# Male, Female or Disabled: Barriers to Expression of Sexuality

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Male, Female or Disabled: Barriers to Expression of Sexuality, by Dr. Sunil Deepak, Thesis for the Degree of Masters of Arts in Disability Studies, Department of Sociology & Social Policy, University of Leeds, UK

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# Contents

# Summary

This research is rooted in social model of disability and emancipatory research paradigm. It explores barriers to the expression of sexuality in a small group of disabled persons in Italy. The research has been carried out exclusively through Emails, Newsgroups and Internet. Thus, the research also explores the possible roles of internet-based information technologies in participatory and emancipatory research.

For this research "sexuality" is considered in its broadest sense, covering the full range of affective and family relationships and not just limited to sexual fantasies and experiences.

Twenty-one (21) volunteers were identified for this research through Italian disability-related Newsgroups and announcements on Internet-forums. The research was conducted through emails.

**Research Methodology**: The participants were involved in all phases of the research. They first helped in defining the broad areas of discussion related to human sexuality for the research. It was followed by an initial phase of individual discussions through email on the identified areas between the researcher and the participants.

From all the individual communications the researcher prepared extensive thematic reports in Italian, which were discussed with the participants through collective emails. On the basis of thematic reports and the related collective discussions, a full report was prepared. It was first shared with participants and finalised with their comments.

Then it was sent to another fifty-six (56) persons including disabled persons, parents and professionals, for their comments. A final report in was prepared in Italian, which took account of the most significant comments received from them. This thesis is an English translation of the final report, which has been edited to conform to the requirements of thesis submission.

**Research Findings**: The research highlighted the following findings:

- Professionals, families and mass-media continue to ignore the barriers faced by disabled persons regarding their sexual needs. These sexual needs tend to be seen in terms of medical model of disability.

- Professionals, families and mass-media also participate in creating disabling barriers around persons with impairments, which have a negative impact on all aspects of their lives. Those same negative attitudes and experiences are internalised by disabled persons.

- The participants felt that for the expression of their sexuality, the "barriers of the heart", including attitudinal, emotional and social barriers, are the ones which are more difficult to overcome. Their personal beliefs regarding the significance of being a man or a woman, coupled with the images of their own bodies, had a particularly significant impact on their expectations regarding fulfilment of the sexuality.

- Mass-media plays an especially important role in influencing the attitudes of families and societies towards disabled persons. It mostly reinforces stereotypes and negative barriers. It also has a critical influence on shaping attitudes, expectations and ideals regarding attractiveness, desirability, love, family life and sex, not just of persons with disabilities, but of the whole society.

- Communication through emails, internet-based forums and chat rooms can give an opportunity to disabled persons to break the walls of their isolation and redefine their own identities through online text-based[1] exchange of ideas. Yet, the impact of these new technologies on the realisation of sexuality of disabled persons remains limited because the transformation of an online contact into real-life encounter needs to negotiate the different barriers surrounding disabled persons.

- Finally, internet-based communication modalities (such as Emails, Newsgroups, Forums and Internet) can be useful tools for participatory and emancipatory disability research, allowing active participation of disabled persons in different research activities, including guiding and controlling of the research. However, these may still exclude disabled persons who have difficulties with text-based communications.

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[1] At the time of the research in 2001-02, the exchanges were only text-based and there were no forums or chat-rooms where people could see each other or share videos.

**Note regarding terminology**: In this report the term “disabled persons” has been used to denote the disablement of persons through the physical, social, cultural and attitudinal barriers, as advocated by disability activists in UK. It recognises that in many countries, the term “persons with disabilities” is preferred.

# Chapter 1: Introduction

> Female, male or disabled? That is a peculiar question, isn't it? It seems almost to be a confusion of paradigms, doesn't it? Disability is not a gender. It is a question of person's abilities, nothing else. Of course, people with disabilities are men and women like everybody else. But maybe the question was not about people's gender or abilities, but categories of public restrooms? (Fritzon, 2001, p. 20)

Sexuality is an essential component of human identity. Yet, a vast number of disabled people never experience sex in their lifetime. This obviously produces mental anguish having the same desires and needs as everyone else. (Owens, 1997) If the human desire to be loved for what you are and not for what you should or could be, is universal, there is no doubt that such a desire assumes even bigger significance for a disabled person, in the sense that your own companion needs to accept you with your physical and psychological limits. (Portelli, 1993, p. 187)

> Getting laid confirms your masculinity or femininity, but for disabled people it may also confirm your adulthood, especially when you need to have everything done for you, need to wear a bib at meal times, and help with toileting. (Owens, 1997)

Sexuality is a taboo subject, to be hidden behind closed doors and not to be discussed in public. Disability is also a taboo subject, often seen as something to be ashamed of and to be hidden behind closed doors. The two taboos come together to negate the sexuality of disabled persons. The two realities, that of sexual-affective sphere and that of disability, have only recently been liberated from the weight of numerous taboos. You can now speak about sexuality and you can also speak about disability but if you try to bring together the two subjects as a common reality, suddenly you find the same old taboos rising up. The two terms are seen in antithesis to each to each other, negating each other. (Malaguti, 1993, p. 1)

> Sex! The word connotes pleasant thoughts such as love making, fun and warmth. Disability! The word conveys the concepts of loneliness, ugliness, incapacity and pain. Sex and disability! The emotional reaction to these two terms together might include such ideas as impossible, frustrated, withdrawn, vulnerable. (Cole & Cole, 1991, p. 79)

The coming together of disabled persons and their collective fight for equality and human rights over the last few decades have led to international recognition about these rights.

States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood. Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. (UN, 1994, Rule 9, p. 28) However, in spite of this formal recognition of sexuality as a part of human rights, there is an enormous gap between what is advocated by international declarations and the reality faced by disabled persons in their daily life.

Attempts to raise this issue or to promote any debate about it, may meet sudden resistance. The tendency is to emphasize repressing interventions, aimed at limiting the sexual impulses rather than interventions which educate disabled persons, and help them in acquiring living skills and in expression of their sexuality. (Veglia & Zoccorato, 1999, p. 21) Families may negate the idea of sexuality of their disabled children or even condemn any attempt to discuss the issue.

> If parents of boys may tolerate the genital dimension of their sexuality (masturbation, going to the prostitutes, etc.), the parents of the girls never accept this. For both groups of parents, it may be even more difficult to accept the affective dimension of sexuality as this brings up the issue of a third person, an outsider, who is becoming significant in their child's life. (Landi, 1996, p. 14)

Most of the research carried out about sexuality of disabled persons looks at it through the medical model paradigm, as a problem which is a part of the impairment, so that the only solutions are denial or suppression of the sexuality. It is seen as something pathological, to be treated, cured and controlled.

> In our experience, most of requests for consultation related to sexuality related problems of disabled persons are, in reality motivated by a necessity of suppressing or controlling dysfunctional behaviour rather than by any desire to open any new sexual or affective prospects for them. (Veglia & Zoccorato, 1999, p. 21)

## Aims & objectives of the Research

The predominant discussions regarding sexuality of disabled persons look at it as something pathological and undesirable, which needs to be controlled and suppressed. This research aimed to look at sexuality from the point of view of disabled persons.

It explored the impact of society, families and physical and cultural environment in negating the sexuality in a small group of disabled persons in Italy. It had two broad aims - understanding the barriers to sexuality faced by disabled persons; and, the role of internet related technology in participatory & emancipatory disability research.

Regarding the first aim, the barriers to sexuality faced by disabled persons, the research looks at the following broad areas.

- In what ways, societies create barriers around persons with impairments, disabling them and more specifically, disabling the expressions of their sexuality?
- In what ways, the barriers created by societies are internalised and influence their expectations and behaviours among the disabled persons?
- In which ways, these barriers affect the sexual desires, fantasies and experiences of disabled persons?
- How can the barriers be overcome and does development of internet related technology help in it?

This research was rooted in social model of disability and in emancipatory research paradigm.

Often sexuality is identified with "genitality", thus diminishing its complete significance. Part of the merit for enlarging the concept of sexuality beyond simple genitality must go to Sigmund Freud. (Mannucci, 1996, p. 25). For this research "sexuality" was considered in its broadest sense, covering the full range of affective and family relationships and not just limited to sexual desires and experiences.

> In fact, we can't limit ourselves by defining sex as a coital activity followed by orgasm, because then we risk excluding a large number of persons from this discourse and excluding ourselves from a broad and gratifying vision of sexual pleasure….Through sexuality we can know ourselves and others in such a rich and profound way, which may not be expressed sufficiently through language and logic. (Veglia & Zoccorato, 1999, pp. 24-25)

*The Research Context*: The Italian National Institute of Statistics (ISTAT) provided the following information about persons with impairments in Italy:

> In 1994, it was found that in Italy there were 2 million and 677 thousand persons with impairments which means about 5% of the 6 years or older population… There are 2 million and 363 thousand families having at least one person with impairment (about 20% of all families). Among these about 2 million are families where the person with impairment is an elderly person…. It is more common to find that persons with impairments live either alone or as a child-less couple or they may live as an "additional member", which means that they don't constitute their own nuclear family group of a couple or with parents, but live with family of someone else. 23.4% of persons with impairments live alone compared to 7.1% of persons without impairments… comparing at different age groups, we find that a lesser proportion of persons with impairments live as a couple or have children. (ISTAT, 2002)

Why there are less "*persons with impairments living as a couple or have children*"? Most of the "scientific research" based on medical model or personal tragedy model, looks at this issue by focussing on the difficulties created by impairments, which render affective and intimate relationships impossible, if not outright undesirable. Statistics alone are not sufficient to explain the real dimension of the problems. For example, the data regarding persons "*living as a couple*" excludes persons having less than 21 years, while there is a large number of adolescents and young adults with impairments, whose awakening sexuality is frustrated by the barriers and negation surrounding them.

This research deliberately ignores discussions about impairments and focuses only on the disabling barriers with a general direction for enquiry rooted in social model of disability in the context of human rights.

The research was conducted entirely through emails without any other direct contact between the participants and the author. Initially all discussions were individual followed by a second phase of collective communications to the whole group to share the initial findings and to discuss their significance. The second aim of the research, exploring the potential of Internet related technologies in participatory & emancipatory disability research, was not discussed with the participating persons initially but was raised by the author in the final phase of the collective dialogue.

