally means 'a portrait of a people.' An ethnography is a written description of a particular culture - the customs, beliefs, and behaviour - based on information collected through fieldwork."*
>
> Harris & Johnson, 2000, as cited in Genzuk, (2003, pg.1)

Ethnography is a method of social science research, which while particularly suited to exploratory research, draws on a wide range of both qualitative and quantitative methodologies (Genzuk, 1999). Ethnographic Research is a type of written research that employs the collection of raw data, such as quotations, descriptions, and excerpts of documents to provide a descriptive study of a culture. It usually involves a small group of people being researched, aiming at the depth, intensity and richness of the material obtained (McCarthy, 1997). The ethnographic method starts with the selection of the research topic, a review of the literature pertaining to the topic and the detection of variables of interest, typically variables perceived as significant by the participants of the research topic. Ethnographic studies tend to investigate unfamiliar or unusual topics (McCarthy, 1997).

The middle stages of the ethnographic method involve involving participants and using them to engage yet more participants in a chaining process. Data is gathered in the form of observational transcripts and interview recordings. Data analysis and theory development come at the end. The Ethnographic Researcher attempts to avoid theoretical preconceptions and instead tries to give rise to theory from the perspectives of the participants in the research and from observation. Yet "*the ethnographer should remain completely objective from the subjects of his research*" as "*ethnography is essentially interpretative*" (McCarthy, 1997, Chpt.2, pg.1).

One of the characteristics of Ethnographic Research requires the ethnographer to participate openly or covertly in people's lives for an extended period of time, although it is not unusual for an ethnographer to live in the place the research is being conducted.

> "*Ethnographers argue, then, that it is necessary to learn the culture of the group one is studying before one can produce valid explanations for the behaviour of its members. This is the reason for the centrality of participant observation and unstructured interviewing to ethnographic method*".
>
> Gensuk (2007, pg.2)

In Ethnographic Research, observing situations, listening to conversations, questioning and collecting whatever data is available to shed light on the issues that are the focus of the research (Hammersley & Atkinson, 1995). McCarthy (1997) describes the relationship between the researcher and the researched as the "rapport" which also has the meaning of 'relationship' in Maltese language. She explains how this rapport needs to be a natural and positive one for the researcher to be accepted and allowed to conduct research.

More recently, Johnson (2000, pg.111) as cited in Garson (2008), defines ethnography as "*a descriptive account of social life and culture in a particular social system based on detailed observations of what people actually do*". McCarthy (1997) claims that research as a form of cultural knowledge is not collected just through the use of language. She underlines the importance of observation and the inferences drawn from it. The job of the researcher is then to construct an inference with an extensive knowledge of the society or group being researched. One of the methodological principles that are used to provide a rationale for the specific features of the ethnographic method is naturalism. "*The notion of naturalism implies that social events and processes must be explained in terms of their relationship to the context in which they occur*" (Genzuk, 2007, pg.3). Naturalism believes that to portray human behaviour in a naturally occurring way there must be first-hand contact with it, in contrast to inferences which are derived from what people do in artificial settings or from what they say in interviews. Using the natural settings for the study the researcher aims to minimize his effects on the behaviour of the people being studied (Genzuk, 2007), while the researcher is trying to augment the possibility to generalise the results derived from the study.

Although the researcher had an overall good relationship with the participants (McCarthy, 1999) and this study aimed at observing situations, conversations and enquiring about the topic in order to collect data (Hammersley & Atkinson, 1995), yet the researcher did not foresee that this research could be carried out as Ethnographic Research. This was due to the reality that that the researcher could not act as an ethnographer, participating and observing the participant's lives as is required of this research (Gensuk, 2007). Thus time constraints as well as the particular topic of this research deterred the researcher from adopting this method of research.

5.6.3 Action Research

The broad umbrella of Action Research includes Participatory Research, Collaborative Inquiry, Emancipatory Research, action learning or contextual Action Research (O'Brien, 1998). Action Research is a practical approach to professional inquiry in any social situation (Waters-Adams, 2006), it involves working with people in their everyday lives as a way of searching for practical ways of increasing our knowledge (Reason & Bradbury, 2006). Action Research is also emancipatory as it leads not just to new practical knowledge, but to new abilities to create knowledge. It can be used by social scientists for pilot research in circumstances requiring flexibility, the involvement of people in the research or practical changes that needs to take place quickly or holistically (O'Brien, 1998). Reason & Bradbury (2006, pg.2) define Action Research as:

> *"A participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview which we believe is emerging at this historical moment*".

They maintain that Action Research seeks to bring together action and reflection, theory and practice, in the pursuit of practical solutions to issues of pressing concern to people, individual persons and their communities. Reason & Bradbury (2006) insist that the primary purpose of Action Research is to produce practical knowledge that is useful to people in the everyday conduct of their lives, while a wider purpose of Action Research is to contribute through this practical knowledge to the increased well-being of economic, political, psychological or spiritual dimensions of human beings and communities. Reason and Bradbury (2006) therefore see Action Research as a way of working towards practical outcomes and creating new forms of understanding. Action Research is rooted in everyday experiences and is concerned with the development of living knowledge, the process of inquiry is as important as specific outcomes. Ideally Action Research involves all stakeholders both in the questioning and sense making that informs the research, as well as in the action which is its focus. Action Research practices can be found in various fields and disciplines such as community development, organization and business, education, healthcare and medicine, social work, as well as human social, psychological and transpersonal sciences.

Action Research allows several different research tools to be used. These various research tools also common to the qualitative research paradigm, include: keeping a research journal, document collection and analysis, participant observation recordings, questionnaire surveys, structured and unstructured interviews and case studies (O'Brien 1998). In terms of validation Action Research seeks the views of others as to the meaning of the data they have collected. Analysis in Action Research is reflection and the planning of new action. Waters-Adams (2006, pg.5) concludes that;

> *"Analysis within Action Research is about possibilities, not certainties. It is not about why things have to be as they are, but rather what possibilities for change lie within a situation. Action within a complex social world is not static; it is dynamic and forever evolving".*

Although the researcher still used data collection techniques valid for Action Research, including keeping a research journal, participant observation, questionnaires and interviews (O'Brien 1998). None the less reflections about the use of Action Research as a research method are similar to those made on Emancipatory Research. In these reflections the researcher outlines the inability of the same researcher to involve the participants in the collection and the analysis of the data collected to the degree required for authentic Action Research.

5.6.4 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) explores the meaning of phenomena held by participants (Smith & Osborn, 2006). It is also a way to organize and analyse data in themes which cuts across the different methods of data collection. Qualitative research includes a variety of diverse approaches which have one thing in common, "*to contribute to a process of revision and enrichment of understanding*" (Elliott *et al.* 1999, pg.2). Smith & Osborn (2006) stress the importance of knowing the type of qualitative method that one is exploring or working with. IPA is a valuable approach when a researcher is trying to find out how individuals are perceiving a particular situation they are presented with. Studies analysed by IPA are usually conducted with small sample sizes and are aimed at exploring, flexibly and in detail, novelties and areas of concerns.

As is generally the case with qualitative research there is no single process for undertaking IPA. In general IPA aims to explore how participants in a research study are making sense of their personal and social world, through the experiences and the events they describe. It explores personal experiences and examines the participants' life. In IPA the researcher tries to get close to the participants' world and takes an insider's perspective, trying to understand what it is like from the point of view or experience of the participants. It assumes a chain of connections between what participants say, what they are thinking and their emotional state. At the same time the IPA researcher realizes that people might find it hard to express themselves, what they are thinking or feeling, or that they might have reasons for not wishing to self-disclose. In these cases the researcher may have to interpret participant's mental and emotional states from what they are saying. Elliott *et al.* (1999, pg.2) concludes that "*ultimately the value of any scientific method must be evaluated in the light of its ability to provide meaningful and useful answers to the question that motivated the research in the first place*".

IPA tends to use rich personal accounts obtained from the participants, whilst exploring their concepts and commonalities. Researchers argue that each person's experience is so individual that true data saturation can never be fully achieved in IPA (Hale_*et al.*2007). IPA has three levels of analysis, the first being examining verbatim transcripts of the interviews, the phenomenological element describing the phenomenon under investigation (Hale *et al.* 2007). This phase allows the researcher to consider initial impressions, words and links that are made during the first few readings. This is done with all the transcripts so that similar ideas and consistencies across all transcripts are identified. It is known as the idiographic or case by case approach, where emerging concepts often called 'themes' are organised (Hale *et al.* 2007). Secondly these themes will be organised or interpreted into major and minor components, with minor themes clustering under major themes. Thirdly the analysis is concerned with translating the themes into a narrative account (Smith, 2006) outlining the meanings inbuilt in the participants' experiences.

Sexuality is a very personal issue and pervades peoples' lives; it is not something easy to talk about. Since IPA is intended to reflect the lived experience, it seemed an appropriate method to use to investigate a topic such as sexuality. IPA is often used in studies concerning sexuality since sexuality is a very delicate topic and the opinions of participants need to be treated very sensitively (Wheeler, 2004). IPA seeks to approach the participants' personal experience and obtain his perspective upon the topic, yet it recognizes that this is not fully obtainable. This is acceptable since the researcher's own concepts and knowledge are used to make sense of the participant's experiences (Smith & Osborn, 2006).

5.7 Research Instruments

5.7.1 Interviews

Field *et al.* (2004, pg. 52) asserts that *"methods of data collection are centered on the breadth and complexity of the information sought, and its sensitive and personal nature"*. A semi structured interview allows flexibility within the interview, permitting the participant to talk about the issues that they feel are most important (Hale, Treharne & Kitas, 2008). McCarthy (1998) discusses the way in which although not wanting to be tied down to restrictive pre set questions, some structure is needed to facilitate discussion with people who through their learning disability are not verbally articulate. At the same time the flexibility in semi- structured interviews lies in the possibility of follow up questions and as Booth & Booth (1994) suggest, people with learning disability give very short answers before waiting for the next question, therefore open ended questions do not in reality help them to speak more fluently.

Yates (2004) claims that the word 'interview' can be literally split into two: view meaning - to develop a shared perspective and understanding, whilst inter referring to the two or more people involved. As in the case of McCarthy's research, this research had the same two potentially challenging points, the interviewees had learning disability and the subject researched was related to their sexual development, which would be difficult for any person to talk comfortably about. Hale *et al.* (2007, pg.88) suggest that *"sensitive questions are best left till the participant has settled and is relaxed"*. The ability to answer questions in an interview is partly a function of intelligence, and people with learning disability have impaired intellect which must be taken into consideration. People's ability to reply accurately can be maximized or minimized depending on how questions are put to them. Hale *et al.* (2008) suggest it is worth spending some time really thinking about what and how, as well as when and where the questions are going to be asked. They also recommend that the researcher is empathic, non-judgmental, shows positive regard for the participants and their views and displays congruence by being genuine in the interest and expressions. None the less Hale (2007, pg.92) argues that *"no matter how experienced one is, in-depth interviewing is an exhausting and often emotional process"*.

5.7.2 Focus groups

Wilkinson (2006, pg 187) suggests that *"focus groups are a good choice of method when the purpose of the research is to elicit people's own understandings, opinions or views"*, while Edwards & Staniszewska (2000), claim they are more appropriate for exploring parent's experiences. Bowling (2002) in fact maintains that this key method of data collection has the capacity to harness the power of human interaction by capitalizing on relationships and consequently generating insights that might not otherwise emerge from single interviews. Focus groups are a way of collecting qualitative data involving a small number of people in an informal group discussion, *"focused on a particular topic or set of issues"* (Wilkinson, 2006, pg.187). Although there are claims that people are inhibited to reveal intimate details when in a group discussion, researchers maintain that focus groups are well apt to explore *"sensitive topics and the group context may actually facilitate personal disclosures"* Wilkinson (2006, pg. 177). Bowling (2002) also considers it as a better way to achieve more open, reflective and informative responses. The participants in focus groups can be a single group of participants meeting on a single occasion, or on several occasions. The number of participants can vary from two to up to twelve per group. Participants may be chosen on the basis of shared characteristics or experiences or as representatives of a particular population (Wilkinson, 2006).

The researcher in a focus group acts as a moderator, setting questions to keep the discussion flowing and the participants involved, especially at interacting with each other. Yates (2004, pg.171) states that *"getting the participants to talk discuss and debate amongst themselves is part of the reasoning behind focus groups"*. The moderator can present other means apart from questions, to involve the participants, such as visual material, or ask the participants to engage in an activity. Thematic analysis such as IPA which was chosen for this study is said to be commonly used to analyze the focus group discussion, which is usually taped and transcribed.

