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

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CHAPTER NINE

> ***"Action without reflection and understanding is blind, just as theory without action is meaningless"***
> **Bradley & Reason (2006, pg.3)**

Pilot Intervention Sex Education Groups in Malta

9.1 Introduction & Background

This pilot sex education project was developed to address the shortcomings and the lack of sex education experienced by people with learning disability in Malta. The findings from the 3 sets of participants; mainly people with learning disability, parents of people with learning disability and service providers who operate in areas of interest to the research, in the main study, consequently informed this intervention in sex education. Such findings from the main research study that directly provided data for the pilot intervention are summarised below according to participant groups:

9.1.1 Findings from participants with learning disability in the main research study

Participants with learning disability reported and confirmed the complete lack of exposure to sex education, received both in mainstream and special school settings. In accounts given by people with learning disability during the interviews there was clear evidence of the lack of knowledge experienced by people with learning disability in specific areas of sexuality. Their desire to know more about the subject was also put forward by the same participants with learning disability through the interviews held. Above all their longing to engage in relationships and intimacy was expressed throughout all stages of the project.

9.1.2 Findings from participating parents of people with learning disability in the main research study

The marked lack of sex education provided to people with learning disability by their parents converged with the wish displayed by parents for some kind of sex education to be made available for their children, now young adults with learning disability. On the other hand another group of parents of people with learning disability denied the need for sex education, as they considered their children to have too much of a sheltered life to ever need such instruction and knowledge. The moral imperative to provide sex education as a human right is understated in Maltese culture.

9.1.3 Findings from participating service providers in the main research study

Essentially a minority of service providers did show interest in initiating a limited amount of sex education instruction for service users with learning disability, although they did not actively adopt that stance. Yet the denial of the importance of sexual knowledge and education for people with learning disability was also manifested by some other service providers in the research. The need to challenge and address these shortcomings in local services shaped the pilot intervention programme described below.

Finally, previous sex education groups such as those run by McCarthy (1999) and Johnson, Frawley & Hillier's (2002) made impact on the researcher, whilst also providing direction. These two sex education services are reviewed further on in the chapter and consequently compared to this pilot intervention sex education project.

9.2 Methodology of the Pilot Intervention Project

9.2.1 Recruitment of Participants in the Pilot Intervention Project

Contact with the researcher was made by a group of non-disabled volunteers, under the name of Ghaqda Flimkien Naslu (GFN) (translated to: Together We'll Get There), to run a sex education seminar for a group of people with learning disability who formed part of GFN. The non-disabled volunteers were referred by the National Commission for Persons with Disability, who were aware that research was being undertaken in the area of sexuality. The participants with learning disability who took part in the in the sex education seminars and formed part of the voluntary group GFN (Ghaqda Flimkien Naslu), had different abilities and gender and their ages ranged from 18 to 35 years.

9.2.2 Measures

During the pilot sex education intervention project feedback was obtained from three key sources: the participants with learning disability who formed part of the voluntary group GFN (Ghaqda Flimkien Naslu, translatable as Together We'll Get There); the non-learning disabled volunteers responsible for GFN, who in turn were responsible for requesting the sex education workshops (these volunteers will be termed 'facilitators' in their roles as sex education facilitators for the participants with learning disability), and finally parents of the participants with learning disability were also involved when feedback about the sex education seminars was sought.

Measures used were idiosyncratic to this particular study. This was due to the limited time available for sex education, the considerable number of participants and the amount of information that needed to be covered during the two seminars. Although the researcher reviewed various tools such as that by Talbot & Langdon (2006), Griffiths & Lunsky (2003) and McCabe (1994), the researcher believed that these above mentioned assessment tools would have been ideal given different circumstances, but possibly too explicit given the culture of the Maltese islands. Furthermore the time constrains present did not allow a gradual exploration of such resources, therefore alternative measures were sought.

9.2.2.1 Measures - Participants with learning disability

A reflective log in which recordings of the discussions that had taken place between the participants and the researcher as well as the facilitators (or volunteers) was utilized. Verbal feedback between the participants with learning disability during the sex education sessions were also kept in the log book. The log book was again used during the seminars with the participants with learning disability. Quotations were recorded directly from the participants with learning disability and the researchers' observations were again logged.

A second method using short semi structured interviews was carried out with 3 of the participants with learning disability, who agreed to and were able to of participate in interviews. Although all participants were asked to participate in the feedback interviews, only 3 participants responded to the request. Interview questions are attached in Appendix 14.

9.2.2.2 Measures - Volunteers from GFN / Facilitators

The non-disabled participants who are here referred to as volunteers or facilitators, gave extensive feedback throughout this sex education pilot project. Due to the fact that the non-disabled volunteers had to run the sex education workshops themselves during the second seminar, so as to accommodate the number and the different abilities of the participants with learning disability, staff training was requested upon the current topic. This staff training was carried out with the non-disabled volunteers prior to the second sex-education seminar. A log book was kept during the staff training and the two seminars, run on separate weekends. The written recordings included verbal feedback given by the non-disabled volunteers and the researchers' observations. Reflections upon the staff training is reported in section 9.5., these reflections are enlisted according to the task (extracted from McCarthy & Thompson,1993) discussed.

Verbal feedback from facilitators leading the sex education seminars was also recorded in the log book. Moreover post seminar questionnaires were then sent via email to the 3 facilitators who led the sex education groups in the second seminar. Questionnaires are attached to Appendix 16.

9.2.2.3 Measures - Parents of participants with learning disability

Parents of participants with learning disability in the two seminars, were contacted through the volunteers of the group GFN, and invited to take part in the research by consenting to a post Seminar interview. It was deemed more appropriate to have the volunteers contact the parents, since they knew them better then the researcher, thus having a better probability that they would respond positively to the interviews.

Only 3 parents responded to the request and these were individually interviewed by the researcher, using semi-structured interviews which were digitally recorded and later transcribed. Interview questions are attached in Appendix 15.

Finally the Findings section 9.6 compromises findings extracted across the 3 groups of participants using 3 different types of data collection tools; log book, interviews and questionnaires. The information that emerged from the 3 forms of data collection are analysed according to the emerging themes, combining data from the 3 groups of participants in order to compare and contrast attitudes and opinions across participants.

9.3 Sex Education Seminar 1 - design and content

9.3.1 Profile of the group of participants with learning disability in Seminar 1

The group consisted of 16 participants of mixed gender and ability, aged between 18 and 35. The variety of abilities, ages and having both females and males in the same group was one of the major short comings of the two pilot workshops. However they provided an opportunity to test the methods and approach. Being a mixed ability group, the more able participants, tended to get along very well with the information conveyed, asking questions and being involved in discussions. Conversely, the less able participants tended to be excluded from the more lengthy and complex discussions. Some of these participants needed time out and asked to leave the room to go for a walk or a rest. Being a mixed gender group, it was also evident that some participants, mostly men, appeared to be uncomfortable discussing some issues, such as menstruation and pregnancy. The participants in both groups were Maltese speaking, so all the content and explanation was translated into Maltese. There was only one participant who had substantial physical disability but this did not inhibit his participation in the seminar.

9.3.2 Design of Sex Education Seminar 1

During the preliminary discussions, the non-disabled facilitators from GFN proposed a list of topics that they wished would be covered during the first seminar. Although the volunteers all came from a background in education, it was evident that they had little or no knowledge of the ways in which sex education was relevant to people with learning disability. They were neither aware of how it should be addressed nor of how the implications of such interventions should be tackled. The proposed list of topics required review and prioritisation, due to the limited time available for the seminar and the wide agenda identified. It was also evident that this would be a one off sex education seminar as being a non-profit group, GFN lacked financial resources as well as man power, and therefore they had a limited budget to address other sex education seminars.

During the planning of the seminar, the list of topics to be discussed was reviewed by me as a researcher together with the volunteers who acted as facilitators during the seminar. The time allocation for the topics discussed was distributed over three, 2 hour workshops. The workshops were designed as part of a "live in" activity weekend, where participants with learning disability were involved in various group leisure activities, including going out for meals and watching movies. The three workshops were then interwoven with these activities.

The content of the three workshops is summarized in Box A, below.

9.3.3 Box A - Content of Workshops in Seminar 1:

Workshop 1 – Our Body

Differences in Gender ; differences in body parts according to gender

Labelling of body parts using appropriate terms with pre written flashcards

Workshop 2 – Puberty and Physical Sexual Development

Menstruation

Erection and Ejaculation

Public and Private behaviours

Masturbation

Appropriate and inappropriate touching

Assertiveness

Reporting Abuse

Workshop 3 - Personal Hygiene

Personal hygiene for women during menstruation

Personal hygiene for men and women during puberty

9.4 Sex Education Seminar 2 - design and content

Subsequently the non-disabled volunteer group GFN contacted the researcher again to propose a follow up seminar, with the intention to continue with the list of topics that were not discussed during the first seminar.

Following discussions with the volunteers, the structure of the group in the second seminar was changed with the objective of making the sex education intervention more effective. For these next three workshops, the participants would be grouped primarily by ability and by gender. The result was three groups: a mixed gender lower ability group, and two higher ability groups, one for men and one for women.

9.4.1 Profile of the group of participants with learning disability in Seminar 2

Group 1 involved six women with learning disability and Group 2, two men with learning disability, (with the participants in both these groups having relatively good cognitive ability and understanding). No participant in these two groups presented a significant physical disability. The participants in both groups were Maltese speaking so all the content and explanation was translated into Maltese. The groups were divided according to gender as from the experience of the previous workshop it was felt, by me as the researcher and the other volunteers, that both men and women would feel more comfortable discussing most issues if they were in same sex groups. Due to the nature of the topics explored in this workshop, being in same sex groups was considered more appropriate and productive, in that participants would be more confident when discussing sex and relationships and raising questions. This conforms to recommendations by McCarthy and Thompson (1993).

Group 3 comprised six participants who had a lower level of cognitive ability and understanding. One of the group members also had mild physical disability, although was independently mobile. These participants followed a different set of topics, revisiting the topics covered in the first seminar and workshops, including; labelling of body parts, differences in the body according to gender and public and private behaviour (refer to Box A). The content of the workshops is summarized in Box B, below.

9.4.2 Box B - Content of Workshops in Seminar 2 (for higher ability groups)

Workshop 1 Intercourse, Conception and Fertility

Intercourse between men and women; missionary position

Conception

Pregnancy

Delivery: Natural and Caesarean Section

Workshop 2: Contraception and STIs

How to use a condom

The contraceptive pill

Sexually Transmitted Infections; Chlamydia, Gonorrhoea, Herpes

HIV and AIDs

Workshop 3: Homosexuality, gay and lesbian relationships

Gay relationships between two men

Lesbian relationships between two women

Possibilities of marriage for homosexual couples

Possibilities of bringing up children for homosexual couples

Homophobia

9.5 Staff Training

In order to have three seminar groups running in parallel, the non-disabled GFN volunteers agreed to facilitate the sex education themselves, based on the agenda and information agreed and planned with the researcher. A staff training session was run two weeks before the workshops, with six people attending. The facilitators were all female, because the voluntary group only comprised females, reflecting experience elsewhere, with the majority of care providers and child educators tending to be female (McCarthy 1999, Wheeler, 2004). The facilitators were all members of the educational profession, four teachers and two learning support assistants.

The staff training was designed to cover five areas mainly; confidentiality, disclosure of abuse, sensitivity, respect and tolerance. The objective behind the staff training was to make the facilitators aware of their different attitudes and tolerance levels, and how this might affect their own preconceived ideas, values and opinions of others. The staff training started with the development of a learning agreement. The ground rules chosen were specifically selected to be appropriate to Maltese culture and the situation facilitators were likely to find themselves in during the workshops. The ground rules addressed considerations relating to; confidentiality, acting on bad or abusive experiences revealed sensitivity discussing sexuality, sharing personal experiences, and respect towards each other.

After discussing the ground rules, facilitators then examined nine tasks chosen from McCarthy and Thompson's (1993) *Sex and Staff Training: Sexuality, Sexual Abuse and Safer- Sex.* These tasks were selected specifically due to their relevance to the context and cultural appropriateness of sexuality in Malta. (A complete guide to each task is found in Appendix 1). The word "*difficulties*" is replaced with the term "*disability*", in line with the terminology used throughout the study. The following nine tasks were addressed in the following order:

- **The relationships people with learning disability have**
- **Major influences and constraints upon the sexual expression of people with learning disability**
- **Staff attitudes and values**
- **Basic myths and assumptions**
- **What people with learning disability need to know about sex**
- **Why people with learning disability have sex**
- **Appropriate and inappropriate behaviour**
- **Staff feelings**

The following are reflections upon each of the nine tasks carried out during the staff training with the facilitators, which were recorded on a reflective log book kept by the researcher. The reflections are based on the responses given to the researcher by the participating facilitators. Their opinions and believes are portrayed through their non verbal reactions as well as their verbal replies.

9.5.1 Task 1 - The relationships people with learning disability have

The facilitators were initially reluctant to mention intimate and personal relationships. Instead they listed relationships with family members, social friendships and friendships at their work places or adult training centres.

The facilitators needed to be reminded that we were also discussing emotional relationships as well as sexual or intimate personal relationships. These latter kinds of relationships were not mentioned initially as participants seemed not to believe that people with learning disability were having or had the opportunity to experience sexual and intimate personal relationships. After being prompted, the facilitators listed the following two forms of relationships, saying that they suspect that there are some (although not many) people with learning disability who have such relationships, namely *"Heterosexual relationships"* and *"Intimate relationships".*

It is worth noting that homosexual relationships were not mentioned at all, reflecting wider findings in the data, in which homosexuality was absent as a theme from the lives and sexual interest of people with learning disability. This is similarly explained by the lack of opportunities people with learning disability have to explore their sexuality and the strong stigma towards homosexual relationships.

9.5.2 Task 2 - Major influences and constraints on the sexual expression of people with learning disability

The facilitators strongly and promptly agreed that parents and extended family were the major reason why the sexual expression of people with learning disability was constrained. They gave reasons including overprotection, treating people with learning disability as eternal children and refusing to accept sexual identity. Social attitudes were seen as the second most important influence and were identified as the way in which society suppresses the sexuality of people with learning disability.

The lack of support services available to people with learning disability was identified as another influential factor, (personal assistants, direct benefits and the opportunity to live independently away from the family), reflected in the lack of sex education available. The lack of sex education at school or other environments that people with learning disability frequent, such as adult training centres, was considered to exclude opportunities for people with learning disability to learning about sex and intimate relationships, again mirroring the preconceived ideas from parents and others who regard people with learning disability as asexual. Sex education delivery in mainstream and special education sectors was also discussed. The facilitators commented on the fact that 'sex education' in mainstream schools is delivered in a standard way to all students, regardless of their learning disability and communicative needs. One participant confirmed that it is at the discretion of the teacher whether the learning support assistant is allowed to support her student during Personal and Social Development (PSD) classes, where sex education is a major topic. If the learning support assistant is not allowed to provide such support, the student's understanding of PSD is questionable, since there is no one to facilitate the learning. In special school settings, no sex education was carried out at all, because it is not promoted due to an underlying belief that it is not necessarily required for students with learning disability.

Staff working with people with learning disability were also seen by facilitators as oppressing the expression of sexuality of people with learning disability. The facilitators observed that staff working with people with learning disability ensure that service users do not get involved in such relationships, believing that if this happened their role would be compromised in the eyes of their employers and the families of service users. Finally the facilitators referred to the Laws in Malta as a major constraint to the expression of sexuality of people with learning with disability. The facilitators had previously (at the beginning of the sex education work) been made aware that people with learning disability remained under the legal guardianship of their parents, who decided what was best for them, even when they become adults.

9.5.3 Task 3 - Staff Attitudes and Values

The aim of this task was to increase the awareness of the facilitators of their values and attitudes about sexuality and to compare attitudes and values within in the group.

The participants agreed that people with learning disability should have the opportunity to experience relationships and considered marriage to be "*the best thing in the world*" for people with learning disability. However, it was observed that it was unlikely that such an event took place in Malta. The facilitators tended to agree that sex leading to pregnancy and parenting was not to be encouraged due to the facilitators' own belief that people with learning disability were incapable of raising a child and due to the poor support services available. It was brought to the facilitators' attention that people with learning disability still have a right to have a child even if it was assumed that they weren't capable of bringing this child up and that this was a Human Right Act (1998) (Article 8 & 12). In addition, with the provided support and guidance, there is evidence that people with learning disability are able to be good parents. (Booth & Booth, 1993, 1994, 1995, 1999; Pixa-Kettner, 1998; Block, 2002; Reinders, 2008; IASSID, 2008).

Sex outside a relationship was sneered upon by most of the facilitators who agreed that it was against their values. Four of the participants stated they would label this as "*it happens but I don't like it*". The rest of the group concluded that young people without disability do have sex just to experiment outside of a relationship. They therefore concluded that this would be a normal thing to do for people with learning disability. Having women and men with learning disability co-habit outside marriage was considered acceptable or normal by all facilitators.

The different values held about hetero and homosexual relationships were evident when discussing sexual relationship between two men and between two women. Three of the facilitators saw such relationships as tolerable, while the other three placed the value stating: "*it happens but I don't like it*".

Someone having sex with both women and men was set as tolerable after some debate. Some participants claimed that no-one had the right to decide the sexual orientation of someone else, observing that the person might be still experimenting in order to define his or her sexual orientation. At the same time it was clear that the participants did not valued such types of sexual relationship. No opposition to sexual relationships between a woman and a man emerged, and they considered such relationships as 'normal', but all agreed that having a number of sexual partners should not be encouraged.

When discussing masturbation, it was evident that the participants were solely focusing on male masturbation. They regarded this practice as somewhere in between being acceptable and tolerable. Masturbation is still a stigmatized issue, especially for women, in Maltese culture.

9.5.4 Task 4 - Basic Myths and Assumptions

The four myths and assumptions were read out to the facilitators and each discussed. The facilitators commented as follows;

9.5.4.1 If people with learning disability are taught about sex, they will be encouraged to experiment with sex.

One of the facilitators expressed the opinion that even though people with learning disability are not educated about sex, they will still physically develop, and therefore have sexual opportunities and experiences without being adequately informed and educated, adding that a lack of sex education risked sexual abuse. This participant also asserted that nowadays the media is continuously portraying sexual images and that people with learning disability were likely to get mixed or muddled messages about sex if they were not directly provided with sex education.

Another facilitator expressed her belief that if you give a person with learning disability this kind of information, then they would try experimenting with sex to confirm this. Although she also added that she thought that there was nothing particularly wrong with this she did believe that if started on the subject, people with learning disability would feel curious to explore it further. The other participants expressed no clear opinion about this.

9.5.4.2 People with learning disability are naturally more 'promiscuous' than other people.

There was agreement amongst facilitators that people with learning disability's tendency to hug and kiss people who were not close relatives or are not in a relationship with them, reflected a lack of education rather then being 'oversexed'. However they did admit that society often regarded this inappropriate behaviour as an element of their sexual nature and dismissed it as an aspect of their learning disability.

The facilitators were reminded of the assumption that men with learning disability were often regarded as sexually dangerous. One participant explained that in the school environment where she worked there was a general belief that people with learning and physical disability were oversexed. Another facilitator said she knew of a boy with learning disability who was in the habit of touching women inappropriately, yet felt that this did not originate from his learning disability but rather from the environment he was brought up in. Another participant explained that boys of that age, without learning disability, who she worked with as a teacher, all were very sexually aware.

9.5.4.3 Women with learning disability should be put on the pill to protect them from the sexual advances of men.

The facilitators found this assumption was confusing and needed further explanation. The possibility of sexually abusive situations which could happen in mixed gender service settings, outside Malta, where women with learning disability may be provided with the contraceptive pill to avoid pregnancy, was addressed. Such settings do not exist in Malta, and other smaller scale settings are run by Catholic institutions would not allow neither sexual relationships and to a much lesser extent the contraceptive pill in their community houses.

The facilitators agreed however, that rather than having unwanted pregnancies they would encourage women with learning disability to take the contraceptive pill. The facilitators still agreed that in such circumstances that sexual abuse would not readily be revealed unless the woman declared it or it resulted in pregnancy.

9.5.4.4 People with learning disability living in the community have more opportunities for sexual relationships than people living in hospitals.

The facilitators agreed that if people with learning disability lived in the community, rather than Church run institutions, they would have more opportunities to meet people and form friendships and develop relationships.

9.5.5 Task 5 - What people with learning disability need to know about sex

Participants listed key points, including, sexually transmitted infections, contraception, pregnancy and parenting of children, different sexual orientations and values.

The point about different sexual orientation was made following discussion about whether it would be wise to expose people with learning disability to homosexual and lesbian relationships. This thinking reflects the belief that heterosexual and homosexual relationships were not valued equally by all facilitators (Carson & Blyth, 2009). The point about values was proposed as one participant stated she would want people with learning disability to understand that it was not acceptable to have sex simply for enjoyment and that they should be in a relationship to have sex.

9.5.6 Task 6 - Why people with learning disability have sex

Facilitators divided people with learning disability according to gender, believing that men and women had different understandings of sex because of their physical gender and their social upbringing. For males they listed a number of reasons for having sex; including hormonal instincts, peer pressure or wanting to look good with your peers, wanting to explore or experiment and sexual frustration.

For females the following reasons included; being in love, being forced into sex by the partner, wanting to keep a relationship through sex, pressure from the family to maintain the relationship and wanting to explore or experiment and hormonal instincts.

An element of abusive male dominance and sexual frustration emerged when listing reasons for women with learning disability to having forced sex. Being in love and wanting to keep a relationship going were both listed for women but not for men. Both men and women were seen as having sex for reasons related to hormonal development and natural human instincts; thus for exploratory reasons and for wanting to experiment with sexuality. Overall however, stereotypical attributions relating to sex and gender emerged.

9.5.7 Task 7 - Appropriate and inappropriate behaviour

The facilitators saw only cuddling as a socially accepted appropriate behaviour that could be carried out at any time and place. However, a number of other behaviours were considered appropriate at certain times and places, and these are listed in Box C:

Box C - Behaviours seen as appropriate under certain circumstances by facilitators

People with learning disability holding hands

Female staff member giving intimate care to a man with learning disability, although participants added that this was to be avoided if possible.

Male staff member giving intimate care to a man with learning disability

Woman and man with learning disability kissing

Sex

Masturbating

Touching private parts of the body under clothes

Touching private parts of the body through clothes

Woman kissing woman

Staff member kissing a staff member

Man and man kissing

Female staff member giving intimate care to a woman with learning disability

The participants considered the following behaviours as never appropriate ;

Person with learning disability and staff member holding hands

Male staff member giving intimate care to a woman with learning disability

Staff member kissing a person with learning disability

9.5.8 Task 8 - Staff feelings

This task was addressed by asking facilitators to work together as partners to solve the hypothetical situations listed below.

- Explaining to a man with learning disability about the clitoris.
- Talking about masturbation with a woman with learning disability.
- Talking to a man with a learning disability about his interest and collection of women's underwear.
- Being asked by a person with learning disability whether you masturbate.
- Explaining where babies come from if asked by a person with learning disability.
- Talking to a woman with learning disability who has been sexually abused, about the abuse.

When the group discussed this exercise, they were assured that everyone would find situations where they felt uncomfortable with a topic and that this was normal and acceptable, therefore making the point that they have to be aware of their feelings in advance of this happening.

These comments were made by the facilitators as the task progressed;

"insir hamra nar" – "I would go very red"

"x'misthija" – "how embarrassing!"

"ma nafx x naghmel" – 'I wouldn't know what to do"

One facilitator whose situation card read: *Explaining to a man with learning disability about the clitoris;* said that she would feel very embarrassed to discuss this with a man and would not be able to. She was advised that she could tell this man that she would ask someone else from the team of facilitators to explain this to him in a one to one session.

Another facilitator who had a situation card that read: *Talking about masturbation with a women with learning disability;* felt that it was better for her to explain to a woman but would have found it much harder to explain this to a man.

The facilitator who had the situation card that read: *Talking to a man with a learning disability about his interest and collection of women's underwear*, claimed that she would not be able to answer and would feel very shocked if such an issue came up.

A facilitator who had a situation card reading: *Being asked by a person with learning disability whether you masturbate;* felt she would tell this person that such personal questions cannot be asked to people you weren't in a relationship with or who weren't very close friends, but that none the less masturbation was acceptable.

A facilitator whose situation card read; *Explaining where babies come from if asked by a person with learning disability,* said she would be fine explaining this but did not go on to explain how she would do it in practice.

The last participant whose situation card read; *talking to a woman with learning disability who has been sexually abused, about the abuse,* claimed that she had already experienced this and thought the best way to tackle this was to direct this person towards receiving support in the form of counselling or therapy and reassure her that you would be available to accompany her if she wished.

9.6 Findings from Seminar 1 & 2

The findings from Seminars 1 and 2 come from data collected through the log book kept throughout the Seminars, the interviews carried out with participants with learning disability and parents of participants, as well as from the questionnaires filled in by the non-disabled facilitators or volunteers. The data that was extracted was then analysed according to the themes that emerged. It is important to note that themes from the three groups of participants were combined so as to compare and contrast attitudes and opinions across participant groups.

9.6.1 Sex within the context of a relationship

Fairbairn (2002) claims that the ways in which people conceive and address issues of sexuality in the lives of people with learning disability are indicative of their own attitudes to sexuality and its place in the lives of people with learning disability. This statement applies to experiences encountered during the workshops facilitated by the volunteers involved. An experience which related to Fairbairn's (2002) assertion involved a volunteer leading a workshop that addressed sexual experiences. The volunteer referred to sexual experiences, such as intercourse, solely within a relationship, ignoring or rather unwilling to mention sexual experiences outside relationships. The volunteer leading the session associated sexual experience with love using terminology referring to sexual intercourse as "*jinhabbu -making love*". Sexual encounters and intercourse were also referred to by the volunteer saying that this happens when two people want to show love to each other – "*ikunu jridu juru l-imbhabba lil xulxin*" or else when they love each other and are married – "*ikunu jhobbu lil xulxin jew mizzewgien*". Examples were derived by the facilitators from the personal experience of the participants with learning disability, such as siblings getting married, being pregnant and having babies. It was possibly seen appropriate by the volunteers to set sexual experiences within the context of loving relationships as this abides to Maltese cultural norms and expectations, where sexual relationships are acknowledged and approved of only within marriage.