After the end of the research process, the author and some of the participants met for a lunch meeting, to know each other and to talk. Those discussions are not part of this analysis.

*Selection of research subject:* The suggestion for focusing the research on sexuality came from a friend who had lost an arm in an accident in Africa ten years ago and commented on the negative impact of this on her identity as a woman and on her non-existent sexual life. At the same time, the author has been involved in studying the process of empowerment among rural poor and marginalized population groups in developing countries and wanted to explore the potential of using information technology instruments in such processes. This research provided an opportunity to bring together these two ideas.

# Chapter 2: Literature Review

Sexuality is a complex issue touching on almost every aspect of life. This literature review briefly touches upon some of its aspects to illustrate this complexity.

### Sexuality, Human Identity and Models of Disability

The notions of sexuality touch the deepest parts of our being and are fundamental to the definition of human identities. Our sexuality is very personal and intimate. As biological beings, everything that is connected with the way we multiply, touches to ourselves and our way of understanding ourselves. (Fritzon, 2001, p. 20). The social identity, the way others perceive our identity, also influences sexuality, and this is particularly important for disabled persons collectively.

> The importance of identity is that reality is constructed around our understanding or belief of the nature of the other person or a group of people… Only the characteristics that fit with the identity type are identified and the type is maintained. As such identity types are relatively stable and assume the status of social reality. (Taylor, 1999, p. 377)

For the medical model of disability, the impairments are the basic cause of all the problems and the persons with impairments need to be “rehabilitated” to lessen the impact of their limitations and help them to live “normally”. Professionals tend to define independence in terms of self-care activities. So, independence is measured against skills in relation to performance of these activities. Disabled people however, define independence as an ability to be in control of and make decisions about one’s life. (Reindal, 1999, p. 353)

> Physicians are trained to understand pathology and physiology, but not necessarily contemporary sexual attitudes and behaviours. Moreover, the sexual information they do possess may be result of personal preferences and feelings as much as scientific knowledge. (Cole & Cole, 1991, p. 79)

Often even sociological research tends to concentrate on the impact of the impairments on sexuality, and is thus based on medical or psycho-analytical paradigms.

> It is evident that scientific literature is looking at this subject mainly through a medical-psycho-analytical viewpoint. Little space is given to a psycho-social approach. (Malaguti, 1993, p. 64)

The social model of disability has challenged the basic assumptions underlying the personal tragedy view of disability. The social model of disability is a result of disabled persons coming together and sharing their experiences, coming to an understanding about the oppressing mechanisms of majority non-disabled society.

> The solidarity broke the isolation in which disabled persons and their families had been imprisoned, creating the opportunities for deeper interpersonal relationships, like friendship and love between disabled persons. It was all putting in to discussion the old prejudices: the "shame" of disabled child, her impossibility of feeling any sentiment for anyone outside the family. The desire of "being together", which animated the new associations, was the first real rebellion to the existing system. We were reclaiming our right to be a person. (Portelli, 1993, p. 46)

Starting from late eighties, mostly disabled, researchers begun to draw on disabled people's experiences to illustrate the complexity of the process of disablement with reference to environmental and social forces. (Barnes, 2001) In the context of social oppression of disabled persons, it is suggested that disability research should be used for political action against the 'disablist society' (Bury, 1996)

## Religion, Social & Family Attitudes

Majority of population in Italy is catholic. The traditional view in catholic church views heterosexual family as the basic fundament of society and post-marital sex as means for reproduction. Masturbation and homosexual relationships are both seen as un-natural and immoral.

> "A gonorrhoea is hundred times better than the vileness of masturbation, better to share the shame in two persons of different sex than to have the same shame growing and accepted in your own body." (Wanroij, 1990, cited in Mannucci, 1996, p. 23)

The Bible touches upon different themes linked with sexuality, among which is homosexuality, which has always been condemned by the catholic church as a sin "*against nature*". (Mannucci, 1996, p. 23) Celibacy and chastity as self-denial and control of senses in the path to reach the God, are themes shared by many other religions as well. For disabled persons especially for disabled women, celibacy may be proposed as a virtue to be cultivated.

> …it was easier to close an eye about the "physiological needs" of men. Thus, the appeals for chastity and virginity for men were pure rhetoric, it was certainly not so for girls and women. (Wanroij, 1990, cited in Mannucci, 1996, p. 24)

Naudé John (2001, pp. 25-26) discusses the different myths related to sexuality of disabled persons – all disabled people are asexual, i.e., incapable of having sexual relationships; disabled people are obsessed with sex and have uncontrollable urges; disabled people are childlike and need to be protected from being hurt or let down; there must be something wrong with a non-disabled person who has a relationship with a disabled person; for the disabled person, it is better to a relationship with a non-disabled person than with another disabled person; etc. Different societies share many of these ideas and as can be easily understood, these have a strong negative impact on sexuality of disabled persons living in those societies.

> Common myths of people with disability portray us as inferior to non-disabled people, sexual, childlike, weak, passive, not good partners or parents, in need of sterilisation. (Kern, 2001, p. 28)

Family represents the first and the most important contact with the outside world for a child. Thus, it is easy to understand the importance of the family attitudes in determining the development of persons and of their sexual identities. Parents and family are the channels through which religious ideas, social ideas and messages from the outside world will pass to the children, be filtered or commented upon.

> As disabled children grow up they become aware of their sexuality in the same way non-disabled children do, i.e., through television, cinema, gossip, magazines, etc. But their social activity is more closely supervised than that of non-disabled children and sexual expression of behaviour is often discouraged. (Naudé, 2001, p. 25)

Parents' concern for safety makes a child-like and regulated existence beyond the years of childhood (Hendey & Pascall, 1998, p. 424), where sexuality may have no role. Family attitudes about gay and lesbian children, may be even more problematic.

> "If he is gay, I don't know, I would try to save him, to get him cured. I know that my son runs this risk. As he can't control his mind, if he will go with thieves, he would also become a thief. If he goes with gays…" "Our daughter? Lesbian? We can never tolerate that" – both husband and wife are horrified. If it was a man who becomes homosexual, perhaps it would be easier to accept it. Why? – He: I don't know… perhaps because lesbians are never seen and we are not used to the idea. – She: I would wring her neck." (Mannucci, 1996, p. 29)

Family attitudes also differ for disabled girls and disabled boys, where girls may have less opportunities for social interaction.

> However, in qualitative terms, there were differences between young men and women in the way they described the effect of violence and fear on their lives, with young women expressing much more damage and limitation as a result of violence and fear than young men… For some women fear had a very limiting effect, producing poor social lives for a majority of women and social isolation for some. Two male respondents admitted poor social lives, but most were socially active, with a wider circle of friends. (Hendey & Pascall, 1998, p. 419-420)

## Role of Mass Media

The social model of disability has been important in understanding the systematic oppression of disabled persons by non-disabled majority society and its institutions. While physical barriers including isolating institutions limit the opportunities for meeting others and initiating meaningful relationships, the continuing negative messages from mass-media are much more insidious and their impact is probably much more stronger than any physical barrier. We're all bombarded from TV and magazines with this so-called perfect body. (Doyle, 2000)

> These negative messages can have a major impact on a disabled persons' sexuality, and expression. This is because most people view themselves in relation to what other people think, and this view is very important in determining whether we feel positive or negative about our sexual identity and expression. So, the messages received about being disabled can have enormous repercussions on how disabled people see themselves. (Naudé, 2001, p. 23)

Popular attitudes often reinforced by mass-media, about marriage and children of disabled persons can also influence the possibilities of social interaction and the choices made by disabled persons and the expression of their sexuality. Thus, while the mass media may depict the children of disabled parents as victims, their lives may be surrounded by the same barriers.

> … the location of these oppressions did not lie in the parent's biology, nor in their failure to provide their children with 'ideal' lives, or a 'normal' family. Instead the source of oppression for these children usually lay outside the family, in the economy, the state and civil society. (Blackford, 1999, p. 679)

## Care, Power and Choices in the Relationships

The need for care can raise additional barriers to expression of sexuality among disabled persons. For some persons, the question of body ownership can restrict their views of themselves as sexual beings. With need for continuous help in dressing, undressing, washing and the management of continence, disabled people can begin to switch off from their bodies. As things are done to them and not **with** them, the bottom half of the body becomes a separate entity, not owned by the individual but by everyone else who comes to dress and change. (Naudé, 2001, p. 24) When persons are not self-sufficient and personal assistants are needed, the right to live one's sexuality could raise additional issues.

> Changing batteries is one thing. Putting on a condom is something else. "The lines already exist," says Letch. "some attendants do toileting, some do not. We're trying to develop a care model which clearly defines what attendants can do and what they can't"… Attendants are not sex workers, nor will they be expected to be. The dilemma is how to give disabled people the sexual freedom to which they're entitled, without compromising the sensitivities and professionalism of those who work with them. (Mascall, 2001)

Relationships also raise issues of power and choices, where disabled persons may have unequal power and choices.

> A person who considers starting a relationship with someone with a disability may wonder what that disability will mean to their everyday life. That disability will in fact, also be his or her partner's disability and that creates an inequality between the

> partners. Because the partner without the disability can choose to live without disability by ending the relationship. (Fritzon, 2001, p. 22)

Relationships also mean coming to terms with feelings of both partners about the impairments of each other, about the limits that this may produce to their living together.

> I wince every time my partner tells me of his discomfort -
>
> his discomfort about my lack of "social acceptability".
>
> Which he knows he is seeing. Possibly no-one else…
>
> I tell him I understand. And I do.
>
> Completely. For don't I feel embarrassed about my disability at times?
>
> Dear God, don't I want to "crawl under the bedclothes"
>
> when my body jerks at inopportune moments?
>
> However, I still hurt. I hurt when he voices these things.
>
> (Marks, 2001A)

### Changing Context & New Technologies

The development of social model of disability coincided with an era of increasing openness about sexuality. A study about sexuality among disabled persons states: "*Because disabled people were not able to make love in a straight forward manner, or in a conventional position, they were impelled to experiment and enjoyed a more interesting sexual life as a result.*" (Shakespeare, Gillespie-Sells, Davies,1996) The changing social norms also mean that at least some disabled persons can articulate and express their feelings, desires and anger about the denied sexuality, much more openly.

