



Graduate School of Development Studies

**The voices unheard – Exploring how young
people with disabilities view and experience their
growing up as sexual beings**

**A case study in Akshay Prathisthan, New Delhi,
India**

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Pham Do Nam
(Vietnam)

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Members of the examining committee:

Dr. Loes Keysers (Supervisor)
Dr. Auma Okwany (Second Reader)

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Inquiries:

Postal address: Institute of Social Studies
 P.O. Box 29776
 2502 LT The Hague
 The Netherlands

Location: Kortenaerkade 12
 2518 AX The Hague
 The Netherlands

Telephone: +31 70 426 0460

Fax: +31 70 426 0799

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List of Acronyms

AP	Akshay Prathisthan
CRC	Convention on the Rights of the Child
CREA	Creating Resource for Empowerment in Action
DPSA	Disabled People South Africa
IGNOU	Indira Gandhi National Open University
ILO	International Labour Organization
IPPF	International Planned Parenthood Federation
ISS	International Institute of Social Studies
NGO(s)	Non-Government Organization(s)
SFCD	Society for Child Development
TARE	The Texas Adoption Resources Exchange
TARSHI	Talk about Reproductive and Sexual Health Issues
UN	United Nations
WiRE	Wisconsin Relationship Education
WHO	World Health Organization

Abstract

Like any people without disabilities, young people with disabilities also experience the natural sexual development and the sexual excitement as well as sexual curiosity (Murphy, 2005; Rutgers WPF, 2006). Nevertheless, partly due to the stereotype of people with disabilities as asexual (Addlakha, 2007; Ansell, 2005; Murphy, 2005; Shakespeare et al., 1996), society unlikely views young people with disabilities as sexual beings. There is a limited research done on this topic, partly due to the fact that sexuality is not considered as important as social inclusion, professional enhancement, capacity building and rehabilitation.

This research explores the unheard stories of young people with disabilities by investigating their views and experiences as sexual beings. It employs qualitative interviewing and ethnographic approaches using concepts of youth, disability and sexuality as analytical lenses, placing emphasis on gender role as crucial in determining different sexual experiences. Acknowledging that young people with disabilities are not a homogenous group, neither in terms of sexuality, the research brings up the opinions and experiences of boys and girls with disabilities. In doing so, it shows the primary difference in sexual expression between males and females, as well as their perception of 'being sexual'. Such perception, for the young men, is linked to sexual conducts and for the women, is linked to the notion of marriage. Moreover, it explains how young people with disabilities cope with social structure including norms and values as they experience the progress of growing up as sexual beings, and indicates their vulnerability as passive patients whose rights are ignored.

By letting young people with disabilities speak for themselves, the research presents some well-hidden details of individuals' intimacy of those who are young, disabled and yet sexual. It concludes that young people with disabilities should not be treated as patients, but rather as right holders whose sexuality needs to be acknowledged and respected so that they are able to enjoy safe, active and healthy sexual life as any young people without disabilities.

Relevance to Development Studies

This study covers the not-often-discussed discourse of sexuality involving young people in developing countries who have disabilities. It attempts to call the attention of scholars and human development workers that not only can social justice be achieved for young people with 'disabilities' by capacity enhancement, profession opportunity, social integration and behavior changing but also by increasing recognition of their sexual 'abilities'. In such views, young people with disabilities should be acknowledged as normal sexual beings; whose full rights are respected and empowered to achieve sexual wellbeing. Furthermore, this research focuses on young people with disabilities to assist them speak out, to participate in societies and to express how they view and experience their growing up as sexual beings and make their voice heard.

Keywords

Agency, behavior, body, exclusion, gender, India, marriage, sex, sexual beings, sexuality, sexuality education, physical and mental disability, vulnerability, young people

Chapter 1

Introduction

1.1 Indication of Research Problem

The idea of conducting a research about young people, disability and sexuality was initially formed when I encountered a breath-taking and daring work by Tom Shakespeare and his colleagues “The sexual politics of disability: Untold desire” studying how the issue of sexuality has always been problematic for people with disabilities. By focusing on agency of people with disabilities, Shakespeare indeed paved the way for researching works to recognize a minority and vulnerable group to raise their voices. However, his research was limited to the Western context and within the gays and lesbians communities only. Nevertheless, the book aroused my curiosity of the contrast from my own sexual experience growing up as a young and able-bodied person to begin shaping up some thoughts on how young and differently-abled people perceive themselves as sexual beings; despite the fact that ‘[societal] attitudes may present more hindrances to an adolescent’s sexual limitation than the limitations resulting from the disability [and] one common misconception is that a disability renders an individual child-like, asexual, and in need of protection’ (Murphy, 2005: 642). According to Shakespeare, this misconception is ‘contributing factor towards the disregard of disabled people.’ (Shakespeare et al., 1996: 10)

Unlike children, those who have been given more attention by governments, politicians, educators, scholars and society as a whole as ‘pillars of the nation’ (Cheney, 2007) limited space has been left for young people who sit inconveniently between the boundaries of children and adult (Ansell, 2005: 13), let alone young people with disabilities. The crucial role of young people has gradually been reinforced by their active participation in the development process and particularly their own dynamic role in political and social change. According to Groce, young people with disabilities are not recognized within the general population but instead seen as “invisible population” (2004:16). Despite disabilities, these young people share with those without disabilities similar needs such as education, vocational training, employment etc.; however, generally their needs are often left unmet (Ibid.: 14).

Disability is not a new topic for research since many similar topics have been done to show the vulnerability of people with disabilities, capacity enhancement, independence and integration. In addition, ‘[attitudes] towards people with disabilities vary historically and culturally, and partly reflect whether a person is considered able to perform useful tasks in a socially acceptable way’ (Kabzems and Chimedza, 2002 as cited in Ansell, 2005: 215). Moreover, the provision for disabled people in Third World societies (Ibid.: 216) is largely influenced by the Eurocentric concept of disability in which,

according to, Addlakha, a disability generally has two interconnected components – medical limitation (s) and social prejudice (2008: 192).

The medical model characterizes differently able people as the vulnerable – those are sufferers who need to be protected and fixed as personal tragedy (CREA, 2008; Ansell, 2005) Whereas the social model concludes that socially constructed notion of disability devalues and denies the accessibility and integration of people with disabilities in society in term of education, jobs, public spaces etc. (CREA, 2008). In India, disability is also viewed as a result of misdeeds in the past or a bad karma (TARSHI, 2010). As a consequence, ‘such constructions of the disabled by the non-disabled have a dual effect of not only justifying the complete marginalization and disempowerment of a whole population group but also leading to the internalization of such negative stereotypes by disabled persons themselves’ (Addlakha, 2007: 2).

Moreover, programs for people with disabilities either focus on children or older adults but rarely include young people (Groce, 2004: 17). In fact, ‘young people with disabilities have needs very similar to the needs of all other young people, as clearly stated in Article 23 of the United Nations’ Convention on the Rights of the Child’ (UNICEF, 2000 as cited in Groce, 2004: 17), yet, their sexual being is seldom mentioned and discussed. Plus, young people with disabilities are acknowledged no longer viewed as children but neither accepted to function as adults (Ibid.). However, ‘[in] fact, [young people with disabilities] are as sexually experienced as their peers without disabilities’ (Cheng, 2002 as cited in Murphy and Elias, 2006: 398)

Disability becomes more challenging when attached with the abstract and multiple-layer concept of sexuality. In many societies, specifically in the Asian context, sexuality is rarely discussed. Even though only a handful of research and working papers raised this sensitive issue, the need-based approach focusing on the voices of young people with disabilities is left untouched. In a hierarchical and patriarchal society such as India, ‘the sexuality concerns of people with disabilities are rarely acknowledged and therefore have not been considered as an important area for study or research’ (TARSHI, 2010). Moreover, sexual issues are believed to be difficult, complex and challenging to deal with vis-à-vis cultural norms and traditional values. Most importantly, voices of young people with disabilities on their sexuality have not been given adequate attention, particularly on their sexual concerns and intimate desire.