5.7.3 Participant observation

In participant observation the researcher aims to be part of the life and activities of the people being researched in the observed context. The purpose of such participation is to cultivate an insider's view of what is occurring not just by observing, also by feeling what it is like to be part of the people being researched (Genzuk, 2007). Genzuk (2007) claims that the extent to which it is possible for a researcher to become a full participant in an experience depends partly on the nature of the setting being observed. Both an outside and an inside view are necessary therefore the researcher must try to be both outsider and insider, "*staying on the margins of the group both socially and intellectually*" Genzuk (2007, pg.2).

> "*Experiencing an environment as an insider is what necessitates the participant part of participant observation. The challenge is to combine participation and observation so as to become capable of understanding the experience as an insider while describing the experience for outsiders*".
>
> Genzuk (2007, pg.2)

5.8 Sampling Framework

Nunkoosing (2005, pg. 698) underlines the importance of being aware of the relationship that the researcher has with the research participants, even if this lasts only for the duration of the project, suggesting that;

> "*All relationships and encounters have a balance of power, and your participants may regard you in a particular light as researcher and / or health care professional. Some of these roles may seem threatening, even though your participant has agreed to take part in your study. They may be nervous about doing so and what will be expected of, and thought of, them*".
>
> Nunkoosing (2005, pg. 698)

Other matters that affect the perceived balance of power and how the interviewer progresses, are the interviewer's gender, sexuality, culture, clothing, accent and apparent social class or status. Mitton, Hale, Treharne & Kitas (2008) found that the fact that the interviewer was familiar with her participants, in that they already knew and trusted her and were used to talking to her, aided the research.

In this study narrative accounts were gathered from several people who are a sample of the population the research is interested in (Hale *et al.* 2007). Although the defining characteristic of the sample is homogenous, their individual experiences and views will be unique and varied but should be able to form thematic coherence (Flowers, Smith, Sheeran & Beail 1997). Researchers (Smith, 2000, 2006) argue that there is no rule governing how many participants should be recruited to include in a study analysed by IPA. Existing studies range from one case study to recruiting over 30 participants, while there are arguments that recruiting smaller samples is more beneficial as it avoids collecting so much data that the research is ultimately unable to report fully on all of it (Collins & Nicholson, 2002; Brocki & Wearden, 2006).

The researcher sought approval from Tizard Ethics Committee prior to contacting service providers, parents and people with learning disability. Following approval, the participants were recruited using a snowballing method, this method is an 'informal' non-probability sampling method employed to reach a target population. Snowball samples are used amongst researchers interested in studying sensitive topics or difficult to reach populations (Berg, 2004), and is useful in situations where the topic or the type of participant makes recruitment difficult (as in this case). It is also referred to as a useful technique in elite interviewing (Burnham *et al.* 2004), offering practical advantages if the aim of a study is primarily explorative, qualitative and descriptive. Snowball sampling is used most frequently to conduct qualitative research, primarily through interviews. It may be applied as a more formal methodology for making inferences about a population of individuals who have been difficult to enumerate through the use of descending methods such as surveys. I personally selected available respondents to be included in the sample, with identified participants asked to refer other individuals, who were representing the population in question.

As the researcher, I contacted the participants either by phone or in person and information about the research study was either related over the phone or face to face. An information sheet was also either handed out or posted to them. A few days after the first contact, a second contact was made and participants were asked whether they wanted to participate and if so when it was convenient for them to be interviewed. In the case of the majority of the people with learning disability, parents and service providers who participated, the interviewer was familiar to them prior to the interview through professional or social connections. As an interviewer I felt that this made a significant difference to the data collected, as many found it easier to answer to questions and to disclose information that was personal. Understanding and trust are thought to be fundamental when conducting such research (Cambridge & Forrester-Jones, 2003).

Confidentiality was explained to people with learning disability by giving concrete examples, saying that what was told to the interviewer, would not be told to their parents or anyone else they know, and given examples of people they know but that wouldn't get to know this information. It was also important to make it clear to the parents that whatever their sons or daughters said during the interviews, could not be reported back to them, unless it was a case of abuse which had to reported and supported.

Participants signed the consent forms prior to the interviews and focus groups, when they were briefed about the subject researched, confidentiality, anonymity, and their rights as participants. Two focus groups were carried out before the interviews. Some of the participants of the focus groups would also be interviewed in a one to one situation at a later stage following the focus group. This order of events was done purposefully, so as to prepare the participants in a better way, giving them time and food for thought after the focus group. Interviews were carried out at participants' homes, in private. Service providers were interviewed on their work premises. Focus groups were carried out in central areas agreed as an ideal meeting place by all participants. Interviews and focus groups were recorded and later transcribed. Once transcribed –videoed focus groups and audio tapes used during interviews were destroyed to maintain anonymity. One participant who would be still recognizable even though anonymized consented to participate accepting the fact that he would be recognizable.

5.9 Ethical Considerations

5.9.1 Ethical procedures and processes

Being of partial Maltese heritage, as a researcher I had a good insight into the cultural background and could adapt to and comprehend the way of thinking of the Maltese. I took account of cultural issues, above all religious beliefs and customs. Language barriers were not an issue as I, the researcher, am both English and Maltese speaking, and was able to use culturally appropriate language while holding interviews and focus groups, since some of the participants were either Maltese or English speaking. Information sheets given to participants were in both English and Maltese.

Only initial difficulties were experienced in accessing people with learning disability, as I, the researcher, have worked in the area for more than ten years and feel comfortable working with people with learning disability, despite the topic being unconventional in Malta. When considering the level of user participation and involvement in the research design, data collection and analysis, the means of empowerment for people with learning disability in this research study comes in different levels of participation. Due to the topic being sensitive and relatively uncommon to discuss, the interviewing was left to the researcher herself, rather than done by the participants with learning disability themselves. Undeniably the participants were of utmost importance for the data collection as their views and experiences were the main source of data.

This research includes the life experiences of people with learning disability, their parents and people who work with them. There are consequently a number of special ethical considerations which inform the conduct of the research, such as the need to make the aims and goals clear to the participants. The researcher anticipated that the people with learning disability (over 16 years of age), involved in the research would be able to give informed consent as they had relatively good verbal skills and their learning disability ranged from mild to moderate. The parents and service providers participating in the research were all able to give informed consent. Participants were contacted by phone initially and asked for an appointment, as this was more culturally acceptable by Maltese custom. The nature of the research was explained to parents, people with learning disability and service providers by the researcher at an initial one to one meeting and information sheets were given. The prospective participants were then given a week to decide about their participation, then contacted again by phone and asked if they had made a decision about the proposed participation. The phone was used in this circumstance as the researcher deemed it as an easier way for the prospective participants to decline participation. If they accepted to participate another meeting would be fixed where they were asked to sign a consent form. If unable to sign a consent form they were asked to signify this on tape.

There were no participants under the age of 16, nor people with severe or profound learning disability who might not be able to give *informed* consent. None of the participants required information in symbols or signing as no one was hearing impaired or was non-verbal. Maltese sign language is used mainly by the Deaf community in Malta rather then by people with learning disability.

5.9.2 Risks, opportunities and management

As the researcher, I had the responsibility to ensure that the participant is exposed to no harm or exploitation (Genzuk, 2007). During this study both psychological and social conditions were taken into account in relation to risk of harm and exploitation. For example, views relating to the levels of understating of participants, levels of consent and consequences, in terms of consent to participation, were evaluated. It was taken into account that all three groups of participants; people with learning disability, parents and service providers, may feel embarrassed during interviews. The researcher sought to be empathic and sensitive and all participants were reminded at the beginning of the interview that they could withdraw from the interview at any time. All participants were assured that they could decline answering on any question they did not wish to answer without justification. The participants were advised at the beginning of the group sessions and the interviews that they were under no obligation to discuss matters that upset them. The interviews and focus groups started with general topics and slowly progressed towards more intimate or personal ones to give participants time to feel more comfortable and at ease with the topic.

Participants were informed before the interview and focus groups, that in case any sexual abuse or harm to the participant or another person is disclosed during the interviews, the interviewer would be assuming the responsibility to take these issues forward to a support agency. Although confidentiality would be kept the interviewer would seek guidance from her supervisors and draw an approach from U.K. policies on disclosure of abuse since there are to date no relevant Maltese policies. In the case of people with learning disability disclosing having experienced abuse themselves, they would be reassured that they would not to be blamed for the abuse and that they would be offered appropriate_support. They would also be reassured that they have done the right thing by disclosing this experience as they could be preventing others from experiencing similar abuse.

Cultural perspectives had to be taken into consideration when tackling issues such as payments to participants. Rather than being paid by monetary means, which is considered offensive to the Maltese, participants were given a small gift of appreciation for being part of the research study, which is a more appropriate Maltese custom.

5.9.3 Informed consent and confidentiality

Before any form of data collection was employed, informed consent from participants needed to be obtained. As a researcher I was conscious that I was in a relatively powerful position compared to the person with learning disability and to their parents or service providers. As part of my initial tasks during this project, I decided on the topic and the main line of questioning, designed the consent form, and decided how to best access the participants. I also arranged focus groups and interviews. In doing this I recognized the power imbalance between me and potential participants and made every attempt to mitigate this by treating participants with respect and giving them choice over venues, days and times that were most convenient to them to meet. I also ascertained their knowledge in the focus groups and interviews, and made certain they knew they could withdraw from these if they choose to at any time. Participants were informed about the topic of research prior to participation and data was anonymised during the transcription of video and audio recordings to prevent the identification of participants. Considering the small population of the Maltese Islands, I made efforts to ensure that people were not identifiable from their quotes unless permission was given from them for this purpose.

5.9.4 The relationship between researcher and participant

The fact that Malta is a small island, with a population of just under 400,000 persons living in just over 120 square meters of land, makes it one of the worlds most densely populated countries. As a result of living in such close knit environments people are inevitably related and are intrinsically known - and know each other, even more so in smaller communities such as that of people with disability. Conducting research with people with learning disability, their parents and service providers on a typically stigmatized subject in such a county, I believe might be perceived a challenge by any researcher in this position. As a researcher, known to most of the participants in the research, informing them of the topic of the research being conducted and the nature of the questions of the interview was the first big step. I must admit that none of the participants bluntly refused to participate, although I did perceive that most service providers did not elaborate on their answers during the interviews. I felt that for the people with learning disability who participated, being familiar with the interviewer was certainly a positive factor. I sensed that they were more at ease when expressing themselves, and when bringing forward their frustrations and their wishes. While with parents, I believe some were truly relieved that finally, someone has taken interest with this subject, which so far they had to tackle solehandedly at home. Undeniably there were those parents who given the slightest opportunity would have swept everything under the carpet, with their religious beliefs and cultural taboos weighing on their conscience. Yet I believe that for those parents, getting to know that there are other parents of young people with learning disability with their same concerns, and most importantly meeting and discussing with them during the focus groups, did give them a positive opportunity in relation to this subject. As for services providers, I suspect that they were the only participants who were bound by their professional circumstances and who possibly felt unable to disclose their personal views upon the subject in order not to compromise themselves and their position within the institution they represented.

5.10 Ethical Principles

The research aimed to meet the four main ethical principles of research (Wheeler, 2004), which involve the safety of the research participant, informed consent, privacy and consideration of adverse events (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979).

5.10.1 Non-maleficence

The use of procedures relating to consent and complaints and the ensured confidentiality of participants was aimed at protecting participants from harm. The researcher recognized that the nature of the research was sensitive and could result in participants becoming embarrassed or experiencing a variety of emotions. However, the researcher would at all times treat participants with respect and empathy and reminded them that they could withdraw from the research at any time. Participants were informed before the interview that in case any sexual abuse or harm to the participant or another person was disclosed during the interviews, the researcher would be taking responsibility of providing support as mentioned beforehand.

5.10.2 Beneficence

The research would allow young people with learning disability and their parents to voice their opinions and experiences upon sexuality. This was a very rare situation in Malta. The possible involvement of the chairman of the National Commission for Persons with Disability might be useful politically and might alert the National Commission about the need to create:

a. a sex education policy

b. compulsory and ongoing sex education specifically addressing people with learning disability

c. counselling services for people with learning disability and their parents in this area

5.10.3 Autonomy

All participants were met on a one to one basis to have the nature of the research explained to them in private. That participation was on a voluntary basis and that participants could withdraw at any time was emphasised. Consent was sought from all participants prior to interviews or focus groups, and only those with capacity to consent would be included.

5.10.4 Justice

It is envisaged that participants would be advantaged by taking part in the research study. By having their voices heard and creating awareness about the topic researched, long term benefits are expected. Participants in focus groups, especially parents had the chance to discuss a rare topic with other parents and share their views and experiences.

5.11 Conclusion

The structure of the research study was explored in this chapter, giving an account of the critical role of the researcher. The chapter continued with an analysis and review of the various methods of research including qualitative, quantitative and mixed methods. Research frameworks and theories applicable to the research question such as Disability Politics and the Feminist Model were also reviewed and discussed. Key qualitative research methods, including; Grounded Theory, IPA and Ethnographic Research were also outlined. Research instruments developed and applied in the research, including; interviews, focus groups and participant observation were also outlined and discussed. In conclusion, the chapter provided an account of the ethical considerations and procedures in place and the sampling framework that was employed by the study.