> And then there are the 'freak show' types. Their motives range from mild curiosity to fully blown fetishism. It's great to hear, at the peak of an orgasm, "I've never fucked a woman in a wheelchair before." Why do I continue to put myself through this kind of abuse and humiliation? I often ask myself that very same question. But I've always been fascinated by human sexuality. And I'm a disability rights activist, whether I like it or not. So why not campaign on sexuality and disability discrimination. (Fay, 2001)

There is an on-going debate about providing “paid sexual services” for disabled persons in some countries, though some disabled activists have argued that such a solution is a part of the oppression and ignores the real issues. “Supplying sex” as a state benefit may not be the answer. As well as attracting tricksters, it would take the element of choice from the disabled person, accentuating their childlike status. (Owens, 1997)

> Today, several Melbourne brothels employ sex workers who specialise in disability, some having rooms tailor-made for mobility-impaired clients. The only barrier is the price. At more than $100 a time, brothel sex doesn't come cheap. And it doesn’t work for women. (Mascall, 2001)

The advances in information technology can provide new opportunities for disabled persons for social interaction and sexual expression, but not everyone agrees with this idea. Many persons, enthusiastic about opportunities for meeting other potential sex partners through Chat groups and Internet, soon become disillusioned with virtual nature of the contacts. Others see internet and virtual reality as an excuse for running away from “real” life.

> It's just that if I could have immersed myself in solely scholastic pursuits like the educative stuff on the Internet, or in chat-rooms and virtual sex, I may not have "kicked myself out the door" (I used to do this literally, in my mind) to find my own life, my own friends, when I realized that my cousins were growing up, getting married, having babies. It would have been so easy, too easy to take the "soft" option. (Marks, 2001 B)

However, there are also other new technologies. Coupled with increasing openness about sexual matters, these can offer new opportunities for sexual fulfilment. For example, some disabled activists have raised the issue of access of disabled persons to products of sex-industry.

> Lanyon combines his job as a recreation lecturer at Victoria University with the design and development of dildos, vibrators and other sex toys specifically for disabled people. Working with a manufacturer, he’s in the process of adding a giant dial to the end of a vibrator, to make it easier to switch on and off. He has designed a “lexi-please” that bends in many ways to cater for the mobility restrictions of some users. (Mascall,2001)

The above exposition of literature review provides a glimpse of some of the issues involved in any comprehensive discussion about sexuality of disabled persons and their complex inter-relationship with each other, ranging from religious, social and family attitudes creating barriers with the active participation of mass media and the emergence of organisations of disabled persons, increasing openness about sexual issues and the development of information technologies.

# Chapter 3: Research Methodology

The research is rooted in social model of disability, which means that it did not enter in discussions about possible or perceived impact of impairments on the sexuality of research subjects. In this research, sexuality is considered in its broadest sense. Sexuality is, in fact, very much a social phenomenon (Way, 1982), in that all of us are social creatures who seek and enjoy "friendship, warmth, approval, affection, and social outlets" (Edwards & Elkins, 1988, p. 7).

The research is rooted in emancipatory research paradigm and the participants were involved in all phases of the study, including the identification of the research areas, understanding the significance of research results and decisions about use of these results.

*Sample selection and size*: As explained earlier, according to data from ISTAT there are about 2.6 million persons with impairments in Italy. Getting a representative sample from such a large group would have been difficult. At the same time, the research plan included a time-intensive on-going dialogue with the participants. Thus, it was decided to limit the research sample size to about 20 persons, possibly belonging to different age groups, different geographical areas in the country, different sexual orientation and both, men and women.

The research was organised in the following steps:

1. An announcement (appendix 1) was placed in some disability related newsgroups to ask for volunteers for the study. There were two main prerequisites for participation – persons should be above 18 years and be a disabled person or a companion/spouse of a disabled person.

2. Persons responding to this announcement were sent more detailed information about the objectives and methodology of the study and were asked to provide some general information, their consent for participation in the research and to comment on sexuality as a human rights issue (appendix 2).

3. The main issues about which information was collected during the research were defined in collaboration with the participants (25 persons who had consented to take part, provided general and demographic information and commented on “sexuality as a human rights” issue).

4. Then over a period of four months, these issues were discussed with the participants through individual emails. 21 persons out of the 25 who had originally agreed, actually completed this phase of the research.

**The main areas related to sexuality explored during the research included**: role of physical, attitudinal, social and internal barriers, influence of family, influence of mass media, sexual experiences and fantasies. All the communications were framed in an open way, letting each participant to define the direction of enquiry, he/she wished to pursue.

All the discussions were in Italian. After completing all individual communications, all the messages received from the participants were analysed by the author and sixteen thematic reports in Italian were prepared. Participants were asked if they wanted to be part of a collective discussion about these thematic reports (preferred by 86%) or if they preferred to continue with individual communications (preferred by 14%). At the same time, participants were asked their comments about methodology of research and the differences between email research compared to more traditional approaches of interviewing. Following the comments from the participants on the thematic reports, a final 10 pages long summary report in Italian was prepared and shared first with the participants and then with external persons. The whole process lasted about nine months.

The final ten-page summary report in Italian was requested by 56 persons/organizations, some of whom wrote back to share their own experiences and to offer comments on the report. These include disabled persons, parents of disabled persons, professionals and students. Two disability-related Italian web sites have put up an article related to the summary report. An enquiry about the report was received from a committee on "Equalisation of opportunities for disabled persons" of Italian Ministry of Social Welfare. Parts of the summary report are also going to be published in a magazine (Acca Parlante) published by Disability information Centre of Bologna.

The present thesis includes English translation of the extracts of the summary report.

## General & Demographic Information About the Research Participants

After the first announcement, a total of 34 persons expressed interest in the study. Out of them, 25 persons accepted to be part of the study and provided general information about themselves. Another 4 persons out of those 25 stopped writing back after providing general information about themselves.

The remaining 21 persons completed the whole research process. In addition, the non-disabled spouse of one of the participants, participated in some communications.

15 (71%) participants were male and 6 (29%) female. The lesser participation of women in this research was discussed with participants. The possible reasons suggested by them included – less women had access to Emails; and, women have more difficulties in talking with strangers about sexuality.

An analysis of communications on the sexuality forum of a popular Italian disability-related website (www.disabili.com) showed that over the last six months there were 42 communications from men and only 6 were from women, which confirms that less disabled women participate in such communications but does not offer any insight about the reasons for this.

The age group distribution of the participants was as follows:

| | |
|---|---|
| 18 – 27 Years: | 3 persons (14%) |
| 28 – 37 Years: | 11 persons (53%) |
| 38 – 47 Years: | 5 persons (24%) |
| More than 48 Years: | 2 persons (9%) |

Only one participant declared himself to be gay, while all the remaining persons were heterosexuals.

The participants had different impairments though majority of them were wheel-chair users (14 persons, 67%). They came from different educational and urban/rural and small city/big city backgrounds. Appendix 3 provides general details of participants.

Among the participants, 13 (62%) had had at least one sexual experience with a partner. Eight participants (38%) had never had any sexual experience with a partner and all of them had an impairment since birth. It has been suggested that persons having an impairment since birth or in childhood face more barriers. (Baldaro, 1987 and Malaguti, 1993) Only 6 (29%) persons were married or had a stable partner at the time of the research.

## Potential Biases and Considerations about the Discussion Process

> Everybody holds certain assumptions and biases depending on their own experiences, upbringing, and training. Interviewers are no exception and have to try deliberately to minimise the weight of their biases. (Roche C., 1999, p. 113)

The persons who joined the study earlier played a more significant role in defining the research areas compared to the persons who joined it later. However, this bias should have limited impact since the areas for discussion were very broad and each participant had the possibility of deciding the areas of enquiry he/she wished to touch.

Considering that the author and majority of participants are men, special care was given to involving the women participants in definition of research areas. Still, at the end of study, two women participants commented that the communications related to sexual experiences were posed from men's point of view.

> Mari: I think that this research should have distinguished between male and female views of sexuality, in the way the questions were posed… I felt that your communications were directed more towards men than towards women.

That gender bias does influence this research is also evident from the title of this thesis, taken from a quote by Fritzon (2001) – "Female, male or disabled?", while the title of this document is "Male, female or disabled". This difference was noticed by the author, only when this document was almost finalised. It is also possible that the research was biased towards a heterosexual view of sexuality, however the only gay participant in the study did not comment on this.

Since the interviews were text-based, probably communications and analysis of messages were biased towards more articulate persons. Similarly, the research excluded persons non-conversant with internet technology and those having difficulties with text-based communications.

The on-going dialogue with the research participants also resulted in questions from some participants to the author. Thus, during the process the author also shared his own views and experiences about sexuality during the dialogue. These dialogues were excluded from the research analysis. It is not clear if these exchanges could have created other biases in the research.

*Limits to the participation*: Though the research aimed to involve the participants in all phases of the process, in reality this participation was limited as the role of reading different individual communications, selecting the parts to be included in reports, actual report writing, etc. belonged to the author.

> Mariangela: My comments about my relationship with a priest have been put under the theme of religion. Actually, for me that relationship had no religious meaning. The way you have put it changes its meaning, though I can understand why you did that. It makes me look back at it in a different way.

For the second phase of the research dealing with thematic reports, majority of participants (86%) decided to receive them and comment on them collectively. However, they were strangers to each other and there was limited collective dialogue among them and some of them continued to write back individual comments.

> Serena: I didn't like the way some persons were commenting on the lives of others, so I decided not to write back. I think some persons are ill-mannered and not ready for a civilised dialogue. This blocks me.

> Mariangela: I shall like to explain why I didn't want to be part of the collective discussion. I have been so ashamed of myself all my life. Some of the things that I told you, I had never talked about them to any one... I don't want them to know me. They can read about me but I don't want any direct contact with others.

On the other hand, during the collective-discussion phase some participants had proposed to organise a meeting, to know each other better. Such a meeting could have been significant for promoting empowerment process among participants but the author was unable to pursue this.

A social meeting with a lunch was only organised a few months after completing the whole research process, when the thesis was almost ready. 8 participants took part in this meeting.

## Ethical Aspects of the Research

The research touched upon some very sensitive issues. The individual communications between the author and the participants gave them a possibility of creating a sense of privacy and confidence. Participants often told things about themselves that they normally would not share with others. Some of the information was related to traumatic experiences.