Interestingly, sexuality, which is discussed quite openly among young people without disabilities, turns into the deepest embarrassment and psychological pain for young people with disabilities. For such reason, talking about inclusive programs, employment and education is easier than sexuality and reproductive needs (Finger, 1992: 9 as cited in Shakespeare et al. 1996: 6). For example, Nguyen Thanh Tung – a young Vietnamese man with physical disability once shared ‘*People think that I cannot have sex; even more ridiculous, they assume my “tool”(sic.) is as dysfunctional as my legs*’ (Nguyen, personal communication, March 8, 2012). ‘Like most adolescent, children and teenagers with disabilities have hopes and desires for marriage, children and satisfying adult sex lives’ (Berman et al., 1999 as cited in Murphy, 2005: 640).

Therefore, a research that attempts to focus on voices of young people with disabilities, on how they perceive themselves as sexual beings is

considered crucial for three main reasons. Firstly it reaffirms the ‘fundamental physiological needs’ of each and every human being regardless of their physical abilities or disabilities. Secondly, it demands serious consideration of human rights, especially sexual and reproductive health rights of young people with disabilities to ‘[ensure] sexual rights for all [including] a commitment to freedom and protection from harm’ (IPPF, 1995:12) so these young people can enjoy equality in dignity and rights. Finally, advocating for these little-heard voices to be spoken is important for social workers and development practitioners since it can be effective means for sexual protection and empowerment among young people with disabilities in order to maintain a healthy active and safe sexual life.

1.2 Research Relevance and Justification

Sexuality as an interesting discourse attracts many scholars but seldom appears in research specifically concentrating on young people with disabilities in Asian contexts. Though sexual and reproductive health programs and sexuality education have recently targeted young people, to certain extents, it seems that no appropriate space is open for people who are young and suffering from disabilities. As mentioned earlier, in response to a modest number of research in this category, which needs to be explored, this research primarily aims to identify the voices of young people with mild and moderate mental and physical disability by opening up to opportunities to freely describe how they view and experience themselves as sexual beings. It also studies the main actors such as parents of young people with disabilities and social workers who play important roles in shaping these young people self-concept of being sexual as well as what they do. Secondly, the voices of young people with disabilities on sexuality are crucial for policy makers and development workers in tackling the issue of disability and sexuality, and to implement appropriate programs to assist in enhancing the healthy, safe and active sexual life for young people with disabilities and encourage them to advocate themselves for a further integration into mainstream society. Finally, the research contributes literature to scholars and advocates who share the same interest and passion in fighting for the social justice of people with disabilities in general and young people with disabilities in particular.

1.3 Research Objectives and Questions

Research Objectives

The research is based on three central objectives: to explore, to understand and to fill the gap in studies about youth, disability and sexuality

- to explore how young people with mild and moderate physical and mental disability perceive and experience themselves as sexual beings
- to understand how young people with disabilities cope with other factors that affect their sexuality as growing up as sexual beings

- to investigate how major actors i.e., families of young people with disabilities and social workers respond to the fact that young people with disabilities are sexual beings as well

Research Questions

The main question of the research objective is: How do young people with mild and moderate physical and mental disability perceive and experience themselves as sexual beings?

The sub-questions comprise:

- Do young people with mild and moderate physical and mental disability accept themselves as sexual beings?
- How do young people with disabilities express their sexual desires?
- How do parents of physically and mentally challenged young people and social workers accept and address this issue?
- Which factors defined by young people greatly affect them (in both positive and negative ways) during the process of growing up with disability and the natural sexual development as sexual beings?

1.4 Methods and Data Collection

“It is okay to be an outsider, a recent arrival, new on the scene – and not just okay, but something to be thankful for ... Because being an insider can so easily mean collapsing the horizons, can so easily mean accepting the presumption of your own province”

(Tan Le -the founder and CEO of Emotiv Lifescience, a bioinformatics company that's working on identifying biomarkers for mental and other neurological conditions using electroencephalography)¹

The formulation of the research questions is based on the general thought that people with disabilities are not “normal” sexual beings. This is an exploratory research in which the focus on young people with mild and moderate physical and mental disability includes single males and females between the ages of 18 and 26 whose voices are often not given adequate attention to, and whose bodies have experienced physiological and psychological changes regardless of the seriousness of their disabilities and causes such as congenital and acquired. Since disability brings in a multidimensional discourse comprising of different types of disability together at different levels, the research centers on a group of young people who have mild and moderate disabilities living in New Delhi, India. Mild disability can be defined by the ability to perform basic life-skills management without assistance as well as communication and the condition that may be correctable and improved by times; meanwhile, moderate disability refers to a stable non-correctable conditions which may require surgery, post-operation treatment and assistance with transportation and communication (TARE, 2012). Furthermore, the research population also includes parents of young people with disabilities, social workers and peers, those who, more or

¹ http://www.ted.com/talks/tan_le_my_immigration_story.html

less, directly and indirectly influence these young people's lives and their perception.

Because sexuality and disability are two sensitive and complicated topics being especially researched among young people in the Indian context; hence, the most appropriate approaches that I use are qualitative approach and ethnographic methodology in which I combine primary and secondary data. Qualitative interviewing mainly includes in-depth and non-structured individual interviews and group discussions. Ethnography comprises of non-participant observation i.e. classroom observation of interaction among disabled group members without interruption, participant observation such as role-plays, discussion to gain insights into their favorite activities and relationship.

Initially, Society for Child Development (SFCD) was the contact in India that I was able to access; unfortunately several problems emerged concerning the issue of logistics, research reliability and my health problem; hence, Akshay Prathisthan² (AP) was selected. Taking up a case study of young people with disabilities in AP for investigation and analysis helps discover young people's understanding and explores how they view and experience themselves as sexual beings. I chose AP for the following reasons: firstly, AP is graded among trustworthy and popular NGOs in New Delhi working directly with young people with physical and mental disability. Moreover, AP has become well-known because it combines and includes educational and vocational training programs, attracting public attention in India, particularly after it was shown on the program Satyamev Jayate³ hosted by Aamir Khan named "Toward Changes". Secondly, AP has been recommended by Talk about Reproductive and Sexual Health Issues (TARSHI) and Creating Resource for Empowerment in Action (CREA) – the two most active NGOs in India working on numerous programs and campaigns to raise awareness of the general public about reproductive and sexual health for people with disabilities in general and women specifically.