CHAPTER SIX

Findings from People with Learning Disability

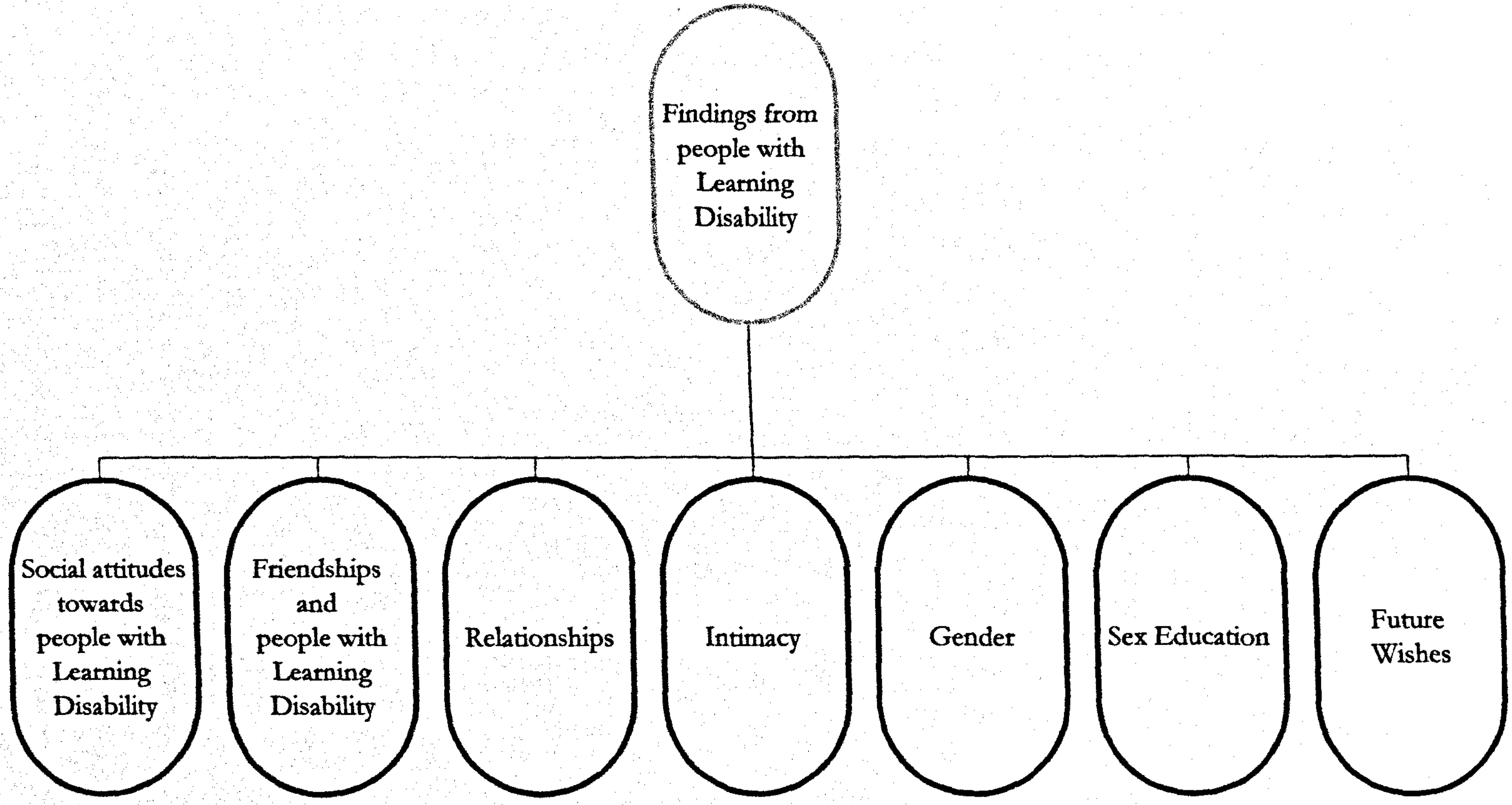
6.1 Introduction to Findings

The number of themes outlined in this chapter that emerged from the data collected, were no doubt influenced by the local situation. The findings reflect current feelings of young people with learning disability in Malta. Hierarchy Chart 1 (on page 219) shows the themes which emerged in diagrammatic form.

6.2 Participants with learning disability

The findings emerged from people with mild to moderate learning disability, a small proportion of whom had additional physical and sensory impairments. The age of the participants ranged between 18 and 33 years. The participants where equally divided between male and female participants. Only 2 of the participants were in paid employment, while the rest attended adult services. A small minority of participants were neither employed nor attended day services. All participants lived at home with their parents, none lived in residential settings, neither institutional nor community settings. None of the participants attended respite services either, but depended on their extended family for support other then their immediate family. There were only 2 sets of couples out of all the participants, involved in relationships at the time of the research.

Findings from People with Learning Disability
Hierarchy Chart 1



6.4 Social attitudes towards people with learning disability

A minority of people with learning disability who took part in the study (10 people in all) reported experiencing negative attitudes towards them when they were out in the community. One young woman with learning and a physical disability observed:

> *"I feel different sometimes when people meet me for the first time; they get a fright, treat me like a child, or else look and talk to my mates instead, rather than to me".*

Other people with disability had similar experiences, one young man with learning and physical disability recalled:

> *"As I grew up I started facing some problems. At secondary school I got bullied by some of my classmates and some teachers acted like I was invisible and never addressed me or involved me in any way. At one point the van driver also did not want to drive me to my house."*

On possibly a worse note a young woman with physical disability recalled this event when interviewed by a local magazine:

> *"I was once going down Republic Street in Valletta. I was alone, minding my own business, heading for the shops. Suddenly this woman, who saw me coming from afar, pulled her son away from me. I turned round and told her not to be silly because I do not have any contagious disease that her son could catch. It's that sort of attitude that really gets to me".*

The majority of complaints came from people with learning disability who had a visually evident physical disability, who in this research were a minority over all. People with learning and physical disability stressed the fact that accessibility was a big issue for them and that the community was still not prepared to treat people who were wheelchair users equally. Inaccessible social and entertainment venues often hindered the social opportunities as reported by the participants in this research. Accessible means of local transport for wheelchair users was also very limited.

6.5 Friendships and People with Learning Disability

Most people with learning disability in the research had a range of experiences with friendships. The majority only had friends with disability like them, if any, while others managed to form networks later in life with the help of the internet. One young lady claimed:

> *"When I left school I was without friends and felt very lonely and depressed. Then I started to explore the internet, chatting and meeting new friends around the world".*
>
> (Woman with learning disability in her 20s)

Another young woman with a learning disability explained

> *"You know like most teenagers do, they see their friends almost everyday. It wasn't like that, just once in a blue moon when they had time and when they weren't too busy".*
>
> (Woman with learning disability in her 30s)

A participant with learning disability added;

> *"I never had a group to belong to, and always felt pretty much alone. Today I feel that my biggest and greatest achievement is to have found a group of really good friends."*
>
> (Young woman with learning disability in her mid 20s)

It was evident that even as early as secondary school young people with learning disability start feeling isolated, they were usually assisted by an adult to support them with academic work. This adult presence unfortunately kept other students away from them. Their segregation in special school settings did not allow them to integrate with other non-disabled students due to its exclusive structural system. It is also worth noting that at secondary school age, young people start ganging up and forming friendships around common interests and experiences, such as the opposite sex. Therefore people with learning disabilities who have not had these experiences are socially distanced from their peers through lack of common ground. It was also apparent from interviews conducted with people with learning disability and their parents, that sociability and autonomy depend on a persons' skill in integrating in a group, and this is often related to the person's ability levels, therefore the more able the better. Mobility and communicative skills underlie such social competences and opportunities. Email, mobile phone texting and telephone conversations all were used as methods of making friends, maintaining friendships and keeping in touch.

> *"Usually I meet my friends in chat rooms and mostly on Hi5 and Facebook, all my friends I got to know from the internet, and nowadays we have become very good friends and we meet and so on".*
>
> (Young woman with learning disability in her 20s)

An issue which prevailed in the interviews with people with learning disability was their dependency on their parents for a range of things, such as transportation and financial support. Since there are still very few possibilities for accessible public transportation, families often purchase more suitable cars for their children with learning disability who also present a physical impairment. This situation tends to restrict the autonomy of the person with disability:

> *"Because it's my father who picks me up I don't feel good if I stay out late because he would have to get up for work the next day, I never stayed out late because of this issue".*
>
> (Young woman with learning and physical disability)

6. 6 Relationships

Relationships in the form of sexual and intimate relationships are uncommon if not rare for people with learning disability in Malta, as confirmed by these findings. Maltese society has experienced and accepted people with physical disability in relationships, some of whom got married and have consequently become public figures because of their unusual situation. Yet people with learning disability have to overcome great barriers including a certain perception of them being asexual, before even establishing relationships. As a matter of fact there are no people with learning disability in Malta who are married and those who are in a relationship are fully supported by their families. A young woman with a learning disability confessed that she tries to hide her feelings towards this matter. She admitted that in reality the fact that she doesn't have a boyfriend makes her feel "*down*", but she acknowledged that both friends and family would like her to have someone to share her life with. Above all, as with friendships, it was evident through the data collected, that people with learning disability do not find a platform and the spaces necessary where to launch and develop these special ties.

One young woman claimed that:

> *"I am single right now and it is very hard to find a guy who can accept me as I am. Some are afraid to talk to me and others just want to be friends. It's hard to build a relationship".*
>
> (Young woman with learning disability in her mid 20s)

Another young woman stated that:

> *"When I started going out with friends in the weekend, the main subject of our talks would always be guys. I realized that it will not be easy for me to experience what they were talking about and it was very painful to accept this".*
>
> (Young woman with learning disability in her early 30s)

6.7 Intimacy

The findings in this chapter convey how society, within the context described, generally looks upon the majority of people with learning disability as not able to understand the responsibilities that come with relationships and intimate sexual expression. One female participant with learning disability claimed that she had never discussed with her parents the possibility of her having a sexual relationship, but acknowledged that her mother believed strongly that sex should only happen after marriage in accordance to Catholic beliefs, stressing that she was not of the same opinion as her mother. Despite this common social position one young woman with learning and physical disability gave her opinion about sexual relationships, stating that:

> *"...it should be more based on commitment...kids these days focus on the sexual component, they should focus more on commitment, and they don't realize what it involves in the commitment part'.*

(Young woman with learning disability in her mid 30s)

It appears that sex and intimate relationships are a very significant consideration for women with learning disability. One participant when asked what sex meant to her stated :

> *" ..a lot.... it is very healthy and being more mature woman."*

(Young woman with learning disability in her mid 20s)

In the case of the participants in the study, gender surely affected the way that people with learning disability look at sexual relationships and intimate sexual expression. The opinions expressed by female participants regarding sex and intimacy, would probably be based on the input given to them by other females in their family and possibly their close friends. In a cultural setting such as that of the Maltese islands, parents greatly influence the life of their adult children and their relationships. This is true for people who do not have a disability and even more so for people who have a disability. When asked whether their parents would consent to them having an intimate sexual relationship, the replies of participants with learning disabilities varied. One stated that:

"It's none of their business. I am an adult and I can deal with it".

(Young man with learning and physical disabilities in his late 20s)

While another admitted:

"If I had a boyfriend, I don't think that my dad would be happy to get him home and he'll be worried too. As he doesn't trust guys at all"

(Young woman with learning and physical disabilities in her early 30s)

When asked what "sex" meant to her, a young woman with learning disability in her mid 20s replied:

"Sex is a way of expressing love to your partner....or, better, it's supposed to be".

The latter comment at the end of her sentence sheds light on the quite well developed perception of sexual relationships that this young woman had. She continued by stating "*it should be done in the right time with the right person*". Another participant also stressed the view that although sex was a good thing, it would be wrong if it was done simply for fun.

6.8 Attitudes and perspective about relationships

The findings that emerged from the female participants on the topic of relationships and intimacy seemed to demonstrate more sensitive and romantic traits than those of the male participants who were more practical in their replies. One woman with a learning disability claimed that if there was something she would like to change about herself it would be her sensitivity "*I get hurt easily*", adding that she thought she could change this by being "*wiser and stronger*". On the same note another participant described herself as "*naïve*", admitting:

> "*I get attached very easily, and put the other person before myself in everything, and then I would notice that it's not worth it, and when it's like that you end up getting hurt*".

The image of the 'ideal man' or the 'ideal relationship' portrayed by a young woman with learning disability proved particularly insightful, describing a partner she thought her parents would allow her to have an intimate relationship with :

> "*...if he was responsible and had a good head on his shoulders and allowed me to come to no harm, protected me from what is dangerous and what I could hurt myself with. You know, he'd want me to be safe and he doesn't think about his own desires only, about mine as well*".