The ethical issues for such a research are fundamental. If the persons involved in the research are vulnerable, it is important to make sure that no harm is caused to participants and adequate support needs to be planned. (Sherry, 2002) Research should also be based on “informed consent” of the participants (May, 1997 cited by Barnes and Mercer, 2001 A). For this reason the following steps were taken the safeguard the participants of this research:

- No information was asked regarding the cities of residence or addresses of participants. Persons were asked to choose any name that they liked for the research. Participants were informed that they had the choice of ignoring any question that they did not wish to answer. The persons were also informed that they could withdraw from the research at any time without any explanations.
- As communications with individual participants covered a relatively long period (4 weeks to 4 months), care was taken to respond with empathy to messages containing emotional information. For such messages participants were asked if they were comfortable with the idea of sharing these with others or if these should remain confidential and excluded from research analysis.
- When thematic reports were prepared, these were shared only among the participants and they were asked to specify the parts they would not like to be included in the reports for public and if they were comfortable with the names they had decided for themselves.
- All participants were asked if they agreed with sharing of the final report in Italian through web pages and news-groups and to specify parts that they wished to be removed from it.
- Even if participants have agreed that their information be shared with others, the author has decided to exclude the particularly sensitive and traumatic parts from all the reports.

## Emancipatory Research, Participation & Expectations

The basic premise of emancipatory research paradigm is the recognition that marginalized, oppressed and excluded people have specific knowledge and skills, which need to be articulated, valued and collectivised. There is a huge gulf between wanting to challenge racism, sexism, homophobia or (dis)ableism and being able to do so in a way that has lasting emancipatory effects. (Corker, 2001)

For this research, a narrative approach was chosen. In narrative research it is generally agreed that interviews should be ‘open and fluid’ in order to enable the subject to ‘take the lead’. (Plummer, 1983) The ‘excluded voice thesis’ postulates that narrative methods provide access to the perspectives and experiences of oppressed groups who lack the power to make their voices heard through traditional modes of academic discourse. (Booth & Booth, 1996, p. 55)

> NO research is objective and there are many researchers who know this and work with the subjectivity that constructs our lives. However, research – or academic research - rather than activism aims to think through and argue coherently so that what is often gut reaction can win arguments based on sound ideas. (Smith, 2001)

Though the initial communication clarified that the research was an attempt to understand the factors influencing sexuality of disabled persons, a few persons did have other expectations from the study.

> RR: Now that I have told you all my problems, I hope that you can give some idea about how to solve them?
>
> Sand: I have told you all about my fantasies and desires. Perhaps you can tell me what you think about my sexuality? Is it normal?

The initial communication had also explained that the research aimed to be an open dialogue and that participants were welcome to ask any questions to the author. Majority of participants did ask more information about the author, the reasons for the study, the way it would be used and sometimes, more personal questions. The information that the author is also a medical doctor, was given only to those participants who asked a specific question about it - it was perceived as a problem by some participants, who decided not to participate in the research.

> Enzo: If I had known that you are a doctor, I wouldn’t have joined this research. Doctors are shit and I have had enough of them. They just want to control you and complicate your life.

Among the general information asked to participants there was a question asking them to explain their impairment. When some participants answered this question by quoting a medical diagnosis like *Ostogenesis Imperfecta*, they were asked to explain what it meant and this also created some confusion. Though the author had decided to not to enter into discussions related to medical model of disability, however such questions created some confusion in a few participants.

> Claudio: Why I had thought that you are a doctor and you understand my condition. If you are not an expert, how can do you do research like this and give any answers to me?
>
> Davide: Showing that normal families are those on the TV where everyone is healthy, is offensive towards us, ill persons. It is like saying that if one is ill then one is also stupid or that one can't be happy.

Davide here called himself an "ill person". He was not the only one in this group of participants who consider impairment as a "sickness". Discussing this further with him, he wrote back: "I have no problem to consider myself a sick person. Honestly, looking at my body, I can't say that I am healthy."

Some other participants raised the issue of impact of their impairment on their sexuality and were not completely convinced by the role of external barriers as explained by the social model of disability.

> Mari: After reading all the reports, now I understand why you insist on talking about disabled people instead of saying persons with paraplegia, etc. However, for me paraplegia is part of me and leaving it out seems like leaving out a part of my identity.
>
> Serena: All this talk about romantic love and fulfilment even if someone has an impairment, I don't agree with it. I know this man who is spastic and can't even masturbate, he begs me to help him. Perhaps I am too hard but tell me, how does it matter, what others think about him? It is his own impairment …

There has been some criticism of disabled activists "reducing impairment to a common denominator in order to increase the political power of (the new understanding of) disability". (Corker, 2001) However, the above comments made during discussions about the final report in Italian, did not provoke any comments from the other participants.

# Chapter 4: Barriers to Sexuality

The research aimed to look at the impact of societal barriers on the sexuality of disabled persons. Barriers can be physical or they can be of attitudes of the persons, who surround you.

> RR: I think that there are two kinds of barriers between disabled persons and non-disabled persons. The first are the architectural barriers and the second are what I call "barriers of heart", which include the attitudinal and social barriers.
>
> Gaia: When all the others in the group decide to do something that you can't do, like going for hiking in the mountains or go sailing in a boat … in such cases, you tell yourself that these are not important, but inside it hurts you a little. Often, so many barriers can be overcome but you don't wish to involve everyone in doing something so that you can participate, so you opt out by telling some excuse. Reality is that you are 'tired', tired of always doing everything with difficulty, always needing to invent ways to do things, which are a 'natural right' for others.
>
> Mariangela: The barriers are a big problem, not only by limiting the occasions for meeting others – in so many places, you can't go with a wheel chair, but also afterwards, when you already have a relationship. A simple staircase affects your relationship – or both of you stay out, or he must "help" you … outside my home, it is difficult to have an equal relationship with others.

Almost all the persons in the research agreed that physical barriers are important but they can be overcome while the "barriers of heart" are more difficult to overcome, especially in relation to social and affective relationships.

> Mariangela: I am always something different – inferior, superior, according to the occasions, but I am never equal, always different. This is so painful … men think that with someone like me, either you have to be serious or it is nothing. It is impossible to make them understand that you would be happy with something light, impossible to make understand that only some sex would be enough.
>
> Davide: The non-disabled persons imagine the disabled persons as someone so infantile, that he can't have sexual desires. In addition, physically the disabled person

> is not a model of beauty. Thus, it is difficult to find a partner. If the person is also homosexual, the problems become even bigger…

Among the attitudinal barriers, attitudes of family frequently came up during the discussions. However, a majority of participants identified this as a difficult area for discussion. Four participants decided not to express themselves on this subject, while the opinions among those who wrote about it, can be grouped in three groups: A small minority felt that their families played a positive role while the remaining were equally divided between - I don't discuss sexuality in my family; and my family has negative impact on my sexuality.

> Max: In our family you don't talk about sex, not because it is a taboo but only because there is deeply rooted parent/son relationship. I don't feel the need to talk to them about it. I don't think that they feel that I am asexual, rather the opposite, but we simply don't talk about it.

> RR: When I was an adolescent, they did explain to me all the things that boys of my age come to know … I and my family are convinced practicing Catholics, so my parents feel that I need to make a sacrifice and that finding a woman is not my destiny. I agree with the catholic view but not with the idea that I must remain single …

> Manuela: My family influences negatively on my sexuality. It is a brake to my already limited sentimental life. My parents don't agree that I can have sex, are afraid that I shall be hurt or something. They feel that they are protecting me but it is an additional problem for disabled persons when they live in families with a closed mentality …

> Gaia: I must say that my family did love me very much, but at the same time, unintentionally, they have contributed to my insecurities. Even now, my relationship with my mother is very conflictual. We talk to each other every day and half the time we fight. My mother is the only person capable of making me feel furious, make me shout and lose my calm, because she knows where to hit me when she wants to fight … I feel guilty and in debt with them for ever … it took me a long time to understand this sense of guilt towards them …

Persons surrounding the children, especially parents can have tremendous influence in shaping their self-images. During this time period (early infancy), children are also consolidating ideas about gender and gender roles, or what it means to be a male or a female

… by age five, most are well on their way to understanding the kinds of behaviours and attitudes that go with being female or male in this society. (Calderone & Johnson, 1990) Even if the sample for this research is very small, still it seems that persons having impairments since birth or in early childhood are more disabled, have lesser possibilities for sexual experiences and this probably again indicates the importance of role played by the family.

Do the families and societies behave differently with disabled girls than with disabled boys? Women with disabilities have particular reasons to fear violence, mainly from men and some sources of protection are less accessible to them … they may be trapped in parental homes by fear. (Hendey & Pascall, 1998, p. 415) Perhaps such issues influence the way families behave differently towards disabled girls?

> Serena: The family influences a lot. First of all, for the mentality, that is, since I am a woman, I must be put under a glass-bell and protected … my family is very good and they love me, they never make me miss anything, even if they do have their defects. The first is linked to my limited self-sufficiency and so they are hyper-protective. I must admit that it annoys me a lot … I am still a virgin. I am sure that if I was a man, I wouldn't be a virgin now.

All the women participants in the research share this view that life is harder for them then for disabled men, though this view is not shared by all the men participants.

**Internal Barriers**:

The past experiences and attitudes of persons and society surrounding us are internalised, influence what we feel and think about ourselves creating additional barriers, are not always easy to overcome. (Rieser, 1990)

> Internalised oppression is not the cause of our mistreatment, it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist. Once oppression has been internalised, little force is needed to keep us submissive. (Mason, 1990)

Majority of participants agree that their own attitudes and feelings are a barrier to establishing meaningful relationships.

> Stefano: The image of being normal that I have is of my presentation of my dissertation for the university degree!! I was talking about my dissertation, and everyone was commenting about how I spoke and not about what I said. But that is my normality, the fact that beyond my way of talking and moving, there is what every person does, my normality … I am afraid of the reactions of others, this fear blocks me, it stops me from expressing me. I want to speak, shout, wave my arms, but this fear of what would the other person think, blocks me. It makes me afraid to come out from myself, to be Stefano … Even I can't understand my own recorded voice. I am the first one to not accept the way I speak and the way I move.

> Marinagela: The professor who operated upon me, he used to take me to the University, where he taught. To his students, he used to show a film with me coming out of the psychiatric hospital, where I looked like a savage animal, and the students used to laugh. Then I was made to enter the room, standing up and walking with crutches. Sometimes the students clapped. I was 15 or 16 years old and I wished to die … from shame and humiliation.