In addition, including young people with mental disability in the research population was not my initial intention taking into account the issue of different types of disability and the ability to comprehend and maintain conversations. However, after my first interaction with a day-care group at AP and through participant observation of how impressive young people with mild and moderate mental disability have overcome their challenges to communicate with others, specifically with their opposite-sex friends. As a result, I decided to broaden my research scope, which not only targeted young people with physical disability, but also mental disability for two reasons. Firstly, sex-related issues, concentrated pleasure, are often raised as an issue for those who suffer from physical disability rather than mental disability. Secondly, including young people with mental disability in my research allows me to understand the difference in sexual perception and experience among those who are physically and mentally challenged, thus contributing to literatures on relevant topics and, may benefit organizations and development

² <http://akshaypratishthan.org/>

³<http://www.satyamevjayate.in/>

workers in implementing appropriate programs that target to enhance sexual and healthy reproductive life for young people with disabilities

The desire to broaden my vision and to get intellectual joy in doing research about young people with disabilities and sexuality has encouraged me to choose India to conduct my research. As a young foreign researcher, I am aware of the pros and cons of my position as an insider (a young researcher) and an outsider. The disadvantage of being an outsider who comes to India for the first time may restrain my ability to integrate and understand my research population, even to meet previously set goals. Despite some initial difficulties e.g. culture shock, the weather and markedly different local cuisines, my first exposure to India has turned out a real interesting personal and intellectual adventure. Eventually I realized that being an outsider was indeed a privilege and advantageous for my research as well because I could raise new or 'unspeakable' questions. Plus being young allowed me to easily have a conversation and to be friend with young people. These advantages of being an insider and an outsider have created a safe and reliable grounds for me to be able to openly discuss with people selected for my research and/or listen to their intimate experiences which they seldom reveal to local social workers.

Primary Data

Topic of young people with disabilities in Asian cultures is often discussed among closed, limited forums; leave alone the topic of sexuality in reference with young people with disabilities. Hence, I chose to work as a research volunteer at AP in New Delhi in hope of learning first hand how my research subjects deal with sexuality in their day-to-day settings.

Originally, I had planned to interview research participants comprising of a variety of age, caste, class and gender. After discussions with my Indian colleagues, I decided not to include the issue of caste and class in my research even though these important factors may influence greatly how sexuality is being perceived and practiced among young people with disabilities. Because young people at AP come from different areas in India, mapping and categorizing them according to their caste and class is problematic considering my only five weeks in India, thus in the end, I chose to work with a limited number of research subjects, and selected them according to their age, gender, type and level of their mental and physical disability. Moreover, I feel that the limited size of sample (comprising of 14 respondents in total) is justifiable because the research does not aim at "surveying" and producing generalizable data but is exploratory and explicitly concentrating on voices and stories of young people with disabilities at AP speaking about their sexuality.

Snowball sampling and purposive sampling were used to map and select research population.

Snowball Sampling

Due to the limitation of access to local NGOs given the limited time of my field work as well as several unforeseen problems at the beginning of my arrival in India and with SFCD, Dr. Madhumita Puri – my initial contact at SFCD referred me to some local contacts in South Delhi. Mrs. Vaidehi Subramani – Head of Social Work Department at AP - was among these new contacts, through whom, I gained access to my other local contacts including

interpreters and different groups of young people with disabilities at AP comprising of day care group, vocational training group and employees at AP.

Purposive Sampling

Though random sampling is more preferable for its accuracy and rigor (Trochim, 2006), I chose purposive sampling to access a targeted group of young people with disabilities. For this method allowed me to deliberately select and reject respondents with same interests and characteristics quickly basing on the research criteria, objectives and research questions together with the mutual understanding built among research participants and the researcher via previous interaction. Furthermore, using snowball effects referring to targeted groups suggested by Mrs. Vaidehi Subramani – my main gatekeeper, has turned out rather complicated concerning the issue of number of participants, age, diversity, communication problems as well as the research scope and limitation.

Therefore, after a week volunteering at AP and spending most of my time with participant observation and interaction, I short-listed 14 potential respondents (9 females and 5 males) for interviews which were divided into two main groups. Group A comprises of 7 young people with disabilities from the age of 18 – 26 (three -X male, X female- respondents from a day-care group, three -X male, X female- from vocational training group and one male/female currently working at AP). Group B includes three parents, three social workers including Mrs. Vaidehi Subramani, Aslam Khan and Sweta Sah – a trainee from Indira Gandhi National Open University (IGNOU), also helped me with orientation and interpretation, and a teacher. The two groups were selected based on criteria set previously and additional criteria of consent, availability and communication ability.

I used one-on-one non-structured interview in which each session lasted for 60 minutes. Some interviews required to be conducted two times due to psychological and personal problems of interviewees in recalling previous experiences and events. Though research respondents could speak broken English, one male and one female interpreter would help for translation and explanation. In respect to respondent's request on the confidentiality and sensitivity of their information, pseudonyms were, therefore, given to research participants except social workers. Plus, a voice recorder was not used during interviews; hence, note taking was my main way to record information. Important dialogues were hand-written, repeated and crossed-checked with interpreters and respondents. In order to ensure the transparency of my research, research objectives were concisely explained to respondents at the beginning of each interview. The accuracy of provided information was double-checked and reviewed after each interview between interpreters and the researcher.

Non-structured interviews were used instead of questionnaires because I believe in 'a commitment to the individual involved, rather than the social scientific community' (Shakespeare et al., 1997: 182); however, questions asked during interviews tried to answer the research question. Due to the sensitivity of this research topic as well as contextual notion of sex and related issues, questions about changes of bodies as puberty commenced and relationship were raised before a focused discussion of how actively their sexual lives are.

Secondary Data

To build up theoretical framework and insights, I have been reading books, articles, journals and newspapers on the topic of sexuality and disability, particularly those related directly to this issue in India. Moreover, I have contacted Talk about Reproductive and Sexual Health Issues (TARSHI) and Creating Resource for Empowerment in Action (CREA) in India with relevant reports and works done previously.

1.5 Position of the Researcher and Ethical Consideration

Before I began this research study, the thinking that people's sexual needs are more or less the same all over the world most influenced me. The issue of young people with disabilities and the perception of their sexuality as seen by the general population as asexual were something that I was challenged by. I wanted to know more from talking to young people living with, and affected by disabilities, to explore and demystify the concept that young people with disabilities are thought of as "asexual", and to understand what the thinkings of young people with disabilities about their own sexual beings are. Therefore, it is of importance that young people with disabilities in my research are treated as the agents, and the right holders who are entitled to fully express and pursue their goals and objectives not as the patients who need to be pitied and protected. I hope that this study will not only help me understand first hand from my research subjects, but it will also help scholars and service providers to better facilitate people and families living with disabilities.

The major ethical problems that I have struggled with are firstly to conduct a research in India as 'a foreign-based researcher' (Dina Abbott, 2007) and from 'a position of clear privilege' (Ibid.) where the majority of concepts used in my research dominated by Global North scholars. This so-called "privilege" position may influence my understanding and assessment of an issue in a different context from what I have been accustomed to, which also leads to 'the undesirability of manipulation versus individuals' rights to privacy' (Gillespie, 1994). Hence, to limit this shortcoming, I have critically challenged my assumptions and generalization by taking into account the issue of socio-cultural disparity and diversity of the Indian context.

Secondly, conducting a research, which touches supremely sensitive issues, may cause 'psychological harm' (Ibid.) to research participants such as feelings of guilt and scare, especially with the presence of interpreters. To limit this risk, I asked for a strong commitment within a social setting from respondents and interpreters to respect the confidentiality of information as well as to protect those participated in the research.

Thirdly, given the fact that the presence of interpreters cum social workers and a teacher may influence the researched in voicing up and the researcher in coordinating discussions. For instance, a teacher at AP chose to sit with a day-care group that I was doing a group discussion in English about their opposite-sex friendship. Yet, a teacher with a firm reason that this topic should not be discussed at school interrupted our discussion. The issue could only be handled once my interpreter explained in details my role as a researcher and reconfirmed the permission from AP to the teacher so she could be more

comfortable with my presence and interaction. To delimit this issue, communicating in English was utilized to avoid the manipulation of interpreters; also interpreters were asked for their commitments to ensure the genuine and accurate information.