9.6.2 Terminology

A lack of adequate terminology was noted in the vocabulary of a participant with learning disability who had not attended part of the previous seminar, where a workshop was dedicated to the topic of adequate sexual terminology. For example, she referred to the 'penis' or *"pene"* in Maltese, as "*dudu*" meaning 'little worm', a term used by young children. Another participant who had attended the previous workshop on terminology had a good recollection of terms used, including the term "*vagina*". Others appeared to have a recollection of sexual terms but needed reinforcement to remember terms or appeared reluctant to use them. The word "*sperma*" or sperm was used by the facilitators when discussing conception and fertilization, one participant with learning disability at one point asked if it could be confirmed that sperm was the same as the slang word which is used commonly to refer to sperm, but which is considered a swear word in Maltese.

Even though a list of appropriate terminology was given to the facilitators to use during the workshops, I found that some of the facilitators still tended to use slang words, although such terms would be familiar to and commonly used by facilitators as well as by some people with learning disability. Such was the word "*whore*" which was used instead of the word *"prostitute"*.

During the third workshop, although aware of the physical differences between homosexual and heterosexual sex, many of the participants were not aware of the appropriate wording related to homosexuality. However, they were keen to learn the appropriate terminology and appeared willing to use it if required.

9.6.3 Gender related differences

It was observed that female participants took different stances towards topics compared to male participants. The female participants for example were mostly interested in pregnancy and child birth, often because they had close relatives who were pregnant or who had just experienced this situation. Female participants asked questions about menstruation and the menopause, the stages of and the use of the placenta. These topics were not made visible by the male participants. A common issue that both male and female participants were surprised to learn about was that babies are born head first and not feet first as initially assumed, during natural vaginal delivery. Although through information they had gathered probably from TV, the participants knew that a cord was cut when a baby was delivered, but there remained a lack of knowledge about the placenta and its use as a means of livelihood and nutrition for the embryo. Caesarean section delivery was also new information for both male and female participants. Despite not coming across this alternative type of delivery or maybe having heard about it but not knowing exactly what it was, female participants showed particular interest in which kind of delivery was the most or least painful.

It was very evident that men were much more at ease and comfortable asking questions and discussing topics in a same sex group, despite the leader being female.

The two males in the workshop who both lived at home were also employed, therefore being more exposed to society. These two participants also had more active social lives than the female participants as being males, their parents tended to overprotect them less and give them more independence. The males were interested in all the topics covered in the three workshops. For the male participants however, questions and discussion focused more on the practical aspects of sex experiences while the emotional concept of love, was not raised at all, unlike the female participants. The male participants also referred to sex outside relationships and experimental sex with a female partner, contrary to female participants who placed sexual experiences in the context of relationships.

Male participants seemed especially interested in knowing more about contraception, and even though this was to be covered in the second workshop, they constantly referred back to contraception when discussing intercourse, conception and pregnancy. When discussing intercourse male participants asked about the practical aspect of sexual intercourse, for example one participant asked if the testicles entered the vagina together with the penis. The male participants raised other queries relating to intercourse, such as why women often experienced pain or discomfort during intercourse. The discussion raised the topic of foreplay and alternatives for lubrication which were not elicited and discussed by the group of female participants. When discussing STIs both male and female participants claimed they had heard about HIV and AIDS but not STIs in particular. However participants had no understanding about how AIDS could be transmitted, neither through sexual relations nor through the sharing of infected needles during drug use, through contaminated piercing or tattooing equipment, or through transfusions of unsecured blood.

One of the male participants repeatedly asked whether condoms protect fully against HIV and STIs. The participants were very impressed with the photo images used and interested in the video clips used to explain what STIs were and how they are transmitted. References relating to herpes especially facial herpes on the lips had a big impact, possibly because they were visually evident. After discussing STIs one participant who had earlier disclosed to the group that he was not keen on using condoms, claimed that after learning about HIV and STIs he would think twice about having unprotected sex, as pregnancy was now not the only issue he had to consider. When at the end of the workshop participants were asked why they thought this information was good to know, one female participant replied that it was good so that if she goes out with a boyfriend she would know these things. Another male participant said it was good for him to know more about STIs and contraception so that if he has sex or sexual relationships, he would be aware of having safer-sex.

Whilst discussing homosexuality, the female participants were mostly interested in knowing more about bisexuality, as although there was limited awareness, they did not have substantial knowledge about it. On the other hand the male participants wanted to know more about the psychological and physiological aspect of male to female trans-sexuality or gender-reassignment.

9.6.4 Cultural implications; Religion and Law

When discussing contraception the volunteer leading the workshop realised that one of the male participants had mistaken the contraceptive pill for the morning after pill. This was noticed when the contraceptive pill was being discussed as a means of contraception and this participant commented that it was not right to take this sort of pill because it was a means of abortion. Although the morning after pill was not an item on the agenda, it was discussed with participants, with the difference between the contraceptive pill and the morning after pill explained. The morning after pill is not available and illegal in Malta and generally considered morally wrong due to religious beliefs. This male participant asked about and strongly voiced his opinion against the morning after pill which he considered a means of abortion, as is interpreted by the teachings of the Catholic Church.

An element of religion was raised in the discussion about abortion by the volunteer leading the group, who overtly said that the morning after pill did mean abortion, as Catholic beliefs state that once there is conception there is life. As the morning after pill is a means of killing that conceived life, it therefore constitutes an abortion.

One of the male participants claimed that he would be too embarrassed to ask for and to buy condoms from a pharmacy. This participant claimed that he would have unprotected sex rather than buy and use condoms.

Some misconceptions were evident from the workshops. These were largely the result of pre conceived ideas that the participants had as a result of earlier teaching by parents or educators. Examples included touching oneself (in private) and letting someone else touch your sexual parts (with your consent), which were referred to by a participant (in Maltese language) as '*pastazata*', meaning wrong or rude.

When discussing homosexuality and homosexual relationships some participants expressed stereotypical homophobic views and opinions. The opinions the participants had evidently been influenced by their family members, and were expressed by statements such as: "*mhux sew (it's not right")* and *"mhux suppost (you're not supposed to do this)"*. Another issue that the participants raised in relation to homosexual relationships was parenting. Many expressed their views saying that it would be disruptive for the child to have a homosexual or two homosexual parents. During the workshop one facilitator associated people who were homosexual with other people in a minority groups and who experience discrimination or oppression, including people with learning disability. Yet some of the participants found it difficult to relate concepts of oppression relating to homosexuality and disability.

9.6.5 Sexuality of people with disability through the eyes of the facilitators

There was consensus amongst facilitators that in Malta sexuality was a stigmatized topic, with people being either afraid or refusing to talk about it. One facilitator admitted that up to a few years ago, when she was a student in a secondary school, sexuality was avoided as a topic altogether. On top of this general stigma and marginalisation of sexuality, she maintained that society assumes that people with learning disability can never be sexually active or that they do not feel the sexual urges that non-disabled people feel. The volunteer concluded that even though Malta has moved ahead in the way it viewed people with learning disability; opinions about sexuality are entrenched and very difficult to change. Collectively, the facilitators believed that people with learning disability have sexual urges and feelings, as do most people and that it was not right to ignore this. Consequently, sex education was considered important and supported.

This was the first time the facilitators had discussed sexuality with people with learning disability. The female facilitators felt quite confident addressing female participants with learning disability who had high cognitive ability, as they found that topics discussed and the information conveyed was understood. The facilitators felt they would have coped with male groups, although being with females made them feel naturally more comfortable.

It was evident to the facilitators that while the female participants were mostly interested in issues of conception and child birth, male participants were more interested in contraception and sexual insertive sex. It was also felt that participants were more comfortable with same sex groups and felt they could discuss things that they had experienced more openly.

The facilitators agreed that an increase in frequency of sex education session would be ideal for the participants with learning disability to reach a good level of sex education. They also observed that the topic needed to be opened up and further developed across Malta. It was found that having appropriate visual aids and resources at hand was useful and necessary during the delivery of the workshops as various issues arose from discussion.

9.7 Discussion of findings

In the following section, this pilot sex education intervention project is compared to international studies, where similarities and differences between other sex education interventions outside Malta, such as McCarthy's (1999) sex education intervention in the U.K. and Johnson, Frawley & Hillier's (2002) project in Australia, are explored, with commonalities and differences identified..

9.7.1 The 3 projects

McCarthy (1999), Johnson *et al.* (2002) and the current study, uncover the participant's struggles associated with sexuality and relationships. Michelle McCarthy, the founder member of the Sex Education Team (Horizon National Health Services – NHS - Trust), conducted official sex education interventions targeted specifically for female service users with learning disability in the U.K. Johnson, Frawley & Hillier, (2002) carried out a project and divided it into two phases involving a research and an action stage. Their research stage formed the basis of the action stage of the project as reported in Johnson, Hillier, Harrison & Frawley (2001). The research stage involved 25 people with learning disability who related their life stories to the researchers. In the second stage, the action stage, these stories were used to provide the basis of sex education workshops and resources. The action intervention was described as unique in the way it focused on attitudes and values. The intervention aimed at treating "*sexuality and relationships as part of everyone's life and not as a problem*" (Johnson *et al.* 2002, pg. 7).

9.7.2 The Funding

McCarthy has been involved in projects involving sex education and sexual abuse prevention for a number of years, often in collaboration with other researchers such as Thompson. Her work has been published in the form of journal articles and sex education material (McCarthy & Thompson, 1993; 1996, 1997). In addition to her role as sex educator and the services associated with it, McCarthy conducted interviews with service users as part of a research study, under the auspices of the Sex Education Team (McCarthy, 1999). She later published her findings about the sexual lives of women with learning disability in *Sexuality and Women with Learning Disability* (1999

Johnson's *et al.*'s (2002) project was funded by the Victorian Health Promotion Foundation for a period of three years. The project was undertaken at the Australian Research Centre in Sex, Health and Society at La Trobe University in Melbourne.

The pilot sex education intervention in Malta was funded by the European Union (EU), as part of a project called Building Blocks for which a group of volunteers under the name of GFN (Ghaqda Flimkien Naslu) had applied for funds. Only the premises and equipment were covered by EU funding, with the consequence that the organisation and running of the project was provided on a voluntary basis.

9.7.3 The Settings

The environments and settings in which the three programmes were conducted were also different. McCarthy (1999) conducted most of the interviews in her office or counselling room, which she also used for sex education sessions. In the current research the premises to conduct the sex education were sought by the organisers of the seminars and were different for both seminars. They consisted of large premises that combined a meetings hall, residential areas such as bedrooms, dining areas and a few more open spaces. Both premises were set in the countryside, belonged to the Catholic Church and were managed by priests or nuns. Discussing the topics with the people running the household was not necessary although there remained a feeling of unease among the volunteers and facilitators during the workshops.

9.7.4 Time Frames

Although Johnson's *et al.* (2002) project ran for three years, the action had a shorter time frame compared to McCarthy (1999). Johnson *et al.* (2002) initially had a two day workshop which included three modules focusing on values, attitudes, being safe and having rights as well as on policy development. However, in Johnson's *et al.* (2002) the total number of workshops were developed, implemented and evaluated over an 18 month period and involved more than 200 service providers, 60 families and 50 people with learning disabilities. The market materials linked to these workshops received positive feedback from users all over Australia, New Zealand and Iceland. This project can therefore be considered larger in scale compared to the pilot project carried out in Malta.

During the sex education intervention carried out by McCarthy, as part of her role in the NHS team, the regularity of the session was not confirmed, although McCarthy (1999) explains that when collecting data for her research she put in "*approximately six to twenty weekly sessions*" (McCarthy, 1999, pg. 109), with some of the women. She claims that not all of these sessions would be just for interviewing participants to be used for her research purposes, namely they centred on individual sex education. This indicates the large amount of time McCarthy needed to carry out ongoing sex education in her post. In contrast the pilot intervention programme in this study had the disadvantage of being a single intervention comprising a total of six workshops covering a total of twelve hours of sex education. McCarthy was able to conduct both group and individual work with women with learning disability, whilst due to the time constrains the pilot intervention was solely based on group work with both males and females participants, thus limiting the potential intensity of involvement.

9.7.5 Referrals

Participants in McCarthy & Thompson's (1997) and McCarthy's (1999) sex education programme were referred by professionals working with them. There is no such referral system in place in Malta. GFN is a voluntary group that organises events and activities for people with learning disability, so the participants would have learnt about the group mostly through networks of people with learning disability. The two seminars carried out were part of 'live in' experiences organised by GFN and the researcher was aware that many of the participants in her pilot intervention programme would have attended the seminar because it was a 'live in' experience meaning that they would be away from home for two days, something which they would have otherwise rarely experienced in their lives. Spending a weekend with friends away from the parents was an adventure for many of the participants. The need for social activities in the evenings and on week-ends has in fact been notable in research (Schwabenland, 1999). At the same time parents of participants might have found this 'live in' opportunity convenient in that there is a certain stigma associated with respite and residential homes for people with learning disability in Malta. Parents take pride in looking after their children with learning disability without ever having to rely on such services, even when they needed them. The 'live in' activity would not have been perceived in the same light as respite care, but rather as something socially progressive and beneficial for their children. It might have also meant a short break for parents, who have lived with and taken care of their now adult children without breaks since the day they were born. Consequently many participants attended the 'live in' and seminars regardless of the subjects being discussed during the workshops. It was observed that for the second workshop, which covered more detailed issues such as intercourse and contraception, less participants attended, a likely consequence of the controversial content of the topics or the unwillingness of parents to allow their sons and daughters to engage with the issues.

9.7.6 Similar findings

The three sex education projects, the researcher's own, McCarthy's (1999) and Johnson *et al.* (2002) had basic similar findings.

- Family members and service providers created obstacles for people with learning disability to prevent them from establishing, exploring and enjoying their sexuality.
- Parents of people with learning disability were concerned about sexual abuse and the vulnerability of their sons and daughters with learning disability.
- People with learning disability lacked formal, appropriate sex education.
- There is a dearth of policies targeting people with learning disability especially in areas related to sexuality, sexual health and sexual abuse.
- People with learning disability experience social exclusion. Lack of friendships and social networks resulted in people with learning disability experiencing isolation and loneliness.
- People with learning disability express their wish to be in a relationship.

Nowadays various materials produced (McCarthy & Thompon, 1993; McCarthy & Cambridge, 1996; Cambridge, 1997b; Grievo *el al.* 2006) have made sex education widely available across the UK, Europe and Australia.

9.8 Concluding reflections upon the sex education workshops

9.8.1 Advantages and Disadvantages of the Seminar

The pilot project was a means of experimenting, analysing and learning from such initial interventions and new experiences. The first seminar consisting of three workshops, was carried out as a mixed gender, mixed ability group. This was the first step to initiating the sex education intervention. However analysis of the first three workshops demonstrated areas where change and improvements could be made. The first considerations for the sex education intervention was the fact that it was not an ongoing series of sessions, rather a one off programme, where topics are discussed only once in each workshop. Since all the participants had a learning disability, repetition on a weekly basis, would have been a more appropriate way for them to receive and retain knowledge and information.

A second issue, which was subsequently addressed in the second set of workshops in Seminar 2, was the mixed abilities in the group. Not every participant could consequently handle information at the same level. The amount and intensity of information would therefore ideally need to vary according to the ability levels of the group. The second group of workshops in Seminar 2, were grouped according to participants cognitive ability, which was an arrangement found to work better. The initial mixed ability group was also a large group, which was a disadvantage to both participants and to the person leading the workshop. This problem was also solved with the introduction of the smaller groups. The initial three workshops where a larger group of participant attended had both female and male participants. Even though the participants found no opposition to being in a mixed gender group, the leader felt that some of the participants felt uncomfortable with the situation and it was resolved that participation would have been higher had there been in a single sex group. In fact when grouped by gender (and according to ability) during Seminar 2, the male participants in particular asked many more questions and admitted they felt a lot more comfortable only being with other men. The female participants did not particularly comment about this situation but a more relaxed atmosphere was observed to have prevailed.

Other issues which did not originate from the participants themselves were related to the facilitators who delivered the sex education in the second Seminar. A possible interpretation is that although it had been discussed previously during staff training, some of the facilitations remained biased in their beliefs and opinions. For instance, two of the facilitators used religious imagery when discussing sexual practices. In one situation a facilitator was observed not to be objective, expressing personal beliefs when discussing the topic of contraception and the morning after pill. The facilitators had made a clear statement that the morning after pill was considered as abortion, which is sinful for Catholics, thus implying a strong religious bigotry.

Another issue derived from the terminology used by some of the facilitators. Although directed in terms of terminology, facilitators still tended to use self-chosen language which was inappropriate for educational settings. For example, more appropriate terms should have been used; the term "*qahba*" which is literally translated to whore was used instead of the term prostitute, which would have been equally understood and more acceptable. This is different from discussing and using slang words used by participants themselves

Other facilitators placed sex in the context of relationships. This is possibly due to the personal understanding of relationships of the facilitators themselves, as even during staff training they expressed disapproval towards sex outside relationships. Putting sex in context of relationships was probably also a more effective way of explaining to the group of participants, which was the group of women with relatively high cognitive ability, as their experiences of love and relationships are those they witness within their families and close relatives. The terminology used during this explanation tied into the latter issue as sex was referred to as *"jinhabbu - making love"*. Whether this was appropriate within an educational session is questionable, but given the context and the nature of the participants, this terminology might be adequate in terms of explanation.

9.8.2 Positive Outcomes

A number of positive outcomes were observed in both seminars. The participants showed interest, asked questions and passed remarks – in other words they actively participated as opposed to being simply recipients of information. They made their own observations, expressed their own opinions and shared their experiences with the leader and other participants in the group. Some of the participants were exposed to new information and asked for further details about several topics, some of which were then addressed in the second seminar (e.g. pregnancy, sperm and homosexuality), demonstrating an interest in learning more.

9.9 Concluding Key Recommendations

In conclusion this pilot project focused on the provision of sex education for people with learning disability and recommendations are set for further interventions to be carried out in a widespread manner and on a national level. Such projects primarily require that participants with learning disability attending sex education are recognised as adult learners (Johnson *et al.*, 2001). Formal sex education requiring State support and funding needs to be formally planned and provided universally.

It is important to consider ethical issues that sexuality raises in relation to people with learning disability. In dealing with personal issues such as sexuality, it is necessary to explore our own moral views, so that we can make thoughtful decisions about how to act in the best interest of others (Fairbairn, 2002). As part of sex education intervention for people with learning disability, staff working with this group of people 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). For this reason it will also be necessary to develop and implement a basic staff training programme on sexuality and learning disability which focuses on "*values, rights and responsibilities*" (McCarthy & Thompson, 1993). Moreover sex education and sexuality policies in educational settings and other services that provide for people with learning disability should be developed and implemented through a collaborative process with a range of stakeholder (Cambridge and McCarthy, 1997).

CHAPTER TEN

> ***"I envision a future in which there are no 'disabled sexualities', only human sexualities; a world in which difference is what we have in common".***
> **Rembis (2010, pg. 56)**

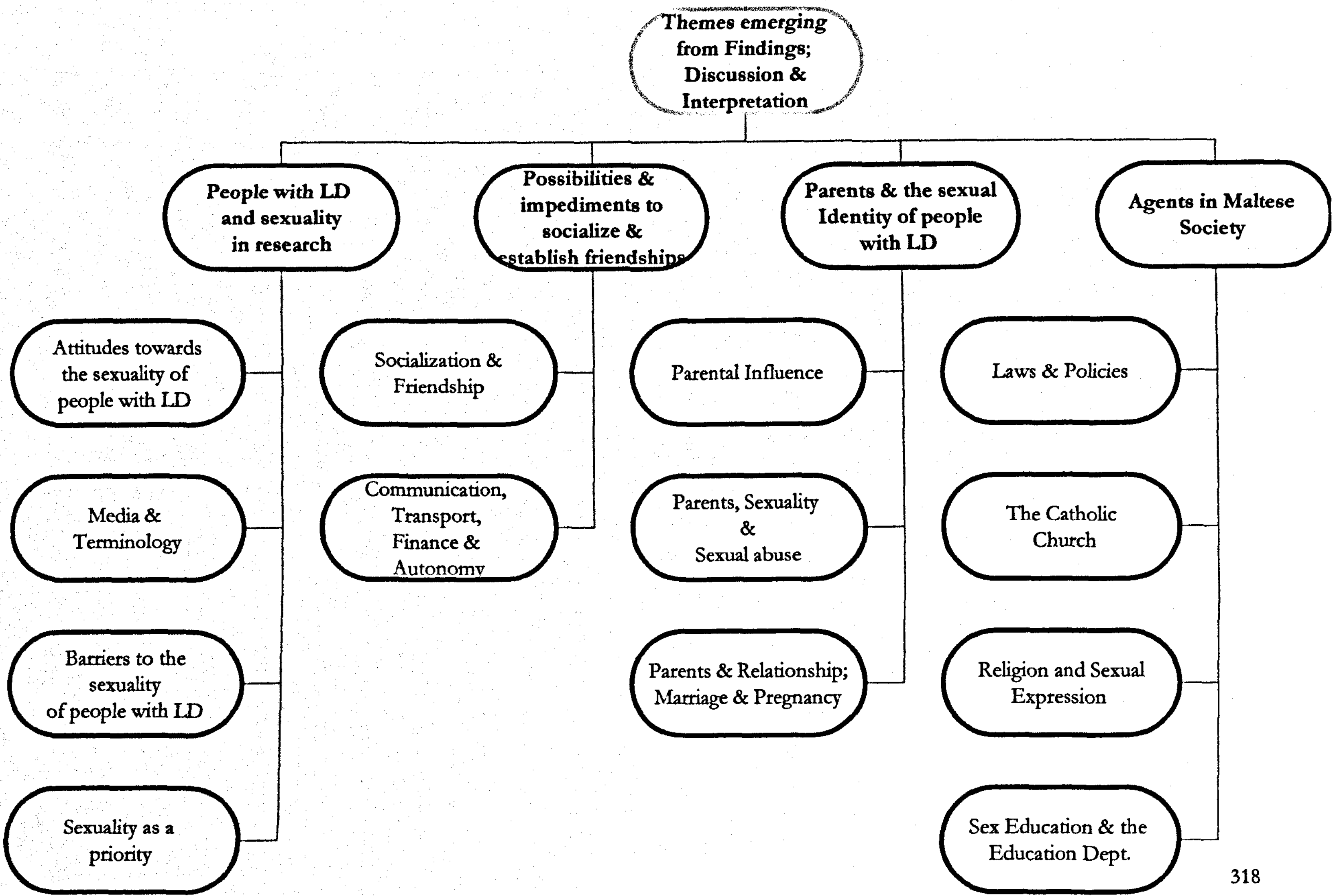
Discussion and Interpretation of Findings

10.1 Introduction

The data obtained through systematically gathered observations utilizing two data collection techniques, mainly interviews with three groups of participants and focus groups, were reproduced then analysed using a rationale that employs thematic analysis. The thematic analysis which employed a qualitative approach was used to investigate the aims set for the research study. Such aims explored the current experiences which people with learning disability have in relation to the development of their sexuality, their sexual expression and experiences in Malta.

The themes chosen for analysis were the ones that emerged strongly from the data that was collected from the three groups of participants; they are outlined in the table on pg. 310. Themes earmarked for this purpose were not only the most commonly mentioned, but were also the most avoided. Other themes discussed were those underlying the opinions of the participants, on a cultural level for instance was the fundamental discussion about the influence of religion in relation to this particular topic. The themes discussed are important as they mirror the lives of people with learning disability in Malta, from how society looks at them to their inclusion in mainstream school and in the community. The themes reflect the ways in which cultural and social influences put stresses on their sexual identity and in turn impact society's beliefs.

10.2 Discussion and Interpretation of Findings



10.3 People with learning disability and sexuality across different research

10.3.1 Attitudes towards the sexuality of people with learning disability

At the very roots of society lie the attitudes that influence the lives of people with disability. Disabling attitudes and structures have made an impact on people with disability, robbing them of opportunities, experiences and equality. Attitudes not only affect the lives of the people involved but also the beliefs of their parents, guardians and service providers. Social attitudes towards people with learning disability were a common theme with all three groups of participants in the study (see Findings 7.4.1). Social attitudes were discussed in relation to a cross section of environments that people with learning disability experience, such as inclusive education environments which were typical of the environments that parents of people with learning disability referred to. People with learning disability, their parents and service providers also made reference to the wider community and society's attitudes towards people with learning disability, with an accent on the way society interpreted the sexuality of people with learning disability. Since Malta is considered to be a Catholic country, as expected the religious aspect is ingrained in the culture. In this study this was found to affect the way society looks at people with learning disability and their sexuality. Both service providers and parents frequently referred to the relation between the sexuality of people with learning disability and religion in the context of Maltese society (Finding 7.4.3; 8.5.1).