> Sand: Meeting others is like facing the final exams. As long as it is with persons who know me, it is ok because they know my problems. However, if I have to meet any new persons, for a long time I worry about the meeting … the non-disabled persons have a tendency to think that disabled persons, apart from being disabled, are also idiots and that makes me furious.

A few participants explained their strategies for overcoming these barriers, which range from self-acceptance, getting out and meeting others and using irony/humour as a strategy for breaking ice with strangers.

> Andrew: As soon as I can accept myself as I am, I don't worry any more about others. Important thing is to accept yourself. When I meet others, I try to give the best of myself, trying to make a good impression. Generally, it works.

> Walter: I remember that I was ashamed to go to the city, I felt observed and pitied. I used to ask myself, what did I do wrong? Anyway, slowly I integrated in the society, and stopped caring about my impairment. The important thing is to get out of your homes. If all disabled persons can go out of their homes, probably the social relationships would increase for all of us, because this would lead to destroying the

> physical and psychological barriers. Children must be educated in a different way about respect for human beings …
>
> Marcello: …irony is a positive thing, it helps you first of all, and then it helps others in feeling less embarrassed. I know that others are embarrassed about my disability, so I joke about it and make them feel that it is nothing dramatic. That they can also joke and talk about it … However, sometimes, I am forced to behave in a ridiculous way, in spite of myself, just to get attention from others and make them laugh, so that they accept to be with me, because when I am serious, I am refused …
>
> Gaia: According to my close friend that I had before meeting Ross, many boys liked me (so I was not so repelling after all), but I was not aware of it and when I was aware, I avoided them (may be unconsciously). The fact was that I didn't feel that I deserved love and desire (yes, even that). The thing which took me longest to accept was that even I could excite a man. Even now it seems strange to me, but at least I take it as a matter of fact … Often, we women, especially disabled women, think that we can be loved only if we offer a lot of love and sentiments, but that is not enough for a relationship. It may be enough for a friendship, but a relationship requires attraction and for attracting someone else, first you have to like yourself …

All participants agree that attitudes in the society, in the people surrounding them and their own feelings are all equally important. These attitude related barriers limit the opportunities for meeting others and for establishing meaningful relationships with others on an equal basis. Among all barriers, those related to the attitudes of family are particularly important in limiting the full expression of sexuality, especially for those persons who have impairments since birth or since early childhood. Gender is also important and women face much more barriers, especially in their families.

# Chapter 5: Changing Environment

The barriers are being challenged continuously by disabled persons with the help of the changing environment. Emergence of mass-media, information technology and the changing dynamics of religion are some of the most important developments affecting the barriers faced by disabled persons.

The last century saw the development of new mass communication technologies – newspapers, radio and cinema. Then over the last five decades, development of television, advertising and new information technologies including personal computers and internet, brought these mass communications closer to our homes.

While these mass-media continued to be under the control of a select few, growth of Internet related technologies can give opportunities to individuals to present their points of views and to network with each other.

Religion, which had a stronger hold on family and societal values in the past has become less-important, while religious values are often being challenged by humanistic values linked to more universal concepts of human rights.

## Impact of Mass Media

If families and communities influenced the attitudes and behaviours of individuals, now probably these mass communication instruments have even more potential for influencing desires, dreams and attitudes of a large number of persons.

> They [disabling stereotypes] form the bed-rock on which the attitudes towards, and assumptions and expectations about disabled people are based. They are fundamental to the discrimination and exploitation which disabled people encounter daily and contribute significantly to their systematic exclusion from mainstream community life. (Barnes, 1992)

The mass-media play a significant role in influencing barriers to the expressions of sexuality of disabled persons. For example, the advertising, media and the easy availability of explicit materials on videotape and the Internet focus on the clinical act of intercourse. This focus places undue strain on sexual adjustment to a disability. (Carp, 2001)

> Walter: All these things in the mass-media don't affect me personally. In any case, we need more information about disabled persons so that everyone becomes aware that disabled persons are human beings like everyone and have the same rights. However, in the TV, the disabled persons are never there.
>
> Max: Everyone says that it is better to be beautiful inside but I think that it is better if you can be beautiful outside as well. I love beauty … any way, you have to learn to distinguish fiction from reality – I have myself never desired the perfect family of Mulino Bianco[2] or to go and live in Beverly Hills … I liked the advertisements of Benetton showing disabled persons, I am in favour of showing diversity of persons – it helps people to get use to certain things, which otherwise remain hidden.

Walter and Max above are more concerned by the invisibility of disabled persons in the mass media rather than by the disabling stereotypes. Mass media also present specific ideas about love, beauty, marriage and desirable bodies and life-styles. How do these messages affect disabled persons?

> Mariangela: It is a complex situation. Regarding my sexuality, I can say that many things "stimulate my desire". I can also say that often they make me feel more alone and when they speak about disability, they make me feel ashamed of myself … I think that the worst thing that the media does is to influence my taste – I mean, they educate my taste so that I look at my body with distaste, so that I am ashamed of myself.
>
> Gaia: I think that very few persons can identify with the models of beauty proposed by mass media, so we all feel a bit inadequate or we just don't care about it. It is like all those pictures of thin girls and our worries about getting fat – women tend to make a tragedy out of it but it seems that men care too hoots about thin girls (for them as long she breathes, it is enough!) So why waste your life running after those things? … The problem is that mass media create values about physical beauty in public opinion, it is almost a question of eugenics.

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[2] Molino Bianco or The White Mill, is a leading Italian company making biscuits, bread, etc. The publicity of this company about happy families having breakfast together was cited frequently by different participants.

> Walter: I was struck by the film, “Born on 4th July”. It has a scene where Tom tries to have sex for the first time after his accident. That really made me feel very afraid because thinking that all persons with that disability are impotent is terrible, especially if it is the first film that you see after your accident! It can really create big psychological problems and to become afraid of women.

If mass media is responsible for creating and reinforcing barriers by promoting disability stereotypes and influencing the aesthetic tastes and desires, it can also be an instrument for fighting those barriers.

> Mari: I identified with the character of Tom Cruise in “Born on 4th July” because he has to fight with the external situation but he also needs to accept the fact that he is now paraplegic and in spite of it, he manages to use his personal experience as the basis for starting a collective fight for the rights of disabled persons.

> Stefano: The image of Antonio Guidi[3] speaking on the television in Maurizio Costanzo show! It has been a big help to me because he is so similar to me. For the elderly persons, when they see me, they can associate me with those images seen on the TV and it helps them in accepting me, and listening to my words rather than getting blocked by my way of speaking.

Almost all the participants agreed that the mass media has an important influence on building the public taste about perfect beautiful bodies and ideals of love and happiness. However, a majority of the participants did not give too much importance to the impact of these stereotypical images in terms of creation of barriers to their own sexuality.

## Internet Related Technologies

> This site is intended to challenge the myths that disabled people are invisible, asexual, unintelligent, undesirable or incapable in any way. This site is meant to be a resource for both the disabled and able-bodied communities, for breaking down stereotypes, raising awareness, and inspiring those with physical and mental impairments to understand and appreciate their sexuality (Erin, 2002)

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[3] An ex-minister in a past Italian government, a disabled person

Erin is a disabled person and he has created a web page to talk about sexuality, which persons from different countries can access and read. If they wish, they can write back to Erin or start a discussion. This is one example to show that the new technologies related to computer and internet can have a strong influence on the life today. Two questions can be asked in this regard:

1. Will this information technology revolution succeed in overcoming the barriers that affect the expression of sexuality among disabled persons?
2. What kind of interactions are there, where the real world meets the virtual world and how does it affect the sexuality of disabled persons?

The opinions in the group are almost equally divided between those who feel that information technology is going to change the lives of disabled persons and those who feel frustrated by it.

> Claudio: These new technologies have no effect on my real life and my sexuality.
>
> Costa: Negative. The new technologies, especially the internet, favour only virtual encounters, where you can't have any real idea about the persons with whom you communicate. For a real relationship (be it friendship or love) you need physical presence because behind a computer, a chat or a telephone you can present yourself as you wish.
>
> Mari: For a disabled person today, Internet is a big opportunity for communicating. As there is no physical impact which can create an initial prejudice, so you can know persons for who they are really and not just how they look!
>
> Andrew: All things considered, this is another opportunity to talk about sex and more in general about our feelings. I have made some new friends through internet. I also met a girl from Rome, whom I had known through chat. It was a positive and enjoyable experience.
>
> Davide: I like talking with other gays in the chat. I also tell them that I am disabled because I want a sincere relationship. I feel that technology is one of the few things, in favour of disabled persons.

When the oppressiveness of the gaze may negatively impact on disabled people, especially when the impairment is visually apparent, meeting online can provide another medium for presenting the self, where visual cues for evaluating others are typically inaccessible (Bowker & Tuffin, 2002, p. 328). However, most of the participants who feel positive towards the new opportunities offered by information technology, also have some reservations about its role in facilitating any "real" contacts. Many participants expressed their frustrations at the difficulties of taking forward the online relationships to the real world.

> Stefano: Through Napster, I have tried chatting. If I don't talk about my disability, then everything can be fine and I get the feeling that others like me. But if I talk about my disability then suddenly they feel that I am strange and are no longer interested in knowing me.
>
> Manuela: The computer and telephone are two things without which I can't live. They have made it possible for me to meet many new friends. However, often I also hate these since they don't allow me a physical contact with others.
>
> Mariangela: I started visiting chat sites two years ago and it was an interesting experience. You can't see the wheel chair on the chat so probably I behaved as if it was not there. However, as soon as I felt that the other person was flirting with me, I felt obliged to tell that I didn't walk. And, in different ways, they just disappeared … the result is that I stopped visiting those chat sites.
>
> Milo: The cybersex doesn't interest me. Perhaps I don't have much fantasy but I rather prefer the warm touch of a woman, to feel the softness of her skin, the sweetness of sucking her body … I want to look in to her eyes when I wake up in the morning. Looking at the computer screen is not enough for me. Only fucking is not enough for me, I want love.

There are studies showing how online environments enable users to consider new ways of thinking about their identity as a textual construction, at once fluid and flexible, rather than fixed, stable and unified. Yet at the same time, by eliminating disability from the social sphere in order to pass as non-disabled, differences are denied and are already marginalized voices are silenced even further. (Bowker & Tuffin, 2002, pp. 329-330). Social interaction through online communication, without requiring physical contact can be useful for breaking out of isolation created by the barriers, for sharing experiences, for networking, but when such communications are seen as a prelude to a desired physical intimacy, the same barriers again rise up in that space where the virtual world meets the “real” world.