1.6 Research Scope and Limitation

The research itself contains some limitations to certain extents and yet I also have consciously delimited them. Firstly, no attempt is made to disprove that young people with physical and mental disability are asexual. Instead, I want to concentrate on exploring how young people with disabilities perceive themselves as sexual beings and by letting them speak for themselves. Secondly, given that disability comprised of different types such as difficult learning, visual impairment, autism, emotional and psychological disabilities etc., and different levels like mild, moderate, severe and profound, my research aims specifically at young people with mild and moderate physical and mental disability in Akshay Prathisthan. Thirdly, the research with a time limit will not allow me to extend the number of researched people to cover interviewing parents of young people with disabilities, social workers and peers; therefore, not allowing me to engage in negative discourses such as social barriers and discrimination. Lastly, I am aware that India has a geographically diverse population that is categorized accordingly to caste and class, thus my research with the smaller focus of AP in the urban India only, may not present similar issues in different contexts.

1.7 Research Structure

The research contains five chapters in which chapter one mainly presents the indication of problem, research relevance and justification, research objectives and questions, methods and data collections, position of the researcher as well as research scope and limitation.

The main concepts used in the research are clarified in chapter two by firstly presenting different terminologies referring to people with disabilities and arguing for the main terminology which I think more suitable in the research studying about young people with disabilities and sexuality. Secondly, I break down the three concepts used as main theoretical framework for analysis in the subsequent chapters including youth, disability and sexuality. Particularly, in this chapter, I conceptualize the notion of youth in the Indian context, linking it with the issue of sexual body and disabled body to highlight the issue of agency, the notion of young people with disabilities as the agent and/or the patient and social exclusion.

Research findings and analysis are presented in chapter three and chapter four. While chapter three answers the first three sub-questions that focus on the voice of young people with disabilities and how they view and experience themselves as sexual beings and by other, chapter four mainly analyses from the point of views of young people with disabilities, the issue of agency and social structure as well as social relations, specifically how contextual factors influence their perception, their parents' and social workers' on sexuality and

their views on the shortage of sex education and its consequences affect their lives.

Chapter five presents the conclusion of the research as well as my reflections and proposed recommendations.

Chapter 2

Conceptualizing Research Topic – Framing The Investigation and Analysis

In this chapter, I analyze three main concepts, which play crucial roles as main theories in proposing the research methodology and forming research questions as well as analytical tools for presenting my research findings. First of all, I reviewed different terminologies used to indicate people with disabilities in the history such as impairment, handicap and contemporary euphemism such as disability and diffability and then I argued for the use of disability as a neutral term when talking about youth, disability and sexuality.

By conceptualizing the notion of youth, I linked it with the concept of sexuality. By doing so, I attempted to differentiate the implication of gender in disabled bodies between males and females that have often been generalized in studies about disability and sexuality. After that, I analyzed the impact of gender roles on different perception of young males and females with disabilities on sexual meaning, sexual drive, sexual partnership and sexual act. In addition, I pointed out how young people with disabilities are viewed in terms of sexual ability by society and how this socially constructed perception of young people with disabilities further excludes them from mainstream society. Furthermore, I highlighted the issue of social exclusion and vulnerability by reviewing child rights, specifically sexual rights and the right to know, by young people having disabilities. Finally, by focusing on the issue of agency and information exclusion, I analyze body changes in terms of biological and psychological aspects of young people with disabilities and criticize the availability, accessibility and effectiveness of sexuality education.

2.1 Terminology Challenge: Disability or Diffability?

Selecting an accurate terminology and meaning seems challenging for '[language] reflects the social context in which it is developed and used. It therefore reflects the values and attitudes of that context, and plays an important role in reinforcing values and attitudes that lead to discrimination and segregation of particular groups in society. Language can therefore be used as a powerful tool to facilitate change and bring new values, attitudes and social integration" (DPSA, 2000). WHO's preferred terminologies referring and classifying people with disabilities as impairment, disability and handicap were criticized by scholars for their discrimination against people with disabilities (Suharto, 2010: 7). Nowadays, the term *people with disabilities* is commonly accepted and used in UN's documents and other international agencies' where according to the United Nations Standard Rules on the Equalization of Opportunities for Persons with disabilities states '[the] term "disability" summarizes a great number of different functional limitation occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness' (UN, 1993)

In addition, other euphemism is also used to refer to people with disabilities such as physically and mentally challenged people or more recent terms like differently-abled and diffabled people, which emphasize the recognition and empowerment of society on the ability of people with disabilities. According to Suharto, the term “diffable” as the portmanteau of *differently* and *able* people was introduced by Manour Fakih and Setia Adi Purwanta in early 1996 to challenge for the replacement of other bias expression: disabled people and flawed sufferers (2010: 9). Despite the fact that ‘the finding of the term diffability is not only aimed at refining the predicate of those who are physically impaired, but it also to combat further dehumanization and violation of human rights norms’ (Ibid. 10). It is somewhat problematic to use the term diffabled people in the research studying about disability and sexuality as diffability is presented as ‘a more equitable and empowering [term], namely that those who are considered flawed sufferers and disabled actually have different abilities’ (Fakih, 2004: 169 as cited in Suharto, 2010: 10). Needless to say the empowering part of diffability on how society changes its negative views of disability in recognizing the ability of people with disabilities and yet I argue how differently people with and without disabilities perform sexual acts. Therefore, by emphasizing different abilities of people with disabilities accidentally implies the discrimination of people with disabilities in expressing intimate desire and needs.

As a result, in this paper, people with disabilities are chosen as a more suitable, neutral and acceptable term. Also, I use an alternative term physically and mentally challenged people to refer to the physical and mental disabilities.

2.2 Being Young, Disabled and Sexual

2.2.1 Conceptualizing Youth – The Becomings and The Beings

Youth is quite a complex and diverse definition, which requires different approaches (Angelina, 2010: 10; Khan, 2012). First of all, when talking about youth, one automatically thinks of age; however, the notion of youth defined by age also varies in different contexts; for example, ‘[according] to United Nations youth are the persons between the ages of 15 and 24 years [...] Danish Youth Council defines youth between the ages of 15 and 34, common wealth program works with ‘young people’ who fall in the age bracket of 15-29 years and German social scientist Gunnar Heinsohn also indicated the age of 15-29 years as a youth age bracket’ (Khan, 2012). In India, youth that is defined by the India’s National Youth Policy falls in the age bracket 15 – 35 years old (Sinha-Kerkhoff, 2006 as cited in Angelina, 2010: 9).

Furthermore, youth is not a homogenous or monolithic group (Khan, 2012 and Wyn and White, 1997: 121) which means ‘it can further be classified into subgroups like female youth and male youth; youth with disabilities, privileged youth and unprivileged youth; married and unmarried youth; literate and illiterate youth; and so on’ (Khan, 2012). As pointed out by Graycar and Jamrozik (1989) differences in gender and class existed in family settings, education and cultural activities also label different definitions of youth (as

cited in Wyn and White, 1997: 121). Hence, age, even though as an important criteria cannot explicitly present the whole notion and meaning of youth.

Moreover, youth as a socially constructed notion with social meaning and category reflect contemporary moral, political and social concerns (Bourdieu, 1978 as cited in John, 2009:1; Wyn and White, 1997 as cited in Angelina, 2010: 11). For instance, in Western agenda, ‘the predominant view over the past 150 years has been of ‘youth-as-trouble’, with repeated moral panics’ (Ansell, 2005: 14) in which young people are typically characterized as ‘spontaneous, energetic, exploratory, venturesome, vivacious, disrespectful, playful and erotic’ (Berger, 1971 as cited in Wulff, 1995:7 as cited in Ansell, 2005: 14).