(Young woman with learning disability in her mid 30s)

It can be argued that the image of the ideal man portrayed by this young woman might be creating unrealistic expectations. Her perception of "*love*" seemed to be a cross in between the values she has been taught by her mother and the romantic feelings of a young woman who is eager to be in love.

> "*Love means total commitment, sexual component is part of it but it's not all of it, commitment, if you are not committed it's not love. If you really feel something in your heart, if you start thinking about them all the time, not all the time but if you start missing them, that's love and total commitment, sacrificing your life for the other, that is total love*".

(Young woman with learning disability in her mid 30s)

Opinions varied according to the participants' age and level of disability. One participant gave a balanced answer when asked what she expected from her boyfriend:

> "*He has to be ready to take a bit more responsibility and sacrifice*".

(Young woman with learning disability in her mid 20s)

Male participants seemed to focus on other issues rather then just romantic relationships and love, with the youngest of participants claiming:

"I want to have sex and I want to get married one day"

(Young man with learning disability, 18years of age)

A common theme that emerged from the both female and male participants with learning disability was their self-image. While a young man with learning disability also in his mid 30s made reference to eating healthily and exercising to remain attractive, a young woman with a learning disability in her mid 30s made particular reference to her self-image saying;

"You know how some people dress grown up; they don't dress in pyjamas all day".

6.9 Sex Education

Sex education, although part of the National Curriculum in Malta, is not necessarily delivered or delivered appropriately to the required level of people with learning disability. Therefore some people with learning disability, as the data collected revealed, obtained information from other sources, sometimes outside the family, including friends, the internet and even people they didn't know:

'My cousin told me about it - what happens at puberty".

(Young woman with learning disability in her 20s)

"...from school, but I learnt more on my own from the internet"

(Young man with learning disability in his 20s)

"I didn't learn about sex at school. My mother told me how babies are made but without too many details. Certain details I got to know from friends. You know, if you hear a word you look it up and you find out!"

(Young woman with learning disability in her 30s)

An individual with learning disability, who participated in the research and who had attended school outside Malta, gave much more elaborate answers as she had been taught sex education consisting of information about "*STDs, contraception and wearing a condom*".

6.10 Wishes for the future of people with learning disability

One of the most profound concerns expressed by young people with learning disability referred to their quality of life and their independence. The majority claimed they were worried because they did not wish to live the rest of their life cared for by their families. Even less they were appalled by the possibility of having to live in an institution if their parents had passed away or were no longer in a position to care for them. Many expressed a wish to live independently. Social benefits in our country don't give people with learning disability enough to live on; the disability pension is only pocket money, claimed a service provider who also has a physical disability. He added:

> "*You can't have enough to buy food, clothes, pay the rent and transport and so on with your pension if you don't work*".

As an aspiration for the future some of the young women with learning disability who participated in the research expressed the wish to live independently. One young woman with a learning disability expressed a wish to live away from her parent's house, believing that with adequate support for daily living activities she would be able to succeed on her own, admitting that at home she got little chance to develop her independence:

"My parents don't let me do things because they are afraid I'm going to get hurt, or there isn't enough room to get around".

(Young woman with learning disability in her mid 30s)

A young woman with learning disability in her 20s considered living independently of her family but with a small group of other people who had the same circumstances:

"We would need very little external help because with our abilities put together we can cope and help each other out, but there's a long way to go until that happens".

In relation to their future, most young women with learning disability, expressed a wish to be in a loving personal relationship with a man, get married have children and raise a family:

"To find a man who accepts me for how I am, who loves me ...in other words to find the right one".

(Young woman with learning disability in her mid 30s)

"I'd like to have a family if that is the case, maybe have a family of my own, get married if that is the case. Just live a simple normal life like other people do".

(Young woman with learning disability in her mid 30s)

"I would like to get married and have kids, have my own flat with all the services I need..."

(Young man with learning disability in his mid 30s)

"My hopes for the future is to travel the world...have my own flat. The cherry on the cake would be to have a family of my own."

(Young man with learning disability in his mid 20s)

"I would also like to get married and have a child of my own one day."

(Young woman with learning disability in her mid 20s)

One young woman with learning disability concluded;

"I hope my dreams come true but I doubt it as the mentality here is slow and don't think people will change it quickly".

(Young woman with learning disability in her mid 20s)

6.11 Opportunities for self-expression

The length of this section of the thesis reflects in part the expressive difficulties encountered by people with learning disability in the research. Compared to the next two sections which focus on parents and service providers, the current section is relatively shorter. In the author's opinion there are very solid reasons why this section which describes the opinions and experiences of people with disability in Malta is shorter. I will discuss what I feel are the two primary reasons.

The first explanation I would give for the limited input from people with learning disability stems from the quality of education people with learning disability receive in Malta. Having worked in the educational field with people with learning disability I can recognize the lack of quality in education when compared to the quality of education received in countries like the U.K., where I have also had work experiences in educational settings. In Malta people with learning disability, both in inclusive and in special settings follow the National Minimum Curriculum, although no adaptations for this curriculum existed prior to 2009. Even so, these adaptations are just offered to teachers as a sample and are not necessarily implemented. Therefore the quality of experiences and knowledge that people with learning disability are exposed to is limited if not hindered by educational practices.

The second reason to which I attribute the limited data collected in interviews and focus groups to is a wholly cultural one. People with learning disability here in Malta are not asked for their opinions. They have hardly ever been given a choice in their daily life situations. Impositions have been made on them and their opinions have never been asked for and much less valued. Therefore I find people with learning disability not only lack articulation, they do not know how to express themselves and how to address a question or a request. Both these facts were encountered during my immediate contact with people with learning disability through my work and also throughout the interviews held with people with learning disability as part of my research. One fact that cannot be ignored is that the topic of research may also be embarrassing and therefore harder to discuss for participants. It can be noticed that while women with learning disability divert their discussion onto romantic relationships and love, men found it much harder to express themselves outside of this realm and as a result where much less expressive then the women participants.

6.12 Conclusion

Whilst quoting the participants themselves, the main findings in this section give people with learning disability the opportunity to make their voices heard, as this chapter reports the findings from this particular participant group. The main findings put a spotlight on the social attitudes towards people with learning disability in a Maltese context. Sex education is another recurrent theme in the findings, its importance and also its absence from the lives of people with learning disability is evident through the data collected from the participants. All these themes and sub themes are depicted in Hierarchy Chart 1 (pg.219) and discussed in further detail in the Discussion chapter (chapter ten).

CHAPTER SEVEN

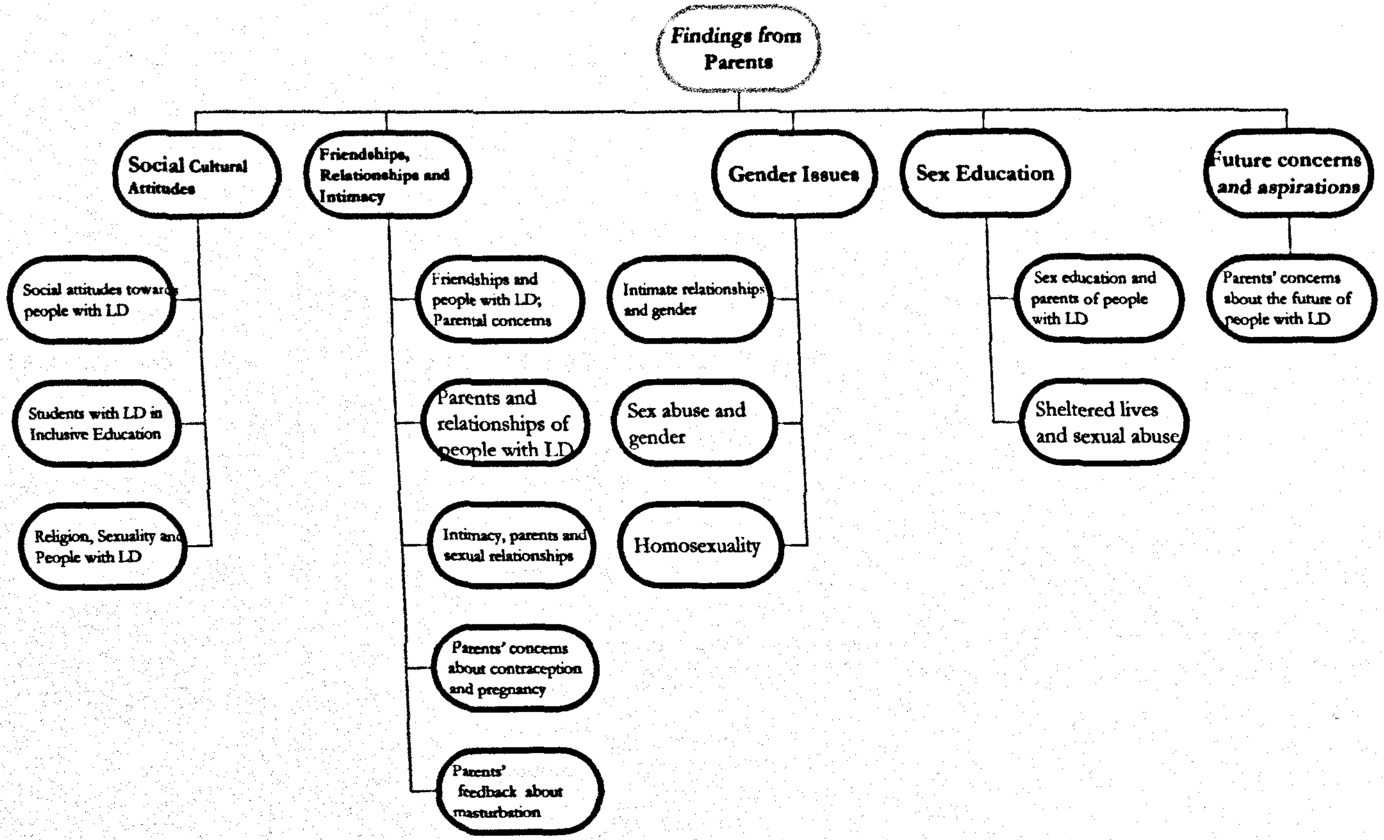
Findings: Parents' Perspective

7.1 Introduction to Findings

This chapter is organized in themes which emerged from the data provided by parents of people with learning disability who participated in the research. Data was collected through two focus groups and through interviews carried out with these parents individually. As explained earlier in the methodology chapter, the focus groups informed the interview questions, giving the researcher information about situations parents of people with learning disability were experiencing. Parents were recruited from different environments with the first focus groups aiming for opinions of parents of students in a higher secondary school. The second focus group recruited parents of participants with learning disability who were no longer of school age but were either in paid work or attended adult services. A number of these latter participants accepted to be interviewed at a later stage. The range of environments targeted aimed at providing a wider spectrum of experiences and opinions.

Parents seemed to give major importance to subjects revolving around sexuality, sexual acts and pregnancy and sex education. They overcame social and cultural barriers and spoke liberally about these matters. Through their differentiated perspectives majorities and minorities of opinions and points of views can be traced through the findings.

Findings from Parents of people with Learning Disability
Hierarchy Chart 2



7.3 Parents of people with learning disability

A number of parents of people with learning disability (15 parents) participated in the research. Parents were recruited only if their son or daughter had a learning disability, some had additional sensory or physical impairments. A number of parents attended 2 separate focus groups, one focus group involved parents whose children attended a higher secondary educational setting while the other focus group compromised a group of parents whose children were past school age and attended day services or were in paid employment. The majority of parents were mothers with a minority of fathers attending the focus groups. Parents ranged between 40 and 55 years of age, with two mothers being foreign, married to Maltese men. The majority of mothers were not employed and had been at home taking care of their household and family since they had got married. All the fathers were still employed and were the family's breadwinner; none of the fathers were unemployed. None of the parents recruited were legally separated or living apart. The level of education of the parents recruited ranged from secondary to post secondary, but none of the parents had tertiary qualifications. There socio-economic status ranged between lower middle class to upper middle class. The group of participants, whose children were above school age, were later involved in semi-structured interviews carried out at a later date. The group of participants, whose children attended a higher secondary school, were requested to make contact with the researcher if interested in participating further in the study. None of these participants responded to the request. Relevant topics of discussion throughout both focus groups informed the interview questions that were later set to the participating parents.