> The recent growth in Internet access has made it possible to investigate the impact of email on personal relationships together with those that are work-related .... results portray a "thin world" associated with email use - one in which people tend to have relatively weak ties with their communication partners and where communication partners are more spread out than in the world of non-email users. (Kanfer, 1999)

### Changing Role of Religion

Religion is not something new. Probably it goes back even before the recorded history of human beings. Yet, the past decades have raised new issues, creating a crisis for the religions. For example, religious dogmas now have to contend with Universal Declaration of Human Rights. This is reflected in the way public opinion and mass media can pounce on any declarations by the religious leaders, which may be seen as infringement on civil and human rights.

Christianity and more specifically, Catholicism predominates in Italy. St. Agostino of Ippona was one of earliest Christian leaders, who codified sexual morals, who felt that sexual intercourse was exclusively for procreation, trying to get the least possible pleasure from the act. (Mannucci, 1996, p. 19). For a majority of Italians, including many church leaders, such a position would be probably laughable today.

Religion was not identified as a specific area of discussion by the participants and yet the issue came up repeatedly during the discussions, showing its continuing and changing importance in their lives.

> George: As a child I used to go to the church. They taught us that homosexuality was an act against nature and wrong. I don’t know if they were right but I am sure that we must respect the choices each of us makes. My family has taught me to think of right and wrong and not to worry about religions.
>
> Marcello: In Italy the religion (Catholic Church and the Pope) enters all our lives and they all try to oppress us, so that we can’t have independent thoughts. However, this behaviour is only false and hypocrite, it just makes that we can’t be together as a

> collective group, that we remain divided in our different pathologies and that we don't ask for our rights as happens in other countries of Europe.
>
> Roberto: The sexual costumes of people have changed so much that the catholic church must also interpret these themes in a different way, even if they have to remain faithful to the dogma of our Faith.
>
> Walter: About my girlfriend – you see, she is a special person! Even if she also desires me, she is very religious, so for her having sex before marriage is not correct (I don't think like that) …
>
> Gaia: The experience of Faith has been very important for me, it helped me to come out of my isolation … but in my parochial group they decided that I should be a nun, while I wanted a family and marriage. Perhaps they thought that it was above my possibilities. They said God wanted this from me, but I couldn't believe that God could have asked this from me if He had given me desires? They were convinced that they knew what was good for me. That's why now I have a healthy diffidence towards those who claim to speak in the name of the God … Finally it all comes to negating the possibilities of having a sexuality, because for some parts of the church, sex is something dirty, to be limited and imprisoned, especially for women and even more so for disabled women.
>
> Mariangela: On our fourth or fifth meeting he told me that he was a priest … he never called things by their names and this hurt me a lot. For once in my life, I wanted to be accepted by someone. I would have done anything to gain his affection … he said that he felt an "anthropological curiosity" for me – imagine saying that to me, when I already felt that so different! He said that behaviour is like water, it takes the colour of the container – which meant that the fault was always mine, it was my container that was not good enough … the maximum compliment that he made to me was that "I was beautiful inside". I was there, nude and ugly outside, I felt hurt … only after a long time I understood that the problem was not mine, it was he, who had the problem.

These voices about religion don't have a logical thread running through them probably because they come in different contexts. Yet they do touch upon the changing role of religion in the lives of participants. They have the strength to oppose it and even refuse it, if they feel that it is interfering with their desires and choices.

The power of mass-media, the development of internet related technologies and the changing role of religion are all part of the changing environment, sometimes allies of tyranny of non-disabled majorities in creating barriers, and sometimes allies of disabled persons in overcoming the barriers.

# Chapter 6: Desires, Fantasies & Experiences

While the concept of sexuality used in this research is much wider than just sexual intercourse, there is no doubt that sexual desires, fantasies and experiences do form the core of sexuality. Increasing there are publications on sexuality of disabled persons, but mostly they are for professionals, looking at disability and sexuality from the perspective of a "problem" and they hardly say anything about sex, love and pleasure. (Hingsburger, 1995)

## Sexual Desires and Fantasies

There were three areas of discussion which directly or indirectly touched upon the sphere of sexual desires and fantasies.

The first area of discussion was a fantasy about *a magic wand* and how we shall like to use it. Almost all the participants expressed a desire to use the magic wand to change the mentality of people, to be more accepting of diversity and of disabled persons. Though some persons did have more personal desires, hardly anyone connected their own sexual desires with the magic wand.

> Manuela: If I had a magic wand, I would like the world to become more humane and more acceptable of disabled persons, without all those barriers which block our autonomy. I would also like to change the mentality of persons in our regards, that is, remove the barriers they create.
>
> Nadia: I would like to make Marcello to be less aggressive and more tolerant, even if I understand why he is like that. He had to fight to be not crushed by others since he is disabled since birth while I became disabled when I was already 18.

The second area of discussion on desires and fantasies was about the following statement – "*Because disabled people were not able to make love in a straight forward manner, or in a conventional position, they were impelled to experiment and enjoyed a more interesting sexual life as a result.*" (Shakespeare, Gillespie-Sells, Davies, 1996)

> Claudio: As I had told you, I have no experience for talking about this. However, if you have a friend or a researcher who would like to test this hypothesis, I am willing to try.

> Max: I certainly agree with this idea because disabled persons do have more fantasy. It is natural, as they miss something, so nature makes sure that they become better in some other aspect.

> Nadia: It is clear that Tom has discovered something, which exists in our intimate life, especially in the life of disabled women.

While the discussions about sexuality were often about barriers and problems, the above statement from Tom Shakespeare et. al. was greeted with joy by the participants.

Though it is more difficult for disabled people to form sexual relationships because of disabling barriers, when they do, any limitations imposed by impairment may paradoxically lead to advantages. (Svein & French, 2000, p. 575) Almost everyone in the group felt that this was indeed true, though those persons, who have never had a sexual experience were not so sure about it.

The third area was that of our sexual fantasies. Do the barriers, both external and internal, disable the sexual fantasies of disabled persons? The aim of these questions was to look at the depth of internalisation of barriers among the participants and if the sexual fantasies reflected those same barriers in any way. Only about 50% of participants agreed to talk about their sexual fantasies.

> Gaia: I think that fantasies are something intimate and if told, they lose their beauty and “individuality” – they are something very personal.

> Mari: When I was in love with a tetraplegic man, who could only move his neck and give me pleasure only through his mouth, I used to fantasise that he is forcing me to make love to another man, while he looks on us and our eyes were united … I never spoke to him about this but I think that this was also his fantasy.

> Mariangela: I fantasise that I am hugged strongly in the arms of someone – he doesn’t have a face. I don’t know where my body finishes. I can only feel my butt on the chair and part of my back, the rest of my body is not in contact with anything or anyone … I have a fantasy where I think of someone penetrating me. I never think of things which actually happened to me, that would be too painful. I only wish, I could make love once without being hit by someone.

Do words play any role in the erotic sphere? What role does the language play in the sexuality? While almost everyone agreed that they use words related to sex and genitals as swear words, only a few men felt that words had an erotic role in their sexuality and sexual fantasies.

Erotic telephone lines bring together the erotic power of words, coupled with that of fantasy. They are also easily available from the privacy of the home, the only barrier being the cost. However, only two participants, both men, had ever used the erotic telephone lines though all participants felt that such services should be available for those wish to use them.

> Gaia: I don't get any kind of pleasure from using vulgar language. I don't mind it if my partner uses it, if I know that it is part of the erotic game and not as a violence.
>
> Carlo: This doesn't refer to me, as I am deaf.
>
> Max: I did use erotic telephone lines, I thought it was kind of squalid … but I did it in particular moments of excitation. Hunger is just hunger, it does not matter how you satisfy it … ever since I have access to internet, I have never used them.

Pornography can be seen as another way of stimulating fantasy, through images coupled with words or sounds. Almost all participants had seen pornographic magazines. Most of them also felt that pornography was not an issue with them and they had no problems with the fact that it is easily available at the news stands in Italy. None of the participants had ever seen pictures of persons with impairments in such magazines.

> If somebody with a disability turns out to be a sex symbol, there will be other people who say jaysus, if she or he can do it, then I can too. (Doyle, 2000)

Marcello echoed a similar thought and wrote that it would be a good idea to have persons with impairments in pornographic magazines since a "lot of people read them and it would make them realise that disabled persons also have sexual needs". However, no other participant seemed to agree with his idea.

> Gaia: I think that porno magazines are stupid. I think that they are the best way to kill your desire for sex and to give wrong education to persons. They show sex as something mechanical and boring, like doing gymnastics … perhaps men like them more?

> Marcello: I think that it is good that now you can buy them without problems. If young men buy them, they can have a direct impact with the other sex, and I don't think the pictures of beautiful woman are traumatic for any one. However, the problem is different – parents are supposed to give information to their children about sex and they are not doing it, so why complain about pornography?

A fantasy is the navigational path we invent to steer ourselves between the reefs and shoals of anxiety, guilt and inhibition. Fantasies, not only express our most direct desires but also portray the obstacles that must be symbolically overcome to win sexual pleasure. (Friday, 1980, pp. 1-2) The usual embarrassment in talking to others about sex can be partly due to difficulties in putting in words something which has deep roots in our affective being and is made of gestures, images, sensations and touch. (Veglia & Zoccorato, 1999, p. 23)

## Sexual Experiences

Masturbation can play an important role in your discovery of a new sexual identity as a person with a disability. It might even be easier than starting with a partner, no matter how recent or long term your disability might be. (Owen, 1997) Self-stimulation is one of those recurrent themes coming up during discussions, more or less accepted in families as well as in institutions. (Mannucci, 1996,p. 28)

> Gaia: I have never tried it and the idea of touching and caressing myself seems strange to me. Perhaps I have never loved myself enough to try masturbating?
>
> RR: I think that masturbation is one of the forms of sexual expression, if it is accompanied by a complete and happy sexual life. If you use it to substitute the real sexual life then it is an alarm signal.
>
> Mariangela: I think that it something inferior – from the experience that I have, I see the relationship with another person as a proper sexual relationship. Masturbation is part of the solitude, it is because you don't have anything else. If you masturbate with someone, as a way of being together, then of course, long live masturbation!
>
> Costa: Adolescence was a bad period for me. For almost four years I was in love with a girl, who never looked at me and I hated the school. My only pleasures were music and masturbation … however, it is the only way you have because you can't have

> proper sex. Now when I do masturbate, I don’t feel satisfied. It makes me feel lonely and makes me miss the life as a couple.