Research from various countries such as the U.K. and Ireland also refers to the attitude society exhibits towards people with learning disability, in particular towards their sexuality. As with the findings drawn from this study, contrasting findings in existing literature implies that there are mixed feelings about people with learning disability and their sexual identity. Wheeler (2004) on the other hand claims that there has been a more positive outlook towards the sexuality and intimate relationships of people with disability in the UK since 2000. Wheeler (2004) claims that the legislation, although not the attitude of the general public, concerning sexuality has nowadays changed. Contrastingly Selina (2008, pg.4.2) who conducted research in areas of sexuality in an Irish context, claims that:

> *"Society at best finds the thought of a disabled person being sexual, repulsive and at worse presumes they are asexual".*

Similarly Morris (1989, pg. 80), herself a person with disability, brings to light an interesting phenomenon, emphasizing that;

> *"Many people assume we are asexual, often in order to hide embarrassment about the seemingly incongruous idea that such 'abnormal' people can have 'normal' feelings and relationships?"*.

Asexuality was also a widely discussed issue by participants in my research. Mona as cited in Selina (2008, pg. 2.1) highlights the fact that;

> *"Societal notions of asexuality and infantilization of people with disabilities have glazed over the fact that adults with disabilities have choices and rights that include sexual and reproductive health"*.

In her writing, Selina (2008, pg. 4.3) renders a picture of how people with significant impairment have typically been raised in Ireland.

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

The latter portrait also typically reflects findings of interviews carried out in Malta in this research as well as interviews carried out by Wheeler (2004) in the U.K. An interviewee, (a young woman with learning disability aged 25), in the present study reported that any outdoor activities, whether a ride in the car around town, a wedding or a barbeque organised by the adult training centre which she attends, was for most part undertaken with her whole family. Other interviewees mentioned the names of their assistants or of other people working with them when they were asked if they had friends, thus reflecting the exact findings of Wheeler (2004).

Selina (2008) reports that she did not explore areas of sexuality related to people with learning disability but kept her research focused on people with physical impairments. This she admits was because participants with learning disability were not available for her research. Selina (2008, pg.1.1) defines a person with disability who uses the services of a Personal Assistant as a Leader.

> *"I have neither encountered, nor heard of, any learning disabled Leaders in the Irish Independent Living Movement*".

In contrast with other countries, such as the U.K., Malta lacks active movements formed and led by people with disability in general, let alone movements led by people with learning disability or movements working for disability and sexuality issues. Azzopardi (2009) confirms that when it comes to disability politics, parents are the only political and organised lobby that exist in Malta. He asserts that in the local context at present people with disability are:

> "*clustered in impaired-based groups*", the agenda of these groups is dominated by "*charity based campaigns... which often demean and humiliate disabled people... and a compulsive need to create more services.*" (Azzopardi, 2009, pg.51).

Azzopardi (2009, pg. 47) reaffirms that;

> *'The absence of a disability coalition in Malta and the need for disabled people to be organised so that they can dictate their own agenda, contribute to developing policy and ultimately experience political power and control'.*

Therefore local literature and research in the area of learning disability, especially literature related to disability and sexuality was very limited. Yet, Ireland and Malta both in the present and in Selina's (2008) study seem to have a common issue with traditions around sexuality and people with disability. As Selina (2008, pg.2) affirms;

> *"Traditionally there has been a taboo around discussing sex and related matters in public. Sex was for marriage and procreation, and disabled people were not expected or encouraged to experience either."*

Likewise Martin (1995, pg. 45) claims that;

> *'There is an astonishing lack of research about the attitudes of Irish people towards their sexuality and almost none about the views and experiences of people with disabilities. While our sexuality is an inherent element of each individual's life and life path, it is clearly influenced and defined by culture and society, which sets the standard for feelings and behaviour which are acceptable or unacceptable."*

In discussing the Maltese context in my research, I described society's attitude towards sexuality and underlined how this limits the sexual expression of people with learning disability. Similar findings by Johnson *et al.* (2002) claim that attitudes of service providers and families present obstacles to the development of relationships and sexual lives of people with learning disability. The majority of Maltese participants commented on the fact that people with learning disability do not really understand that sexuality came with responsibilities, believing the latter notion to be alien. Others simply opposed the fact that people with learning disability should have an active sexual life, due to the possibility of procreation (hence disregarding the possibility of effective contraception), whilst having a family and raising a child was simply out of the question.

In her research about sexuality issues in Ireland, Selina (2008) depicts a situation which seems to mirror the situation here in Malta, where sexuality and learning disability seem not to be related.

> *"Although fewer people with physical and sensory impairments are growing up in institutions in the Ireland of the 21st century, there are still many barriers in society which preclude disabled people from becoming independent, active, valued members of the community. The result of these factors is that disabled people have often been denied the opportunity to develop or explore their sexuality and they have certainly had little opportunity for sexual expression".*
>
> (Selina 2008, pg.4.3)

Selina (2008) mentions a number of studies and articles by researchers such as Morris (1989), Owens and Child (1999) and Shakespeare (2000), that document the fact that many non-disabled people genuinely believe that disabled people are incapable of sexual expression or sexual pleasure. Hamilton (2009, pg.3) also maintains that beliefs that equate learning disability with *"an inferior, abnormal, unequal and subordinate social position"*, jeopardize their sexual equality. Selina (2009, pg. 2.1) also asserts that;

> *'Many never consider that disabled people also require access to services related to sexual expression such as adult shops, family planning clinics, adult websites, pubs and clubs and other places where social relationships are formed, or services are provided".*

Selina (2008) asked her participants if they thought that society views disabled people as sexual beings, the replies she gathered were rather negative, just like the ones collected from parents of people with learning disability in Malta in this study. One parent participating in the present research recalled the negative attention encountered by her son with learning disability when he took his girlfriend with Down's syndrome out and especially when they used to kiss in public. Similarly Selina (2008, pg. 4.2) reported;

> "*We are just there to be cared for and we don't have any desires or any needs ourselves and 'who could love us anyway?' is what society at large thinks, I think*" (Rose: Interview)

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

One of Selina's (2008 pg.4.2) interviewees maintained that in relation to sexuality and people with disability, society was;

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

In her research Selina (2008) also found that people with disability see sexual expression as a need, not simply something one wants. This I believe can also be generalized to the context of people with learning disability in this research. Selina (2008, pg.4.2) maintains:

> "... *I noticed that sexual relief has been referred to as a need, which is similar to pain relief, whereas sexual expression is referred to as pleasure and a want or desire. ..... I asked the interviewees.... 'Is sexual expression a need or a want?' All of the leaders interviewed believe that sexual expression is a need".*

One of Selina's (2008, pg 4.2) interviewees said;

> *"Yes it's a need. I can't think of anything sadder than any individual with a disability, or without, who wants to do something sexually and who never, ever got the chance to do it. Choosing celibacy is fine but many people with disabilities have a forced choice not to participate"* (Glen: Interview)

Shakespeare (2000) concurs on this interviewee's last point and maintains that;

> *"Most people are not looking for sex itself, they are searching out intimacy, warmth, validation, connection, relationships, and the importance of friendships, rather than sex. They are looking for physical touch, something often lacking in disabled people's lives"*.
>
> Shakespeare (2000, pg.164)

On the same note participants in this research replied in similar terms reported in Findings 6.6 and 6.7, underlining loneliness, isolation, desire and the need to be in a relationship. Ratzka (1998) concludes that to overcome the negative attitudes of society there is the need for support, in order for people with learning disability to share experiences and insights as well as to recognize that they are not in this situation alone. He adds that:

> *"By learning to appreciate each other as the capable, interesting and caring people we are, we can immunize ourselves against negative attitudes".*
>
> Ratzka (1998, pg.1)

10.3.2 Media and Terminology

It was observed that the majority of people interviewed had what could be called 'inappropriate terminology' when referring to people with a learning disability. Both parents and service providers used words which could be described as demeaning and stigmatizing. People who were over forty were seen to use inappropriate terminology more often. This latter group of people consisted of both parents or services providers, although this was mainly the case for people who did not work in close proximity to people with a learning disability, such as in services for pre marriage preparation. Such terminology included the word "*mental*" short for mental retardation, when referring to people with a learning disability. Other terminology included the word "*problem*" when referring to a disability.

On the theme of sexuality and people with disability, the parent of a forty year old woman with physical disability, in an article published in the local Times of Malta (20th August 2009) by journalist Galea Debono that discussed collective independent living, claimed that;

> *"I am aware of the possibilities that could result and I believe males and females would need to be segregated at night".*

His belief that sexual and intimate relationships happen only during the night and that gender segregation needs to take place, reflect the mentality and the attitude very often found in the typical Maltese population.

Other fine examples in this article are the terms used throughout. The term "*mental problems*" is used very probably to describe both people with psychiatric disabilities and those with learning disability, without distinction between the two. The phrase "*confined to a wheelchair, but otherwise fine*" leaves not much to be said about the way people in Malta, even parents of people with physical disability in this case look at people with learning disability. The wheelchair is no longer, or has never been in this case, a mobility asset, and a person is only fine if he does not have a learning disability. In another article in a local magazine, Bezzina (2009, pg.1) used the same kind of terminology. Her article's introduces three women with;

> "*Special physical needs...all experiencing the hardships of living with severe physical special challenges. By bringing out their stories in the open I hope to free them, and women like them, from the isolation of thinking that it is their problem or that they are alone.*"

It is also noticed that the women with disability in the article, themselves use outdated terminology reflecting the medical and the charity models Maltese people have been influenced by. One young lady stated;

> "*I suffer from uncontrollable jerky movements, stiff muscles and lack of coordination*"

Other forms of reference and terminology made by the journalist included "*suffering from a condition*" and "*constrained to a wheelchair*".

The chairperson of the National Commission for People with Disability in previous years commented about a video clip used for charity purposes in this manner.

> *"I am writing to you more as a disabled person, than in my official capacity as KNPD Chair. Look at this advert, personally, I am 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 insist 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".*

In general parents commented about the lack of exposure given to disability in the media in Malta. It was felt this did not allow society to get familiar with or relate to idea of disability. The media can act as an oppressive tool which can misrepresent people with disability, and this imagery remains largely unchallenged (Priestly, 1999; Mason & Reiser, 1994, Azzopardi, 2009). The media lately was implicated in the negative image of people with disability portrayed by one local and one foreign politician in two separated instances. In one instance, local politician Leo Brincat (2009) was being interviewed live for a media channel, and when asked if he could stand up, he replied "*yes, I am not disabled*". There was obviously an outburst by the few politically active people with disability who made their opinions known through internet social network mediums, such as Facebook. Unfortunately no one wrote about this in the newspaper and confronted the politician, who on his part merely sent his apologies back through Facebook. In the other instance President Barack Obama in a TV show, compared his bowling skills to those of a Special Olympics competitor. In this case before Barack Obama's interview was aired on the Tonight Show, the White House acted quickly in order to hush up an uproar the comment could have instigated. Two hours before the show went on air, White House spokesman Bill Burton made a brief statement to the reporters on Air Force One:

> *"The president made an off-hand remark making fun of his own bowling that was in no way intended to disparage the Special Olympics. He thinks the Special Olympics is a wonderful program that gives an opportunity for people with disabilities from around the world."*

Huffington Post (23 rd August 2009)

In a recent news paper article, a parent of a 40 year old woman with disability forwarded an appeal to other parents of people with physical disability *"like her"* to come forward and discuss possibilities of independent living. The way the article was articulated reflected very little knowledge about the politics of disability from the journalist's side, not to mention the attitude adopted by the parent addressing the article. It was for instance the parent who negotiated the interview with the journalist although the person with disability in question did not have any sort of learning disability. The hierarchy of disability was very evident as the parent commented about the fact that:

> *"Church and state homes only cater for persons with mental problems, who are a bigger burden on their families"*.

(Parent of a person with physical disability cited by Galea Debono, 2009)

Firstly the use of the term "*mental problems*" needs to be analysed, since in Malta there is a tendency to use the words and meanings of mental health and learning disability interchangeably. This phrase portrays a negative image of people with disability, especially as the word "*burden*" has a disparaging and demeaning tone. The journalist continues to discuss the quality of life of the woman with physical disability, stating that she lives with "*persons with mental issues, with whom she could not communicate*". Unfortunately her poor quality of life is attributed to the type of people she is living with rather than the management of the accommodation she is set up to live in; "*after a day's work she has to lock herself up in her room, away from their screaming*".

Priestly (1999) acknowledges that newspapers focus only on a limited number of disability issues, usually relating to fund raising, charity events or personal interest stories. In addition the language used to report such issues is frequently oppressive, tending to generalise, patronise and marginalise the experience of disability.

Another instance of outdated and inappropriate terminology was used during a television discussion show, specifically enquiring about the sexuality of people with disability. The guest at the show was a person with physical disability. The term mental illness was used by the host to refer to people with learning disability on national television. He was prudently advised by the guest that mental health and learning disability were completely different subjects. A service provider in the research claimed that progressive images of people with disability are being actively inhibited or excluded by various entities, including the media. Priestly (1999) claims that the recent growth of charity advertising further represents disability as a tragedy. The local abundance of charity-based "*heart breaking*" appeals project people with disability as "*in need*" and reinforce the "*tragic*" imagery of people with disability

(Azzopardi, 2009; Priestly, 1999). The service provider explained that the media favours the use of stereotyped symbols; portraying people with a learning disability as sexually out of control or as asexual beings, from the deformed sexual predator to *'Snow White and the seven dwarfs'*. He gives an example of the portrayal of people with disability in books, referring to Snow White who he describes as a very beautiful young woman but she was all right, as nobody thought any wrong because she lived with seven dwarfs, as they were dwarfs and so it didn't matter, he explained. He concludes that the media sends out very damaging images, either by portraying people with disability as superheroes or as super victims, as all extremes sell and make good TV and good publicity for selling newspapers.

This same service provider was interviewed by Micallef (2006) for a local Maltese newspaper, following his disagreement with the way people with disability where portrayed in a televised fund raising variety show that was aired around Christmas time. The newspaper article (translated from Maltese) read;

> *"The filming of people with disability or of sick people that were screened during the programme 'L-Istrina', touched people's hearts in different ways. There were those who felt sorry for them and gave their donation, (maybe also to get a chance to participate and win one of the prizes available), and there were those who did not have the courage to look at the suffering these people have to go through, and just changed channel".*

The article continues by stating that:

> *"The clips screened during this show were intended to reach a fund raising target...that is ....to touch the heart of the people watching the programme, so that they donate. As I see*

it, so as to touch someone's heart you are not going to show joyful images, but you are going to press onto the person who is broken and sad, I personally don't like these type of images…no mater who uses them…. When you show these kind of images so that other people take pity on the person, you are depriving that person of his humanity… ….money will not solve all the problems…it can lessen current problems but money alone does not solve problems, and its wrong to make people believe that it does.

…it is also about time that as a society we become more mature in the way we celebrate festivities such as Christmas. There is a need to stop portraying wealth alongside misery so that wealth is better appreciated.

Although I do blame the media for displaying these images, I also blame the public. When these issues are discussed with representatives of the media, they admit that unless they display these images, people do not donate money.

….It is also true that a lot of people with disability do like playing the victim. Certain times the person who is the victim is given privileges that she/he otherwise would not have. For them the privileges are more important than their dignity. But I myself do not agree with the principle that the end justifies the means.

….Several times in any fund raising campaign, the impression that is given, is that the money will bring a cure to the disability… and the truth is not necessarily this.

The clips usually portray a person, on her own, which gives a sense of isolation. This is not necessarily the case…many times the filming is stripped of colour and is shown in black and white, so that it looks sad. Then they are spiced up with some tragic music from films like The Pianist or Schindler's List so that they transmit an even sadder

> *feeling. They are even shown in slow motion, so that the person with disability appears to be sinking in the problems.*
>
> *....The repercussions to these images are big, especially when people with disability are seeking employment, as the general impression is that people with disability are not productive and depend on others....we are trying to escape the imagery that people with disability are a weight on society but these images are showing the opposite.*
>
> *There is an element of voyeurism in programmes such as "Tista tkun int" (It could be You!). in the olden days people used to gossip from behind their window louvers, as Maltese culture goes...nowadays instead of staying behind the louvers, people stay infront of the TV. Many are those, although they do not admit it, enjoy watching other people's tragedies, as it's a consolation for them that they are not in the same situation.*

Recently in a personal communication on a social networking site, a service manager for a local NGO that provides a variety of leisure and therapeutic services for people with disability stated that;

> *"We always try and put a positive message across but it means we sacrifice fundraising income, which means less for the beneficiaries. Catch 22".*

This statement reflects a managerial outlook, focused on financial aspects but obliged to comply with pressures made by people with disability themselves to expose people with disability in the media in a dignified manner. It transpires that in Malta most NGOs do not have people with disability at managerial level influencing the way people with disability are portrayed in the media. Azzopardi (2009) asserts that the charity model encourages a mentality that states that people with disability are to be treated in '*a special kind of way*', as long as this creates enough sentiment and emotion.

The worst effect of charities according to Mason and Reiser (1994) as cited in Azzopardi (2010, pg.34) is *"the way they separate disabled people from non-disabled people"*.

10.3.3 Barriers to the sexuality of people with learning disability

The findings of my interviews with people with learning disability and their parents brought to the surface evidence of obstacles faced by people with learning disability which in turn impact on their opportunities to socialize and to form friendships and relationships. The participants living at home as well as those in community houses, in parallel to findings in Wheeler's (2004) studies, were found to have low levels of control over the activities they do in their leisure time, if they do any activities at all. McCarthy (1999) had also reported that the overall situation for people living in community houses was minimally better than those living in institutions with regards to control and sexual pleasure. Hamilton (2009) underlines that significant forms of support are required for people with learning disability to engage in safe and fulfilling sexual lives.

Pownall (2010) underlines that social exclusion not only limits access to formal sources of information but also to opportunities of establishing relationships. This association seems to be limited as Selina (2008) also finds that government policy tends to assume that social exclusion is about not having a job, and that the only way to be socially included is to get qualifications, training and paid employment. A service provider in this research had also agreed that key issues usually pursued by service provision are education, training, housing and health

Davies (2000, pg.1) maintains that;

> *"It is fine to be celibate and single, if it's by choice. However, ableism, body fascism, and economic disadvantage are key social factors that cause many disabled people to remain single and isolated against their will."*

Participants in Wheeler's (2004) study who were involved in groups formed by people with learning disability claimed that being part of these organisations allowed them more leisure and social activities. The use of internet chats, Facebook and Hi 5 as well as mobile phone texting all proved to be excellent resource for communication, for those who could access it. However, Wheeler (2004) states that high call charges and limited income did constrain this resource as well. Interviewees mentioned lack of access both with regards to means of transport and to places frequented by young people, also citing lack of sex and relationship education at school and limited independent living opportunities. Wheeler (2004) also underlines the restriction of autonomy in living arrangements expressed by his participants; he claims that simply moving out of the parental home does not necessarily result in an increase of the individual's independence.

The latter opinion also applies to other living arrangements, and was a similar opinion expressed by service providers and participants with learning disability who lived in community houses.

Selina (2008, pg. 4.3) similarly maintains that;

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

The above issues relate to opinions expressed by Shakespeare (2000) and also to findings in my own interviews with people with learning disability and service providers reported in Findings 6.1; 6.5; 6.9; 6.11; 7.7.1; 7.5.1 and 8.4.1.

Wheeler's (2004) findings bring to light an overall picture which describes people with learning disability as leading restricted lives even when not living in institutional settings. Simons *et al.* (1989) had also reported similar findings stating that although people with disability preferred living in the community than in institutions, their social lives were still restricted. As with the participants in my study, Wheeler's (2004) participants reported they didn't have enough privacy. Parents of people with learning disability as well as service providers in my study also claimed that they would want to have a say in any sort of relationships, this ranged from just keeping an eye on the couple and intervening when there were times of difficulty to intervening about the depth of the relationship. Some young people with disability thought that their parents wouldn't like it if they had to have a sexual relationship as confirmed in Findings 7.7.2 and a service provider in Findings 8.7.1.had claimed that he doubted seriously whether the residential setting would allow an intimate relationship.

Hamilton (2009) insists that people with learning disability find the support of those working directly with them crucial, when it comes to forming friendships and intimate relationships. Interestingly enough a common phenomena among Wheeler's participants was that parents, families or paid carers were seen as being able to determine whether or not these participants could express their sexuality in any other form rather than a limited form of heterosexuality.

As one of Selina's (2008, pg.4.2) interviewees puts it:

As one of Selina's (2008, pg.4.2) interviewees puts it:

> *'If we wanted to we couldn't, and if we could we shouldn't"* (Glen: Interview)

Shakespeare (2000) also underlines that barriers to sexual expression are primarily social, he mentions financial barriers and he affirms that self-image and socializing require monetary assets. On this Ratzka (2002, pg. 2) echoes;

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

10.3.4 Sexuality as a Priority

Hamilton (2009) maintains that it is a common belief that people with learning disability do not have "*sexual drives*". *Valuing People* (2001, 2009), the governmental white papers issued in the U.K., also emphases the importance of the acknowledgement of the sexuality of people with learning disability. These papers identify the need for people with learning disability to understand their sexuality and to have opportunities to form relationships as with the rest of society (Clarke & Cropley, 2010). In her research based in Ireland, Selina (2008, pg. 2) reports that;

Selina (2008, pg.2) discusses the issue of sexuality with participants with disability who were part of movements for people with disability, who state that sexuality:

> *"hasn't been seen as important as some of the other battles".*

Such answers reflect those presented this research's findings.

In the present research a service provider reported that currently in Malta social benefits don't give you enough to live on, but are rather regarded as pocket money, which will not allow you to buy food, clothes, housing and transport expenses. If a person with disability is not employed with a stable income, the disability pension will not allow him much opportunity to socialise and to show himself at his best. He acknowledged how non-disabled young people get into sport, showing their qualities in terms of physical strength, beauty and ability. On the contrary people with disability do not often have much physical ability to display and might not get the opportunity to do this, he claims. He refers to people who are wheelchair users as an example, who have great difficulty with clothes and find that their clothes don't fit properly. Very often their clothes are too big because parents or they themselves buy clothes simply because they are easy to put on and are easy to take off. He also referred to the line of thought of some parents who do not believe that people with disability need clothes that make them look attractive, because they believe they will never find a partner. He concluded that while there are many opportunities for young non-disabled people in which to indulge in the game of sexuality, for young people with disability there aren't.

Morris (2001, pg. 4) concludes that participants in his research described social exclusion as

> "*...finding it difficult to do the kinds of things that non-disabled young people their age do, such as shopping, going to the cinema, clubbing, etc.*"

A Maltese service provider reported identical findings where he insisted that there is a policy lacuna in many areas and that a policy on sexuality is not necessarily at the top of priorities of the National Commission for People with Disability. He underlined that this was not because it was not important, but rather that there were other issues that took priority, like mainstream educational issues and employment. He made reference also to the issue of care support for people with disability who have lost their parents or whose parents are not able to look after them any longer. In Malta young people with disability are likely to be cared by their families even though they might like to consider living independently. He also added that the National Commission was a small entity and it was not like in foreign countries where critical masses of people were interested and worked on a particular issue.

On this topic Selina (2008, pg. 2) maintains that;

> "*It is really only in the past decade, particularly with the growth of the disabled people and independent living movements, that disabled people are starting to question why social, leisure, relationships and sexual expression have not been addressed with regards to access and support services*" (Equal Status Act, 2000)

Yet Selina (2008, pg.4.2) adds that personal assistants in her research believed that a lot of people with disability were much happier when they were in a relationship. She concludes that:

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

10.4 Possibilities and impediments to socialize and establish friendships

Social relationships are reported to be associated with positive outcomes, such as happiness, high self-esteem, confidence and good mental health (Forrester-Jones *et al.* 2006). The present research aimed at recognising and reading the possibilities and impediments young people with learning disability encounter at establishing friendships and socializing. The findings from all three participating groups have friendship as a common theme. The emphasis on this theme by all groups of participants indicates the importance this issue has in the life of people with learning disability. The following discussion interprets the findings that emerged from all three participant groups and compares them to findings in other research studies carried out internationally. The findings displayed an imbalance between the possibilities and the impediments. Impediments could be classified both as physical and as situational. Key elements were recognised in the findings and are discussed here;

10.4.1 Socialization and Friendship

Stronger focus on policy and practice that empowers a range of different social contexts from which to derive potentially supportive networks is required so as to contest the segregation experienced by people with learning disability (Forrester-Jones *et al.* 2006). Inclusion of people with disabilities in social networks so as to establish friendships is not common practice in the Maltese community. In fact, negative attitudes towards people with disability in wider society still stand, as evidenced by the participants with learning disability and their parents in this study. People with learning disability themselves reported that their image had been portrayed in a biased and disabilist ways, bared as people in need - especially in need of money. Playing on society's emotions so as to collect money, not only in Malta but in general, has worked against the integration of people with disability in society, as their image remained connected to those emotions of pity displayed by the media.

Cheng and Urdy (2002) in their research on sexual behaviours and people with physical disability found that their participants remained socially isolated, and that the more severe and visible the disability, the poorer the body image and the lower the emotional well-being of the person. Although it is not absolutely necessary to socialize so as to establish friendships or even relationships it is usually an asset to and an opportunity to meet people. Throughout the interviews with young people with learning disability, their parents and service providers, the researcher found that opportunities and possibilities were hindered by a series of factors. Yet the possibilities existed and a few participants showed resilience. In my findings, as with Wheeler's (2004) findings, individuals referred to as friends by a majority of people with learning disability were sometimes either relatives or other people who worked with them, only a minority had friends other than these two kind of persons. In my research a young woman with learning disability referred to people employed to work with her as her friends.