7.4 Social attitudes and Inclusive Education

7.4.1 Social attitudes towards people with learning disability

There was a broad consensus amongst parents of people with learning disability who were interviewed as well as those who participated in the focus groups, that the attitude towards people with learning disability in Malta has changed in the last 30 years. They felt that people with learning disability are more accepted now, whereas two or three decades ago they would have witnessed a strong sense of ignorance and stigma within society:

> "*Everybody wanted to know what she had. At times I felt inferior to other people*".
>
> (Parent of a 30 year old woman with learning disability)
>
> '*They used to avoid me they didn't know what to say*".
>
> (Parent of a 21 year old woman with learning disability)

The majority of parents concluded that society's attitude had become much more positive over the years and that there was now more exposure and acceptance towards disability in general in Malta. One parent noted that the introduction of social benefits for people with disability led to people deliberately becoming more visible and exposed in order to obtain these benefits. People had to be more explicit about disability and this led to them being more present in society. The stigma and ignorance encountered 30 years ago, was reported to have gradually faded, although the majority of parents did insist that the tendency to pity people with learning disability was inbuilt in the culture. The majority of parents thought that within Maltese culture, stigma is still very present, if not part of the culture itself. Words like "*jahasra*" (pitiful being) and "*miskin*" (unfortunate being) which give a sense of pity to the noun they refer to, are still very much used in conjunction with people with physical and/or learning disability.

> *"I think there are more people that pity them, there would be help, but not help to live a normal life, help them because they are pitiful; 'ghejnhom jahasra' (help the pitiful). That shouldn't be but there is still that attitude. To help them you have to encourage them. We are still way back in this issue".*

(Parent of a 19 year old woman with learning and physical disability)

Parents reported that stigmatising ideas about people with disability reveal themselves in the ignorance shown by society in certain situations:

> *"Even if I go out with my daughter with disability, people will stare at you or look away".*

(Mother of a young woman with learning and physical disability)

One parent concluded that the very act of integrating herself in society rather than segregating herself to disability support groups, made her daughter feel and cope better with her disability:

> *"She always wanted to integrate with non-disabled people so she wouldn't feel like she was a 'jahasra' or 'miskiena'......In our local parish they provided mass exclusively for people with disability, but she never wanted to go. She used to tell me ...I feel like a, 'miskina' and feel sad".*

(Parent of a young woman with physical and learning disability)

7.4.2 Students with learning disability in Inclusive Education

The majority of parents who had children with learning disability and who were interviewed as part of the study had experienced having their sons or daughters attending inclusive education in mainstream schools, with a minority having experienced special education. Opinions varied. Parents' experiences 30 years ago tended to be very negative, as Inclusive Education had not yet been adopted in mainstream schools in Malta, so Special Education had been the only option for them then. It was felt that 20 to 30 years ago, when Inclusive Education was not an option, or had just started to be introduced, special schools played a positive role in education and exposing students to a better quality of life. One complaint some parents had with regards to special education, was that the academic potential their child had was never been recognised, which has resulted in them being unable to find employment nowadays.

Parents who experienced mainstream schools over the last 10 years still complained that proper integration in mainstream schools had still not taken place, although others reported that mainstream schools offered inclusion for their child and a "*normal*" experience of education. These parents thought that inclusion within mainstream schools had improved and most were happy with the kind of education and integration their children had received:

> "*...they live a normal life like their siblings*".
>
> (Parent of a 16 year old boy with Down syndrome who has two siblings).

Inclusion currently therefore seems to be given more importance and is better organised and more effective than it was in the past. Parents of people with learning disability who are in their late 20s and 30s had often not been given the option of mainstream education and there was not the opportunity to have a learning support assistant to support the student in the classroom. Therefore they did not have access to inclusive education. At that time the schools reserved the right not to accept people with learning or physical disability in the school if they didn't deem them suitable for the environment. It was entirely at the school's discretion whether to accept a student or not. Some parents recount that when their child attended mainstream education they were singled out for having their disability and for not developing and performing at the same level as the other students. One parent recalls how she was called in by the school and told bluntly that she had to remove her child from the school and send him to a special school for children with disability:

"*They asked me to go to school. I was pregnant at the time...they told me what no parent should be told in such a manner, but then is there a way to say such a thing?*"

(Mother of a young man with learning disability)

Parents later had to fight a tough battle to have their children included in mainstream schools and to have the support of a learning support assistant. Parents recall that their children were still not properly included in mainstream education, even though they were admitted to the school and provided with a learning support assistant:

"*They didn't want her at the school*" and "*she was always on her own...*"

(Parent of a student with learning disability who is nowadays in her late 20s)

One parent who lived abroad also recounted having experienced a very hard time accessing her daughter's secondary mainstream education.

" *...she wasn't integrated. They gave her a tough time*".

(Parent of a young woman with physical and learning disability)

It was reported that when this particular student reached high school, the problem was resolved.

"*....there were other disabled kids there and they hung out together*"

This highlighted the need to be accepted by other non-disabled peers, but still meant that a sort of group segregation operated.

Although the policy of inclusive education (Equal Opportunities Act, 2000) in mainstream schools has the wider objective of promoting inclusion in the community and society, the majority of parents of people with learning disability reported that this has not happened. By and large, parents stated that their sons and daughters, who had attended a secondary mainstream school, now had no friends, as their school friends had not kept in touch with them. This resulted in young people with learning disability lacking social opportunities, with little alternative to using disabled people's groups to access social contacts.

7.4.3 Religion, Sexuality and People with Learning Disability

Generally parents had mixed feelings about the Church and its teachings, but the majority of parents were of the opinion that the teachings of the Church were not relevant to sexual relationships of people with learning disability. Parents affirmed that the Church needed to change its point of view if people with learning disability were to have acceptable relationships. One parent commented:

> *'It's all very well to sweep everything under the carpet....but the reality is different"*.
>
> (Parent of a young man with learning disability in his mid 30's)

One parent stated that she believed strongly in the teaching of the church but that her husband disagreed remarking that:

> *'I don't agree at all, if she comes to tell us that she wants to live with her boyfriend, well the Church doesn't allow anyone to live together...."*
>
> (Father of a young woman with learning disability in her late teens)

Another parent questioned the relevance of the church's teachings relating to contraception, which on paper is not acceptable by the powerful Catholic hierarchal institution.

> *"Contraceptives... I don't know if they are accepted by the church, but then again I never talked to a priest about this, so I don't know what his answer would be when we come to that. She is disabled with special needs, so maybe he will understand when I talk to him".*
>
> (Mother of a young woman with learning disability in her late teens)

7.5 Friendships, Relationships and Intimacy

7.5.1 Friendships and people with learning disability; parental concerns

All parents seemed to be aware of the importance of friendship for their sons and daughters. In this context the parents of a young woman with learning disability stated:

> *"We like to know that she is socializing of course, this is her life and socializing encourages her and helps her throughout life. The more friends she has and the more experiences she has, the better. If she didn't have friends outside from her family, what kind of life would it be? It's good for her to be away from us parents, not to always be with us, to be with friends, to feel more independent and to live a normal life. And when her friends have a problem and they ask her for advice and she helps them she feels that she is useful and her self worth increases".*

Parents of people with learning disabilities, people with learning disabilities themselves and service providers all reported a lack of opportunities for people with disabilities to establish friendship. The relative lack of friendship in the lives of young people with disability is consequently a weighty concern for the parents of these young people, who see that their sons and daughters are lonely.

A parent stated:

> *"She doesn't have a lot of friends, she has so many cousins, they hardly phone her, that breaks my heart…they never phone her so she is always by herself".*
>
> (Parent of a woman with learning disability in her 30s)

The majority of parents commented on how when their sons and daughters left primary school, even when they attended secondary school and college, their school friends never telephoned them to invite them over or to socialize with them. Parents of a young person with physical disability, who also had a similar experience, had lately built a social network of friends via the internet. They maintained that:

> *"At school she never had problems they always loved her, but then when she grew up it was different, her friends who go out with her she met through the internet, they are not the friends she had at school but I think this happens to everyone".*
>
> (Parents of a woman with learning and physical disability in her 30s)

> *'We are in the ME group, but we hardly ever go out with the group, because it's not good to segregate yourself. I 'm not saying you do not attend but I don't find it healthy that they segregate themselves to a group. It's important that they are a mixed group. Her friends are mostly without a disability and she goes out with them, she has friends with disability too".*
>
> (Parents of a young woman with learning and physical disability)

A parent of a young woman with learning and physical disability was of the opinion that:

> *"If a person with disability finds another person with disability like her they have less chance to cope, I believe that the other person has to be normal".*

"*Normal*" can be interpreted not having a physically disability since the person quoted had a physical disability. Yet in order "*to cope*" the non-disabled partner would be presumed as needing to deal with all the issues of daily life without support of their physically disabled partner.

7.5.2 Relationships ; Parents and relationships of people with learning disability

With regards to relationships between people with learning disability, the majority of parents agreed that everyone needed someone to love, and that people with learning disability have feelings like everyone else, consequently they should live as normal a life as possible in this respect. The ones who did approve of relationships gave reasons varying from companionship and friendship and to coping in life. None the less only a minority of parents did indeed wish for their sons or daughters to be engaged in a personal and intimate relationship.

There was a general awareness amongst parents, that because of the lack of opportunities to socialize, there was very limited opportunity for their sons and daughters to engage in either friendship or even less in a relationship:

What opportunity does she have to find someone if she is here all the time"

(Parents of a young woman with learning and physical disability)

Parents of a young people with learning and physical disability stated:

"...there aren't many people with disability in a relationship and I think there aren't many because of these things; like the lack of facilities, because if there was for instance adequate accommodation there would be more chance for these things to happen".

'I don't see anything wrong, but I see it nearly impossible because of the way we are here in Malta. That two people have a disability and cope on their own, I think is impossible, its not that I don't accept it, but I realize how many things adapted for these particular needs

one requires to live that kind of life. If there were the facilities it would be a nice thing but here in Malta we are still backward".

"That's why I find it hard for two with a disability to live together, according to how severe the disability is, or else you'll have the facility of help from outside."

On a more positive note when asked if she could see people who had a learning disability in a relationship, one parent affirmed:

"It's difficult but I don't see why not. I wish it but I don't know if it's possible for it to happen".

Another responded that the family accepted her daughter's previous relationship and

"Even my parents and siblings, they like the fact that she had somebody".

Overall, parents agreed that relationships amongst people with learning disability had become more acceptable to society but not completely acceptable. Some parents thought that society would not make a big issue out of people with a learning disability being in a relationship, interpreting this as *"sweet"*. Others thought that society looked upon this as *"something extraordinary"* and parents of a young woman with physical disability maintained:

"I think three quarters of the population do not accept it, they would fuss about it. I had a friend who became disabled through an accident and I hear people saying how can she get married, for what? This is how they look at them they don't accept it, nearly everyone if not everyone!"

A majority of parents stated they would wish to have a say in the relationship of their son or daughter, ranging from *'just keeping an eye and intervening when there were times of* *difficulty'* to '*intervening about the depth and nature of the relationship'*. Some parents agreed that they would need to monitor the relationship of their son or daughter, without interfering too much, for example, being ready to intervene if the relationship became violent. Parents felt that both sets of parents of the two people in the relationship should monitor and provide support as it would be less strenuous and more consistent than if just one parent was doing this. An element of overprotection was evident as one parent whose daughter was in a relationship with another young man with learning disability reiterated that:

> "*...we never had any problems, he was a really good boy but he had a problem, his mother was so so so overprotective* !".
>
> (Mother of a young woman with physical and learning disability)

A hierarchy of disability often emerged when discussing relationships between people with learning disability. One parent said she believed a relationship between people with learning disability could work depending on the severity of the learning disability the people involved have, implying that it would be ok for more able people. Another parent recalled how her son, who had a learning disability, had felt stigmatized by people who look strangely at him when he was dating a girl with Downs' Syndrome. As he himself later explained, onlookers would assume he was non-disabled and that he was taking advantage of her, especially when they used to kiss in public. He himself was put off the relationship with the girl because of this issue. When he later had another girlfriend with a learning disability, he did not experience the same reactions in people.

7.5.3 Intimacy: Parents and sexual relationships

The majority of the parents felt that their sons or daughters developed physically before they developed a conscious awareness of their sexual identity. A minority of parents of young people with learning disability related to society's inhibition towards sexuality, and how this interferes with the sexuality of people with learning disability. Some regarded mixing with non-disabled people as beneficial to the development of the sexual personality of people with learning disability. One parent related how her disabled son had been given a brutal introduction to sexuality through emotional and physical abuse. Some parents made it obvious that they wanted their sons and daughters to be engaged in a platonic, more than an intimate and sexual relationship. Others admitted they did leave their sons or daughters unsupervised with a friend in their bedroom or in their home when they went out. Generally kissing was considered as acceptable but anything more intimate was seen as unacceptable.

When asked about intimate and sexual relationships only one parent commented that "*that would be really wonderful* (for their son) *to fulfil their relationship*". All others voiced concerns relating to pregnancy. Only a minority of parents stated that sexual relationships between people with learning disability were normal and natural and were approved of as long as a form of contraception was being used. These parents stated;

> "*Once they are a couple, I as a parent, am not going to tell my daughter whether or not to kiss her boyfriend, especially if they are living together. I'd think that they'd try and do everything if they were a couple*".