Some people with short or missing limbs, weak muscles or bad coordination may find it impossible to masturbate, and obviously get unbearably frustrated, although most people prefer not to think about such things, and the frustration goes unmentioned and ignored. (Owens, 1997) Though almost all the participants seemed to agree that masturbation was perfectly legitimate and normal, they also see it as something negative since it is the only sexual choice available to most of them.

During the research there was a debate in Italian parliament about a law for allowing institutional prostitution. The theme of paid sex workers for disabled persons also comes up frequently in some Italian disability-related newsgroups.

> Sometimes the disabled person manages to find a professional sex worker, but I’ve known blind people who are unaware that such services exist because “that kind of thing” isn’t read out on talking newspapers. Deaf people and those with speech difficulties are unable to phone up to make an appointment, and the hurdles for people with mobility problems can be enormous. Most working flats are upstairs, massage parlours inaccessible. The “going rate” is usually beyond most people’s means, and requesting a sex worker to visit you, usually doubles the cost. (Owen, 1997)

Among the research participants also, the theme of paid sex workers created some debate.

> Claudio: I have never been to a prostitute, though I think that those who wish to go to them should have the possibility.
>
> Mariangela: In 1997, I casually knew a man who was working as a gigolo. He proposed it to me and I agreed after some hesitation. I always wanted to feel the sensations of sex without being raped or hurt by violence. But when the moment came, I just gave him the money that we had agreed without even taking off my coat … I want the luxury of being of a romantic? I don’t know, but I was just incapable of it.
>
> Marcello: My first sex was with a prostitute. My friends collected all the money so I could also try it.

> Mari: It is a difficult subject! I have some disabled friends, who regularly go for sex to prostitutes, because otherwise they would have no opportunity for sex. I respect their choice. However, I think that this is not correct because the existence of such services makes it more difficult to build a society with a progressive culture – where sex is not a taboo and where disabled persons are not a taboo.

Most of the participants felt that they would not like to use the services of paid sex workers, though all of them agreed that it is legitimate that those who wish to do so, can have this possibility. Like for masturbation, most participants see paid sexual workers as a denial of their right to "normal" relationships and being a symbol of lack of choices available to them.

"Devotees" are persons who like to have sex with persons having impairments. Most of the participants had heard about it through Internet though no one had any experience with such a person. Most of the participants had conflicting ideas about this.

> Andrew: I have heard about it recently and I would like to meet such a person but I don't know how to find her.

> Carlo: I don't want to be seen a category – I don't think you get love by being a category.

> Mari: I have heard and read about devotees. No, I don't like the idea and I would never wish to be with such a person, who doesn't see me as a person but looks only at my disability.

> Milo: I would love it, do you know how can get in touch with someone like that?

> Mariangela: Do I want someone like that? If you know someone, let me know! I am only joking, I don't think I want a person who wants me only because I am disabled and not because I am Mariangela, though it would be the first time in my life that my disability is actually useful for something!

Four participants had had episodes of sexual violence and rape in their past. All four of them still continue to have very strong feelings about the subject.

> Mariangela: When I was 17, Franco raped me and when I was fighting with him, he was saying "Enjoy it stupid. This is your only occasion. Look at yourself, who would wish to do it to someone like you …". I could hear voices from the other room, but I

> don’t know why I didn’t cry out aloud. For a long time, I felt guilty about not shouting and calling for help ... No I have yet not overcome it. I don’t feel anger, I just feel compassion for me.

Sexual desires, fantasies and experiences of disabled persons reflect the disabling barriers, which affect other aspects of their lives. The “problems” relating to sex and relationships for disabled people may be caused more by negative self-image, lack of self-esteem and social pressures than necessarily by physical impairment or loss of function due to disability. (Naude, 2001, p. 25).

# Chapter 7: Internet and Emancipatory Research

The research also aimed to study the possible role of emails and internet in emancipatory research process. The discussions on this issue can be grouped in two main areas:

- Role of emails in conducting interviews and its advantages/disadvantages compared to other "live" interview techniques
- Potential for promoting an emancipatory process through emails/internet

## Emails, Newsgroups and Internet as Main Instrument for Conducting Disability Research:

*Emails for conducting research interviews:* The experience of participating in a research through emails was discussed during discussions on thematic reports. Different participants had experiences of participation in surveys and interviews previously and were thus able to compare the two and comment on the differences.

> Mariangela: The first difference that I felt was that to an interviewer with a recorder, I would have said the first things that came to my mind. While in this way, I could write down my feelings. This is because the relationship is different. To have the other person in front of me means that I have to expose myself to his judgement … and emails gave me a space for reflection! Sometimes, it took me days to answer a question. … If you had been here physically, I would have answered you, but through emails, sometimes I was not writing to you, I was talking to myself. The fact that in your messages, I never had the feeling of being judged, that also helped. When I asked you anything, I felt that you were answering me sincerely and honestly, and that helped me to be sincere and honest.

> RR: The advantage of this kind of interviews compared to the traditional way of doing these is that here you are not required to answer intimate and embarrassing questions without thinking. Probably when you write there are less inhibitions and fear. The disadvantage for the interviewer is that you don't get the answers immediately but you have to wait for them …

> Max: I think that the positive thing about email interviews is that you can answer in sincere and honest way since the interviewer is not in front of you. I can also imagine

> that for the same reason, some persons can write what they wish and give completely false answers.

### Emails & Internet for Emancipatory Research

The term 'emancipatory disability research' was coined by Mike Oliver, almost ten years ago. (Oliver 1992, cited by Barnes, 2001) The social model of disability has been an emancipatory concept in the lives of many disabled people. (Tregaskis, 2000, p. 343)

> Emancipatory research is about the demystification of the structures and processes which create disability, and the establishment of a workable dialogue between the research community and disabled people. (Barnes, 1992, p. 122)

Apart from the process of the emancipatory research which must involve the researcher and the researched in equal partnership in different phases of the research, which was attempted in this research, it is important to know if it actually helped in "demystification" and in creating a collective consciousness about social model of disability? The answers from the participants were very diverse though some of them commented that the research had helped them in looking at the collective needs of disabled persons.

> Gaia: I am reading the reports on our answers and it is getting to be very interesting. It is an "experience" in the sense reading what others think and feel, makes me feel very close to them … first I was speaking alone and now I hear voices of others and that is very beautiful. … I have to say that reading what you have written, what we have written, it is such a strange and moving experience that I can't describe it. Every evening when I download my mail, I am hoping to see another of these reports and then after reading them, I think about them for a long time. When I started participating in this research, I didn't think that it would be such an involving experience. Reading your words is like looking at myself through a mirror.

> Mariangela: I have read the report in the morning and for the whole day, I kept on thinking about it. I am reflecting on things that I had never thought about before. I went some times to the disabled people's organisation – but it is full of persons complaining all the time. I didn't want to go back there again. I never felt part of a group of "disabled persons". When people earlier used to say the "world of disabled persons", I couldn't understand what they meant. I never thought that by having similar needs we become similar persons … reading this report, it was like a flash of

> light in my head. Perhaps when the non-disabled persons say “you all”, it is not so strange after all.
>
> Walter: The reports are becoming very interesting. Reading what we all are saying, I feel a great desire to LIVE! And to shout that WE are also there!
>
> Carlo: I don’t know what to say. I don’t share most of the opinions that have been expressed in this group.
>
> Claudio: I wanted to make some considerations. I think that the criteria of this research by grouping together persons with different disabilities is very generic. I think that persons with sensorial problems (deaf persons, blind persons) have different problems compared to a person having tetraplegia…This has not been touched in this research.
>
> Matteo: Thanks for the reports. They are interesting but also banal and obvious. Nothing new comes from them. They all seem to say that each of us lives our sexuality in different ways …

Two primary principles of ‘empowerment’ and ‘reciprocity’ are at the heart of the emancipatory research. (Barnes and Mercer, 2001 B, p. 40) Emancipation requires an understanding of barriers surrounding the disabled persons and it also needs collective action to remove those barriers. What is the best way to remove the barriers surrounding the sexuality of disabled persons?

> Andrew: I don’t know. I prefer to look after my problems by myself. I don’t care what others think or do.
>
> Mariangela: We have to work on tastes and attitudes of people. What influences these most? Probably advertising. A person with a non-harmonic body, paralysed or non-integral, would perhaps never be the “preference” of people. I don’t see any way of escape. You can’t order persons to make love to me, I would never be “desirable”.
>
> Max: Everyone in the society needs to be informed – sexual education is not there at all. Society thinks that we are like angels, unsexed. Most of all we need to work on other disabled persons.

> RR: We have to involve parents and teachers. However, we need to work most with mass-media.
>
> Mari: Unfortunately, the way is long and difficult. It is a battle of civilisation that must be fought at many fronts and it must involve all the political and social community. Even doctors have their responsibility and I wish they can be freed from their prejudice that a disabled person is only half-a-person. But doctors are also a product of this culture which supports that view.

As mentioned earlier in this document, some participants did express desire to meet, which was not followed up. If the aim of the emancipatory disability research is to promote a collective transformation among disabled person for a political and social action against oppression, this process could not be completed in this research, also because of time constraints. At the most this research can claim to be a participatory process leading to some understanding of collective oppression of disabled persons in some participants.

However, by itself a research cannot ever directly lead to empowerment of disabled people. (Barnes & Mercer, 201 B, p. 40) Thus it would make more sense to call it ‘participatory’ rather than ‘emancipatory’ research. Still this research shows that Emails and Internet can be useful instruments for a participatory approach to an understanding of social model of disability and if these are used for an emancipatory process rather than for a time-limited research, these could play a role in empowerment of disabled persons.

# Chapter 8: Conclusions

This research aimed to explore the impact of different barriers on the sexuality in a group of disabled persons in Italy. Different cross-cutting issues influencing their sexuality were decided through the discussions with participants, which probably form the core of the debate about their sexuality.