All parents in this research expressed concern about the fact that their children didn't have friends and a social life. This finding does not seem to be exclusive to the Maltese population as international research has made the same claims (Jahoda & Pownall, 2010). Parents claimed they felt sorry about this situation because they had expected school friends or their extended family, such as cousins, to keep in touch and include their children in activities they organised. Parents called this situation "*loneliness*" and the majority stated that their children went to school and back home and went nowhere else. They also wished that there was some kind of entity that took care of these activities, some agreed that it was important to mix with non-disabled people but some did not mind if it was just people with disability mixing together as long as they went out and did something. The prospects to meet and maintain friendships seemed to be mostly possible within circles of people with disability themselves, like in the case of some of the participants who made part of a swimming team for people with disability. Leisure has been an area which has been reported to lead to friendship, integration in the community and to social networking (Srivastava quoted in Forrester-Jones, 2001) The experiences of people with learning disability in Malta mirror the experiences of Australian people with learning disability in the findings of Johnson *et al* (2002) who experienced "*loneliness and isolation*". A further rather revealing and frustrating fact is that the least successful of all the recommended strategies at the end of Johnson's *et al.* (2002) project was the breaking down of the barrier towards socialization. Services in fact claim that sustaining friendship networks for people with learning disability is one of the greatest challenges (*Valuing People* , 2001). Prevailing negative attitudes was one of the reasons they gave for the lack of success of this strategy. Pownall (2010) also refers to the marginalised social position of people with learning disability, linking this to their developing sexuality. As reported in the Learning Disability Day Service Reform report (2010, pg. 17), the white paper *Valuing People* (2001;2009) underlines how people with learning disability should *"not be left isolated and that services should provide them with a stimulating environment in which to meet others, and form relationships"* (Clarke & Cropley, 2009). Such initiatives outlined by the Department of Health (2001) suggest that person centred planning encompasses the facilitating of friendships and the development of new community contacts.

A minority of young people with learning disability who participated in the current research study and who had a higher degree of learning disability showed more dependence on their parents and other people to organise their social life and keep them networked with their friends. They socialized with other people with learning disability rather than with people who did not have a disability. It was evident that the parents of these young people organised get-togethers and outings for their children as they needed their support to do this. Young people with learning disability often were encouraged by their parents to make friends and socialize, although at times these same parents tended to be very overprotective over their children and treated them not as young adults but still as children (Pownall, 2010). Although the majority of parents were in favour of their children socialising, at the same time they were apprehensive of allowing them to be independent, even in cases where the disability was very mild and not physical. This was possibly due to the fact that this was a new experience also for the parents. Some parents even found it difficult not to supervise them when they went out. Yet it seemed some parents did not make enough effort on their behalf to organise activities or to encourage and establish these networks. They considered activities to which they also attended on the same level as a social event where their children would be only in the company of their friends. Some parents contented themselves with the fact that their children, although young adults or teenagers, went out with them, for meals or to family activities for instance. Some of the people with learning disability, who participated in the research, seemed to attend only occasional pre-organised events. In some cases some of the activities they attended were family events, such as barbeques and weddings. Very few parents saw friendship and socializing as an important factor to their children's quality of life besides their health.

The introduction of inclusion of students with learning disability in mainstream schools surely supports the concept of the social integration of people with disabilities, but again students with disability themselves reported little if any close friendships with their non-disabled peers once in secondary school. The importance of socialisation with non-disabled peers as a means for people with learning disability to learn the social etiquette of friendship is highlighted by Noonan & Gomez (2010). One service provider, who worked in a college for students of post secondary age, commented that it seemed as if it did not look cool to hang around with people with disability when you're a teenager. All participants with learning disability in the research stated that their school peers had not kept in touch with them after secondary school. A number of young people with learning disability who attended a college setting, found it hard if not impossible to socialize and integrate with non-disabled people as they were always accompanied by a non-disabled adult, such as a learning support assistant. They also tended to remain in a group with other students with learning disability. Their parents also regarded their academic life and their academic and vocational aims as more important then establishing friendships and being part of a social network. Although their parents did wish for their children to socialize, there did not seem to be enough interest as they did nothing about organising transport and logistics for activities they could attend.

10.4.2 Communication, Transportation, Finance and Autonomy

Studies have reported how the degree of learning disability is a strong predictor of objectively measured quality of life variables, including the range and frequency of social activities (Forrester-Jones *et al.* 2006; Stancliffe & Lankin, 1999). In many cases meeting and maintaining friendships even with non-disabled people was also possible as long as there was a good means of communication available (Cambridge & Forrester-Jones, 2003), such as mobile phone texting, but especially through online social network places, such as chat, Facebook and Hi Five.

Two of the people with mild learning and physical disability in the research both had networks of friends which they had established and maintained through the internet. This reflects their capability to access the computer, to use a keyboard or verbally communicate, to read and exchange communication with other parties. Both these two young women socialized with the friends they had made on the internet in the Maltese community. Their friends supported them and regarded them as any other friend without a disability. Such methods of communication seem to have added to the opportunities and quality of life of many people with disability (Noonan & Gomez, 2010), subject to whether they have the means to access them. It seems though that these resources are restricted to people with certain levels of ability, both physical and intellectual, for instance the fine motor skills to use a keyboard or a mobile phone or the cognitive ability to spell. The majority of young people in this study didn't have the skills to access the internet and to chat and get to know people over internet, either because of cognitive abilities or skills they lacked. People with learning disability who do not have these skills seem to remain further marginalized due to their restrictions.

Impediments to socialise due to physical disability and accessibility were an issue to many people participating in the study. Young people who require special transport needs had to rely on their parents for transport, and while this was not always possible, it also restricted their independence (Forrestor-Jones, 2001). As a means of transportation all people with learning and physical disability depended on their parents to get to the places they required. Having physical disability meant that they needed specific transport facilities and most were fully supported by their parents. Others found it taxing and sometimes discouraging because places were not accessible. When going out in the evenings in a group, it was always important to choose an accessible place and to book ahead if necessary.

Lack of income also impacts on the opportunities people with learning disability have to express their sexuality. Wheeler (2004) claims that employment would have positive effects on various aspects of the lives of people with learning disability, including forming networks and social relationship, improving self-esteem, assisting in overcoming prejudice and stigma and providing material rewards, with which goods and service can be purchased thus facilitating increased levels of independence.

Activities such as buying fashionable clothes and makeup, going to pubs and clubs, hiring accessible transport, purchasing or accessing adult material, hiring a prostitute or going on accessible holidays can be prohibitively expensive. Transport in particular was mentioned by participants with learning disability in my research, as many had physical disability and required wheelchair accessible transport. They therefore depended on their family to drive them to and fro, as renting accessible transport is very expensive in Malta. Several researchers (Wheeler, 2004;

Nunkoosing & John, 1997) have agreed that this could be considered as limiting the opportunities for community participation and for meeting people who might potentially become friends. Findings from the participants in my research varied, from those whose parents financed all their expenses and who lived very comfortably, to those who lived on their disability pension in community houses, while their lifestyles varied according.

Ratzka (1998, pg.1) insists that;

> *'For many of us who have extensive disabilities our sexual liberation does not so much depend on sex counselling or mechanical sex aids but on the availability of tax-funded personal assistance services which empower us to take control over our own lives".*

Since finance has been one of the priorities required to achieve further independence the importance of direct payments cannot be overstated. In Malta as in Ireland we do not have a system of direct payments, whereby the person with disability receives funding to directly buy in the services they need. This kind of situation deters people with disability from being allowed to spend their income on something like a personal assistant required for facilitated sexual expression, which in Ireland is a service to which people with disability are entitled. Selina (2008) explains that since the person with disability is not empowered to directly buy in the services they need, they often have to spend months, or years on waiting lists in order to access under funded and overstretched public services.

The two women with learning disability referred to here above, were capable of meeting their financial requirements. One of them had a job while the other was financially well supported by her parents. This meant that they could buy and wear fashionable clothes, and cater for the needs women have, like hair and make up, accessories etc. Both these young women had the opportunity to show themselves at their best in public places with their friends. With regards to people who had a greater degree of learning disability, parents needed to support them financially and planned their outings as well as their transportation, even if they were mobile. The parents of these two young women believed in the importance of good quality of life for people with learning disability considering it more important than their academic and vocational life. When quality of life was not encouraged by the parents, as was the case with other young people who participated, the latter often found themselves marginalized and lacked a social life and a network of friends. One common trait in both these young women was their determination and their assertiveness. Throughout the life experiences they encountered, they remained steadfast battling against discrimination and against the image of people with disability as someone to be pitied, known in Maltese as the "jahasra u miskina" image.

10.5 Parents and the sexual identity of people with learning disability.

10.5.1 Parental Influence

A body of evidence suggests that parents influence their children's development and identity from the day they are born. Generally as children grow up, they start forming their own opinions and making their own decisions. However, choices and decisions that people with learning disability make remain heavily influenced by their parents. Sexual identity starts to emerge when children are still young, amongst others with their choice of clothes, their type of play and the friends they make. People with learning disability are often not exposed to these experiences, even their clothes are chosen for them. The majority of people with learning disability are dressed in an asexual manner, groomed in an asexual manner and treated in an asexual manner. Even worse, young people with learning disability are dressed and treated as children not as teenagers or adults. There are also a variety of reasons why people with learning disability lack knowledge related to sex education. Reasons include protecting them from things they are assumed not to be able to handle and helping them lead a sheltered life (Grieveo *et al.* 2006). Yet there is increasing evidence that "*treating people with learning disability as if they are asexual, eternal children with child-like interest and pursuits*" (Peckham,2001, pg.131; Pownall, 2010) has increased their vulnerability (McCarthy, 2001). Pownall (2010) confirms that mothers of people with learning disability in her research were acutely aware of their children's limited opportunities to develop intimate relationships which in turn translated in less urgency to address sexual matters with them. Pownall (2010) concludes that "*continuing dependency and limited opportunities for intimacy*" were reasons for avoiding the subject of sex.

When exploring the way people with disability look, such as what clothes to wear and buy, one service provider in my interviews claimed that people with learning disability didn't have much of a choice. He also claimed that parents of people with learning disability choose for them, clothes which are asexual and unappealing as they do not see the need for them to look as young fashionable people. With McCarthy's (1999) participants the choices varied between women with learning disability who asked for staff's help to make choices, to staff that made choices for the women themselves. McCarthy (1999) claims that these situations vary according to the attitudes of the individual staff members, as with the attitudes of individual parents. Hendey & Pascall (1998) bring forward the issue of control that parents exercise on their children when they have a disability. This is presently witnessed in Malta, where the way many people with learning disability live their lives, depends heavily on their parents and their parent's opinions on what they wear, where they go and how they live. Henday & Pascal (1998, pg.423) report that:

> *"The parental care situation extended parental control over their lives, keeping them as children despite their years".*

On the same note Baker and Donelly (2001, pg.74) discuss this tendency of overprotection and claim that;

> *"Parental overprotection is often cited as a hindrance to social experiences".*

This was the case with one of the participants in Wheeler's (2004) study, who reported considerable restrictions from his father. Wheeler (2004) in his interviews with men with learning disability found that his participants felt that they were treated like children and were not recognised as being adults, they had difficulties in their relationships with their family and some expressed the wish to live independently. Amongst the reasons given for this was the fact that *"they perceived themselves as not being allowed to grow up"*. Ratzka (1998, pg.1) supports this stating that;

> *"In countries without personal assistance services many of us have to spend their lives with their parents. How can one develop a mature sexuality, if one has to live in forced dependency and childhood".*

Azzopardi (2009) in his research in a Maltese context found that parents and the social context in general de-skilled and deprived people with disability from choosing to live their life the way they wanted to and to fight for what was theirs. These views were also expressed by participants in my study who reported that their parents did not let them do things because they were afraid that they would get hurt or because there wasn't enough room in the house for them to get around in a wheelchair. Others commented on their image, claiming that they were felt underdressed for any occasion and for their age.

All parents in this study felt that the responsibility of a child with learning disability would be lifelong. In fact parents' greatest worry was the future, when they would not be able to take care of their children any longer. Their urge to protect and make choices for their children emerged from the interviews and focus groups as reported in research by Garbutt (2008). Making important choices like sterilization, contraception and breaking off a relationship were amongst the situations parents had been involved in through their children's experiences. A majority of parents felt that sexuality was a choice, a choice that would complicate their children's life, an experience that could lead them to get hurt and suffer. Being made fun of, experiencing heartbreak or feeling less accepted were amongst the situations parents did not wish or want their children to find themselves in, although these are situations that even non-disabled people have to experience. In this study a minority of parents were positive about their children with learning disability being in a relationship although they did not specifically encourage sexual relationships. Only a minority of parents approved of intimate relationships and thought that they were only natural. These parents had the awareness that people with learning disability have the same needs and urges of non-disabled people and have decided to give them a full experience of puberty and teenage and adulthood, exposing them to experiences and situations their non-disabled siblings are exposed to and treating them in the same way. Supporting without being intrusive is reported by parents to be a tricky skill to master but an effective way to bring up young people with learning disability without neglecting their rights.

10.5.2 Parents, Sexuality and Sexual Abuse

Without any doubt parents in this research were found to be a key factor to the prospects of forming and maintaining relationships for people with learning disability in Malta. Participants with learning disability who were in a relationship were backed by their parents in many aspects. Their parents accepted them being in a relationship and believed that although they had a learning disability they had the right to live a normal life like anyone else. Parents, who supported their children in their relationship, were found to encourage them and their partners' families to maintain good relations. They supported them financially at times and also provided assistance when they wanted to go out or go somewhere together. A minority of parents thought it was healthy for them to have an intimate relationship although these opinions varied according to gender and level of disability of the people concerned. Garbutt (2008) on the other hand reports that many parents were positive about their children having relationships, but were concerned about lack of information and support. Pownall (2010) also confirms that evidence from cross-sectional studies (Cysjekkt & Bryde,2004; Karellou, 2007, Swango-Wilson, 2008) identify younger parents as being more accepting of their children's sexuality. Pownall (2010) confirms that; "*societal attitudes are not static...younger parents of individuals with intellectual disabilities are becoming more accepting of their offspring's sexuality*". The majority of parents saw these relationships more as extended friendships and companionship, and didn't particularly like the intimate element of it. Pownall

(2010) on a similar track found that while parents encouraged the siblings of people with learning disability to have safer-sex, and gave them greater freedom, they delayed the possibility of people with learning disability themselves to become sexually active.

Consequently, the majority of parents were not keen on their children having a relationship as their image of their children, although now grown up, remained that of perpetual children. It is a known fact that parents have the tendency to treat their children with learning disability not as adults but as children. Selina (2008, pg. 2.1) gives us reasons such as:

> *"Children do not have sexualities and so parents find it difficult to see their disabled offspring as sexual beings and not as vulnerable and impressionable people at risk".*

Society plays an important role in influencing parents of people with disability on this subject, as many parents agreed that society saw relationships between people with disability as out of the ordinary. Society's sometimes negative view of relationships was also partly the influence of outdated religious beliefs that are not flexible so as to accommodate a diversity of people. The Catholic Church which is still predominant on the Maltese Islands influenced parents and their way of looking t the possibilities of relationships and intimacy between people with learning disability. This was also evident in Wiegerink *et al.* (2010) who claim that in the medical spheres sexuality is not discussed by health professionals. The relevant topics in these environments are primarily physical, behavioural and educational issues, leaving the awareness that this person with disability is a sexual being needing space for positive body image and sexual feeling unstated (Wiegernick *et al.* 2010).

A service provider working in education who participated in this study also confirmed that parents needed to realise that their children were aware of sexual issues and that their children were themselves sexual beings. While another service provider working in the educational field who participated in the research, remarked that some students were very overprotected because the parents were afraid that they would get interested in others. He claimed that the parents would resist this as well as what things to teach them, while some parents were willing to let them engage in this discussion. In relation to this another Maltese service provider explained that parents who are below the age of 50 seem to accept much more their children's sexuality and talk about it openly. He claimed that they aspire to them having a fulfilling a relationship as possible. On the contrary though he admitted that there are also others who are of the same age, and not necessarily of any less education, who thought differently and who still stereotyped their children as perpetual children. He also made reference to some parents, who were possibly older parents, who still looked upon people with disability as being asexual. He claimed that over the last 20 years the National Commission had spoken out extensively, in favour of the idea that people with disability are like anybody else, both in feelings and in aspiration and as a result most people accepted it. He concluded that he believed that the vast majority of young people under the age of 30 took this for granted and don't even think twice about it.

A minority of parents in the research were found to shelter their children completely, in a way that they overlooked their sexuality (Garbutt, 2008). That same minority refused to see them as sexual beings simply because they had a learning disability. An element of parental control over a son or daughter with learning disability also emerged. They refused to teach their children about sexuality as they believed that they led such a sheltered life that they wouldn't need to be exposed to such facts. The minority of parents in the research who had not taught them any sex education, further more prevented them from viewing visual sexually related material, even people kissing on TV. Pownall's (2010) research findings concur, the majority of parents in this study asserting their fear of pregnancy, with most parents not considering possibilities of contraception and others just finding it too hard to let go. All mothers of young women with learning disability in this research feared having to take on the responsibility of bringing up their grandchildren, as they saw their children as not capable of managing such a task alone. While Pownall's (2010) participants saw potential vulnerability as a reason for addressing sexual issues with their children, Wheeler's (2004) participants claimed that their parent's concern about their vulnerability had a restrictive effect upon their lives. Similarly in this study, one service provider himself with a disability concluded that parents wanted to shield their children because they believed that people with disability have much less chance of being in a permanent relationship than non-disabled people. Therefore he claimed that they try to protect them from feelings and urges that may cause them pain and that believe they cannot fulfil or satisfy. He claimed that what they tried to do is almost to stop the inevitable, as removing suggestive pictures or stories and shielding them from certain friends, would inhibit the tides of sexual feelings. He maintained that these will however happen on their own as parents often realize much later. He concludes that, nowadays with the internet there is no way in which you can shield a young person without being unjust.

As in Pownall's (2010, pg.16) findings, parents *"felt a continuing responsibility to ensure the safety, health and welfare of the child"*. Parents' overprotection seemed to be a way they thought would protect them from possible abusive situations, in a way that living sheltered lives decreased the chances to experience abuse. Issues of protection can be closely linked to gender stereotypes (Pownall, 2010), and female sexual vulnerability. A majority of parents claimed they warned their children, meaning that they warned them about the possibility of getting pregnant if they had sex. That sexual abuse could take place in a situation when the parents were not or would not be present was not seriously considered by all, even though there is evidence that people with learning disability are at a higher risk of sexual abuse, (Hogg,2001; Sobsey *et al.*1991, Turk & Brown, 1993). A minority of parents claimed that if an abusive situation arose, their children would come to tell them about it, this contrasted with Pownall's (2010) findings, where given the eventuality parents were not sure that they would be informed. A minority of parents though did not acknowledge that sexual abuse was a possibility, therefore they didn't plan to give their children sex education. Even though research indicates that abusers tend not to be strangers on street corners but familiar trusted people (Peckham, 2007). Being dependent on adults for intimate care, being socially isolated, lacking self-esteem and being eager to seek approval according to Cheng and Urdy (2002), makes people with disability more vulnerable to sexual exploitation.

Cheng and Udry (2002) state that more attention needs to be paid to protect females with physical disability from sexual abuse and exploitation, due to their higher tendencies of experiencing forced sex. Several of the participants in McCarthy's (1999, pg.174) research acknowledged having experienced sexual abuse, possibly due to their living environments.

> *'In addition to their own experiences, which are extensive, seven women knew of others who had also been sexually abused".*

The fact that McCarthy's participants did not live at home with their families possibly did make a difference, although it was reported by two service providers in my research that they each worked with a woman with disability who had experienced sexual abuse from a family member at home, but nothing was directly being done to compensate. The findings that single out men with learning disability as the biggest single group of perpetrators of sexual abuse against people with learning disability must not be underestimated (McCarthy 1999). Yet possibly due to the fact that institutions are segregated by sex in Malta, physical and sexual abuse was reported between women with learning disability by service providers participating in the research.

Issues of sexual abuse throw light on the absence of relevant policies in Malta. National documents, such as *No Secrets* published by the D.O.H. in the U.K., which addresses issues of abuse and vulnerability of adults with learning disability, are still missing in the Maltese context. It is a fact that definitions, guidelines and procedures to develop policies and procedures in order to protect vulnerable adults from abuse are required both as preventative and as responsive strategies to deal with such issues.

10.5.3 Parents and relationships, marriage & pregnancy

> *'More often then not, parents and professionals are still endlessly discussing the extent and degree of permissiveness, responsibilities and consequences of sexual behaviour involving people with learning disabilities...in all these well intentioned discourses, what is unheard is that one important voice: that of people with learning difficulties..."*
>
> Lesserlliers (1999, pg. 137)

In my interviews I found that parents preferred platonic relationships rather than intimate and sexual relationships. The majority of parents were concerned about pregnancy and would want their children to be protected from getting someone or getting themselves pregnant. Parents mostly claimed that they did not wish to have responsibility to raise their grandchildren. Family support in raising children in a Maltese context is cultrally considered the norm (Cutajar, 2003). Issues of people with learning disability being able to make sensible choices independently with regards to contraception and sexual relationships was reported in Jahoda & Pownall's research (2010). Some parents in the study were further concerned about pregnancy due to their daughter's medical health condition. Davies and Jenkins (1997) and Block (2002) also found that a number of parents in their study preferred to discourage their children from marriage and parenting, or simply prevented them from having sexual relationships. A majority of the parents who participated in my research stated they wanted to have a say in the depth of their children's relationships, especially the sexual relationships. One parent stated that she would stop her daughter from having such a relationship.

Wheeler's participants also mentioned the fact that parents were more protective over their daughters then they would have been over a son (Pownall, 2010; Dilorio, Pluhar & Belcher, 2003). This was the case with some of the parents who participated in my study who reported that if her son had a sexual relationship she would be happy about it. She also acknowledged that if had been a girl she would have felt different about it. She finally concluded that she had to admit that she would be worried about him getting someone pregnant or forcing himself onto someone.

One service provider commented on the implications faced by people with disability when parents do not approve of the relationship. He claimed that if parents of the couple with disability, who are in love, are opposed to their feelings, the disabled couple do not have much chance of finding alternative support. Similar findings by Davies & Jenkins (1997) reported parents who sought to dissuade their children from the idea of marriage and parenting. This relates back to my own findings, where parents seemed to acknowledge the need of relationships between people with disability and did not mind their children being in a relationship, but some preferred it to remain platonic and not turn into an intimate relationship. Parents of a young woman with learning disability in their interview exclaimed that because of the mentality and the current situation with support in Malta, the few couples with physical disability that are married are unique in their status. Other parents expressed their fear to leave their daughter with disability with a man, to be taken care of by someone else other then her parents who have cared for her all her life. They concluded that they preferred if they had simply a friendship or the start of a relationship.

As for staff working with people with disability, accepting that they were in a relationship, the participants and service providers in my study, seemed to agree to a superficial relationship, but if faced with an intimate relationship I have my doubts about how positive they would be about it. Day centres are reported to restrict opportunities for people with learning disability to be in a relationship (Davies and Jenkins, 1997) whilst fostering a *culture of caution and prohibition* (Johnson *et al.*, 2002). Despite these reports, research recommends that services need to achieve a balance between ensuring the safety of vulnerable people and the possibility to have happy fulfilling relationships (Carson & Blyth, 2009; Noonan & Gomez, 2010).

Contraception was mentioned by a few parents in this research, the forms of contraception mentioned were the pill, condoms and sterilization. Two mothers agreed that they would have their daughter use the oral contraceptive pill if she had a sexual relationship with a man. This finding was in accordance with literature (McCarthy, 2009a; 2009b) that suggests that women with learning disability are often prescribed the contraceptives in order to prevent unwanted pregnancies. Even though literature also suggests that women with learning disability are also prescribed the contraceptives to manage their menstrual problems, but it is also sometimes given to women who are neither sexually active nor experience menstrual problems (McCarthy, 2009b). McCarthy (2009b, pg. 368) concludes that reason for the latter administration of contraceptives is what she calls the "*just in case*" approach.

As barrier contraceptives, condoms were mentioned by a mother of a young man with learning disability, as she stated that he had been taught how to use this form of contraception. Sterilization was mentioned during a focus group by a few parents who claimed that they still preferred this method as it was a secure method of contraception, and were disappointed that it was not available any longer. Sterilization seems to be regarded as a reliable method of contraception for women with learning disability, by a majority of parents whose concerns focused on limited compliance towards oral contraception and the vulnerability to sexual assault (Servais *et al.* 2002). There was no mention of consulting their children about the methods of contraception in the form of contraceptive pill or even sterilization, as it seemed the decision would be taken solely by the parents. As McCarthy (1999) also disclosed decisions to use forms of contraception were generally taken by others than the women with learning disability themselves, with arguments against this kind of contraception revolving around irreversibility, discomfort and ethical issues with informed consent (Servias *et al.* 2002). A noticeable difference between contraception methods in this and the latter study is the use of the Depo-Provera slow release hormone injection, which is not used at all in Malta (McCarthy, 2009a; Servais, 2002). The over use of this contraceptive is investigated and underlined by McCarthy (2009b). The coil which is also mentioned in McCarthy's study is also not commonly used in Malta and certainly not seen as an option for women with learning disability. Most evident is the lack of use of oral contraceptives for non-sexually active women, who use medical contraception for menstrual management, as opposed to other studies (McCarthy 2009; Servias *et al.* 2002). While Servias *et al.* (2002) underlines that menstruation can be considered criteria for normality, caregivers might be relieved of the duty of managing issues related to sexuality through contraception.

As for the parents of people with learning disability who participated in the research, the majority were against the possibility of their children having offspring, as they feared for their immediate health or the responsibility that they themselves would have to carry. Only one parent saw this as a positive thing, she also stresses the importance of the support needed to be given from the families on both sides.

Llewlyn and McConnel (2002) discuss the importance of support given by families. Wheeler (2004) adds that this is essential given their close involvement, as well as lack of friendships that might offer support and the often transitory nature of relationships with social workers and community nurses. Only one parent had strongly stated that she found it wonderful if her son was in a relationship and even better if he was in a sexual relationship, as long as they were both protected. She did underline that she was aware that a pregnancy would be quite disastrous in a way, unless both sets of parents could work together and were in agreement that if a child would come along that both sets of parents would help. Being a foreigner she claimed that in the UK people with learning disability did have children. She was aware that this was their right long as they were able to take care of that child with the help of the family or social support.