7.5.4 Parents' concerns about Contraception and Pregnancy

Contraception was discussed by parents in the interviews, mostly by mothers who mentioned that they would put their daughters on the contraceptive pill if they got involved in a sexual relationship. Most parents were in favour of contraception, as this was seen as the easiest way to avoid an unwanted pregnancy.

One mother stated that she would have to resort to contraception if she found out her daughter was having intimate relations, but she wouldn't use them as precaution as she believed it would encourage sex. A minority of mothers insisted that sterilization was a better means of contraception, one stating that she had questioned doctors about sterilization, but had been told that this intervention was not permitted. Condoms were only mentioned by one parent, whose son had been taught how to use them during sex education. Implants were not mentioned at all possibly because they are still not generally available in Malta.

One parent of a woman with learning disability in her mid 30s, insisted that her daughter had to practice abstinence.

> *"I always warn her and I told her... and she was good at that...sometimes I needed to go through her room ...so I find them kissing, that's normal, that's ok, but I always warned her to be careful."*

Pregnancy was generally seen as a big issue, while the minority of parents who accepted sexual relationships, putting down the condition that these were acceptable as long as pregnancy did not result. These parents insisted that sexual relationships had to depend on the nature and length of the actual relationship. Casual sex although not mentioned is presumably not tolerated, again restating that sexual relationships were acceptable as long as they had a lasting and steady relationship, which was presumably more valued then casual sex. A bias in favour of men in sexual relationships was also discernable. Two parents stated that maybe they were in favour of sexual relationship because they had a son rather than a daughter.

The majority of parents mentioned the fear of what they called "*consequences*". They dreaded the idea of their child conceiving and having disabled children, with a common agreement between parents that they did not regard their daughters capable of bringing up children, and feared the responsibility of having to bring up a grandchild themselves.

> "*...the only thing that bothers me is that she could get pregnant, that is the only thing. How is she going to take care of the baby? That's the only thing because other from that there is nothing wrong, but having a baby is going to be tough.*"
>
> (Parent of a young woman with learning and physical disability)

A minority of parents who had daughters, expressed concerns about the health of their daughters in the case of pregnancy. They feared that their daughters would not be physically capable of bearing children, creating a life threatening situation which should be avoided at all costs.

Only one parent supported the fact that people with learning disability had a right to have their own family as long as they are able to take care of them with the necessary support. She also admitted that many parents were afraid of being left with the responsibility of a raising a baby themselves. Generally parents saw it as their duty to provide support if a child was conceived by their daughter with learning disability; with ideally both sets of parents providing this support. The majority of parents were concerned about this issue as they were not keen on providing support, especially a significant amount of support, needed to bring up a child if their daughter with learning disability got pregnant.

7.5.5 Parents' feedback about masturbation

The majority of parents avoided mentioning masturbation probably because it is a stigmatized topic in Maltese culture. Direct questions were not asked about the subject during the interviews as the researcher foresaw that the participants would feel awkward if they were approached directly about the subject.

Only two parents mentioned masturbation. One mother said that she knew her son masturbated and that she thought this was normal and healthy as long as it was not excessive. Another parent reported that she was unsure whether her daughter masturbated, and although she had never seen her doing this she suspected she did. The parent claimed that she would not try to stop her if she did, adding that she believed that her daughter did not close her bedroom door while she masturbated, as she had not been taught that this is a private thing.

7.6 Gender Issues

7.6.1 Intimate relationships & gender

Parental attitudes to gender and sexuality surfaced from discussions with parents relating to sexuality and sexual abuse. Parents of young men with learning disability generally observed that they would like their sons to engage in a sexual relationship, despite acknowledging that they would not support this if their child was female. The exception was seen as being engaged in a relationship that was long term and stable. Parents confirmed that they felt in the same way towards the other non-disabled female siblings in the context of sexual relationships. Parents of young women with learning disability when asked the reasons for their concern related to intimate relationships identified a number of reasons; including pregnancy.

7.6.2 Sexual abuse & gender

When discussing sexual abuse all parents agreed that being female involved vulnerability and the risk of sexual abuse was exacerbated for women with a learning disability. One mother responded that her daughter who had both learning and physical disability would not be able to fight physical abuse, as she already had had a similar experience. Others seemed more concerned about the cognitive functioning and understanding of their children, fearing that their learning disability would mean that they would not understand what would be happening. Sex education was not brought up by these parents when these issues emerged, presumably because it is not yet readily available to people with learning disability, so consequently they do not rely on it.

7.6.3 Homosexuality

Homosexuality was mentioned by only one parent, this was not surprising as it is still a social taboo. As with masturbation, homosexuality was not directly addressed as a topic in one of the interview questions with participants, so as not make participants feel uncomfortable. Social stigma is still evident in the lack of local literature and research about homosexuality. The parent who did bring up homosexuality related an episode she witnessed when she had found her son sexually experimenting with another boy. She commented that she had been upset when she discovered this but decided not to intervene, interpreting the behaviour as teenage experimentation, rather than homosexuality per se. No other parent mentioned the subject of homosexuality during the interviews. Since it is such a stigmatized subject the researcher felt she should not to bring up the subject of homosexuality during interviews unless the participants themselves mentioned the topic.

7.7 Sex Education

7.7.1 Sex Education and parents of people with learning disability

The majority of parents interviewed responded positively to the idea of sex education, admitting however that they didn't know what their sons and daughters knew or didn't know, regarding sexual acts and sexuality more widely. The majority thought they possessed no knowledge about sexuality, they acknowledged that their children knew very little about their bodies. Generally, it was felt that they lacked knowledge about privacy, abuse, contraception and masturbation.

Only a minority of parents had given their children a form of sex education. One parent who had lived abroad explained that at the time of her daughter's puberty:

> *"...in **** we used to have these educational videos, and we got that when it was time for her to see it, then we showed it to her".*

The majority of parents admitted to finding issues related to sexuality difficult to respond to with their sons or daughters with learning disability, acknowledging that they would prefer it to be undertaken at school, as they believed that their children tend to take in more information and advice. One set of parents agreed that the content of sex education should be the same as that taught to non-disabled students, others thought it important to teach people with a learning disability about safer-sex and sexually transmitted infections as they are more exposed to a wider society nowadays. One mother remarked that sex education was beneficial for her daughter because:

"It helped her a lot, I saw she grew up when she learnt these things and she matured more".

(Mother of a young woman with learning disability in her 20's)

Conversely, other parents reported that they had not taught their sons and daughters about sexuality as they lead a very sheltered life which had not allowed them to have such experiences. In short, that the parents thought they did not need to have any sex education knowledge. Consulting parents about what level of sex education they would want their children to be exposed to was felt to be imperative.

"If this is not done you are bound to have instances of what is called inappropriate behaviour, in other words private behaviour in public environments, so you still have to teach them that things are private, that there is a certain time and a certain place".

(Mother of a young man with learning disability in his 30's)

Parents of young people with learning disability who attended mainstream school knew that some sex education had been provided in school during personal and social development (PSD) lessons, as with their non-disabled siblings. However they were not aware if this had been done at a level appropriate for children with learning disability. Actually, it was reported that schools had never liaised with the parents on how or what to deliver in sex education, while a service provider for the National Commission for Persons with Disability added that although they knew sex education was carried out in schools, the Commission had nothing to do with this.

7.7.2 Sheltered lives and Sexual Abuse

The majority of parents believed that young people with a learning disability should and will lead a sheltered life. They did not have an extensive social life; have few friends, who they keep in contact with by phone, mobile text messages or internet chat. They tend to socialize either with school friends or friends they meet through sporting activities (Special Olympics). They are usually allowed out with friends whom the parents trust, who are older or more mature, and therefore more responsible, alternatively they go out effectively supervised, with family members, usually being driven to their destination or where there is a short walking distance in day light. Most young disabled people's social life is defined through their parents. Nearly all of them go out with parents, as a consequence they would have a limited network of friends, allowing them only the occasional outing or meeting. Some go out with parents because of lack of access which does not allow them to go to places of entertainment when they have a physical impairment. In the case of students with learning disability attending a post secondary college, these were reported to be brought to college and picked up again by their parents or by means of a taxi. Very few of them actually used public transport, and many had their facilitators and learning support assistants with them all day. Not all parents seem to consider the sexual abuse threats that can be found at school, in the same family or even within what they call a sheltered life. Parents claimed that at times they don't feel they need to teach their children about abuse because of the sheltered life they lead. The majority of parents regarded bullying in the school environment as more worrying than sexual abuse;

"I rather see her vulnerable to abuse at school, like being bullied".

Parents stated that they tended to warn their sons or daughters about the dangers they might encounter but without going into detail. Some parents thought that the fact that their son or daughter had a learning disability made them more vulnerable to sexual abuse because they would be more naive. For this reason their sexual rights are neglected and priority is given to the potential of being a victim of sexual abuse, thus becoming the focus of protection (Noonan & Gomez, 2010).

> *"In life you don't know who you're going to meet; they might try and take advantage of her."*
>
> (Parent of young woman with learning disability in her 20s)

Most parents also considered that women were more vulnerable to sexual abuse then men because of their gender, and having a physical disability made them even more vulnerable; "*she would probably say no, but then physically…!*" In relation to the possibility of harassment when using the internet for socializing, they also expressed the view that this was quite safe;

> *"on internet chat if something bothers her, she immediately backs off".*

Another parent in particular said that because their daughter was verbal and had the ability to tell them if someone had bothered her, she was not sexually vulnerable;

> *"I don't see her vulnerable to sexual abuse because she would surely come to tell us, with her kind of character, it could happen but she would surely come and tell us…. She has her mobile phone and she can call or message, and I see her mature and it helps. If she is out and someone is bothering her she wouldn't go again".*

A minority of parents expressed concern that their sons might commit abuse, for example, by sexually imposing themselves on someone else.

7.8 Future concerns and aspirations

7.8.1 Parents' concerns about the future for people with learning disability

All parents expressed concern about their children's future in different areas of living and in different respects. These included the lack of employment opportunities and day services availability. The absence of these two, denied people with learning disability the possibility of a better quality of life.

The lack of respite care and of long term residential care facilities were also primary concerns all parents expressed. Their concern about the lack of services present for people with learning disability when parents were not in a position to care for them any longer was emphasised. Parents were worried about when they would not be able to care and protect their children because they themselves would have passed away or would be in a position which made them unable to look after them.

> *"We always worry about what is going to happen when we're gone, that is the main thing for us".*

Generally parents expressed a wish to see their children housed in the community where they could enjoy a normal life, with adequate support services. They admitted that nowadays, siblings were more reluctant to adopt the responsibility to care for disabled relatives unlike in the past. Parents consequently lived with the anxiety of what will happen to their disabled child once they are not able to provide care or die.

One set of parents underlined the importance of financial autonomy for people with disability as this was seen as a way for them to buy the services they required. Rather than being housed in a community house one parent expressed his wish for his daughter to remain at home in the environment she is used to, but in receipt of daily services and support.

> *"I wish that there will be someone to take care of her. I think that its important that she is financially capable because we are still so far away from having the services that could cater for her needs that I don't see able to happen in the immediate future. So if the person with disability is at least financially stable he can manage for instance to get support coming in a few times a day. I don't see it as a service that will happen any time soon. I wish that she remained in her environment at home and she received the services from here".*

When asked if they could imagine their children living independently with a partner of their choice in the future, parents responses varied:

> *"I don't see anything wrong, but I see it nearly impossible because of the way we are here in Malta. That two people have a disability and cope on their own, I think is impossible, its not that I don't accept it , but I realize how many things adapted for these particular needs one requires to live that kind of life. If there were the facilities it would be a nice thing but here in Malta we are way back".*

> *"No I wouldn't say, the couple that exist are unique and here in Malta its difficult, maybe to have a special friendship but not a couple that goes to live together".*

It is noteworthy that parents of younger people who had milder forms of learning disability and who attended a post secondary College seemed to have fewer longer term fears for their sons and daughters. Rather their concerns were more of an immediate nature, such as their lack of friendships, loneliness, lack of employment and lack of prospects after leaving college.

7.9 Conclusion

In Maltese culture parents are considered the sole and the long term care givers for people with learning disability. Thus their opinions and beliefs influence the life of their children with learning disability. These findings aimed at attaining a cross section of the points of view of parents of young people with learning disability in Malta. Findings are themed and illustrated in Hierarchy Chart 2.