The most fundamental question emerging from this research was - What is the meaning of being a man or a woman for each of us? All the barriers to the expression of our sexuality - physical, social, cultural and the ‘barriers of the heart’, all revolve around this core question. Thus, a person's sexuality cannot be separated from his or her social development, beliefs, attitudes, values, self-concept, and self-esteem. (Nichcy, 1992)

> Max: In spite of my feeling very confident about me, I am convinced that no one can really stay with me for long time because I am not equal to others, I am not a proper man and this feeling, I can’t remove it from my mind.
>
> Stefano: For me to be a man, means to be accepted for what I am, for what I feel, to feel myself accepted, important and reciprocated.
>
> Walter: It is important that the man has the control during the sex, my girl made me understand that. Even if I am paralysed, I was able to make love like a real man … I won’t be a normal father for my child. I wouldn’t be able to take him out on bicycle like other fathers do, but I can explain the value of diversity to him and I would teach him to respect all human beings.
>
> Serena: If I was man, I wouldn’t be a virgin, but after all, I am a woman and so I am still a virgin, perhaps because women have less desire than men? Or because I am afraid to be called a slut? I don’t know, perhaps both of these, even if I don’t want to accept it …

Physical barriers surrounding the disabled persons are the first obstacle limiting their opportunities for meeting others and forming affective relationships. Yet, almost all participants agree that the worst barriers are those of negative attitudes and values in the society. These influence their views defining their identities as a man or a woman. As Frtizon (2001, p. 21) says, At some point everyone has felt insecure in relation to their own sexuality and has asked themselves if they will find a partner and if they will be successful in their sexual life … If you do not find a partner or if your sexual life sometimes causes you frustration, you always wonder if it has anything to do with the disability. Finding partners, ideals of love, children and family are all closely linked to this meaning.

> RR: For me, there is a big difference between love and sex. Sex means just giving your body for satisfying an urge or a need, without expressing your feelings. Sex is an end to itself. I am not looking for sex, I am looking a girl with whom I can build a long-term relationship.

> Mariangela: I have a disabled friend, who once told me that she wanted to have a baby. I think it is very selfish of hers. It won't be good for the child to have a disabled mother.

The barriers to sexuality influence disabled men and women differently. Growing up with a physical disability enforces a view on the young women's bodies as not being 'up to scratch'. While this applies also to disabled young men, women's bodies consist of more parts that are subject to subordination and social control than do men's bodies. (Haug 1987) It has been suggested that persons having an impairment since birth or in childhood face more barriers. (Baldaro, 1987 and Malaguti, 1993) The impact of the barriers created by attitudes of family and community in the realisation of sexuality among disabled persons is clearly seen even in this small sample of participants involved in this research as all the persons, who did not have any sexual experience, have an impairment since birth.

The emergence of information technology is described as the emergence of a new era, denoting a fundamental shift in society from the industrial era. (Michailakis, 2001, p. 478). Through websites, persons can question the popular beliefs about disabled persons and their sexuality, challenge the myths, fight against the stereotypes and create a platform where disabled persons can share their ideas and experiences (Erin, 2000). However, this study indicates that the transformation of online interactions into physical intimacy is often filled with difficulties and frustrations. Solitary masturbation and sexual fantasies may be the only possibilities of any sexual expression for some disabled persons but are seen as frustrating and unsatisfactory since these are not the result of free choice but the only sexual expression available to them.

Finally, the research also shows that emails, newsgroups and internet can be useful tools for involving disabled persons in a dialogue for a better understanding of the underlying mechanisms of the barriers and to promote long-term collective social and political action.

> Gaia: For me sexuality is a conquest. I was born in a small village in south and I think that in some places, free and knowledgeable sexuality is a conquest for all women, disabled and non-disabled …. at the end, you realise the first prison from which, you need to come out is your own prison – you have to be aware and convinced that you are a person like all others and you have rights, that everyone has rights, both disabled and non-disabled and that life is not easy for any one. You have to fight with society, with family, with teachers but you also have to fight with yourself and like everyone else, if you wish to have your rights, you need to fight for them. You have to be committed, because if you are not convinced of something and are not willing to fight for it, in this world nothing falls down from the sky in your lap.

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# Appendix 1: First Announcement

Hello. My name is Sunil and I live in Bologna. As part of my Master's course on Disability Studies at the Leeds university in UK, I am planning to conduct an email research on the sexuality in disabled persons and I am looking for volunteers.

The research will involve discussions about the factors influencing the sexuality of persons – sexuality here means affective relationships, ideas about love, marriage and family as well sexual fantasies and experiences.

For participating in this research, the person must fulfil the following conditions – the person must have an impairment or be a companion or spouse of a disabled person; the person must be above 18 years of age.

If you fulfil these two conditions and are willing to participate in this research, please send me an email for receiving more detailed information about the research.

Thanking you for reading this message. Cordial best wishes,

Sunil Deepak

Bologna, Italy

# Appendix 2: First Information About the Research to Persons Answering the Announcement

Dear ……,

Thank you for showing interest in my proposed research on issues influencing sexuality of disabled persons.

This research is based on social model of disability, which means that it starts by looking at the different ways in which non-disabled majority society creates disabling barriers around persons with impairments. The research will focus on the way these disabling barriers create obstacles to social interaction and forming of meaningful relationships for the realisation of your sexuality.

The research is also based on the premise that disabled persons themselves are experts on issues affecting them and thus my role in this research is to promote an interactive bi-directional dialogue without any intention to provide any expert advice or service. The research can touch the following areas: physical barriers, social barriers and attitudes, internal barriers in disabled persons, role of families, role of mass media, and sexual fantasies and experiences.

During the research, you will be free to ignore any parts of my communications, if you do not wish to talk about them. You will be equally free to ask me any questions that you wish, though I shall also be free to not to answer any questions. In that way, it is not a usual research but rather a dialogue between equals.

All your communications will be treated as confidential by me and without your express consent no parts of your communications will be used in any way.

Though the final report of this research will be prepared in English for my course, an initial report in Italian will be prepared and sent to you for your comments. If you wish, the English version of my final report will be sent to you before submitting it to my course.

If you accept these conditions, please answer the general questions given below. I expect that the initial communications with you for this research will take about 4-6 weeks, though the total duration of our discussions will depend a lot on the issues that will be raised by you and me.

You will be free to withdraw from this research at any time during our communications. I promise to not to disturb you in any way if you decide to withdraw from this research. If you decide to not to answer this email, I shall take it to mean that you are not interested in participation and you will not receive any further communications from me.

With thanks and best wishes,

Sunil Deepak

Bologna, Italy

## General Information

1. Your name (You can choose any name that you wish to take – if you desire, you can also change it at any time during the research):

2. Your age:

3. Sex: Male_____ Female______

4. If you live in rural area or small city or big city:

5. Nature of your impairment:

6. Your age when the impairment first developed:

7. Your education (primary school, secondary school, college, etc.):

8. If you live alone or with parents or with a companion/spouse:

9. Marital status (unmarried, companion, married, separated or divorced):

10. Have you ever had a sexual experience with another person: Yes____ No__

**First question for starting our discussion**: Some people believe that sexuality is basic human right. What do you think?

## Appendix 3: General Information about the Participants

*(In the order in which the participants joined the research)*

1. Female, 46 years, living alone, divorced, living in a big city, college education, impairment at 38 years, paraplegic following an accident[4], wheel-chair user.
2. Male, 28 years, living with parents, unmarried, living in big city, high school education, impairment since childhood, rheumatoid arthritis.
3. Male, 28 years, living with mother and a sister, unmarried, no sexual experience, living in a small city, college education, impairment since birth, spastic tetra paresis and difficulty in speaking, wheel-chair user.
4. Male, 47 years, living with his mother and a companion, living in a small city, college education, impairment since early childhood, difficulty in walking.
5. Male, 48 years, living with parents, living in rural area, no sexual experience, middle school, impairment since adolescence, tetraplegia impairment following an accident, wheel-chair user
6. Male, 43 years, living with parents and a sister, living in a small city, high school education, unmarried, impairment since adolescence, paraplegia and hearing-speech impairment following an accident, wheel-chair user.
7. Male, 23 years, living with parents, had sexual experiences but no fixed companion, living in a small city, high school education, impairment since birth, spinal atrophy impairment, wheel-chair user.
8. Male, 27 years, living with parents, no sexual experience, living in a small village, college education, impairment since birth, lumbo-sacral meningocele, wheel-chair user.
9. Female, 49 years, living alone, unmarried, living in a big city, attended college for some time but did not complete the degree, impairment since early childhood, poliomyelitis with impairment in both legs, wheel-chair user.
10. Male, 33 years, living with parents, unmarried, no sexual experience, living in a big city, college education, impairment since birth, cerebral palsy impairment.

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[4] The terms used here for describing impairments are the same as those expressed by participants

11. Female, 36 years, living with husband, living in a small village, college education, impairment since birth, Spina Bifida impairment.
12. Male, 31 years, living with parents intends to live alone soon, living in a small city, college student, Impairment since birth, Osteogenesis Imperfecta – impairment with frequent fractures, wheel-chair user.
13. Female, 33 years, living with parents and a brother, unmarried, no sexual experience, living in a big city, middle school education, impairment since birth, Spinal Atrophy impairment, wheel-chair user.
14. Female, 24 years, living with parents and a brother, unmarried, no sexual experience, living in a small village, college student, impairment since birth, Muscular Dystrophy impairment.
15. Male, 34 years, living alone, unmarried, had many sexual experiences, living in a small city, high school education, impairment at 21 years following an internal haemorrhage, left hemiplegia impairment.
16. Male, 40 years, living with a companion and a daughter, living in village, high school education, impairment since early adolescence, scapulo-humeral dystrophy impairment.
17. Male, 35 years, living with mother, college education, living in a big city, unmarried, no sexual experience, impairment since birth, Spastic Tetra paresis impairment.
18. Male, 38 years, married living with wife who is also disabled, high school education, living in a small city, impairment since birth, born without a leg and some spinal problems.
19. Female, 39 years, married, living with husband who is also disabled, high school education, living in a small city, impairment when she was 18 years, amputation of a leg following an accident.
20. Male, 28 years, living with parents and a brother, middle school education, living in a small city, impairment at 18 ears of age, paraplegia following a motorcycle accident, wheel-chair user.
21. Male, 35 years, living with a companion, high school education, living in a big city, impairment at 24 year age, paraplegia following an accident impairment, wheel-chair user.