Within Maltese culture, parents are usually very proud of marrying off their children and expect anxiously the arrival of grandchildren. Whilst grandchildren would be a blessing in the case of non-disabled children, this would be one of the greatest worries parents have if their children with learning disability are having sexual relations. In the case of people with learning disability, one may even say that parents never see that their children will have these kinds of opportunities in the future, and that they are not geared towards this type of future. Fairly their worries circulate around how much support their children need to cope with every day life, but these seem to take over the emotional needs of everyday life as well.

10.6 Agents in Maltese society that work towards a suppressive attitude towards the sexuality of people with learning disability

Throughout the research findings the following themes were distinguished as contributing to the quality of life of people with learning disability, either their absence or their presence affected the way people with learning disability developed, explored and expressed their sexuality. The following sections discuss the implications of these themes in lives of people with learning disability.

10.6.1 Law & Policies

Oliver and Barnes (1998) view social policies as the process that will move people with disability *"from an exclusive to an inclusive dimension"* Azzopardi (2009, pg.19). In Malta laws and legislations, such as the Equal Opportunity Act (2000), that amongst other issues tackles education, employment and accessibility, have been amended in the last years. Yet there is still a long way to go for Malta to be a par with other European countries. As a service provider in the research underlined that there is a lacuna of policies in the area of sexuality and furthermore when sexuality is combined with people with disability. These findings were mirrored by Johnson's *et al.* (2002) findings in an Australian context. Johnson's *et al.* (2002) intervention project proposed that sexuality be regarded as a health promotion issue for people with disability. This policy stressed the need for adequate sex education for people with learning disability, their families and service providers. Other countries such as Belgium hold sexual relationship policies and contraception policies which are present in institutional environments (Servais *et al.* 2002). As Azzopardi (2009, pg.8) affirms;

> *"In the last decade, the disability community in Malta has made significant progress on the 'services' dimension but has fallen short in policy*".

Rule 9.2 of the U.N. Standard Rules on the Equalisation of Opportunity of people with disabilities deals with Family Life and Personal Integrity. It states that;

> *'Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. [...] Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies*". (United Nations, 1994: 9.2)

The UN Standard Rules recognises disabled peoples' right to sexual expression but legislation underpinning rights is only useful if people are given the necessary support to exercise these rights. This belief of equality seems to be far fetched to the Maltese as found during the research through statements which are discussed below. Some participants commented on the fact that people with disability "*do not really understand these things*" and that "*sexuality came with responsibilities*", something in their point of view alien to these people. Others simply opposed the fact that people with disability could have an active sexual life and therefore procreate, or raise a child, leaving out the possibility of nowadays effective contraception. As for people with disability as parents who could raise a child, some views seem to revolve around the stigma and the difficulty the child would encounter by the rest of society.

Researchers claim that it is also important to note that international laws are only effective if individual countries adopt them into domestic law. In *A Strategy for Equality* (1996), the Report by the Irish Commission on the Status of People with Disabilities, Chapter 18 specifically deals with sexuality and disability. It sets 15 recommendations for what the Irish Government should provide or fund in order for people with disability's sexual and relationship needs to be met. Selina (2008) who researched facilitated sexual expression in Ireland claims that none of these 15 recommendations refer to facilitated sexual expression. (Commission on the Status of People with Disabilities, 1996a: 55-57). Fyson (2007) claims that in the absence of sexuality policy guidelines, staff are uncertain if or when sexual behaviour is responded to, and in which manner. McCarthy (1999) insists that sexuality policies need to ensure proactive support, which means that sexuality; sexual abuse and sexual health should be routinely discussed as part of Individual Programme or Care Plans, and reviewed regularly. She maintains that sexuality policies and guidelines should always support the person with disability in his sexual life not prevent them from having one. She concludes that it would be ;

> *"..entirely appropriate that learning disability services should have policies which address the provision of sexuality support".*
>
> McCarthy (1999, pg. 238.)

Through Selina (2008) one comes across the work of Gray (2001) in her paper about addressing the issues of sexuality and disability at the Spastic Centre in Australia. Gray (2001,pg.1) ;

> *'While there has been plenty of information about people with disabilities being seen as asexual and therefore denied the opportunity and support to have interpersonal*

> *relationships there has been a dearth of literature or evidence on how to do it without the fear of legal ramifications"*

Selina (2008) reports that Belgian and Dutch local government authorities finance people with disability in order to access prostitutes and that brothels in Australia are being made wheelchair accessible. Davies (2000, pg.4) adds;

> *'Individual professional sex surrogates working with therapists in California and a few other states in the US have disabled people among their clientele. In the Netherlands and Denmark the state runs a dedicated licensed brothel for disabled peoples' needs."*

Domestic laws such as those which relate to sexual expression are key elements for addressing the issue. We take for instance prostitution laws in Holland where prostitution is legal therefore as Selina (2008) puts it, their laws governing sexual expression are arguably more advanced than in Ireland. This obviously benefits the sexual expression of people with disability, and allows their sexual needs to be met. Selina (2008) illustrates the account of a man with disability in Tilburg, Holland who receives a monthly allowance from his local authority towards the cost of visiting a prostitute, (Dagblad, 2001). Selina (2008) underlines that neither disabled peoples rights legislation nor domestic or international laws would have given this man access to this service if prostitution had been illegal in Holland. Selina recalls that in 1979 in the U.K., Tuppy Owens founded the 'Outsiders Club' for people with 'physical or social disability'. In an article commemorating the Club's 20th anniversary Ms. Owens (cited in Selina, 2008, pg. 6.1) states that;

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

Selina (2008) though comments that although decrimalising prostitution may lead to greater opportunities for sexual expression for some disabled people, it is highly inappropriate for disabled people to be used as a reason for changing the laws related to prostitution.

In Malta, Genitourinary Clinic consultant and sexual health promotion head of department, Dr.Carabot, complained to the Social Policy Minister Mr. Dalli, after a proposal for a national sexual health policy, was withdrawn from the 2010 National Budget. Massa (2009) in a local newspaper, The Times of Malta (2009), quotes the Social Policy Minister who said that if the policy was going to be implemented in an effective, comprehensive way it would cost "*hundreds of thousands of Euros*", which would explain why it was left out. A spokesman for the Ministry of Finance (2009) claimed that:

> "*It is all a matter of choices and priorities and I stress that in no way am I saying the national sexual health policy is not a priority. Most of the ministries' proposals were taken on board but it's impossible to implement each one*". Massa (2009)

Carabott insisted that the policy was crucial to the island's sexual health as once it was published it would provide the framework and overall direction of where Malta should be going. The Minister of Social Policy was asked whether in the present economic climate such a policy was still a priority. He rebated that;

> "*It is a priority, as are the waiting lists; the medicines that people will die without... For some it may be a bigger priority than others. For the minister the priorities are very different*".
>
> Massa (2009)

Dr. Carabot has been for the past eleven years, the only public health official consistently campaigning to raise awareness of sexually transmitted infections. He has also been pushing to have a National Sexual Health Policy, but despite these efforts three drafts have been prepared since 1999, but none have been accepted. Carabot reported;

> *"I would like to make it absolutely clear I have been actively lobbying for the introduction of a National Sexual Health Policy because I believe it to be essential for the health and well-being of our young people".*

Carabot has long been insisting on the need to raise awareness about sexually-transmitted diseases and pushing to see the policy's introduction, especially since 70 per cent of the 14,000 people who visited the Genito-Urinary (GU) Clinic in Malta since 2000, are reported to have never used a condom. The sexual health policy, which has been in the pipeline for 11 years, should serve as a stepping stone for the

drafting of a strategy of implementation by the end of February 2011. Controversy erupted when a few days after the Sexual Health Policy was officially released, the Bishop of Gozo Mgr. Grech, stated that the educational system could be abusing students if; *"instead of helping them control their sexual energy, it offers them information and methods, such as contraceptives, inducing them to give in to the culture of pleasure"*. Mgr Grech later clarified his comments reaffirming that any teaching on sexuality should address the *"respect and love between spouses before tackling the physical aspect"*.

Malta's Archbishop Mgr. Cremona and Gozo's Bishop Mgr Grech at a later date, addressed this aspect of human sexuality as part of an overall message to the Nation, focused on children. They emphasized the *"need to bring to the attention of our youth the beauty of God's holistic plan"*. The main thrust of the bishops' letter was an appeal for Maltese to keep in mind the "*significance of the crib in our families*" during Christmas time, with a scene of baby Jesus flanked by both parents. Their letter made reference to the many babies who were raised in situations mirroring Christ's birth, but they claimed that in many cases this vision was "*marred*", either by a child being born to a single mother, which they claim, resulted in an upbringing "*shrouded by suffering*", or raised by separated parents and therefore denied the love of both.

The National Sexual Health Policy, which took 10 years to see the light of day, is said to be a watered down version of previous unpublished drafts, as the final version was sent to the Church's Curia for its views and their feedback was taken aboard (Massa, 2011). Such propaganda at a national level leaves Malta in a position vividly described by the Maltese Green Party's chairman; "*Despite everything, there are some people who seem to want to keep Malta like the 'presepju' (crib) of the Mediterranean*", Mr. Brigulio was cited in an article on a local newspaper by Bonello (2010). As Montebello (2009) concludes there does not seem to be a serious strategic plan for a change in the structure of the Catholic Church so that this meets the reality of modern times or the contemporary needs of Maltese society.

Albeit research (Tabone *et al.*, 2003) claims that young people's attitudes in Malta towards sexual issues contrast starkly with the Church's teaching, issues that arose early this scholastic year on the University of Malta campus, support the above allegations. The issue of whether there should or should not be a condom machine at the University and the distribution of condoms during freshers' week, practically took over a well-attended and heated debate held on Campus. A Medical Students' Association representative said that the condom machine was a symbol of the need to make a distinction between the Church and University and raise awareness about the importance of having a healthy sexual life. The Medical Students' Association stated that they would work towards having a condom machine on campus because many students wanted it. Fr. Zammit, a priest forming part of the Faculty of Theology argued that just because the majority of students wanted something it did not mean that it was the best option, Fr. Zammit added that if there was agreement by the majority about paedophilia or the use of heroin, it would not make these a good thing. Even though condom use is increasingly recommended as protection against sexually transmitted infections (Servias *et al.* 2002), Fr. Zammit argued that since condoms were not 100 percent safe, but could give the illusion of safety and increase risky sexual activity, it would inevitably lead to more people contracting diseases. He also pointed out that the only country in Africa where the number of people with HIV and AIDS had decreased in number was Uganda, where abstinence and being faithful were promoted. His statements clashed with the statements Health Commissioner Androulla Vassiliou made in a communication to member states and the European Parliament, launching the new strategy in Brussels this week, (Oct 2009).

> *"A correct and consistent use of condoms remains the most effective means of HIV prevention through sexual transmission....We need to encourage people to take responsibility for themselves and their partners by talking about and practising safe sex and going for HIV testing".*

Seconded by Fr. Zammit, students supporting the '*Moviment Kattolici Studenti Universitarji*' (Catholic Students' University Movement) argued that they would be offended if a condom machine was installed on campus and supplemented their argument by stating that;

> "*University was not a place for sex and that the distribution of condoms promoted a promiscuous lifestyle giving the wrong impression to* Freshers".

Abela (1998) claims that sexual decisions for the Maltese youth are increasingly being seen as a private matter, no longer influenced by the traditional teachings of the Church. The local alternative paper "Ir-Realta" (The Reality), quotes the University student's association named the Liberal Movement, stating that "*...for many years University of Malta has been under the grip of reactionary and conservative forces which have treated students as tools of ideological agendas rather than helping to create an honest academic atmosphere. In other words the University Council, run by the Christian Democrats, essentially ensures that the University remains an ideological playground readily accommodating the Nationalist Party's and the Catholic Church's policies*". The Medical Student Association who had conducted a survey that found 71 percent of students agreed there should be a condom machine at University and 49 percent said they were in favour of the morning after pill, 55 percent said they were in favour of divorce, 79 percent expressed themselves against abortion, 49 percent said they agreed with gay marriage and 70 percent were in favour of cohabitation. Their claims were seconded by Tabone *et al.* (2003), who claimed that participants in his research agreed with cohabitation, contraceptives and pre-marital sex conducted outside a love relationship.

Telephony company Vodafone also ruffled feathers with its controversial campaign, at the University's Freshers' Week, when it was offering free condoms attached to a promotional flyer on campus. The telephony company said it was also inspired by the endless debates on whether the University should have a condom-vending machine on campus. Letters to the local newspaper the Times of Malta described the campaign as "*vulgar and unfunny*". Although the legal age for sex is 18, the telephony campaign tried to subdue criticism by replacing the condoms with coloured lollipops for under-18-year-old students. Yet religion is power!

A person on the Times of Malta Blog commented;

> *"I can think of many things you can do non-sexually with a condom but sadly not a lot you can do with a lollipop other than eat it".*

When taking into consideration that the Mayor of one of the towns in Malta requested that the phallic-type sculpture, set in a roundabout close to the Maltese national airport, be uprooted as a sign of respect for the Pope, who was visiting the islands in April 2010, it is not too surprising that condom machines are banned from University campus. Mayor Schembri called the art work; shameful, vulgar, obscene and embarrassing. Concluding *"that it was not the most fitting way in which to greet the Pope, especially by what is considered to be the most Catholic country in the world"*. The creator of this sculptor Mr. Vella Critien said his Mediterranean column was not a phallic symbol but a modern 3D representation of a symbol that has been used since Egyptian times. He explained that it points at eternity, using abstract and irregular aspects, in a futuristic and avant-garde style (Times of Malta, 2010).

10.6.2 The Catholic Church

The Council of Europe (2003) reports on the relationship between sexual values and the sexual health patterns and policies in European countries. It notes that the Western European countries are generally more tolerant towards sexual issues then Eastern European countries and that strong Catholic countries in both East and West Europe, including Malta, have less tolerant attitudes overall (Cassar, 2009).

Selina (2008) and Drummond (2006) both highlight how traditional Roman Catholic ethos has been an influential factor on attitudes in Ireland. The same stance can be adopted for Malta. It can therefore be said that historically the morality of both these countries has been dictated and shaped by the teachings and beliefs of the Roman Catholic Church. In Ireland Selina (2008) recalls that there has been an uncomfortably close relationship between Church and State and that this has had a number of implications for Irish citizens. As in Malta the Irish Constitution only recognises sexual expression within marriage. While in Ireland contraception was legalised in 1979, but until recently the vending locations were strictly restricted, in Malta buying contraceptives is not illegal, but it is natural family planning that is promoted by the Church. Montebello (2009) argues that drastic changes in sexual habits among the Maltese and Gozitans show a consistent increase in a variety of sexual practices which are considered by the Catholic Church as illicit.

The Church has influenced the image of people with disability, particularly people with learning disability, by portraying them in angelic asexual ways. This image influences parents and carers of people with learning disability to believe that their sexuality is non-existent since they are 'pure' beings. On the other hand the Church encourages sexual relations only if two of the opposite sex are bound by the sacrament of marriage, and have the intention of procreation. This leaves people with learning disability with limited opportunities and a narrow margin of choices. In her research based in Ireland, Selina (2008) collects evidence about sexual expression from people with disability. In one of the interviews, her participant stated that there is a predominant attitude that people with disability are asexual, yet that this attitude was not exclusive to Irish society. The interviewee asserted that this attitude could be traced back to Catholicism. He also suggested that those countries that approved of and encouraged sexual expression as well as facilitated sexual expression for disabled people were not particularly Catholic countries.

Malta's official religion, as per the Maltese Constitution, is declared to be Apostolic Roman Catholic, "*even though in real terms it probably does not mean much*" restates Montebello (2009, pg. 115). Yet Montebello (2009) argues that the authorities of the local Catholic Church still seem to think that they represent the whole Maltese population of Malta and Gozo and that they still hold the right to speak on behalf of the whole nation. To prove this point various government discussions and decisions are regulated by the Catholic code of morality, even though this particular morality is probably not embraced by the majority of the Maltese population any longer (Montebello, 2009). In this research a service provider at a college in Malta commented on the implementation of religious activities and the presence of religious icons at the college, stating that "*they overshadow religious diversity*". This controversial issue was raised in Italy by a Finnish-born woman whose two non-Catholic children attended Italian schools. The mother won €5,000 in damages after she took her case to the Strasbourg Court, arguing that the crucifixes violated religious and educational freedoms.

The European Court of Human Rights ruled (3rd November 2009) that Italian schools should remove crucifixes from classrooms, sparking uproar in Italy, where just like in Malta, such icons are embedded in the national psyche. The Courts maintained that the presence of the crucifix could easily be interpreted by pupils of all ages as a religious sign and they would feel they were being educated in a school environment bearing the stamp of a given religion. It argued that secular, state-run schools must observe professional neutrality in the context of public education, where attendance is compulsory. Two Italian laws dating from the 1920s, when the Fascists were in power, state that schools must display crucifixes.

In a written ruling the Court claimed that:

> *"The presence of the crucifix ... could be encouraging for religious pupils, but also disturbing for pupils who practiced other religions or were atheists, particularly if they belonged to religious minorities".*

The court added that;

> *"The State (must) refrain from imposing beliefs in premises where individuals were dependent on it,"*

... concluding that the aim of public education was *"to foster critical thinking".*

Italy said it would appeal against this Court ruling, insisting that crucifixes on school walls were a common sight and part of every Italian's life; they believed that removal could disturb children who were Christians. Italy's non-discreet heated national debates on how to deal with a growing population of immigrants, mostly Muslims, in relation to this court sentence, is likely to become another battle cry for the centre-right government's policy to restrict newcomers. Maltese Archbishop Cremona, denounced the decision by the European Court of Human Rights to ban crucifixes in Italian classrooms as a "*new form of censorship*". Archbishop Cremona said that should this situation arise in Malta one day, it would be his duty to insist, along with Maltese Christians, that the crucifix should retain its place in public places. He claims that the majority should have a right to express their beliefs and the minority too should not be denied their rights. Mgr Cremona said that, should such a ban ever be imposed on Malta and he needed to go to hospital, he would be the first one to take a crucifix with him. Both local political parties agreed that the court should never have got itself involved on this issue and should have left it up to individual States. The political party currently in power stated that it would continue to defend Christian values.

The long-term implications of the ruling in Italy appear unclear as yet. Such a decision is considered by legal sources as generally binding on the respondent state but other signatory States retain a political discretion as to whether to get in line with the Court's judgment. However, there is no legal obligation for other member States to do so, even if the judgment of the Court will, when it becomes final, be a precedent that may be claimed by any person against any state that is a member of the Council of Europe.

10.6.3 Religion and sexual expression

During the sex education pilot intervention project (reported in Chapter 9) a strong religious element originated from the volunteers who took part. These volunteers although not fully trained at delivering sex education per se were all educators in mainstream schools. None the less their own religious beliefs transpired through their workshops. Baxter (1996) confirms that sex educators and counsellors need to have an awareness of individual attitudes, beliefs and practices regarding sexuality. The imposition of religious beliefs upon the participants with learning disability, especially in the areas of sexual relationships and contraception, by the volunteers overshadowed Baxter's affirmations.

The right to impose moral standards on others brings even more complex moral problems (Fairbairn, 2002). Homosexuality for instance was a topic that brought about much moral debate and controversy. Selina (2008) reports that homosexuality in Ireland was only decriminalised in the late 1980's, while it has never been illegal but rather stigmatized in Malta. Unlike Malta Ireland has made more progress at legalising divorce, which has been recognised since 1996 while it is still unavailable in Malta. Abortion is still illegal in both countries. In a nutshell a billboard outside a political party's headquarters in 2004 in Malta's capital city, prior to a referendum run to decide whether to join EU or not, read;

'EU means legalizing; Homosexuality, Divorce and Abortion!"

Local newspapers recently reported that Attard, a former candidate of an alternative political party in Malta, who is also openly gay, filed a complaint to the police and called on the head of the Church's Media Centre to resign because of the contents of a book which was being sold at the Church's Media Centre and advertised prominently on the Media Centre's website, (Times of Malta, Orizzont). According to Attard, the book called "The Catholic Church and Homosexuality" by Atila Sinke Guimaraes, states that God sent AIDS to punish gays, that homosexuality is diabolic and equal to bestiality and paedophilia. It says homosexuals are worse than murderers and that even the devils are disgusted by homosexuality. All kinds of natural calamities and diseases are attributed to homosexuals and refer to homosexuality as a contagious disease. Attard insisted that the Church should withdraw the book. Attard who tried to obtain legal advice from a number of sources including the Police Legal Section, claims that to date in Malta there is no law condemning hatred towards the gay minority. He insists that the Catholic Church is inciting hatred against the Maltese gay community and underlines that this is not ignorance but hatred. The book's summary states that:

> *"This book covers briefly the Catholic tradition regarding homosexuality, which will clarify the issues once and for all, with no doubt left in anyone's mind about the intrinsic evil of this disgusting, unnatural practice, and how the Church and society have always legislated against it."*

The opening quote on the front page of the book reads;

> *"If any one lie with a man as with a woman, both have committed an abomination, let them be put to death: their blood be upon them"*
>
> Leviticus 20:13

Attard made a series of recommendations that could be followed, including recommending that whoever is importing these books to Malta be held responsible and that the employment of the person responsible for allowing the book on the bookshelves is terminated. That disciplinary action is taken against the person who translated the back cover to Maltese, and the person who uploaded the book summary on the Media-Centre website. He suggested that political parties speak up about this issue and that an unambiguous public apology to all gays is made by a senior Church official. Finally he suggests that the Catholic Church should make a public declaration that no such books will be imported.

None of these recommendations have been followed.

Selina (2008) regards the growth of the gay and feminist movements in Ireland, legislative changes and the influence of the media as having all contributed to changing the silence about sexuality. She underlines the fact that traditionally Irish society has not been comfortable talking about sexual activity. This is echoed by parents of people with learning disability who where interviewed in this study. They claimed that there was a cultural tendency to avoid such topics, and that they themselves are inhibited by their own sexual background.

Just like in Malta, in Ireland the majority of the long stay institutions have been run by religious orders or the state. In Malta the first well established charitable institutions which opened in the 1890s had "*strong religious bias and focused exclusively on people with social problems and with an accent on moral regeneration*", as described by one of

the participating service providers. On the same note the key focus in these institutions in Ireland, as Selina (2008) explains, has been to meet basic needs. She underlines that since many of these places were also hospitals there was a high instance of medical intervention to 'cure' the disabled residents of their impairments. Activities that are run by these institutions or community houses in Malta, as explained by several service providers who run or work in these places are religion oriented. Examples of activities range from Sunday mass in the community parish or in the neighbouring community parish to encourage awareness. Other examples of activities always circulate around the disability community with a religious overtone. With regards to leisure and socialising, one of Selina's (2008) interviewees said;

> "*At best you'd go to the pictures but someone else would choose the picture and if there was sexual content in it and you were in a Catholic institution like the Sisters of Charity or whatever, then you never got to see anything with a sexual overtone*". (Glen:Interview)

10.6.4 Sex Education and the Education Department

Cheng and Urdy (2002) who researched sexual behaviours of physically disabled adolescents in the U.S. claim that their participants' sexual development and their specific needs for sex education should not be overlooked. They claim that although sex education programmes have been promoted in the US, studies about adolescents with physical disability suggests that their knowledge about sex, birth control and sexually transmitted infections still lags behind. Although the National Minimum Curriculum in Malta in mainstream schools includes education on sex, sexuality and

health, information on sex related issues tend to be given sporadically as Cassar (2009) claims. Cutajar (2003) claims that in research carried out in Malta, reasons for unwanted teenage pregnancies summed up to: failed use of contraceptive methods and limited experience in their use, problems in obtaining contraceptives, inadequate knowledge about effective contraception and the non-use of contraceptive method due to the unplanned and spontaneity of the sexual act. Still unfortunately the education department in Malta, run by the Ministry of Education, seems to have over looked the education of people with disability for decades at an end. Although much improvement has been done in academic education in the last ten years, sex education is still overlooked. Wiegerink *et al.* (2010) claims that all their participants in the Netherlands had received sex education about reproduction, birth control and sexually transmitted infections, with schools providing 99% and parents 36% of information. This is reaffirmed by the Council of Europe (2003) that claims some countries, especially the Netherlands, which have a higher openness on sex, have lower adolescent birth rates due to sex education in schools. In Maltese Special Education this topic is still not regarded as important and although there might be teaching staff willing to touch on the subject, adequate structures for training and resources are not available.

Upon the subject of sex education Selina (2008, pg.2.1) who conducted research in Ireland, states that people with disability;

> "*....are not equipped by society to be sexually responsible. Relationships and sexuality education in mainstream schools does not include information specifically relevant to disabled people".*

Selina's words strongly reflect a situation in Malta where sex education in mainstream schools is delivered equally to students but it is not delivered specifically to the needs of people with disability and where people with learning disability lack accurate information about sexuality. The importance of a persons' cognitive stage and level of understanding is reiterated by Garbutt (2008). A service provider in this study underlined that there is a query about the adequacy of the material, especially if sensory impairment was also present. If the material consisted of verbal explanations then Deaf students would miss out quite a lot. He also maintained that he did not consider the classroom environment appropriate for a child with intellectual disability, as they would need to have things explained in a different way, or they may be at a different stage of their sexual development.