Nevertheless, youth as troublesome sometimes presents ‘political both potential (and threatening) political actors themselves’ (Ibid.), this explicitly is demonstrated in the active role and the ability of youth in mobilizing and becoming vital elements for social and political movements in the Middle East. This proves that the Western implication of youth as troublesome varies in different contexts and should not be always considered as negative, particularly the troubles caused by the depression and frustration of unemployment.

It is quite interesting to note the gendered notion of “youth as trouble” viewed in a different society. To be more precise, in the Western context, youth viewed as troubles probably indicates both males and females, though the image of female youth is not vividly associated with troublesome or female’s problem is often linked to premature sex and unwanted pregnancy; these issues are avoided in public discourse. However, in an Asian context, this notion often refers to young males; even in any political upheaval occurred in the South youth participation is understood as males not females. Therefore, not only do age and the social meaning play vital roles in conceptualizing youth but also gender; gender is obviously an important tool to indicate and analyze youth behaviors in different contexts.

While youth has reconfirmed its important segment in society, young people are still categorized as a marginalized group and whose voices are often neglected (Khan, 2012; Wyn and White, 1997). According to the latest ILO report on the Global Youth Employment Trend in May 2012, unemployment rate among youth has risen from 12.6 per cent in 2011 to 12.7 per cent in 2012 which means nearly 75 million youth are unemployed around the world (ILO, 2012:7). Not only is unemployment seen as a major cause of depression among youth, other issues such as health, education and social policy somewhat leave youth behind. As for youth with disabilities, they inevitably become an invisible population. UN states in the Fact Sheet of International Year of Youth that ‘[youth] with disabilities are amongst the most marginalized and poorest of all the world’s youth, whose basic rights are not well met and for whom full societal’ (UN, 2010-2011)

Despite of the marginalization and the so-called “victimology” of youth, Wyn and White criticized the notion of youth as “victim” for it traumatizes young people simply as passive recipients and ignores the issue of youth “agency” on how young people respond to marginalization process (1997: 140). The fact is that too many studies concentrated on portraying young people as the patients or passive receivers and forgetting that ‘[they] are not only social *becomings* but also *beings* that are active in their own right’ (Angelina,

2010:10). Hence, this paper is an attempt to emphasize and highlight the issue of youth agency, particularly of young people with disabilities and how the gendered notion of youth determines the embodied sexuality, experiences and the exercise of agency between males and females.

2.2.2 Young and Sexual Body

I initially encountered the whole abstract notion of body in a book of Wendy Harcourt called “Body Politics in Development”. Like its title, Wendy as a feminist unpacked and rewrote “the truths of the body” (Harcourt, 2009: 18) by not only raising the issue of gendered bodies but also focusing on the implication of oppression and power of the body discourse in development. What impresses me most is the entire notion of body in which the body itself is not viewed as a homogenous concept biologically and socially but it is rather analyzed in many dimensions such as invisible bodies, reproductive bodies, productive and caring bodies, violated bodies, sexualized bodies, techno-bodies etc. And according to Harcourt, the body influences one’s health, rights, living conditions, security even their intimacy and sexual experience (Ibid.: 13). Therefore, based on different types of body researched by Harcourt, I also re-unpack the notion of body and yet I look deeply in the issue of disabled bodies and link them to the fact that these bodies (young) are growing into sexual bodies as well as analyze the impact of disabled and sexual bodies on male and female’s sexual meaning and sexual drive.

Sexuality is a complicated term to define. It is comprised of many issues such as sexual identity, sexual behavior, sexual orientation, relationships, roles, self-expression, pleasure and eroticism and so on; moreover, sexuality is not manipulated by an individual but society, norms, values, regulations and religious ideals (TARSHI, 2010). For example, premarital sex is considered sinful in Catholicism. World Health Organization provides a definition about sexuality as ‘a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships.’(WHO, 2002)

Though all issues related to sexuality, likely associate with men and women, the notion of youth is also frequently attached with sexuality, particularly ‘[being] young is a time of growth and discovery, in which young people develop into adults. They form their own identities and learn how to move through the world in which they live. Sexuality is an integral part of this progress’ (Rutgers WPF, 2006: 4). That is to say, the physiological and psychological changes are most identifiable during this stage of growth of a human life. Therefore, sexual experiments either with oneself or others also commence at this stage (Ibid.).

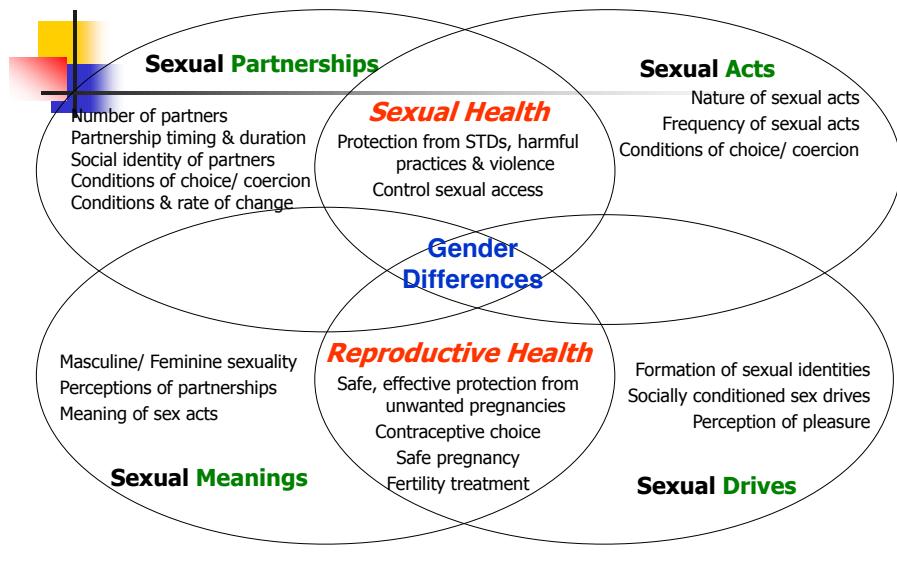
Nevertheless, developing along with young and sexual bodies is the socially constructed perceptive – ‘a social material base to “be-in-the-world”’ (Keyser, 2012) particularly social and cultural notion of gender differences on sexuality which leads to formation of gender roles. Like the Western dominant notion being a male and a female, in Asian context, “being a real man” and “what it is to be a man” are also based on the expected roles of a husband and

a father implies the heavy responsibilities (White, 1999 as cited in Cleaver, 2002: 9) and the act of leading roles; for instance, he has to be strong, macho and somehow aggressive while feminine sexuality is highlighted by their submission and obedience. As stated in Rutgers WPF, '[a] social and cultural perspective finds its roots in the idea that sexuality is based on the social and cultural norms and values within which it is developed. The diversity of cultures, religions, traditions and beliefs around the world define sexuality for individuals, as well as within relationships (2006: 6). Also, according to theories of "sexual scripting" of Gagnon and Simon (1973), social and cultural environments form the given sexual meanings or sexual norms that accept or even challenge young people's needs and experiences (Rutger WPF, 2006: 8). In this way, though sexual development is believed to be a natural process, the diversity of sexuality differs across societies, and needs to be investigated, rather than assumed, and more so in the case of the combination of young people, male or female, being with disabilities and being sexual, within a specific culture.