CHAPTER EIGHT

Findings from Service Providers

8.1 Introduction to Findings

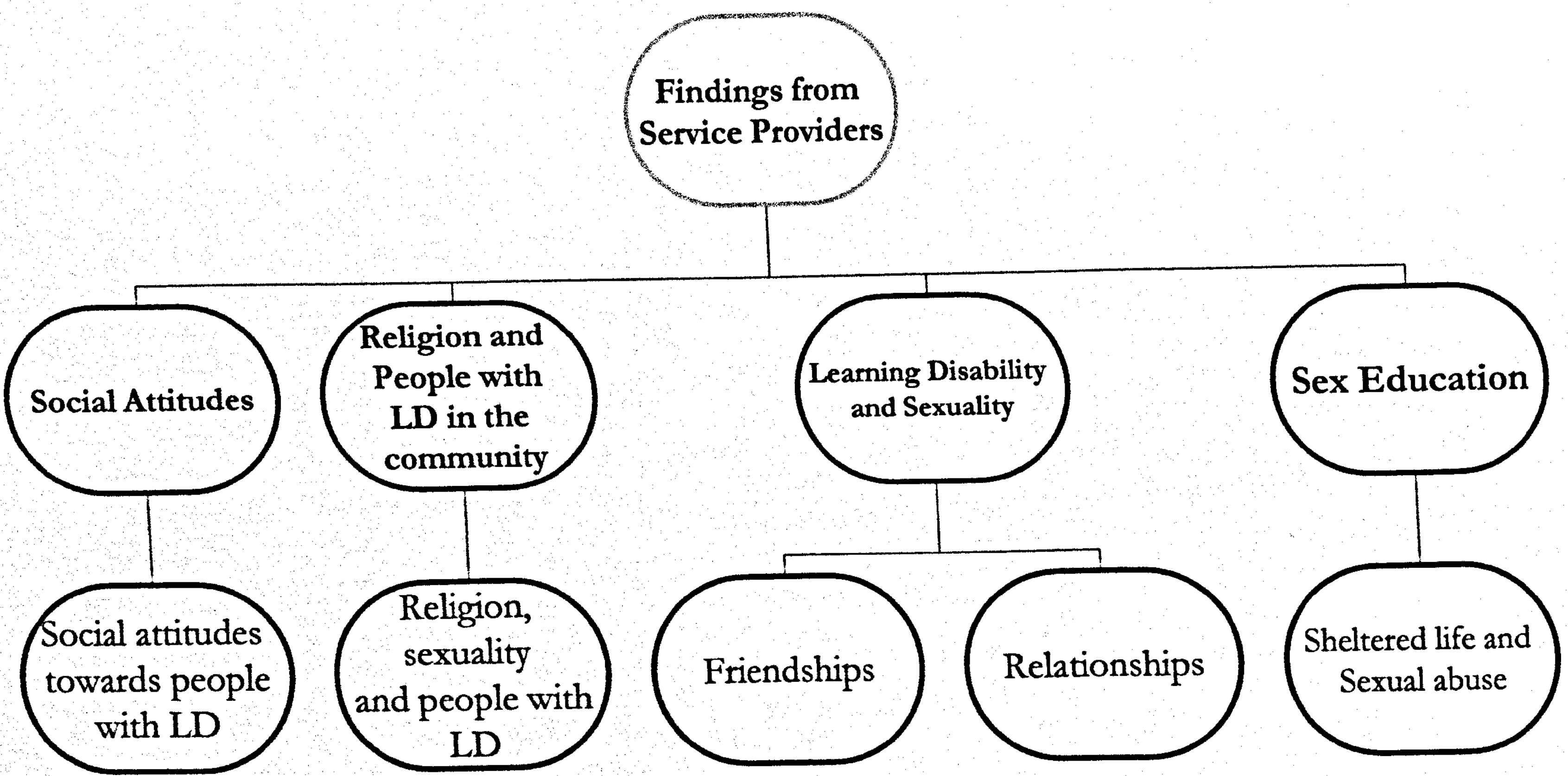
Service managers and service providers from educational, community, institutional, residential and governmental settings were interviewed separately to establish their views about their experience in the field of disability.

8.2 Service Providers participating in the research

In total ten Service Providers participated in the research, their ages ranging between 38 and 55 years of age. The majority of service providers were predominantly male, possibly reflecting a patriarchal society where women still do not hold higher management positions. The only four women who took part in the research, one held the position of educator, two were councillors and another was residential home supervisor. The other male participants held positions including those of managing directors of residential homes, chairperson of a commission of people with disability, director of educational services, university lecturers and teachers. Two of the service managers interviewed were also clergymen. There was only one service manager with a disability amongst the service providers interviewed. He happens to be the only person with an acquired physical disability that has an influential role in Malta as a service manager. Although there are a few other people with physical disability in Malta who have leading roles in special groups, for instance such as the National Muscular Dystrophy Group, as a rule people with disability do not have leading roles in disability groups nor in local disability politics. Findings from the data collected from local service providers revealed the following themes and sub themes illustrated in Hierarchy Chart 3.

8.3 Findings from Service Providers

Hierarchy Chart 3



8.4 Social Attitudes

8.4.1 Social attitudes towards people with learning disability

Social attitudes towards people with learning disability in various settings were explored through the views of service providers working in the field of disability. One service manager stated that in general society's attitude towards people with disability in Malta was changing in line with changes in Maltese religious culture:

> "*...as disabled people are seen more as individuals, rather than as children - or possibly good beings or at worst when they are seen as the vehicle for the salvation of others, where you pray for the forgiveness of other people's sins*".
>
> (Service manager in charge of a governmental entity for people with disability)

This service provider himself a persons with physical disability, maintained that in society once people get over the initial shock and the novelty wears off, they tend to accept the fact that people with learning and/or physical disability are involved in a romantic relationships and move on. Yet again when asking service providers (of residential homes) about the integration of residents in society, it was reported that, even though residential homes are set in the community, residents tend to mix with residents from other homes rather then with people without a disability from the community itself. As with the findings from other participants there emerged again the fact that social platforms for inclusion in the community and integration with non-disabled people is lacking.

The service provider admitted that a level of squeamishness was still associated with people seeing a person with a disability in community settings:

> *"We still have got instance where if a young man or woman with an amputation goes to swim in a swimming pool people walk out of the pool and complain to the manager to get them barred from attending".*
>
> (Service manager in charge of a governmental entity for people with disability)

Lack of exposure to people with disability in general tends to make non-disability friendly communities, with an accent on the lack of accessibility and unequal opportunities. This participant concluded by maintaining that Scandinavian countries advocate higher level of independence and achievement for people with learning disabilities, asserting that this is partly because their social services are better funded and more effectively organised, offering a better quality of life.

8.5 Religion and Learning Disability in the Community

One service provider was of the opinion that Malta, being a conservative Catholic country, keeps on a par with other countries that have a conservative Catholic culture, such as Ireland, Spain and parts of Italy. He claimed that although the Church has added to the problem faced by people with disability in general, it has also from time to time tried to resolve it.

> *"When a priest in the late 1960 started calling disabled people 'angels', it was the complete opposite of the culture of the time which saw them as 'devils', creatures to be feared, creatures of sin and creatures to be hidden away. This was a deliberate over emphasis, designed to push the pendulum to the other extreme".*

The majority of service providers agreed that there are currently concerted efforts to diminish this exclusion from society, for example, individual priests striving to include people with disabilities in parish activities and in organised activities for young people. He also commented that there are many making efforts to ensure their churches are more accessible to people with physical disability, enabling them to take part in mass and including them in the wider community. He recalled two incidents that happened ten years ago, one where a parish priest was approached by a group of parents who pressured him not to let a child with Downs Syndrome receive first Holy Communion with their children. They argued that he would spoil the event and the records of the event for them, putting pressure on the priest to exclude the child from celebrating first Holy Communion with them. It was reported that the priest refused to give in to these requests. A second instance was recalled when a non-governmental organisation (NGO) for people with learning disability was beginning to organise Confirmation and First Holy Communion exclusively for the children with disability that attended the NGO but not as part of their local communities and parishes . This segregative form of celebrating Holy Communion was stopped by the archbishop who insisted that children with disability had to go through the various milestones to receive Holy Communion together with their community, and that nobody in the community can stop them from sharing this experience. The chair person for the National Commission for People with Disability concluded that:

"In a way the church is guilty of many things, and we have to admit that, its maybe too slow. However attempts are being made. I also have to say that over the past two years, we as the Commission have had a much better response from the Church in our efforts to change things".

From the interviews carried out, it appears that the majority of people with learning disability have developed a strong sense of religion, originating from their family beliefs. In the case of some young people with disability, their sense of religiousness was used by their parents to teach them what was morally right and wrong according to their beliefs based on the teachings of the Catholic Church. It was reported by a service provider in an educational tertiary setting which was part of the research study, that there was *"a strong religious atmosphere"* in this setting. This was believed to overshadow religious diversity, as for instance only Christian festivals such as Christmas were taken into account and celebrated. A chapel was built on the school premises and at Christmas time there was a big crib set up in the entrance hall. On certain occasions when mass was celebrated, all class lectures were suspended, even though the mass would be very scantly attended. Lately crucifixes were hung in every classroom even though this was criticized as being contradictory to diversity.

8.5.1 Religion, Sexuality and People with Learning Disability

Only one service provider raised the issue of marriage and people with disability, not a learning disability in this case. As part of the interviews with service providers it was identified that in Malta anyone wanting to get married in Church, needs to attend what is known as the Kana preparation programme for marriage, which is obligatory for Catholics. The findings reported that the Kana marriage preparation programme does not cater for people with disability. The Chairman of the National Commission for People with Disability claimed that this was the situation, not withstanding the fact that for the last 15 years the National Commission had been asking for the introduction of the issue related to disability.

> *"The reality is that you may have a disabled child, that you may become disabled yourself, that your partner may become disabled. Just as you don't like to think about these things but they still exist, we told them at least lets give them the opportunity to say listen its not the end of the world, there is much to be done and if you stand by the other, the worst thing is if one turns against the other because of the pressure that comes with it, But nothing came of it".*

The service provider reported that one of the arguments used by the leaders of the Kana Movement was that talking about disability to young people might get them thinking that every child they will have is going to be severely disabled. The provider added that on the other hand people with (physical) disability that have attended the Kana programme, have reported they felt that the majority of the programme is irrelevant to them. They found that it did not address the real concerns that people with disability encountered in their lives in Malta. The only disability that the Kana Movement reported to have dealt with was Deafness; this is because they made arrangements to take the couple out of the group as the medium of communication is different, so rather for operational reasons than for considerations relating to the recognition of disability per se and treating people with disabilities in inclusive ways. So far there has not been a couple with learning disability who have enquired about or requested that they are married in Church. Possibly when the circumstance arises legal issues of capacity to consent will have to be invoked and ancient laws will need to be reviewed to make this possible.

8.6 Learning Disability and Sexuality

Service providers that participated in the research found the topic of the interviews surprisingly unusual if not challenging. Some might have found it threatening, especially if involved in religious organisations where sexual pleasure and activity outside marriage is not approved of by the Catholic Church. Service Providers reported that people with learning disability express their sexuality in a variety of extreme ways; from simple teenage flirting to exhibiting inappropriate sexual behaviour, such as putting their hands in their pants in public. Others were described as being extremely reserved.

A first hand account about the how people with disability in general experience their sexuality was given by a service provider himself with a physical disability. He explained how generally people with disability have no expectations when it comes to self-esteem and self-image, which also leads to them not pursuing an education. Lack of self-esteem also effects how people project themselves and their identities and interests:

> *"You won't bother to keep yourself smart, dress up, or to feel that you are attractive to others because your self-esteem is so low. It's a reflection of your own state of despair".*

He referred to clothes as an example of self-image, which he referred to as being problematic for people with disability, as it is difficult to find clothes that fit well, and they would have to be adjusted to look good. He also claimed that:

> *"In the mind of some parents, they don't have to buy clothes that will make them look attractive, because they will never find a partner or intimate friend".*

He also highlighted the lack of opportunities people with disability have to show themselves at their best.

> "*Because non-disabled kids go into sport, so boys can show how strong they are....girls go into dance and they show how nice they are how nicely they dance what gymnastics they do. They are also in an innocent and perhaps not so innocent way showing off their bodies, and showing off to each other and it's all the idea of display. Now one you don't have much opportunity to display and two you don't have much to display*".

Another service provider described how he found that parental attitudes and values towards disability and sexuality are split. He maintained that there is a minimal number of people with learning disability whose parents are below the age of 50 who accept very much their children's sexuality and who talk about it openly, aspiring for their sons and daughters to have a fulfilling sexual relationships. He also admited though that then there are others who are of the same age, and not necessarily any less educated, who think differently and still stereotype their sons and daughters as perpetual children. The recent case of the Pillow Angel (Gravelli, 2007) illustrated this, with the service provider claiming that a few parents, probably older parents, look upon their sons and daughters with disability as asexual and therefore as angelic.

Asexuality was also discussed with one service provider who claimed that asexuality was:

> "*Certainly less than in the past, as in the past asexuality was actively encouraged by the Catholic Church*".

The service provider recalled how a leading figure of a local charitable institution with the best intentions used to call disabled people:

> "*angels...who are completely removed from human sexuality....stressing that it is something dirty to infer that they had an interest in sexual matters*".