The majority of Selina's (2008, pg.4.3) participants seem to agree that people with disability are not receiving adequate sex education, if receiving any at all. One of Selina's interviewees reported:

> *"There was never any education in terms of sexuality. The one thing in the institution was there were the female 'wards' and the male 'wards' and we never really got to see each other except in school maybe, or across in the corridor"*. (Rose: Interview)

Conversely a Maltese service provider related to the above statements by maintaining that in Malta the attitude is to let sleeping dogs lie and not raise issues that have not started to manifest as yet. He concludes that when these issues are not dealt with properly and nobody talks about them in school then the parents have to shoulder the problem at home.

Pownall (2010) affirms that support for people with learning disability in the area of sexuality should also undertake talking to and supporting the families of those involved, as parents often lack information and professional support about how to address issues of sexuality. Parents in this research as well as in international research from Garbutt, (2008) and from Pownall (2010) reported feeling uncomfortable, embarrassed and not prepared to tackle sexual aspects. Both in Ireland and in Malta it is very difficult for people with any sort of disability, especially a learning disability, to access useful and appropriate information on sexuality or issues related to sexual expression, if any at all. Volunteers in the sex education intervention project claimed that sex education was a major drawback for people with learning disability to express their sexuality. Selina (2008) claims that in Ireland there are agencies who produce leaflets on issues such as contraception or sexual health in alternative formats for people with different needs to access. However she claims that the bigger barrier is that their content is not very relevant to disabled people's needs or abilities. Wheeler (2004) who conducted research with people with learning disability in the U.K., reports that although the participants in his research had received sex education, their knowledge and understanding of certain issues were either limited or incorrect. He puts down three possibilities that might have caused this; that the sex education had been delivered a long time before the interview, that the participants were unreceptive to the education given or that the information was limited or presented in an inappropriate manner. Female participants in research by McCarthy (2009) also showed lack of knowledge in areas of contraception, reproduction and menopause.

As with Wheeler's (2004) and Garbutt's (2008) participants who gained information from informal sources such as television programmes, the internet and magazines, participants in this study claimed they got information about sexual issues from the internet, from friends and even from people they did not know. Some of McCarthy's (1999) participants were reported to have had sex education at school (special school) or at the adult training centre they attended, contrary to findings in this research, where it was reported that sex education at special schools was even far less available than in mainstream schools and unheard of in adult training centres. The majority of the participants in this study had received information from other women, such as their mothers, sisters and friends, this mirrored the source of education of some of the participants in McCarthy's (1999) study. Another issue in common between the sex education in the latter two studies, is the nature of the information received, which basically sought out menstruation and pregnancy. None the less some other participants in McCarthy's (1999) study had clearly been influenced by sexist and damaging messages that are in circulation.

The findings showed evidence of contrasting perceptions of sexual relations between Wheeler's (2004) male participants with learning disability and the women with learning disability in this study. Wheeler's male participants thought predominantly about penetrative heterosexual intercourse and physical activities such as kissing, hugging, fondling, touching private places and masturbation. The women with learning disability who had the cognitive ability to answer questions related to the meaning of sexual relationships spoke of sexual relationships in connection to commitment and as a way of expressing love. These contrasting replies could be attributed to gender issues and could be said to be related to cultural implications in the upbringing of the participants.

A minority of female participants in this study referred to contraception as something they had learnt about at school, in mainstream sex education, and were aware of two contraceptive methods, the condom and the pill. None the less they didn't have awareness of how and where to get contraception from, as this additional information did not seem to have been tackled during sex education. Knowledge about sexually transmitted infections seemed very vague, presumably because it seemed a long way away from their reality.

Although Wheeler's (2004) participants seemed to have an overall wider knowledge, they also still lacked accuracy about specific issues of contraception. Wheeler (2004) in his research also found that his male participants had not received sex education that related to the female body and relationships. He assumes that educators could have been of the opinion that these men would not have held relationships and would not have sexual active life, as sometimes parents of people with disability in general also tend to assume. Wheeler (2004) concludes that failure to provide what he calls socio-sexual education may increase possibilities of abuse, sexually transmitted infections and unplanned pregnancies. He maintains that it may also be denying the receiver the opportunity to experience relationships in a positive way. Similarly McCarthy (1999) recounts that the quality of women's sexual experiences is determined by the nature of their relationships with their partners but also by their level of self-esteem and assertiveness, the availability of sex education and support. She adds that being taught about menstruation and reproduction is not likely to protect from sexual abuse, while;

> *"...for sex education to be meaningful it needs to address and develop moral autonomy and to do this it needs power and inter-connecting relationships of power.*
>
> (Thompson, 1994 quoted in McCarthy ,1999, pg. 240)

Since women and men conduct different sexual lives, sex education, advice and support needs to be adapted to one's gender. Although Wheeler (2004) claims that sex education is often hetero sexual, regardless of the increasing number in homosexual communities. McCarthy (1999) agrees that development of anti-heterosexist, anti- sexist and anti-racist sex education is relatively new and unevaluated. She adds that new resources available contain lesbian content and imagery but also agrees with the availability of a same gender approach to discussing sexuality.

In relation to all the above findings, a report issued in Malta by the National Committee for Social Affairs presented a report entitled; Education and Prevention, Responsibility and Fidelity: the best national strategy for sexual health (2007), illustrates the current situation in Malta. In this report by the Genitourinary Clinic (GU) for 2007 (Carabot, 2007) indicated an increase in the number of patients infected with sexual transmitted infections who attended the clinic. In 2007, 2221 patients visited the clinic, 40% of these were between the ages of 15 and 40, and

71% of the patients were single. The report indicates that 89% of the patients were of heterosexual orientation. Of the 42 % of patients attending the clinic who reported having casual sex, 28% were married and admitted they had sexual relations with prostitutes. It must be observed that 70% of the patients, who attended the GU clinic, reported they had never used contraception. The fact that there might be other people infected with sexually transmitted infections who did not attend the clinic was also taken into account. The World Health Organisation estimates that for Malta's capacity, 13,000 people are infected with such sexually transmitted infections every year. . The report states that *25.4% admit to the practice of anal sex.* The use of the word "admit", literally translated from Maltese, puts anal sex, which is typically related to homosexuality in a negative light.

As quoted and translated into English from the report;

> *Members of the committee have agreed that sex education does not mean just promotion of safer-sex through contraceptives such as condoms and other forms of contraception, but also teaching how these are used, and how couples should mature in their relationships, including their intimate relationships. They admit that although contraceptives drastically reduce the probability of sexually transmitted diseases and unplanned pregnancies, risks are still present, especially when they are not used correctly. Condoms do not offer 100% safety from sexual transmitted diseases, and abstinence is part of the strategy that aims at postponing sexual relations to when one is of a more mature age.*

Falzon (2010) responds in the Sunday Times of Malta that with respect to sexually transmitted infections; *"it is certainly true that abstinence is the best way to avoid them. Just* *as starvation is the best way to avoid food poisoning or spending summer in a dark room the best way to avoid sunburn*". As a national strategy towards sexual health, Malta is looking at the ABCD strategy (Abstinence, Being faithful, Condomise, Don't do drugs), that is adopted by the World Health Organisation. The committee for social affairs ascertained that the following three values had to be the targets towards a national sexual health strategy agenda;

- Education and prevention
- Responsibility
- Fidelity

With regards to sex education within schools, the committee agreed that the present time allocation of half an hour of sex education during the PSD lessons is not enough and that the current educational reform should also address this, together with teaching about the use of sensible and controlled use of the internet. The committee underlined the important role parents should play in establishing responsible values in their children. They add that secondary schools should plan educational campaigns in favour of sexual responsibility, and have meetings with both parents and students themselves. The educational campaign should transmit a positive message for every age, especially to adolescents, withholding that it's not about not having sex but about what to do with individual sexuality. The committee agreed that the national strategies towards sexual health should specifically age related. The committee maintains that sex education is to be provided according to the developmental age of the person concerned, for instance at pre adolescent age sex education requires education about abstinence and postponing sexual acts till the individual is of a mature age. While with post adolescent people, sexual responsibility should target contraception, their use, where they can be kept, the difference between contraceptives and sexually transmitted diseases and prevention from pregnancy.

The Malta Personal and Social Development Association (MPSDA) reported that sexual education in schools was "*scanty and uncoordinated*" and suggested that schools undergo external audits to ensure sexual health education was imparted in line with the national minimum curriculum Callejja, (2010b). The recently released sexuality policy underlined widespread lack of preparedness and effective technical skills possessed by teachers, who are meant to discuss sexual issues with students during PSD (Personal Social Development) classes. It also insisted on the lack of professional educational resources for teachers and lack of standards and coordination by teachers of different subjects in addressing sexual health. Although all these issues address sex education for students in the mainstream, one conclusion can be made about the availability and delivery of sex education, specifically to people with learning disability. The MPSDA emphasised the importance that needs to be given to the provision of continuous professional development for PSD teachers. Although abstinence is still very prominent in the committee's discussion, and reference is made to sexually transmitted diseases rather than sexually transmitted infections, the report concludes that:

> *"In Maltese Culture taboos and misinformation about contraception are keeping the message promoting sexual health from getting across clearly".*

Recommendations made by the committee are numerous, but there is only one mention to disability in the whole report:

> *"k. Education towards sexual health that represents cultural diversity, sexual orientation, disability and race".*

10.8 Conclusion

Discussion is the bridge between existing current facts and the future implementation of strategies. In this chapter the various themes that emerged from the data findings are discussed, whilst being compared to international research and practice. This chapter highlights the major themes and denominative sub-themes.

The first theme to be discussed involves the current research about the sexuality of people with learning disability in comparison to the current findings of this study. Moreover it addresses the importance sexuality is given in the lives of people with learning disability, by those who have significant influence on their lives. Societal attitudes towards the sexuality of people with learning disability and reflection about the terminology in use are addressed. In addition one other sub-theme portrays the influence of the media and its imagery of people with learning disability.

The second theme to be discussed involved the possibilities and impediments to socialize and establish friendships for people with learning disability. This chapter appraises the barriers encountered by people with learning disability when establishing and exploring their sexuality. It reflects aspects that can hinder or promote the sexuality of people with learning disability, including; communication , transportation, finance and autonomy are reviewed. Opportunities to establish relationships and a sexual identity, involving control and decision making opportunities in the areas of relationships and sexuality are further discussed.

Another major theme discussed portrays the influence and opinions of parents on the sexual identity of people with learning disability. It debates parents' view of people with learning disability getting involved in relationships, marriage and pregnancy. None the less it explores issues of vulnerability and sexual abuse.

The final theme looks into the agents in Maltese society that are working towards a suppressive attitude towards the sexuality of persons with learning disability. The three emerging sub-themes discussed are highly influential on a national level and involve current laws and policies and the lack of them, the Catholic Church and Sex Education. The findings and discussion ultimately direct this research study towards 5 substantial key recommendations presented in the last chapter.

CHAPTER ELEVEN

"Philosophers
have interpreted the world.
The point however is to change it"
Karl Marx

Conclusions & Recommendations

11. Summary of the most significant findings

Themes that emerged from the findings which originate from the three sets of participants overlapped consistently. A prominent theme that overlapped in the findings for both parents and people with learning disability was the lack of opportunities for the latter to form part of society. Places young people frequent, such as youth centres, sport pavilions, religious organisations and other sites offering leisure facilities do not seem to cater for this minority. Parents confirmed this reality, by confirming that their children did not have any friends and their lives revolved around their family and paid carers (Llewellyn & McConnell, 2002). From an outsider's perspective this fact is the result of the lack of inclusive practice present at a national level. Inclusion of people with learning disability in educational settings has only been introduced ten years ago in Malta, while integration into the community is still not daily practice in this context. This isolation resulted in limited opportunities to socialize, therefore to meet people, form friendships and develop relationships. This was reported by all three groups of participants. While friendships and relationships were on the agenda of people with learning disability, not all parents felt they would be supportive of relationships between people with learning disability. Many parents feared relationships and what they called the "*consequences*" of intimacy, especially if they had a daughter rather then a male child. Parents seemed to prefer their children to have friendships rather then relationships, as pregnancy was a widespread concern amongst parents throughout the findings. Social stigma, morality and religion were underlying issues that supported the parents' present beliefs and fears.

Sex education was an overlapping theme that emerged from all three participant groups. Sex education or rather the lack of it, across educational setting, services, day and residential centres is evident across findings. Yet the necessity of such education is acknowledged by all participants in the research, as the basis of formation for the sexuality of people with learning disability. The need to educate parents and personnel employed to support people with learning disability is also recognised. At a National level suitable policies that undermine amongst others the need for sex education, such as Sexuality Policies, Vulnerability and Abuse policies and Sex and Relationship Policies are still missing in the National framework.

The recommendations made in this chapter tie in with theories by O'Brien (1987), formerly discussed in the literature review in relation to friendships and relationships in the life of people with learning disability. All 5 recommendations deriving from the finding of this study, if implemented form the basis of living a fruitful and rewarding life. Suggestive elements of Social Opportunities are linked to O'Brien & Lyle's (1989) recommendation for "*community presence*" and "*participation*" which are associated with opportunities of employment, leisure, education and community living. O'Brien's (1987) "*community participation*" in turn encourages the formation of friendships and relationships with other community members. Recommendations for Independent Living support O'Brien & Lyle's (1989) "*choice*" and "*competence*" encouraging the availability of options in all areas of life as well as the development and increase of independence and social skills so as to achieve a valued social role.

The recommendations stemming from the findings are now outlined and discussed and are organised in five key areas:

- **Social Opportunities**
- **Independent living**
- **Sexual Equality**
- **Socio sexual education**
- **Policies**

As other researchers (McCarthy, 1999; Wheeler, 2004; Selina, 2008) in the area of disability have previously underlined people with learning disability are not a homogenous group. Therefore this study cannot provide a single approach for people with learning disability and their experiences of sexuality. However this study did demonstrate that people with learning disability in Malta experienced similar situations to people with learning disability in other countries.

An underlying aim of the study was that its findings would make a contribution to the lives of people with learning disability and support their right to sexual expression. Having discussed the issues that emerged in detail in the findings and in relation to other studies, a series of key recommendations for applying the learning of the study were formulated. They highlight the key changes required for people with learning disability in Malta to achieve better quality of life. On a broader level it is also to be hoped that the opinions expressed by the participants of the research would guide authorities to establish policies and bring practical changes in the way service and support are organised. Above all it aims at bringing a change of attitude towards people with learning disability and their sexuality at individual and systematic levels.

11.1 Recommendation 1. Social Opportunities

Research reports that social networks offer "*opportunity structures*" for relationships and different sources of formal and informal social support such as friends and carers (Forrester-Jones *et al.* 2006 pg. 285). A definite theme that emerged from the findings was the social isolation and the lack of friendship experienced by people with disability. This is experienced by both men and women and at a range of ages, starting at school age and culminating at tertiary school or late teenage years (Tyne,, 1989). Various factors appeared to hinder their integration in society, including social attitudes, physical accessibility, finance and above all opportunities to establish and maintain friendships.

In accordance with U.K. legislation and policy (*Valuing People* 2001; *Valuing People* Now 2009), the right to choices and the right to inclusion in society in underlined in this recommendation. In practice a project that provides leisure activities involving people with learning disability in the community consequently need to be developed. Examples of such enterprises are suggested by Jones & Jenner (2005) in Forrester-Jones *et al.* (2006), as the specialist be-friending schemes and dating agencies. Parental involvement in acquiring premises, resources and planning activities would be a useful contribution, although parental involvement in the leisure activities themselves would not be ideal. The project would need local or government funding support. This project has the potential to attract up to hundreds of Maltese young people with learning disability, as have other projects and organisations such as LANDS (Living

Ability Not Disability), GFN (Ghaqda Flimkien Naslu) and Special Olympics. To avoid further segregation the project would need to involve non-disabled young people and reach out to those isolated in their own lives and communities (Forrester-Jones *et al.* 2006).

Such projects might include:

- **After school activities for primary, secondary and post secondary students, with and without learning disability.**

- **A buddy scheme integrating students with learning disability in networks with non-disabled students in mainstream primary, secondary and post secondary schools.**

- **Creating opportunities for young people with learning disability to socialize within groups of young people in the community, e.g. youth centres, sport groups etc.**

- **Creating possibilities for young people with learning disability to learn how to access the internet and establish and maintain networks and friendships through the internet.**

- **An entity that organises social activities for young people with learning disability, (such as LANDS, GFN Ghaqda Flimkien Naslu, Special Olympics), especially for those requiring wheelchair accessible transport and support.**

11.2 Recommendation 2. Independent living

Wheeler (2004) claims that although there is an emphasis about social role valorisation and promotion of quality of life, people with learning disability are still denied the right to take decisions and make choices in several areas of their lives. Areas of choice making range from simple accommodation, employment and finance to sexuality and personal relationships (Noonan & Gomez, 2010). Wheeler (2004) insists that choice making is a skill that can be taught and that people with learning disability need to be given the opportunity to exercise choice.

> *"Parents and professionals need to move from a paternalistic approach which is dependency inducing to one where clients and carers are working in alliance".*
>
> Wheeler (2004, pg.89)

Independent living is one of the issues widely discussed by people with learning disability themselves. Living outside the parent's house either out of necessity or out of choice is still problematic for many people with learning disabilities in Malta due to the lack of available resources. The establishment of small community houses and the conversion of big institutions into smaller residential accommodation are slowly taking place, but do not cover the diversity of requirements. Working towards independent living is therefore a future goal for the Maltese authorities and service providers. Projects carried out in the U.K. to implement independent living, as in *Valuing People* (2001) and *No Secrets* (2009) and the Independent Living Strategy (2008), set out measures aimed at improving the choice and control people with disability have over the services they need to live their daily lives. The strategy contributes towards the implementation of the United Nations Convention on the Rights of Disabled People, particularly Article 19 which relates to living independently and being included in the community and Article 23, respect for the home and the family.

Independent living would not just mean physical and emotional independence from parents, it would also require to promote autonomy. As Wheeler (2004) maintains, moving out of the family house does not mean a person is living independently. Therefore people with learning disability would be supported in a way that requires that exercising choice.

Actions might include:

- **Social support in the form of housing and personal support workers for people with learning disability who would like to live in the community as independently as possible of their parents and families or large institutions.**

- **A review and revision of the current legislative infrastructure relating to the rights of people with learning disability in Malta.**

- **Financial autonomy through the introduction of direct payments or personal budgets.**

11.3 Recommendation 3. Sexual Equality

It is evident from the findings that sexuality needs to be addressed more openly and seen in a more positive light (Garbutt, 2008), especially when it is associated with people with learning disability in parallel, images of asexuality and heterosexuality need to be revisited and revised as people with learning disability also experience diverse sexualities as do the wider population.

The start is to accept that young adults have a developing sexuality, and that parents of people with learning disability need to be supported to alter their attitudes towards a more positive expression of sexuality and the body. As Garbutt (2008) recommends, a balance needs to be found between protecting people who are labelled to be vulnerable and the right of all human beings to have relationships and family lives (Noonan & Gomez, 2010). Parents can indispensably contribute to educating their children in the area of sexuality and liaising with other entities to deliver this kind of education. Practical issues such as body image, contraception and intimate relationships need to be addressed openly by parents and educators. Thus rendering sexuality no longer a taboo, but a normal area of development and part of young persons as well as adult's life.

It is also evident that services need to ensure that staff training and required support is provided for responding to sexuality and people with learning disability. Care providers need training in areas of sexuality, sex education, rights of people with learning disability, duty of care and attitudes and values (Johnson *et al.* 2002). Issues of capacity to consent, recognising and reporting sexual abuse and living safer-sexual lives for example, remain unexplored in Malta and therefore need to be incorporated as training agendas.

Actions should include:

- **Counselling for parents of people with learning disability related to the sexuality of people with learning disability.**

- **Training of administrators, care staff and educators in educational and school settings, day services, respite and residential homes and educational entities that offer services to people with learning disability.**

- **The establishment of Advocacy Groups for people with learning disability that promote sexuality and relationships and the funding for the facilities of such groups.**

11.4 Recommendation 4. Socio sexual education

Research suggests that sex education should begin at an early age, underlining that children with learning disability, like other children, need structured teaching and informal supports to learn that their bodies belong to them and that they have the right not to be abused (McCarthy; 1999; Garbutt, 2008). They also need to learn that their bodies can be sources of interest and pleasure and about appropriate and inappropriate social and sexual behaviours. Sex education needs social as well as biological and should emphasise the positive aspects of sexuality as well as sexually transmitted infections and pregnancy. Discussion about the emotional aspects of relationships should therefore be given more importance. McCarthy (1999) concludes that equipping children and young people with knowledge and skills that will be useful to them throughout their adult lives should be seen as a priority. Access to education on basic social, emotional, sexual and skills on a practical level are considered necessary to function within the community (Grieveo *et al.* 2006).

Micallef (2004) underlines the need for providing sex education programmes for people with learning disability in Malta. This is still overlooked even though the National Policy document on special education in Malta states that; *"it is the duty of the State to ensure the existence of a system of the schools and institutions accessible to all Maltese citizens catering for the full development of the whole personality."* Yet although the full development of a person's personality cannot exclude sex education we are still far from these standards (Micallef, 1995).

The right to sexual expression and information as well as the need to protect people with learning disability from sexual abuse and exploitation needs to be balanced with the need to protect their sexual rights, such as the right for information (Noonan & Gomez, 2010). Thus education in order to make informed choices, in both mainstream and special schools, is required as supported in the U.K. by such documents as *Valuing People* (2001) and *Valuing People No Secrets* (2009). It is also recommended that sex education is given in an appropriate manner according to the level of ability of the student, and that adequate resources are used by motivated and supported educators (Garbutt, 2008). A review of the existing sex education curriculum available for mainstream schools is required so as to investigate adequate adaptations for people with learning disability. Sex education needs to link people with learning disability with their families or the people who support them work with them (Johnson *et al.* 2002).Drummond (2006) concludes that all stakeholders must be equally represented in the development of a best approach. Therefore unless primary caregivers are included in discussions about sexuality, the opportunities of realistically addressing the sexuality of people with learning disability are lost (Drummond, 2006).

Sex education for people with learning disability in educational and community settings also needs to be an ongoing developmental process, not a single intervention in one place or time. Socio sexual educators are needed to train and support staff working with people with disability and also to work with people with learning disability directly themselves. The delivery of socio sexual information requires being up to date knowledge about the laws and policies.

Adequate training packages specifically for people with learning disability and possibly also with sensory impairment, targeting safer-sexual lives need to be developed to support the provision of better sex education.

Actions should include:

- **Appropriate on going sex education for people with learning disability, targeting every level of disability with appropriate material.**

- **Adapted material for teaching sex education to people with learning disability as part of the Maltese National Curriculum.**

- **Train the trainer system where educators are provided with training on the specific sex education delivery targeting people with learning disability.**

- **Liaison with parents of people with learning disability about the content and delivery of sex education provided in school settings.**

11.5 Recommendation 5. Policies

In compliance with McCarthy's (1999) and Johnson's *et al.* (2001) ideas, policy is seen as a strategy to emphasise the appropriateness of supporting people with learning disability to express their sexuality in appropriate and safe ways, rather than preventing them from expressing their sexuality (*No Secrets*, 2000; *Valuing People* , 2001; *Valuing People No Secrets*, 2009). Government and non-governmental organisations as well as services should ensure that they have enabling policies related to people with learning disability, compromising a sexuality policy, a sex education policy and a sexual abuse policy. All these should recognise diversity and promote equality (McCarthy,1999; NDA, 2005). Staff working in services should be made aware of these policies through training and guidance and should be advised of the fact that it is not acceptable to prevent men and women with learning disability from expressing their sexuality and not respond to issues relating to sexuality when they arise.

Policies need to be formulated at national level then be more specifically targeted at services through operational guidelines (Mansell, 2010). Polices should also be accessible to part time staff and service users themselves and be related in innovative ways. Appropriate training about the application and review of policies should be also provided. Importance should be given to the creation of a policy that recognises the vulnerability of adults with learning disabilities, which cover lawful sexual acts and guide staff and carers of their responsibilities to report sexual abuse and exploitations.

Actions should include:

- **A review and revision of the current legislative infrastructure relating to the rights of people with learning disability.**

- **The submission of a sexuality policy targeting specifically people with leaning disability, co current with the National Sexual Health Policy.**

- **Sexuality policies for Governmental and Non-governmental organisations and services.**

- **Sexual Abuse Policies related to vulnerable people with disabilities.**

- **An agreement to review such policies.**

11.6 Implementation of Recommendations

Analysing how the recommendations can be taken forward is neither straight forward nor impossible. It is a reality that services do experience exhibition of sexuality from service users with learning disability. In order to provide appropriate responses to these exhibitions, services require a framework that deals with sexuality. Although currently sexuality policies are still not in place in any of the local services, the need of these is being felt. Co-operation with entities that provide services for people with learning disability, such as Special School settings and Day Centre settings have shown interest in the prospect of investing in setting policies and training personnel.

On the other hand setting policies in place would automatically tie with giving people with learning disability their sexual equality. Sexuality policies need to recognise people with learning disability as sexual beings as well as their right to information. Thus such policies would tie into sex education as well as staff and parent involvement in sex education. Roping these three recommendations together sets a starting point to the implementation of the future provisions. Advocacy and self-advocacy groups have shown interest in sexuality issues as the word spreads of a possibly formal source information and education. Groups lobbying for equal opportunities for people with disability have long been awaited to put pressure to change current antiquated legislation that underlies the rights of people with learning disability to live a better quality of life. Such dissemination of information is bound to eventually create a demand for these legislations to be reviewed.