One aspect to reflect clearly the diversity of sexuality is how different societies handle the issue of youth and sexuality education. For instance, in the Dutch society, the issue of youth and sexuality is viewed rather openly and positively in which 'sexuality is not a problem nor is it something that needs to be controlled' (Rutger WPF, 2006: 8), this allows practitioners and policy makers approach young people by providing rooms for self-reflection and participation, by equipping them with proper sexual and reproductive health information and even solve sexual-related issues. On the contrary, society in an Asian context where "sex as a moral discourse" (Fisher, 2011) constrains the public discussion of sexuality with a claim that 'exposing [young people] to this knowledge will "give them ideas" and lead them down the path to premature sexual relationship and unwanted pregnancies' (Fisher, 2011: 38)

Moreover, gender as the vital analytical term in body politics referring to sexual differences of human relations affected by psychosocial, political-cultural, scientific and economic elements is lived differently in different places, bodies and locations (Connell, 2002; Sjoberg, 2007 as cited in Harcourt, 2009: 14). Thus, the notion of sexuality perceived by young people is precisely determined by the gender differences, especially in sexual partnerships such as heterosexual, homosexual and bisexual; sexual acts including the frequent sexual involvement of young people and sexual expression via touching, seeing, thinking etc.; sexual meanings and sexual drives. For instance, boys/men since their early age, are expected to be tough. Meanwhile girls/women are thought to behave in an opposite way (Holmes, 2009:3). This gendered implication, hence, shapes the ideal notion of masculine and feminine sexuality, in patriarchal society particularly, as boys and girls growing up. As a consequence, they react naturally to the "illegitimate" law that men have to take a leading role in relationships even when they are allowed to be promiscuous while women are strictly supervised. Most importantly, the social construction of gender and the so-called gender advantage are likely enhancing the superior role of men in society than 'benefit women' (Ibid.)

Figure 2.2.2
Gender Differences and Sexuality Connection



4333-LK - BODY

14

Source: R. Dixon Mueller 1993 as cited in Loes Keysers, 2012, Course 4333, lecture slide

While debate as well as objection on youth and sexuality education has been going on around the world, for those who are young and experiencing sexual development but being affected by disabilities, their sexual needs and expectations are likely kept in silence. Even when common people, scholars and policy makers have gradually focused their attention on young people and sexual and reproductive health issues, a noticeable gap has been left untouched for a group of people with disabilities whose bodies are young and experiencing the same sexual development. As argued by Tepper, 'sexual pleasure in [young] people with disabilities has remained remarkably silent in the disability advocacy and the disabilities studies agenda. People with disability are just joining the fray' (2000: 287).

2.2.3 Young, Sexual and Disabled Body

It is quite challenging to place the three important elements of young, disabled and sexual altogether in a body for analyzing because these three concepts are basically dimensional, taking into account the issue of intersectionality. For this reason, I intertwined youth and sexuality in previous sections to highlight the natural progress of sexual development in any young person and pointed out gender differences in expressing sexual identities and experiences shaped by the given social and cultural meaning and expectation. In this section, I put these concepts together and analyze the embodied and gendered sexuality in

young and disabled bodies. I also make an attempt to clarify the issue of agency of people with disabilities, those who are young, disabled and sexual, by reviewing two notions: on the one hand seeing them as victims and passive receivers – thus as patients, and on the other hand, viewing them as agents – the right holders who deserve to be treated equally.

The Patient

Either young or old, people with disabilities are labeled as asexual (Addlakha, 2007; Ansell, 2005; Murphy, 2005; Shakespeare et al., 1996). This socially constructed notion of sexuality of people with disabilities determines and challenges their sexual behaviors. ‘While society told them one thing, their hearts and bodies told them another’ (Werner, 1987: 491). They are not usually considered as sexual beings and this leads to the generalization that they need to be protected for the fear of sexual abuse and violence. Despite ‘disabled people have the same range of experiences of their sexuality as any person’ (CREA, 2007) even they are fully aware of their feelings and functions; yet expressing them seems to be impossible (Werner, 1987: 491). Hence, instead of guiding them and recognizing them as sexual beings, young people with disabilities are turned into passive receivers who are believed to be fragile. Though, as a passive agent, young people with disabilities still exercise their choices and express their sexuality in certain aspects within the social structure that supposedly forms them to meet its expectation and norms. Yet, they often face with in the sense of social justification.

‘Sex is supposedly not something that [people with disabilities] bother [themselves] with’ (Shakespeare et al., 1996: 17) but ‘[...] the indomitable nature of human spirit. Part of that indomitable nature is not just [their] intellectual but [their] sensuality and enjoyment of life’ (Newfield and Donnelly, 2006: 57). Indeed, ‘sexuality is a key to self-esteem, dignity, respect and belonging’ (CREA, 2007). On the other hand, denying sexuality as one of ‘fundamental physiological needs’ (Maslow) of people with disabilities will put them in a dilemma of being oppressed and exposed, becoming more vulnerable to sexual molestation. Shakespeare has also pointed out the issue of ‘internalized oppression’ that ‘[...] the damaging emotional and psychological barriers that prevent disabled people from becoming fully functioning human beings, with health sexual identities and active, life-enhancing sex lives: these include certain attitudes and assumptions held by opposed people that create a situation of self-denial or self-harm’ (Shakespeare et al., 1996: 42)

As for young people, ‘[like] most adolescents, children and teenagers with disabilities have hopes and desires for marriage, children and satisfying adult sex lives’ (Berman et al., 1999 as cited in Murphy, 2005: 640). In addition, ‘adolescents and young people with disabilities must cope with all physical changes, emotional anxieties and social conflict of able-bodied adolescents [...] Clothing and fashion, music and media, community activities, social events and school experiences contribute to the development of personal identity at this age [...] These years are full of sexual overtones, messages and activities for those who can access them. However, the adolescents with disabilities may be more of a spectator on the sidelines than a participant’ (Addlakha, 2007 as cited in TARSHI, 2010).

Unlike young people without disabilities, those with disabilities are categorized as victims of their own disabilities. Plus, they are treated as patients whose problems are created by the stereotype and social constructed notions of disability, specifically about their sexual conducts and sexual expression.

The Right-Holder

Young people with disabilities are viewed as patients a time so long that subconsciously the society forgets that they are right-holders who are entitled to full rights like any human beings and therefore, whose rights deserve to be fully respected and recognized. In fact, in the past, the right-based approach had been adopted and promoted among development workers and policy makers dealing with disability related issues where they mainly targeted on education, employment and social inclusion. Meanwhile, general recognition of the sexual rights of people with disabilities as well as their sexual beings are not given adequate attention. Thus, specific programs implementing in enhancing sexual and reproductive health for young people with disabilities still are limited in number.

UN General Assembly of Standard Rules on the Equalization of Opportunities for Persons with Disabilities affirms 'persons with disabilities must not be denied the opportunity to experience sexuality, have sexual relationship and experience parenthood' (1993). World Health Organization also mentions about sexual rights in the "Report of a Technical Consultation on Sexual Health" in which several important points should be taken notice of such as the right to 'seek, receive and impart information related to sexuality; decide to be sexually active or not and pursue a satisfying, safe and pleasurable sexual life' (2002). Yet, according to Renu Addlakha, a sluggish alteration is acknowledged for people with disabilities; moreover, disability is put under a big umbrella as normal people in which rights indicated to specific individuals and groups are left invisible (2008). In addition, 'sexual behavior and reproductive health [of people with disabilities] have not yet found articulation in public discourse' (Addlakha, 2007: 112). Therefore, '[young people] with disabilities seem to be participating in sexual relationship without adequate knowledge and skills to keep them safe, healthy and satisfied' (Murphy, 2005: 640).