Himself a person with physical disability this service provider asserted that over the last 20 years his organisation had voiced the opinion that people with disability are like anybody else, in feelings and in aspiration. He felt that most people accept this view and the vast majority of young people take this for granted possibly because of their exposure to people with learning disability in mainstream schools. A service provider with disability commented on how:

> *"Traditionally from a religious point of view we have always been seen as having to be somehow, better, purer than other people, it's like you are compensating for your imperfections by trying to be spiritually perfect and therefore you were supposed to be shielded from these things".*

From an educationalist point of view, a teacher working specifically with students with learning disability stated that asexuality is a cultural issue that people with learning disability are faced with. She claimed that:

> *'In Malta there is a misconception about people with learning disability. In Malta it's like sex is forbidden for these people".*

On the other hand a service manager concluded that:

> *"There is more openness then there used to be in the past and there is less shock when you talk about sexuality and disabled people".*

He maintained that in today's society there are examples of people with disability expressing their sexuality, which was not the case in the past. Referring to people with physical disability, he went on to say that there was an increasing number who are living together, some of them conventionally married and some cohabiting. He expanded this observation by adding that society has a public and a private view with regards to opinions about people with (physical) disability having a relationship.

> *"In public everybody seems in favour of disabled people fulfilling their sexuality where they can and how they can...but then in private...I think it's all very well as long as it does not hit their family as long as its not one of their children who is involved with the disabled person, as long as the disabled person doesn't come around to their house".*

The service manager also referred to a number of people with both learning and physical disability who experienced active resistance from the family to them developing a sexual identity and expressing themselves sexually.

8.6.1 Friendships

The theme of friendships for people with learning disability seemed to focus on the aspects common to all three groups of participants. Lack of friendships and lack of environments where friendships can emerge and develop was a common theme between participating groups. These aspects common with all three participant groups were centred on accessibility, equality and opportunities.

One service manager, himself a person with physical disability, maintained that there is a lack of opportunity for people with disabilities to socialise, which he identified as a major problem. He repeated that people with disability also lacked opportunities to be present and visible in positive ways. He underlined that lack of accessibility particularly reduced the opportunity for people with disabilities to socialise.

> *"They tell you it doesn't matter we will lift you. As if anyone likes to be lifted in front of a room full of people!"*
>
> (Service provider with physical disability)

Another service provider, who operated in an educational post secondary setting, gave the same views as the other participant groups, he commented:

> *"I think there are few students between the ages of sixteen to eighteen years who want to be seen with people with disability. I think we have to deal and accept that. Friendship establishment is clearly a difficulty, yet the phenomenon of lonely students is not just for people with disability, it is a phenomenon that hits sixteen to eighteen year olds. We have students who do not need support but that say that they are lonely and don't have friends, especially students that would be coming from small church schools."*

8.6.2 Relationships

Service managers who participated in the study all agreed that people with learning disability were sexual beings. Although a minority of service providers, who happened to be clergyman and work in community or institutional residential homes, asserted that sexuality was not displayed solely in a sexually intimate manner.

A participant, whose work involved teaching with young people with learning disabilities in secondary school, confirmed that:

> *"These people feel attracted, sometimes to other people with learning disability and sometimes to persons with no disabilities*".

One service manager in a residential home stated that one of the residents in the community house currently had a boyfriend.

> *"So I told her there are some rules to follow, if she is going out she has to inform one member of the staff, she has to take her mobile, leave it on and make sure it is charged and she can go. The boyfriend comes to the house and joins us; he has a mild intellectual disability*".

Yet although this couple could spend time together alone outside the house, unsupervised time together in the resident's room, was not allowed. When discussing these issues with another service provider of a residential home, she explained that *"there were serious doubts about if the house would allow an intimate relationship".* They also reported services such as day centres which restricted the opportunities of young people with learning disabilities to develop relationships. Capacity to consent and a history of sexual abuse of the residents involved were amongst the reasons given by the management of the service. Other issues such as masturbation were reported to not be discussed in residential settings, as not everybody in the management agreed that residents should be allowed to masturbate.

The overall data collected from service providers with regards to people with learning disability and relationships tended to have a negative streak. The issues found in establishing friendship seem to escalate when people with learning disability are trying to establish close relationships. A service provider, himself with a physical disability, commented on the difficulties encountered by young couples with disability, referencing issues, such as;

> *"What to do if both persons are in love and the families are opposing? What do you do? How do you run away if you are disabled? It's very difficult to run away".*

Other service providers interviewed exclaimed that it seemed to them that the majority of parents overprotected their children with the aim of preventing them from meeting and getting interested in other people. The majority of service providers were of the opinion that not many parents would approve of their sons or daughters having relationships. They referred to the fear of pregnancy but also to the fear that their children might get hurt, doubting their ability to cope on their own in a relationship. One service provider addressed the fear that parents had of not being capable of supporting their children in a relationship, in terms of financial and physical support. One service provider also raised the consideration that up to six years ago, if both people in the relationship had a disability and received a disability pension, once they got married, one of them would loose their pension. This has now changed because as somebody said:

> *"What you are telling us is to live together, not to get married and be good Catholics".*

8.7 Sex Education

Service managers from the field of education as well as from residential community and institutional homes agreed that sex education in Malta is not structured, not available and much less enforced. One Service provider underlined the fact that while some parents would be willing, not all parents would want their children to be exposed to sex education. Yet parents were at times expected, according to a majority of service providers, to be the key person to teach people with learning disability sex education. An educational service provider observed that any sex education given in such settings must always be at the discretion of parents. He argued that in accordance to Maltese legislation, people with learning disabilities remained the responsibility of parents even over the age of 18, because of the nature of their disability and the vulnerability and dependency they encountered. He consequently believed that parents had to be taught about sex education before the people with disability themselves.

Another participant in the research commented by saying that ideally people with disability should be able to talk about sexuality with somebody and ask for advice or information, something that was not presently happening. He maintained that sex education needed to be conducted sensitively, on a planned and individualized basis:

> *"I don't know if the material they use is adequate, if they are using visual aids and a person is blind they won't see, certainly if they are using verbal speech a Deaf student might miss quite a lot, and clearly I would not consider the class appropriate for a student with intellectual disability because they would need to have the explanation in a different way and it could be that they are at a different stage of sexual development so it may not be simply a matter of chronology".*

The provider went on to explain that many parents find the idea of sex education very worrying and would rather not know about it. He exclaimed that it was essential that parents acknowledged that their children were sexual beings despite their disability, as this was not generally the case. He also asserted that it was likely they would get very upset at the idea, as their child could not be interested in knowing about sex. He explained that instead they would state it in the following terms:

> *"I know what he is interested in; it's got nothing to do with that..."*

The service provider concluded that

> *"The opportunities to control a disabled child are much greater and over a much longer period of time".*

Another service provider commented that sex education is mostly provided in respect to needs or behaviours displayed.

> *"I think the attitude in Malta is let sleeping dogs lie. If the child is not manifesting issues - than don't raise them. Then having said that I don't know whether if in special schools they do raise the issues, if they are then dealt with. They are not dealt with probably, they are covered over and nobody talks about them, and that is wrong".*

He continued by observing that it is frequently parents who then have to shoulder the problem at home:

"You'll get a young man or woman indulging in behaviour which they don't even know is wrong or rather inappropriate in that place at that time".

A service provider in a community house, who provided residential care for people with learning disabilities, confirmed that most residents must have received sex education at some point in their lives, as they seemed to know about sex. However he was not exactly sure about what they did or didn't know and their level of knowledge. When asked if the management of the house would provide sex education, the manager responded that he would be willing to provide it. He added that if the resident was a male he would do it and if the resident was a female, then a female manager would provide it. Another service manager claimed that some of the residents in the community house did masturbate. Since this was seen as not being permissible, the community house's management was therefore reported to not believe that residents should be taught about, hence encouraged to masturbate. The management feared that residents might start to do this in public if they were allowed to do it at the residential home, with people gaining a negative impression of the residential home itself. Underlying this concern is the fact that most residential homes for people with learning disability in Malta are run by the Church, making it much more difficult to establish the acceptance of masturbation, as it is not a behaviour tolerated or desired by the Church.

A provider of educational services acknowledged that the difficulties encountered with sex education start at a national level. Unfortunately there is still no official policy available to be used as guidance. However he believed that providing sex education for people with learning disabilities was essential, stating that it was:

> *"A very important component of their life, as they are the same as anyone else and have their urges and wishes, which is only natural".*

This participant admitted that across mainstream and special schools, sex education was not available for everyone. Another participant in the research, who worked as teacher in a special school, reported she had at one point raised the subject with her students. She underlined the importance of discussing issues of self-esteem as an initial step to providing sex education, "*it is important that they feel good about themselves*". She continued, by adding that it is then possible to introduce more specific sex education, such as "*parts of the body that are private*", issues such as dignity and privacy can be revised.

A service provider working in a college for young people over 16 reported that they provided discussion groups about self-esteem, self-maintenance, and hygiene, care of the self, friendship and addiction which were open to all students. There was however, no specific sex education sessions as such, neither at an individual or group level or specifically targeted to people with learning disability. Although it seemed that some of the students with learning disability who attended the college had received some level of sex education from their parents, the details were unknown and varied between students. The service provider also commented that it was important to consider national attitudes towards sexuality, arguing that although PSD (personal social development) is listed as a curriculum subject, this is not directly sex education as such. Furthermore, although information about contraception is given, it would be unwise to expect sex education to be provided along the same lines as in Western Europe, for example, where social attitudes are more open about sexuality. Again he underlined the importance of teaching about assertiveness and the prevention of abuse in this context.

An educational service provider concluded that teachers do not have the necessary training and do not have required resources to work on sex education. One teacher who had worked with young people with learning disability for three years explained:

> *"I never addressed this part of the curriculum because I have never received training in sexuality education....teachers were not provided with resources like videos or CDs".*

It was also underlined that for some teachers *"it is not a priority on their agenda"* while at times the utility of sex education *"doesn't even cross their mind'*. Otherwise it was concluded by this service provider that it was best that the teacher knew the students and got some training at delivering sex education, rather than bringing an expert in sex education to address the students.

8.7.1 Sheltered lives and Sexual Abuse

There was consensus between participants in this particular group, that parents found it difficult to explain sex and relationships, although they did warn their children against the possibility of sexual abuse. A service provider argued that realistically no ones' life is going to remain sheltered for good as parents and siblings will not be there forever:

> *"You have to teach them for their life long and for their everyday life".*

One service provider maintained that parents tend to want to shield their children from exploring their sexuality because they are trying to protect them from feelings and urges that may cause them pain or difficulties, believing that their sexuality cannot ever be fulfilled or satisfied. The service provider claimed that the majority of parents consequently believed that people with learning disability have a lower chance of having a fulfilling or long term relationship than a non-disabled person. A service provider himself with physical disability admitted:

> *'I know that was the case when I was growing up, that I was being shielded both by my parents ....what they were trying to do is almost stop the inevitable. It was as though if they took away suggestive pictures or stories, or if I were shielded from certain friends, it was as though the tides of sexual feelings wouldn't happen. But they happened on their own, and they realized this much later that is wasn't a question of shielding you from the world, because the world still intrudes."*

A participant working in residential care related an example of a young woman in her 30s who was being denied access to the internet on the basis that there were a lot of bad things, possibly referring to pornography and sex chat, on the internet, concluded that:

> *"Of course there was never any argument that there were also a lot of good things on the internet, and at the age of 35 she had the right to make up her own mind'.*

Sexual abuse was a theme that service providers seemed to have at the back of their minds but that they had not tackled and dealt with in authoritative ways as yet. In some of the settings participating in the research there were known experiences of sexual abuse. Tying in with discussions on sexual abuse, the myth of living a sheltered life was discussed by service providers in relation to sex education and sexual abuse. The following discussions are grouped according to the environment the service provider worked in.

Educational setting: Teachers working at a College for young people over 16 years of age, who were participating in the research, stated that they took into account the possibility of sexual abuse on school premises. They claimed they responded to this possibility by asking the students with disabilities directly if they thought they could take care of themselves on the school grounds.

Community residential home: At a residential home, the service manager stated that he was aware that one of the residents had been sexually abused while others had perpetrated sexual abuse. He described a situation which had taken place where two female residents, undressed and tried to change the continence pad of another female resident, without her consent, as they had witnessed a carer do this earlier. Although he dismissed this as a case of abuse, he stressed that it had happened because the carer had previously changed the continence pad in the presence of the other two residents. No disciplinary action had been taken against the carer.

8.8 Conclusion

Service providers are important influential figures across different settings in the life of people with learning disability. Thus their opinions about the sexuality of people with learning disability are of utmost importance. This chapter lists the opinions derived from service providers who operate in a Maltese context. Their outlook and beliefs are themed as illustrated in Hierarchy Chart 3 on page 250.