11.7 Concluding Personal Reflections

In his report about stigmatization encountered by researchers in the field of sexuality, Troiden (1987) concludes that human sexuality is a stigmatizing line of work. Such occupational stigma is bound to make sexuality educators look *"sexually suspect"* and give false impressions such as that of having an obsessive interest in or fear of sex (Troiden, 1987). This stereotypical stigmatization model illustrated by Troiden (1987) depicts sexuality experts to occupy sexual extremes, such as extreme sexual desire, extreme sexual expertise, or vast sexual experience. In my role of researcher in the field of sexuality I have encountered such stigma as described by Troiden's (1987) model. Malta being a small, fundamentally Roman Catholic country, sexuality is not a topic of discussion or investigation. Extracts from the discussion chapter in the study (Chapter Ten) refer to issues related to sexuality, sexual relationships and Maltese culture. Such references include to the extensively awaited Sexual Health Policy, being watered down by the Curia (Massa, 2010), and the dispute between the Health Authorities and the Church about the use of contraception (Times of Malta, 2010). Other instances such as teaching about contraception, which is prohibited in church schools and ambiguously approved of in governmental schools in Malta, is highlighted by the outburst by Gozo's Bishop who alleged that the system would be abusing students when teaching them about contraception, since it would be *"inducing them to give in to the culture of pleasure"*. The discussion chapter also highlights an earlier dispute over the installation of a condom machine onsite the University of Malta, which resulted in the condom machine never to be installed. (Times of Malta, 2010; Bonello. 2009; Camilleri, 2009)

Furthermore as Ratzka (1998, pg.1) outlines, strong social taboos *"surround talking about and researching in the area of sexuality and intellectual disability support".* This claim proved to be a very accurate when put into a Maltese context. Beliefs that people with learning disability are asexual proved to be widespread, as many were dismayed by the topic of research. Sex education, the right to form and maintain relationships and discourses of intimacy, homosexuality and parenthood were all un-discussed topics. The National Sexuality Policy, published in November 2010, proves the above statements when it clearly makes no mention to people with learning disability, albeit it does encompass all others who do not conform, under the open-ended descriptor of 'diverse groups'. Further controversial issues revolved around religion and sexuality, and the dominance of Roman Catholic religion on the nature and purpose of sex, masturbation and homosexuality (Fairbrair, 2002). All these areas of concern transpired through the data collection and findings in the research and were later discussed in an international context.

Although personal beliefs are not meant to protrude through the study itself, in my role as a researcher in this field, my personal beliefs do indirectly influence the direction towards which the recommendations could be taken forward and implemented. Furthermore, I am positive that I have certainly raised awareness about the overlooked fact that people with learning disability are sexual. This research might have even in certain scenarios raised the question if maybe not disseminated the belief, that people with learning disability actually have the right to have sexual relationships, have a right to information and equal opportunities in this field.

Although guidelines to best are reported in literature and research, it is evident that attitudes of parents, service providers and the wider society towards the sexuality of people with learning disability has not adjusted accordingly, but rather adheres to what is deemed morally permissible. As a professional who has been working with people with learning disability in a variety of environments for the last fifteen years, my beliefs have been shaped according to my experiences through my . The research aims and questions set by this study confirmed my former belief, of the position young people with learning disability held in society. This conviction came from my daily contact with young people with learning disability, in school settings and through my work as a volunteer with the Special Olympics National Swimming Team. Parental concerns were also an issue that I had the opportunity to encounter through my profession as a teacher for people with learning disability in special educational settings and in my role as assistant swimming coach. The findings in this study confirmed my previous impressions, which were presented in a concoction of wishes, hopes and fears.

A finally deduction made through my findings and also through current happenings that occurred throughout the period in which I was doing this research, is that Malta is challenged by its own culture. Cultural implications, varying from social stigmas, morality issues and political implications with the Roman Catholic ethos will relentlessly challenge the process of change in this country. Quoting a parent during an interview in the initial phase of the research who claimed that such institutions would rather *"let sleeping dogs lie"*, I must conclude that this research and its reverberations have stirred up something that has the potential to improve the quality of life of people with learning disability.

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Appendixes

A1	Complete guide to the staff training activities used in Chapter 9
A2	Information sheet for people with learning disability
A3	Information sheet for parents and service providers
A4	Interview protocol
A5	Interview questions for people with learning disability
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A11	Consent form for Focus groups; parents and service providers
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A13	Setting Ground Rules
A14	Questions for participants with learning disability who attended the sex education sessions
A15	Questions for parents of people with learning disability who participated in sex education pilot intervention project
A16	Questionnaire for facilitators leading sex education sessions and participating in the Seminars

Appendix 1 Complete guide to the staff training activities used in Chapter 9

Adapted from Mc Carthy & Thompson (1994), Sex and Staff Training, Sexuality, Sexual Abuse and Safer Sex. Pavillion Publishing.

Section Two

INTRODUCING SEXUALITY

2.1 What relationships are people with learning difficulties having?

Aim For participants to consider the range of sexual activity and sexual relationships that people with learning difficulties engage in.

Time Approximately 15 minutes.

Materials Flipchart and pens.

What to do

A brainstorm: ask participants to call out the types of sexual activity and relationships that they know people with learning difficulties have. Write these up on a flipchart. Responses will probably include: sex between men and women; sex between men; sex between women; long-term relationships; short- term relationships; sex outside of a relationship/'casual' sex; one person having a number of sexual partners; sex for money; masturbation; sexual abuse; use of pornography.

Key points

- It will probably emerge that the range of sexual activities is just as wide for people with learning difficulties as for other people.
- The sexual behaviour of some people with learning difficulties is often well known to staff, either because they see it, because the people involved tell staff about it, or because someone else reports it. Which sexual behaviours are staff most likely and least likely to know about?
- If sexual abuse or exploitation are not mentioned by participants, add these to the list. The exercises in *Section Five* look at these issues in detail.

2.2 How common are relationships?

Aim	To give all participants the opportunity to think about the actual nature of the sexual expression of clients with learning difficulties. This introductory exercise allows people to talk in a small group about their work-setting and situations which are familiar to them, and could quickly ease participants' anxieties about having to talk about sex.
Time	30–45 minutes.
Materials	For each small group: a copy of ***Handout 1: Frequency Sheet*** and a set of cards photocopied and cut up from ***Handout 2: Sexual Experiences Cards***. If you would prefer participants to work on a larger sheet of paper, prepare a ***Frequency Sheet*** on flipchart paper for each group, using ***Handout 1*** as your guide. Similarly, the cards on ***Handout 2*** could be enlarged during photocopying.

What to do

Divide participants into small groups of four or five. Give each group a copy of the ***Frequency Sheet*** (***Handout 1*** or flipchart paper) and a complete set of cards prepared from ***Handout 2***. Each card describes a type of sexual relationship or sexual activity.

Ask each group to consider the people with learning difficulties with whom they have come into contact, and to place each card in the column on the ***Frequency Sheet*** where they feel it belongs. If group members have had different experiences — for example, if one person has never known of a person with learning difficulties becoming pregnant yet another person has — the card can be put in a middle position; perhaps on a line.

Allow 10–15 minutes for this, then bring groups together again for feedback.

Compare the positioning of cards by the different groups and explore why these patterns of sexual behaviour occur.

Key points

- This exercise should enable participants to see that there is a very wide range of sexual expression amongst people with learning difficulties, as in many other groups of the population. Probably no cards will be placed in the 'It doesn't happen' column, emphasising the point that having a learning difficulty does not in itself rule out *any* particular sexual activity.
- Some relationships/activities will be relatively uncommon, such as marriage, and sex leading to parenting; encourage participants to consider why this is so.

4.11 Staff feelings

Aims For participants to consider their own 'gut feelings' about some of the difficult situations with which they may be faced.

For participants to recognise that they may have their own personal limits as to what they are prepared to discuss.

Time 35 minutes.

Materials For each participant: a card photocopied and cut up from *Handout 18: Personal Feelings Cards.*

What to do

Divide the group into two groups of equal numbers. (If there is an odd number of participants, someone will have to drop out and observe.)

Ask one group to arrange their chairs in a small circle, facing outwards. Ask the other group to arrange their chairs in an outer circle, facing inwards and opposite to someone in the middle.

Give each person in the inner circle a card prepared from *Handout 18*.

Tell those in the inner circle to ask the person opposite them *how they would feel* dealing with the issue on the card. Stop the discussion after one minute, then ask the people in the outer circle to move round clockwise one place. Once there, give them another minute to discuss their feelings in response to the new situation presented. Continue this until the people in the outer circle are back in their original places.

Collect the cards, and ask participants to change places with the person opposite them. Give a new set of cards to the people now in the inner circle and repeat the process so that everyone has an opportunity to respond to a variety of situations.

Blank cards are provided on *Handout 18* so that you may add other issues as appropriate.

When the process is completed, bring participants together again for feedback.

Key points

- Staff are likely to have different levels of discomfort, but there are some subjects which will make most people feel uncomfortable and unable to cope; for example: sexual abuse of children.
- Reassure staff that there are few, if any, people who feel confident to face *all* situations. Feelings of embarrassment, shock or anger are normal and should not be perceived as personal failure.
- If staff experience a very negative reaction to a situation, ask them how far they should hide/reveal their feelings to the person(s) concerned. What might the effect of this be?

Handout 1

FREQUENCY SHEET

It happens a lot	It happens occasionally	It happens very rarely	It does not happen	Not sure

Exercise 2.2 How common are relationships?

4.9 Appropriate behaviour

Aim	For participants to consider the appropriateness of different kinds of intimate touching in settings where people with learning difficulties live or work.
Time	40 minutes–1 hour.
Materials	For each small group: a copy of ***Handout 16: Acceptability Chart*** and a set of cards photocopied and cut up from ***Handout 17: Behaviour Cards***. If you would prefer participants to work on a larger sheet of paper, prepare an Acceptability Chart on flipchart paper for each group, using ***Handout 16*** as your guide. Similarly, the cards on ***Handout 17*** could be enlarged during photocopying. NB: Do not include the last four cards from ***Handout 17*** unless you wish to extend this exercise into a discussion of gender and personal care.

What to do

Divide participants into small groups with between three and five people in each. Give each group a copy of the ***Acceptability Chart*** (***Handout 16*** or flipchart paper) and a set of cards prepared from ***Handout 17*** which describe different kinds of sexual behaviour and intimate touching.

You could add different situations to this list which cover the types of sexual behaviour seen at the setting under consideration, particularly those causing concern.

Ask the groups to position the cards on the Chart according to whether they think the behaviour described is **never appropriate, always appropriate** or whether there are **some restrictions** as to when it would be acceptable. For this latter category ask the participants to write on the Chart, by the card, the circumstances in which the touching/behaviour is acceptable or unacceptable. Tell participants to assume that the touching/behaviour is consented to in all cases.

Key points

- The positioning of the cards will very much depend on the values of the participants, the setting and the abilities of the people with learning difficulties.

  If cards are placed in the 'never' column, it is useful to ask where these things *could* realistically happen; for example, if participants say that a day centre is not the place for intimate touching between couples with learning difficulties. Staff need to recognise that the day centre could be the only opportunity people have, because of difficulties meeting elsewhere. Saying it should not happen at the centre is, therefore, effectively saying that the people involved can *never* do it.

- Point out any differences in a particular behaviour's acceptability because of differences of gender. For example, how do staff respond to a woman and a man kissing compared to two men with learning difficulties kissing? Participants may argue that the setting should reflect and teach society's standards (i.e. give the message that two men kissing in public is inappropriate, perhaps because of the reaction they might receive). Alternatively, participants might assert that society's prejudice against intimate relationships between people of the same sex should *not* be reflected in the service, so no discrimination should be made over who can kiss whom.
- Very different behaviours may be acceptable or unacceptable at different times in the same setting. For example, intimate kissing may be appropriate whilst dancing at a centre party, but not during a normal work session.
- Are there different standards between what is expected of staff and what is expected of people with learning difficulties? If so, encourage participants to consider why this is the case and whether it is appropriate. For example, if it is not expected of two staff members to hold hands at work, is it acceptable for two people with learning difficulties to hold hands in the same setting?

EXTENSION

This exercise can be extended to include discussions about the importance of gender for personal care by including the last four cards from ***Handout 17***.

Key point

- It will probably emerge that female staff are allowed much greater freedom to be alone with and/or to carry out intimate care tasks than male staff. People often express very strong feelings that this is unjust towards male staff. Help people to consider *why* the situation has arisen whereby precautions are more necessary for male staff and to recognise that this is a feature of other caring professions, too.

4.8 Sexual opportunities

Aim	To raise participants' awareness of the opportunities that people with learning difficulties have for developing sexual relationships.
Time	20 minutes.
Materials	For each small group: a copy of *Handout 15: Opportunity Chart*.

What to do

Divide participants into small groups of four or five. Give each group a copy of *Handout 15* and ask them to examine their own client group's realistic opportunities for relationships.

Allow ten minutes for this part of the exercise, then bring all the groups together again for feedback.

Key points

- Check that the opportunities mentioned are more real than imagined. For example, if participants say that their clients have opportunities to meet a potential partner at the pub or disco, how realistic is this?

  Particularly, how attractive are people with learning difficulties to the wider population?
- Participants need to acknowledge that for many people with learning difficulties, their pool of potential partners may be quite small; the people they live with, and those they meet at the day centre and social clubs, may well be exactly the same people.
- What do participants believe their *clients* would say if asked where they could find a girlfriend or a boyfriend? How realistic are their clients' expectations?
- Have some sexual opportunities been overlooked, such as men with learning difficulties going to public toilets to have sex with men? If this is the case, is it that staff are unaware of or do not value such contacts?
- Participants may recognise that some people with severe or profound learning difficulties have *no* opportunities to develop intimate relationships, because they need very high levels of staff supervision.
- How can staff offer practical support to people with learning difficulties in developing and maintaining friendships and intimate relationships?

4.3 Sexual relationships between women and men

Aims To raise participants' awareness that personal problems are difficult for *anyone* to talk about, and to help them appreciate that, just like anybody else, people with learning difficulties may nevertheless experience emotional and/or sexual problems.

Time 30–40 minutes.

Materials For each small group: a copy of ***Handout 10: Problems in Sexual Relationships***, and a copy of ***Handout 11: Sexual Relationships Between Women and Men With Learning Difficulties***.

What to do

Divide participants into small groups of three or four. Give each group a copy of ***Handout 10*** and ask them to spend five to ten minutes answering the questions it contains.

Stress that these are intimate matters; almost everybody finds it hard to talk about them.

Bring all the groups together again to discuss their responses.

Ask participants to return to their small groups and give each group a copy of ***Handout 11***.

Allow five to ten minutes for consideration of the questions on ***Handout 11***, then bring all the groups together again for feedback.

Key points

- Although this exercise relies more than most on generalisations, participants can usually identify patterns of behaviour based on either their own, or other people's relationships, and/or expectations of how women and men behave.
- This exercise usually reveals that women with learning difficulties are disadvantaged in their sexual relationships with men. What responsibilities does this place upon those carrying out sex education?

2.5 Basic myths and assumptions

Aim	For participants to consider how the sexuality of people with learning difficulties is affected by some common myths and assumptions. This exercise aims to generate useful broad discussion about sexuality before specific, maybe more explicit, areas are focused on.
Time	15–20 minutes.
Materials	For each small group: a copy of *Handout 4: Myths and Assumptions*.
What to do	Divide participants into small groups of three or four. Give each group a copy of *Handout 4*. Ask groups to discuss each statement and decide whether they agree or disagree with it. Ask them to also consider how each myth or assumption developed, and what effect it has had on services for people with learning difficulties and on people with learning difficulties as individuals.

Key points

- *Myth 1*
  There is no evidence to suggest that teaching people with learning difficulties about sex will make them go and do it if they were not already inclined to anyway. There is, however, plenty of evidence to show that many people with learning difficulties will become sexually active despite having received no reliable information, guidance or support.
- *Myth 2*
  What is promiscuity? What seems like a high number of sexual partners to one person may not seem many to another. If some people with learning difficulties appear to have lots of sexual partners, remember that this may also be the case for some staff, their friends or family; these latter relationships, however, are less likely to be known about.
  How much support do people with learning difficulties receive in developing the necessary skills to maintain long-term relationships? In view of this, is it surprising that some often break and make new relationships or have sex outside relationships?
- *Myth 3*
  Although this argument is often given as a common reason for issuing the contraceptive pill to women with learning difficulties, it must be remembered that the pill only protects women from unwanted pregnancy, not from sexual advances or sexual abuse by men. Women with learning difficulties are often very poorly protected from sexual abuse; the use of contraception can give staff a false sense of security.
- *Myth 4*
  This is frequently assumed to be the case, yet the converse is often true. People with learning difficulties living in community settings often have greater levels of staff supervision, greater transport difficulties and less time to be alone with peers to make and pursue sexual relationships than their counterparts in hospitals.

4.2 Why do people have sex?

Aims	For participants to consider people's reasons and motivation for engaging in sexual contact with others. To enable participants to recognise, through a simple exercise, the complexity of human sexuality.
Time	25–30 minutes.
Materials	Flipchart paper and pens.

What to do

Write, on a flipchart, the following four questions:

- **Why do women with learning difficulties have sex with men?**
- **Why do men with learning difficulties have sex with women?**
- **Why do men with learning difficulties have sex with men?**
- **Why do women with learning difficulties have sex with women?**
(If participants do not know of any clients having this kind of sexual relationship, you could ask them to consider why women with learning difficulties do not often have sex with women.)

Divide participants into four small groups. Ask each group to list, on flipchart paper, their responses to one of the questions. Allocate a different question to each group. Ask participants to think of both positive and negative reasons for sex.

Allow ten minutes for this part of the activity then bring all the groups together again for a plenary session. Ask each group for feedback on its responses.

If time allows, encourage participants to consider whether the reasons why people with learning difficulties have sex differ from those of the wider population.

Key points

- Hopefully, participants will put forward some of the very complex reasons why people with learning difficulties have sex beyond assumptions of sexual pleasure.
- Sexual pleasure is often more readily identified as a motivation for men to have sex than for women. Encourage discussion as to why this is so.
- Sexual pleasure is sometimes seen as a less important reason for same-sex activity. Reasons are likely to include 'lack of access to the opposite sex'. There is no evidence to confirm this assumption, but there is clear evidence that just because men have sex with women, it does not stop them having sex with men.
- There is rarely one straightforward reason why people express themselves sexually in the way they do. Try to help participants see that there will rarely be any simple solutions to the issues and problems that they face in assisting clients with this part of their lives.
- Because both women and men with learning difficulties have lived in segregated settings, the rarity of sexual contact between women might indicate essential differences in women's and men's sexuality.

2.4 Staff attitudes

Aims	To help staff clarify the values they hold regarding different sexual lifestyles, and to explore what effect their attitudes have on the sexuality of people with learning difficulties.
Time	Approximately 45 minutes.
Materials	For each small group: a copy of ***Handout 3: Values Continuum*** and a set of cards photocopied and cut up from ***Handout 2: Sexual Experiences Cards***. If you would prefer participants to work on a larger sheet of paper, prepare a ***Values Continuum*** on flipchart paper for each group, using ***Handout 3*** as your guide. Similarly, the cards on ***Handout 2*** could be enlarged during photocopying. NB: Remove the two cards in ***Handout 2*** on sexual abuse for this exercise.

What to do

Divide participants into small groups of three or four. Give each group a copy of the ***Values Continuum*** (***Handout 3*** or flipchart paper) and a set of cards prepared from ***Handout 2***. Each card describes a particular type of relationship or sexual lifestyle. Do *not* include the two cards on sexual abuse for this exercise.

Ask groups to discuss each card and try to reach agreement about where to place it on the ***Values Continuum***. Direct each group either to think about people *with* learning difficulties having these relationships, or people *without* learning difficulties. This will allow a useful comparison to be made at the end.

Tell participants to assume consent in all sexual relationships and to consider how they value each *type* of relationship *per se*, not to think of the quality of an *individual* relationship. Thus, they should not be thinking that if a particular marriage is good, they will value it highly and if one is bad, they will not value it. Rather, they should be encouraged to think how they value the institution of marriage, for itself.

Some participants may feel that they ought to value all relationships equally. Encourage people to consider what they *do* feel, not what they think they *should* feel.

Allow 10–15 minutes for groups to place their cards, then invite them to look briefly at other groups' lists. Bring all the groups together again for a plenary session to discuss the choices people made, the reasons, and the implications for people with learning difficulties.

NB: Remind participants to be sensitive and respectful in their choice of language; some of the relationships discussed will be those that people in the room have chosen.

Continued

Key points

- Have participants valued any relationships differently depending on whether the people have learning difficulties or not? For example, is marriage less acceptable for people with learning difficulties?
- Have participants valued any relationships differently depending on whether the people involved are of the same or opposite sex? Is it easier for people with learning difficulties to have relationships with someone of the opposite sex? How much do people with learning difficulties know about lesbian and gay lifestyles?
- Are people with learning difficulties expected to 'prove' their commitment within relationships more than other people? For example, are they expected to demonstrate that they fully understand the 'meaning' of marriage, when other people are not required to do so?
- Do participants believe that their own personal values affect the work they do? Do they see themselves as an important influence on the personal and sexual relationships of people with learning difficulties?
- This exercise aims to encourage people to accept that their values *do* influence their work. This is then a useful starting point before moving on to consider how staff personally respond to different situations.

▨ 2.3 Influences on sexual expression

Aim For participants to consider why some forms of sexual expression are more common than others, and to be aware of the major influences and constraints on the sexuality of people with learning difficulties.

Time 20–30 minutes.

Materials Flipchart and pens.

What to do

With the whole group together, ask participants to brainstorm what the major influences and constraints are on the sexual expression of people with learning difficulties. List all suggestions on a flipchart. (If you have done *Exercise 2.2*, help the group to relate back to the relationships/activities on the cards).

Key points

Influences and constraints will probably include some of the following:

The Law
Do people know what it actually says, and also how it is interpreted? Emphasise that the law in this area is complex; for more detail refer participants to *Sex and the Law* by M. Gunn (FPA, 1991).

Staff influences
How much authority do staff have? Do they bring their own moral values to work? Is it possible to leave values at home?

Staff role
Do staff see themselves as enablers or protectors of their clients?

Staffing levels
How does the level of staff supervision affect the possibility of relationships developing?

Parents/family
How much influence do relatives exert when a person with learning difficulties becomes an adult?

Conflict
What happens when there is a conflict between staff views and parents' wishes, or between an adult with learning difficulties and his or her parents?

Policies and guidelines
Do these exist? What do they say? Do they support staff who may otherwise feel uncertain or threatened about 'allowing' a sexual activity to take place? Are there policies on issues such as the use of pornography in establishments?

Equal opportunities policies
Can these help to provide positive images of lesbians and gay men?

Peer pressure

Do peers exert pressure for people to have a sexual relationship? Is having a sexual relationship a way of being more 'normal'? How much choice do people with learning difficulties have about the people with whom they live, work and socialise? Are these often the same people?

Physical environment

How and when can people meet? Is there any access to private space and time? Who controls it? Do people with learning difficulties have any significant control over their environment? How has the move from hospitals to 'care in the community' affected relationships?

Education/knowledge/information

Who gives this? What gets said, what gets left out? Do people get information about things perhaps outside their own experience? Are people kept in ignorance about some things? If so, why?

Medicine

How has the availability of contraception affected opportunities for relationships? What would happen if there was a vaccine for HIV? Does an individual's medication affect her/his sexuality?

Television

How important an influence is television for people with learning difficulties? What range of relationships does television expose them to? How well do they understand the dynamics of the relationships they see?

Abilities

How does a person's learning difficulty affect his or her opportunities and ability to have a sexual relationship? What social skills are required to form relationships?

Appendix 2 Information sheet for people with learning disability

Who is doing the research ?

My name is Claire L. Azzopardi.

I am a research student at the Tizard Centre, a department at the University of Kent in the U.K.

What is it about?

I am doing research with young people with learning disability, their parents and service providers in Malta.

I am trying to find out about the relationships young people with learning disability experience. I might ask questions like:

- Would u like to have a girl/boyfriend? Why?
- Did u have any lessons about sex at school?
- What things would you like for your future? Eg live together, get married, have children

Do I have to take part?

If you feel embarrassed by some of the things I ask you, remember that you do not have to answer any questions or comment upon anything that you feel you don't want to talk about. You can also decide not to continue with the questions at any time.

Your name and personal details will be kept private and no one will know what we talked about. I will not tell your parents or anyone else what we talked about.

Please take a couple of days to reflect on whether you would like to take part in my research. If you would like more information about the research please do not hesitate to contact me on

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If you would like to take part in the research please tick (/) here

If you would not like to take part in the research please tick (/) here

Please sign here

____

Your contact number

____

Appendix 3 - Information sheet for parents and service providers

My name is Claire L. Azzopardi. I am a research student at the Tizard Centre, a department at the University of Kent in the U.K. I am doing research with young people with learning disability, their parents and service providers in Malta.

I am trying to find out about the relationships young people with learning disability experience. I might ask questions like:

What do you think about people with learning disability having personal relationships?
Would you like / not like our son/daughter to have a boy/girlfriend? why?
Do u deem sex education as important? why? what areas do you think it should cover?
Do you regard your son/daughter as a person capable of having sexual experiences?

You might feel embarrassed by some of the things we talk about either during the interviews or during the focus groups. Kindly remember that you are not obliged to answer any questions or comment upon anything that you feel you don't want to talk about. You can also decide to opt out of the research at any time. Your name and personal details will be kept private and no one will know what we talked about. Talking to me will not effect your son/ daughter or your services in any negative way.

Please take a couple of days to reflect on whether you would like to take part in my research. If you would like more information about the research please do not hesitate to contact me on ______________________________.
If you would like to take part in the research please tick (/) here __________
If you would not like to take part in the research please tick (/) here ________

Please sign here ______________________________________

Your contact number ___________________________________

Appendix 4 Interview protocol

Contact the parents of person with disability who you would like to participate in the research by phone and inform them that you would like to an appointment to discuss your research and what kind of participation you would like from them.

Contact the person with disability who you would like to participate in the research by phone and inform them that you would like to an appointment to discuss your research and what kind of participation you would like from them. Inform them broadly about the research topic and its aims.