To sum up, young people with disabilities, even if they are more or less recognized as right-holders, are still limited in their roles as passive agents, depending on different contexts, different disabilities and the diversity of sexuality. Particularly, they still struggle to re-claim the rights to be recognized as sexual beings and then ask for benefits from sexual and reproductive health programs implemented across the world. Moreover, 'too often even programs with the best intentions have treated persons with disabilities as a "target" – passive recipients of services. In fact, persons with disabilities constitute a significant stakeholder group that should have a place at the table whenever health programs are planned and decisions are made. Their involvement is the best assurance that programs will meet needs effectively' (WHO, 2009: 9). As a result, instead of being treated as a right holder in full sense, young people with sexual and disabilities are not even given the chance to raise their voices to prove their own sexuality, declaring themselves as sexual beings and demanding for sexual rights granted to them like any human beings.

Concluding Points

By conceptualizing and clarifying main concepts of youth, disability and sexuality, I have posed problems of how young people with disabilities are viewed by society in term of sexual ability and how the socially constructed notion of youth and sexuality. This constrains and challenges young people with disabilities in exercising their agency as well as treats them as passive receivers rather than right holders. In addition, I pointed out the gaps in researches about youth, disability and sexuality particularly in the Asian context where sexuality is still a discourse sensitive to many, highlighting the invisibility of young people with disabilities as a subgroup who have the full right and yet whose voices are too often neglected. This chapter explains and substantiates for the framing of the research topic as well as analysis and claims. In later chapters, I will further explore the perception and experience of those young people whose bodies are young, disabled and sexual by letting them speak for themselves. And from their point of views, I analyze how they cope with and/negotiate their agency with the social structure.

Chapter 3

I am, I have and I can - Identifying voices of Young People with Disabilities at AP in India

“Because I have a right to be heard, I have a voice”

King George IV in the movie “The King’s Speech”

This chapter presents my findings and analysis of what has been found during my research at AP in New Delhi, India to answer the first three sub-questions targeting group A and group B namely and respectively ‘*How do young people with disability express their sexual desire?*’, ‘*Do young people with mild and moderate physical and mental disability accept themselves as sexual beings?*’ and ‘*How do parents of physically and mentally challenged people and social workers accept and address this issue?*’ The chapter, therefore, concentrates on analyzing the agency of young people (I am) with physical and mental disability (I have), their perception of sexual beings (I can) and whether or not the major actors accept them as sexual beings.

3.1 Gender and the Experience of Sexual Pleasure

This section mainly explores voices of young people through their sexual experiences and gender differences in determining different sexual behaviors and acts. Primarily, I emphasize on the sexual experience of the respondents that people tend to neglect this common, however, intimate pleasure of young people with disabilities. As argued by Mitchell Tepper, the pleasure discourse is the implication of the missing discourse of pleasure in sexuality and disability and the importance of sexual pleasure in improving a life quality of young people with disabilities (2000). During my five weeks interacting with young people at AP, I learned that there is the difference in sexual experiences and sexual behaviors between males and females in group A, with a higher incidence of male respondents being actively involved in sexual and physical acts, and a revelation of the female respondents in sexual pleasure in a more “tender” way i.e. psychological ways.

3.1.1 Male: Sexual Desire and Physical Acts - the Expression of Sexual Pressure

If Maslow indicates sex as one of human’s basic needs; Ancel Keys pinpoints the loss of sexual drive as human starvation (Keys et al. 1950). Apparently, sex is a heated topic with an important role in the human’s lives. Nevertheless, this subject becomes depressing and problematic when it associates with young people with disabilities. For, [the] sexual problem of [young people with disabilities] are aggravated by a widespread view that they are either malignantly sexual, like libidinous dwarfs, or more commonly, completely asexual [...]’ (Murphy, 1987:83 as cited in Shakespeare et al., 1996: 4). Moreover, according to Addlakha (2007) people with disabilities are considered physically less

attractive. Therefore, this stereotype has become a nightmare that obsesses their relationship with others. Sameed shared '*I feel sad when people do not accept us for who we are, also as human beings like anyone. They judge us by our disabilities and ignore our feelings and desire*' (Sameed, 20, male, personal communication, 2012). Obviously, how society views young people with disabilities impact how they look at themselves and treat others. In some cases, misconception makes them deny their own sexuality and accept the fact that they might not be "normal". Farhad, another male respondents expressed his self-pity of his disability that lead to self-denial, "*At first, I did not want to be in relationship with anyone. I am scared of how people look at my disability and me.*" (Farhad, 21, male, personal communication, 2012).

Disability itself may restrain young people's mobility, communication ability. In fact, the social conception, particularly the medical model of disability, that argues people with disabilities need to be protected, sheltered and fixed, not only considers young people with disabilities as broken, but also, undesirable and impotent. Thus, this stereotype affects the ability of young people with disabilities to perform gender functions and sexuality (Rembis, 2009:53), as the sharing of Shivam "*Girls don't love me, they are scared of my disability*" (Shivam, 22, male, personal communication, 2012)

Regardless of the social notion of the non-existence of sexual desire among people with disabilities, all male respondents in my research responded positively to my question and the general assumptions from society. The research finds out that male respondents (in group A) involved in different forms of sexual activities weekly either in solo forms or dual forms. This highlights sexuality as a source of pleasure founded in intimate and emotional experience of human relationship (Murphy, 2005: 642) and young people with disabilities are not beyond this source. Thus, this pleasure boosts self-confidence in young people, expressed by Sameed "*When I am in a relationship, I feel happy and more confident. I feel love and to be loved*" (Sameed, 20, male, personal communication, 2012).

Sexual acts are found in different form among male respondents to release sexual pressure and desire such as masturbating, watching pornography, reading erotic novels and talking about sex with their peers. This proves that whether having or not having disabilities, young people have all sexual practice in common such as self-exploration. Moreover, sexual desire can be expressed through self-discovery, erotic talks with peers and intimate conservations when genital contacts are limited (Addlakha, 2007). "*I like talking about girls with my friends; we talk about their bodies, boobs, shapes of their bottoms [laugh]*" (Farhad, 21, male, personal communication, 2012). "*I masturbate when I am at home alone; sometimes I visit [pause] porn websites to get aroused and then take care the rest by myself [grin] [Don't you have sex with your girlfriend?]We only meet each other once a week, sometimes twice; I just masturbate when I feel like having sex*" (Sameed, 20, male, personal communication, 2012).

Unlike the supplemental sexual behavior of a considerable number of Asian young men, who often experience their sexual intercourse with prostitutes as a source of entertainment with no string attached as Larson

(2012) mentioned in his article based on the Johns Chart⁴ (2011). It is believed impossible for young male respondents to access to brothel due to socially constructed concept of people with disabilities. People with disabilities are viewed as vulnerable and they need to be protected or having sex with people with disability is considered disgusting etc. *I don't go for prostitutes but my friends do [his friends are non-disabled], I have not thought of that. I am happy with my girlfriend and my sexual drive is always under controlled [...] when I have problems with my erection, I use "Stay-on"* (Sameed, 20, male, personal communication, 2012), Farhad shares his viewpoint straight-forwardly *"me? Visiting prostitutes? People will laugh at me"* (Farhard, 21, male, personal communication, 2012). It is important to note that not only do young male involve in sexual activities but they know how to "make use of" medical technology to enhance their sexual lives.