Let them understand that the answers they give will help people understand more the needs of persons with disability like themselves /like their son's/daughters

After speaking to parents and / or persons with disability about research, interviews and focus groups, allow them a few days to think about it and phone them back within a few days.

If parents and/or persons with disability agree to participate obtain consent in writing or in any other form as necessary.

Whilst doing interviews ensure that venue is private and that participants are at ease.

Check that the participant is happy talking to you in private or if they want someone else to be present.

If a parent wants to be present for the interview of a person with learning disability, explain to them that all interviews are confidential.

When introducing yourself to the participant before the interview ask them whether they mind you asking them some questions or talking to you about their personal life now.

Inform them that the interview is confidential and that you will not tell anyone what they tell you.

Remind them that they can stop the interview at any time and leave.

Conduct the interview in a respectful manner without barriers present and without dominating the space or intimidating the person.

Ensure someone knows exactly when u are starting the interview and when u are finished if interviewing a person with learning disability in private.

Terminate the interview if the client says they want to stop or seem distressed.

Ask them if there is anything you can do for them if they look uneasy or distressed.

Allow the participant to have a break if they want.

Thank them for their help at the end of the interview.

Ensure they have support if they require or seem worried before you leave
Thank parents (if interviewing persons with learning disability in their home), or staff (if interviewing persons with learning disability at a service).

Appendix 5 Interview questions for people with learning disability

Name of Interviewee:

Date:

Opportunities of socializing

Where do you go to meet with your friends?

Do you sometimes meet new people when you meet these friends?

Do you keep in touch with these friends by phone, texting, internet chats?

Do you decide where to go when u go out? How do you get there? How do you go home?

Who gives you the money to go out? Do you think its enough?

By what time do go home?

Do you sometimes bring your friends home?

Can you stay alone with your friends? Like in our room or is there usually someone?

Self Perception

What do you like about your body?

Do you think you are good looking?

Why do you think girls/boys like you?

Is there something you would like to change about yourself?

How could you change this?

Knowledge about sexuality

Did you have any lessons about sex at school?

If not where did you learn about sex?

Can you remember what it was about?

Can you remember who did it?

What does sex mean to you?

Is it a good or a bad thing?

Are there some wrong things about it?

Do you think your parents would allow you to have sex?

Intimate relationships

Do you have special friends, like a girlfriend or a boyfriend?

Would you like to have a girlfriend or a boyfriend?

How did you meet your girl/boy friend?

How long have you been together?

What is different about your girl/boy friend to other friends?

What does love mean to you?

What do you do together? Go for walks, cinema, for ice cream?

Can you have time together on your own? At home? Outside?

What do other people think about you having a boy/girl friend?

Hopes for the future

What things would you like for your future? E.g. live together, get married, have children

Do you think you would need some sort of help to achieve this?

Appendix 6 Interview questions for parents of people with learning disability

Name of Interviewee:

Date:

Societal Attitudes:

1. How do you see societal attitudes towards people with learning disability in Malta?

2. How was your experience with societal attitudes and your son/daughter with ld?

3. What do you think are societal attitudes towards friendships between people with learning disability? When they are seen together as a group? When they see a female and a male together?

4. What do you think about people with learning disability having personal relationships?

5. Do you think that parents should have a say about their children's' personal relationships? Why?

6. Do you think there should be a limit to the depth of a relationship between people with learning disability?

7. Would you like / not like our son/daughter to have a boy/girlfriend? Why?

8. What are your perceptions about sex between people with learning disability?

9. How do you see the personal development and fulfillment of your son/daughter in the social and emotional areas?

10. Did you teach your son/daughter about sexuality? About puberty? About reproduction? If not did anyone else do? Whose job do u think this is?

11. Do you deem sex education as important? Why? What areas do you think it should cover?

12. How do you think this knowledge will be of benefit for your son/daughter?

13. Do you perceive your daughter/ son as vulnerable? In which way? Do u see him as sexually vulnerable? Does this thought worry you? Do u do anything about it?

Appendix 7 Interview questions for service providers

Educational Setting

Could you describe the context we are going to refer to?

How many students with learning disability are there?

What kind of disabilities?

What services does this college offer to students with learning disability?

What improvement could be made to meliorate the life of these students?

Does the college have any policies that have any relation with the students with learning disability ?

Your Role:

Can you explain what your role as inclusion coordinator consist of?

The students:

What kind of difficulties apart from the academic difficulties, do these students encounter?

Does the college help to build their social life?

Is there a space where persons with learning disability can integrate with non disabled peers?

Do you think the college helps in the establishment of their sexuality?

Have they ever had formal sex education, either at secondary or at tertiary level?

Would you think they would benefit from this?

Do you see them expressing their sexuality publicly at the college?

Are there any of the students who are in a relationship, to your knowledge?

Do you perceive any of the students as vulnerable?

The parents:

Have you had the opportunity to meet and liaise with their parents?

What kind of suggestions and requests do they generally forward?

What kind of fears do the parents put forward?

Do you think the parents have tackled sex education at home?

Do you think they have tackled the whole picture or the minimal possible?

Do you think parents should be consulted on what sex education would consist of?

Do you think the parents would approve of their children being in a relationship and having an active sexual life?

What do you think would be their main concerns?

Do they exhibit concern with regards to their safety in terms of abuse since they have never had formal sex education?

Appendix 7 Interview questions for service providers

Administration & Management Respite Community House

How many clients live in your house and what is their gender?

What kind of disabilities do your clients have?

Do you think we house manages the clients in an age appropriate way?

What kind of quality of life would you say your clients have?

Do you think the rights of your clients are a priority and are respected in this house?

Do your clients have any kind of personal management plan?

Do they get to make choices with regards to their everyday and long term life?

Are they integrated in the community? Do they have a social life? Does the management promote this?

Would a relationship between clients be permissible in your house?

Would a client be allowed to have a relationship outside the house?

Do your clients receive or have they ever received any kind of sex education?

Can you tell if your clients have been victims or perpetrators of abuse? What is done in such cases where a client experienced abuse?

Considering the sheltered lives lead by most people with learning disability in Malta, would you still consider exposing them to a complete view of sex education necessary?

What were the issues you tackled with managers and staff in the house relating to the sexuality of the clients.

Do you find trained staff when u are employing?

Is there set in-house training for staff ?

Are there any policies or procedures the staff can follow when in certain situations? E.g. sexuality policies, abuse policies, intimate care procedures? If not why do you think we still lack these policies, and whose job is it to design them.

Appendix 7 Interview questions for service providers

Chairperson, National Commission for People with Disability

How do you see that Maltese society looks at the sexuality of persons with learning disability nowadays?

Do you think Malta is at par with foreign countries in terms of the mental perception and the practises related to sexuality and persons with disability?

How do you think persons with disability who are in a relationship are looked at by society ?

Do you see stereotypes such as that of asexuality present in Maltese culture? Why do you think these stereotypes persist?

What would you say are the reasons that keep persons with disability from developing their sexuality?

Do you think that our religion as well as services lead by religious institutions contribute to the taboo related to persons with learning disability and sexuality?

What more could be done to allow persons with learning disability to establish and experience their sexuality?

Has the National Commission ever come across issues of sexuality and disability so far? E.g. sex education in schools, cases of sexual abuse, policies?

Would you regard sex education as a right of persons with learning disability?

What do you think about the way sex education is delivered to persons with disability in mainstream schools? And the fact that it is not delivered to persons with learning disability in special schools?

Does the National Commission have an awareness of the present lack of policies related to sexuality? E.g. sex education policies, sexuality policies, sexual abuse policies? How do you see these developing?

Appendix 8 Ethics Forms

The University of Kent Tizard Centre

ETHICAL REVIEW CHECKLIST

Section 1 Details of project organisers

Name of main organiser:

Ms. Claire L Azzopardi

Names of those involved and role (and affiliation, where non-Tizard):

Prof. Paul Cambridge and Prof. Glynis Murphy

Signature of supervisor (to confirm the proposal has been checked and approved by the supervisor) ....

Section 2 Title of Project

Intimate relationships: a no go zone for people with learning disability in Malta?

Section 3 Purpose of Project

This should be a brief outline (i.e. one or two paragraphs) of the project in lay-person's language and assume that the reader is not familiar with the area of the project. It should be clear how the project fits with existing knowledge and its intended benefits (e.g. to conceptual knowledge, specific groups, services etc.)

Sexuality of persons with disability is becoming more accepted in Europe and the U.S. but Maltese cultural and societal attitudes still nowadays suppress the sexuality of persons with disability. This research aims to investigate what agents within the Maltese society are working towards a suppressive attitude of the sexuality of persons with disability.

Having worked with people with disability for the past ten years in various countries while also on an island which embraces religious beliefs that condemn contraception and homosexuality, and reprimands single parenthood, I have had the opportunity to observe how the sexuality of people with disability remains shelved. Ideas of asexuality among persons with learning disability is clearly prevalent in Malta and people with disability rarely seem to have the opportunity to experience having intimate relationships.

One issue I plan to investigate in my research is the quality of sex education young people with disability are receiving both in special school and in mainstream school settings. The aim will be to investigate how young people with disability are coping with establishing and expressing their sexual identity and developing relationships. Since parents tend to be the most dominant factor in the life of young people with disability, the study will also query the influence parents have on their children's sexual identity and expression.

The research seeks to recognize and give a reading of the possibilities and the impediments found by young people with learning disabilities in expressing their sexuality in the form of relationships and love, in the view of their parents and today's society. It will also explore reasons why parents feel responsible for the sexuality of their youngsters and often cast themselves into roles that limit the intimate relationships and sexual lives of their children.

The study aims to identify the lack of knowledge, create awareness and recommend services aimed at parents of and persons with disability while diminishing the attitudinal barrier towards the sexuality of persons with disability in Malta.

Section 4 Conduct of Project

a) Location

Families in the Maltese community.

b) Brief description of participants (and number); control participants (if any) and number

- Young persons with learning disability, both male and female, between the ages of 15 and 35 who are in or are not in an intimate relationship with another person with disability.
- Parents of young persons with disability (not necessarily the parents of those young people participating in the research)
- Service providers, eg residential home director, head of special school

c) Brief account of how requirements of the Data Protection Act will be complied with

- Confidentiality of participants will be respected. Whatever information is passed on

during interviews, this shall not be disclosed. Interviews will be recorded, and tapes will be kept under lock and destroyed after data is transcribed.

- Soft and hard copies of information will be anonymised. At interview level participants will have their names changed, while services will have their name and locality changed.
- *Protocols and guidelines*

- *Legal requirements*
- *consultation*

d) Expected start date and duration

May 2007 to May 2012

e) Frequency and duration of procedures

- Focus groups for parents and service providers – estimated 6 persons
- Interviews with parents – estimated 10 persons
- Interviews with young people with learning disability – estimated 10 persons
- Research findings will be discussed with a small advisory group from the National Commission for Persons with Disability.

f) Payment of participants

No payment will be offered as this would be taken as an offence in Maltese culture. Refreshment during focus groups and thank you gifts will be given to participants.

g) Source of funding

The funding of the project will be met partly by Mrs. Janatha Stubbs a British philanthropist who resides in Malta, who will be paying tuition fees, while travelling, living and all other expenses will be paid by the researcher. There are no conflicts of interest in relation to the finder and the sources of funding.

h) Brief account of methodology/techniques (please give summarised account of measures to be used. If using a non-standardised questionnaire, please include an example of it).

Methods of qualitative data collection will compromise participant (persons with learning disability) observation, semi structured interviews with participants with and without learning disability and focus groups with parents of persons with learning disability.

Focus groups will be carried out for parents and service providers and these will be carried out prior to the interviews. Consent to be video taped will be requested from participants. This due to the possibility that participants use gestural innotations as is typical of Maltese culture, also because there is more possibility that persons in a group speak all at once which would make it difficult to analyse by using simple voice recording.

Tools used will involve semi structured interviews which will be carried out with persons with learning disability and with parents of persons with learning disability (separately). There will be different interview schedules, starting with the parents and transgressing down to the persons with learning disability themselves. Interviews will be transcribed and used for data analysis.

This is a sensitive new topic for Maltese culture and will be the use of Interpretative Phenomenological Analysis to decode the data according to a feminist theoretical framework has been deemed as the most appropriate method.

Findings will be discussed with a small advisory group made up of 3 persons from Malta's National Commission for Persons with Disability. Although this is not Action based research, the researcher would like as much input from persons with disability themselves as is possible.

Section 5 Ethical considerations

This section should address at least the following:

1. The rationale for the decision to pay, or not to pay, participants and the likely impact on participation.

The participants will not be paid by monetary means as this is considered an offence to the Maltese. Participants will instead be given a small gift as a thank you for participating in the research study, which is more appropriate according to Maltese custom.

2. Any risks to participants: this could include any forms of harm, loss or damage or inconvenience. Please consider physical risks (e.g. injury), psychological risks (e.g. people becoming upset), social risks (e.g. embarrassment or rejection).

During this research psychological and social risks will be taken into account as the most likely forms of risk. People with disability, parents and service providers may feel embarrassed during interviews. The researcher will seek to be empathetic and sensitive towards participants. All participants will be reminded at the beginning of the interview that the can withdraw from the interview at any time, that they can pass on any question they do not wish to answer. The participants will be advised at the beginning of the group that they are under no obligation to discuss matters that upset them.

Participants will be informed before the interview that in case any sexual abuse or harm to the participant or another person is disclosed during the interviews it will be reported to a support agency (Appogg).

3. The intended feedback to participants (and, where relevant, to other service users/carers/advocates/services) and how this should be given.

At the end of the project the data will be analysed and report findings will be discussed with an advisory group made up of members of the National Commission for persons with disability. This will put sexuality of persons with disability in the political agenda of the NCPD. A copy of the final research document will be available at the library of the NCPD.

A two page summary of the final document will be produced to inform all participants without a learning disability of the findings while an accessible version will be made available for the persons with learning disability.

4. Issues relating to confidentiality during the project, and in any subsequent data analysis, conference presentations and publications.

Any data will be anonymised during transcription of recordings to prevent identification of participants.

5. Anticipated difficulties, particularly those relating to power imbalances between the researcher and participants, and how these will be dealt with. If you think the service user complaints' slip provided by the Tizard Centre (see pages 3-4 of this document) will not be suitable for your research participants, then please amend it and attach a copy with this proposal.

The researcher recognises only initial difficulties in accessing persons with learning disability, as the researcher has worked in the area for more than ten years and feels comfortable working with people with disability albeit the topic is unconventional. As for parents and service providers involved in the research, the researcher may feel under pressure with some of these latter as the topic researched is a cultural taboo and is not commonly discussed with parents or service providers. Any participants will be thoroughly informed of the research topic prior to accepting participation,

6. Information about any other ethical procedures which need to be, or have been, completed (e.g. permission from service providers)

The researcher will wait for clearance from Tizard ethics committee prior to contacting service providers, parents and persons with disability. The researcher does not foresee difficulties relating to research with persons with disability, parents or service providers.

7. How the research meets the four main ethical principals of research, namely non-maleficence (not causing harm), beneficence (doing good), autonomy (treating people with respect and giving them sufficient information so as to make their own choices) and justice (who will be advantaged/ disadvantaged by the research?)

The research will meet the four main ethical principals of research;-

Non-maleficence

The use of procedures relating to consent and complaints and the ensured confidentiality of participants should protect participants from harm. The researcher recognises that the nature of the research is sensitive and may result in participants becoming embarrassed or experiencing a variety of emotions. However, the researcher will at all times treat participants with respect and empathy and will remind them that they may withdraw from the research at any time. Participants will be informed before the interview that in case any sexual abuse or harm to the participant or another person is disclosed during the interviews it will be reported to a support agency (Appogg).

Beneficence

The research will allow young people with disability and their parents to voice their opinions and experiences upon sexuality. The involvement of the National Commission of Persons with Disability and other service providers will politically draw upon the need to create:

a. a sex education policy,

b. compulsory and ongoing sex education addressing specifically persons with disability

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

Autonomy

All participants will be met on a one to one basis to have the nature of the research explained to them in private. That participation is on a voluntary basis and that participants may withdraw at any time will be emphasised. Consent will be sought from all participants prior to interviews or focus groups.

Justice

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

How the research will pay attention to cultural issues

The researcher will be sensitive to cultural issues, above all religious beliefs and custom. Being half Maltese the researcher has a good insight into the cultural background and can adapt to and comprehend the way of thinking of the Maltese. Language barriers will not be an issue as the researcher is both English and Maltese speaking and will be able to use culturally appropriate language while holding interviews and focus groups in both languages, since some of the participants are either Maltese or English speaking.

8. The level of user participation/ involvement in the research design, data collection and analysis, and any implications for the research.

The means of empowerment in this research study comes in different levels of participation. Participants will be of utmost importance for the data collection.

Focus groups held with parents will be used to shape the in depth interview questions to be held with both parents and persons with disability. Because this is a sensitive relatively uncommon topic to discuss the interviewing will be left to the author rather than done by the participants with learning disability themselves. At a higher level of participation a small advisory group from the National Commission for Persons with Disability will be requested to discuss of the data findings and the recommendations.

Section 6 Consent

This should address at least:

1. How is it intended that informed consent will be obtained from participants (materials relating to consent e.g. consent letters should be attached).

The researcher anticipates that the persons with learning disability, (over 16 years of age), involved in the research will be able to give informed consent as their learning disability ranges from mild to moderate learning disability. The parents and service providers participating in the research are all able to give informed consent.

Participants will be contacted by phone initially and asked for an appointment, as this is more culturally acceptable by Maltese Culture. The nature of the research will be explained to parents, persons with learning disability and service providers by the researcher at an initial one to one meeting. They will then be given time to decide about it and contacted again by phone to be asked if they have decided to take part in the research or not. The phone will be used in this circumstance as it will be easier for the prospect participants to decline participation. If they accept to participate another meeting will be fixed where they will be asked to sign a consent form. If unable to sign a consent form they will be asked to signify this on tape.

2. Procedures for gaining permission from participants who are unable to give informed consent (materials should be described, and where possible, attached) There will be no participants who are under the age of 16 and I will not be interviewing persons with severe or profound learning disability who might not be able to give informed consent.

Appendix 9 Consent form for interviews; people with learning disability

This is Claire L. Azzopardi

Thank you for agreeing to talk to Claire to help with her research.

We hope that everything was alright when you talked to Claire.

It is Claire's job to treat people properly. This means she should:

- Be polite
- Treat you as an adult
- Make sure you know what is happening

But if you did not like things Claire did, you can complain.

This means you tell us and we will try to do something about it.

HOW TO COMPLAIN

- The first thing you could do is tell Claire herself about it, if you can.

- If you would prefer to talk to someone else first, then you can phone boss. His name is Paul Cambridge and his/her phone number is
- (what about those u cant speak English! Can they call the local supervisor to speak Maltese? And they might not be able to make an international call so can

we just give the name of the local super ?)

- Or you can write to him at the following address: *[insert correct address]*

- If you find it hard to make a complaint, you can ask someone else to do it for you. Ask someone to help you.

- will listen to you carefully. Then he will need to talk to other people. After a short while, he will get in touch with you to let you know what has happened.

If something bad happened when *Claire* was talking to you, it will help us to know this. We want to learn how to stop this happening again. You will not get into trouble if you tell us.

Some complaints are big.
Some complaints are small.
It's always OK to tell us about it.

Thank you.

Tizard Centre Research Ethics Committee

Risk Assessment for student dissertation project

Name of student: Claire L. Azzopardi
Supervisor: Paul Cambridge, Glynis Murphy

Start date of project : May 2007
Proposed end date of project: May 2012

Location of study: Malta

Type(s) of activity involved in research project and with whom (please tick to indicate which group of participants are involved in each type of activity)

Type activity (e.g. observations, questionnaires, interviews etc)	People with learning disabilities	Parents	Service Providers
Semi Structured Interviews	/	/	/
Focus groups		/	/

Please outline any risk of harm to participants and describe how this risk will be minimised:
Participants will not be subjected to any physical risks. During this research psychological and social risks will be taken into account as the most likely forms of risk. People with disability, parents and service providers may feel embarrassed during interviews. The researcher will seek to be empathetic and sensitive towards participants. All participants will be reminded at the beginning of the interview that the can withdraw from the interview at any time, that they can pass on any question they do not wish to answer. The participants will be advised at the beginning of the group that they are under no obligation to discuss matters that upset them.

Please outline any risk of harm to researcher and describe how this risk will be minimised:

Researcher will not be subjected to any physical risks. Although topic is unconventional, researcher will prepare herself through reading and through practising how to handle situations beforehand.

Please confirm that you have read the *Personal safety guidelines for Tizard Centre members* by signing below.

Signature ________________________________
Date ____________________________
Please tick the following in relation to Tizard forms:

I have read/completed the following:

1) Confidentiality and Accuracy of Data ☐

2) Guidelines on reporting bad practice or abuse ☐

3) Personal safety guidelines for researchers ☐

Appendix 10 Consent form for interviews; parents and service providers

- I have been given an oral explanation / information sheet about the kind of questions I will be asked
- I have had the research project explained to me
- The researcher answered questions I wanted to ask
- I was given time to reflect upon whether I wanted to answer these questions
- I understand that what I will say will remain secret
- I understand that its ok if I decide at any time not to take part
- I understand that none will be able to do me any harm because of the questions I answer

I would like to answer the questions (/) here_______________

I don't want to answer the questions (/) here _______________

Please sign your name here______________________________

Print name____

Contact Address____
____
____

Date _____________________________

Appendix 11 Consent Forms for Focus Groups (parents/ service providers)

- **I have had the research project explained to me**
- **I have been given an oral explanation / information sheet about the nature of the focus groups**
- **The researcher answered questions I wanted to ask**
- **I was given time to reflect upon whether I wanted to take part in the focus group**
- **I understand that what I will say will be kept private**
- **I understand that i can decide at any time not to take part in the focus group**
- **I understand that nothing I say will affect me or my family/ my services negatively**

I would like to answer the questions (/) here______________

I don't want to answer the questions (/) here ______________

Please sign your name here___________________________

Print name____

Contact Address_____________________________________

____

____

Date __________________________

Appendix 12 How to complain

This is Claire L. Azzopardi

Thank you for agreeing to talk to Claire to help with her research. We hope that everything was alright when you talked to Claire.
It is Claire's job to make sure you know what you are participating in, but if you did not like things Claire did, you can complain. This means you tell us and we will try to do something about it.

HOW TO COMPLAIN

- The first thing you could do is tell Claire herself about it, if you can.
- If you would prefer to talk to someone else first, then you can phone her boss. His name is Paul Cambridge/ Duncan Mercieca and his/her phone number is
- Or you can write to him at the following address: *[insert correct address]*
- If you find it hard to make a complaint, you can ask someone else to do it for you. Ask someone to help you.
- Paul or Duncan will listen to you carefully. Then he will need to talk to other people. After a short while, he will get in touch with you to let you know what has happened.

If something bad happened when *Claire* was talking to you, it will help us to know this. We want to learn how to stop this happening again. You will not get into trouble if you tell us. It doesn't matter whether the complaint is big or small. It is important that you tell us about it.
Thank you.

Tizard Centre Research Ethics Committee

Appendix 13 Setting Ground Rules

It is important to establish ground rules at the start of the training session, particularly because participants are going to be expected to discuss very difficult subjects, or when personal information about participants can be revealed.

Confidentiality – information revealed during the course should not go further.
If during the training session participants reveal details of practise that is unacceptably bad or abusive, then the trainer has to decide what to do with the information. A responsible course of action would be to encourage the participants to follow up these concerns with relevant agencies.

Participants might find discussing sex difficult, trainers should be sensitive to make allowances for this and feel able to opt out of the discussion at any time.

It is wise to avoid asking participants directly to share personal experiences as this is likely to bring up negative experiences. This could be distressing to the participants concerned and disruptive to the course.

Respect for other participants; an explicit agreement not us use sexist, racist or homophobic language and asking participants to respect different lifestyles.

Respect for other participants may include not talking whilst someone else is talking.

Appendix 14

Questions for participants with learning disability who attended the sex education sessions

Was it your first experience at sex education? If not where had you learnt before and what content did you cover?

Did u feel most at ease during the first seminar when you were mixed genders or in the second seminar when you were grouped by gender?

When and for what do you think this sex education will benefit you?

Do you wish that there were more opportunities for you to learn more about this subject or simply to revise what you have learnt?

Appendix 15

Questions for parents of people with learning disability who participated in sex education pilot intervention project

What made you send your son or daughter to the two sex education seminar?

Do you think that sex education is important for people with learning disability and why?

Do you believe that people with learning disability should learn everything there is to know about sexuality or only some things which you think they might need to know?

Are there topics which you deem more important and which you think are essential for people with learning disability to learn? Can you list them?

Did you ever teach them about sexuality yourself? On what did you focus mostly this teaching? Do u think that it is different when they are taught about sexuality by a non-member of the family?

Would you like there to be more opportunities for people with learning disability to learn more or more consistently about sexuality?

Do you think there could be a negative side to this learning?

Appendix 16

Questionnaire for facilitators leading sex education sessions and participating in the Seminars :

How have you come to be involved with this group of volunteers (GFN)?

How do you perceive the sexuality of people with learning disability in Malta?

How did you feel discussing or listening to discussions about sexuality and people with learning disability?

Was it the first time you experienced sex education directly relevant to people with learning disability?

Were there situations during the sessions where u felt uncomfortable, embarrassed or at a loss of words?

Did the gender of the participants make a difference to the sex education session in relation to you as the leader of the session?

Did the gender of the participants make a difference to the sex education session in relation to topics discussed?

Did the gender of the participants make a difference to the sex education session in relation to the other participants of the same or different sex?

Do you think the sex education given out during the seminar will benefit the knowledge of the participants with learning disability?

What would you add or change to the sex education seminar if you could?