Furthermore, while body image heavily affects female respondents in initiating body esteem, boosting sexual esteem, not exactly in actual forms of partnered behaviors but more in a sensual form (to be analyzed and discussed in the next section), body image is more or less not a significant factor that influences male respondents' sexual esteem. According to Taleporos and McCabe physical disability tremendously affect sexual esteem of people with disabilities (2002), findings in my research demonstrate that it is gender role that plays a crucial part in determining the confidence of young people with disabilities in relationship as well as in sexual intercourse. Gender roles and the impact of patriarchal society will be further analyzed in the next chapter, in which, I will highlight the notion of masculine and feminine sexuality conceptualized in patriarchal society.

Sameed shares his opinion about sexual esteem, *"When I am in a relationship, I don't think much about my look and my appearance as long as I am happy. My girlfriend is a normal girl [sic] and she loves me. [Do you feel unconfident because of your disability?] No, by look, people can tell that I am a person with disability, but my girlfriend finds me interesting and that's all I need"* (S, male, 20, personal communication, 2012). *"I am not worried about my disability. I believe I will become healthy soon if I try to visit physiotherapist often. When I have a girlfriend, I don't think of disability"* (Farhad, 21, male, personal communication, 2102). Obviously, not only is sexual esteem generated by the process of self-awareness of people with disabilities, but also affected by how their partners treat them. In this case, Sameed's girlfriend considers him as a "normal" person, that, hence, boosts his confidence in establishing relationship. Thus, I conclude that important external factors including partners' behaviors and feelings play a vital role in re-confirming body esteem and sexual esteem of people with disabilities.

3.1.2 Female: Sensual Feeling and Body Image – Something More than Physical Acts

While male respondents share their active and satisfied sexual lives by engaging both solitary behaviors and actual physical acts with a partner, female respondents enjoy their pleasure in a more sensual way. As Gomez explained '[sensuality] is awareness of one's senses (touch, taste, smell, hearing, seeing, thinking) and taking pleasure in those senses' (Gomez, 2011: 1). The females in

⁴ <http://prostitution.procon.org/view.resource.php?resourceID=004119>

my research feel sexually excited by reading romantic novels, watching romantic movies and having their bodies appreciated by opposite-sex friends, which, sometimes cause arousal, indicated by the gushing of fluid from their vaginas. Recalling about her pleasure, Amrita eagerly shared, *"I don't feel comfortable being touched by male friends but I like to attract their attention [how?...] by taking care of my appearance. The feeling of being appreciated is so good [Do you have any idea if comments given to you are good or bad ones? ...] I don't know but I can tell from their facial expression that they talk about me and I feel proud of myself"* (Amrita, 22, female, personal communication, 2012). Plus, 'sexual arousal [which] can be initiated by sight, sound, smell or thought (psychogenic arousal), support[s] the contention that the brain is the major sex organs in humans' (Dennis, 2004: 390 – 392 as cited in Murphy, 2005: 642). This, therefore, proves that sexual ability and arousal are not associated with disabilities.

Interestingly, the so-called sexual "pleasure" among female mostly perceive from their body images as defined by Slade 'a loose mental representation of body shape, size and form which is influenced by a variety of historical, cultural and social, individual and biological factors, which operate over varying time spans' (Slade, 1994: 302 as cited in (Taleporos and McCabe, 2001: 293). *"Boys think that I am a normal girl so I become more confident. Some even come and ask for my phone number when I am at a supermarket"* (Amrita, 22, female, personal communication, 2012).

George Taleporos and Marita P. McCabe had a thought-provoking research about body image and body esteem, which, according to them, is seldom discussed in literature that body image have both negative and positive effect on body esteem of people with disabilities (Taleporos and McCabe, 2001). These effects have been found among female respondents in this research, in which those who suffer from mild mental and invisible physical disabilities are often proud of their body images. Despite the fact that 'our society values bodily characteristics that people with physical disabilities are less likely to possess, including physical fitness, sporting attainment and the 'body beautiful', as it is represented in the media' (Lawrence, 1999 as cited in Taleporos and McCabe, 2001: 294), *"Everyone says I am pretty and I am happy. I don't think of my disability"* (Amrita, 22, female, personal communication, 2012)

"I like dressing up and I like nice clothes. I don't want to have a boyfriend because my mother says it is not good for me but I like having boys look at me. I feel happy." (Taran, 20, female, personal communication, 2012). Since receiving comments from male friends on what they wear, their make-up and hair increase their sexual satisfaction than actual physical contacts; female respondents prefer making themselves prettier and more attractive in front of men, regardless of their disabilities. Therefore, the self-awareness of body image helps boost body esteem and self-confidence in young people with disabilities, as discussed by George Taleporos and Marita P. McCabe about the link between body esteem and sexual esteem that is regarded as positive factor enhancing the capacity of sexual satisfaction of people with disabilities (Taleporos and McCabe, 2002).

However, it is important to notice that body esteem varies among individuals on how they accept and respond to sexual desire. Most importantly, it depends on different types of disability that they have. As for the case of Kavita who suffers from polio, though she is fully aware of her sexual

development, her disability prevents her from actual act. ‘*I like to be pretty. I put Kajal on every day [Kajal is a black solid made from charcoal used by Indian women to emphasize their eyes, commonly known as eye liner]. Every women want to be beautiful so do I but simply my disability restricts my mobility so I don’t have many chances to meet up with male friends*’(Kavita, 20, female, personal communication, 2012)

Despite the level of negative and positive impacts of body image on how female respondent express their arousal, young people with disabilities have their own ways to experience themselves as sexual. Thus, the concept of being sexual is not necessary limited within human’s sexual desire or the ability to have a healthy and active sexual life like most male respondents. However, being sexual also refers to sexual satisfaction and mental pleasure emerged from different senses experienced among female respondents- the sensual beings – ‘the power of simply experiencing your senses as awake and alive can also create a flood of pleasurable feelings’ (WiER, 2010)

3.2 I, myself as Sexual Beings vs. They, themselves as Sexual Beings – Sexual Self-Esteem, Psychological Well-being and Marriage

Unlike the disparity in experiencing sexual desire as well as body image and its impacts between male and female respondents, the majority of interviewees in group A accepted themselves as sexual beings personally. They also reconfirmed their sexual ability as well as expressed their wishes for love, marriage and children. Nevertheless, significant findings have been found in the role that gender differences count, specifically in manipulating the perception of being sexual between males and females. As for men, being sexual automatically links to “the penetration” (Foucault, 1984); meanwhile, females think that being sexual means being marriageable. Also, gender differences affect how the level and type of disability influence males’ and females’ sexual self-esteem, psychological wellbeing and marriage expectation. For instance, being a man in Indian society is an advantage, even he himself suffers from disability, and the chance for him to marry someone is higher than a female. Lest, though parents of young people with disabilities and social workers also accepted themselves as sexual beings but this varies individually, a significant gap is found between personal opinions and actual actions.

3.2.1 I, myself as Sexual Being

The first half of chapter 3 mainly focuses on analyzing the three elements of agency namely “I am” (young), “I have” (disability) and “I can” (experience sexual pleasure and acts), this part attempts to analyze the issue of agency exercised within a certain social structure.

Agency, according to Amartya Sen, is the pursuit of goal and objectives (Sen, 2005: 221). Meanwhile, Erhard Berner refers to the capacity that an individual has in order to decide what action to take (Berner, 1998:4). More precisely, agency is the action and wills of individuals to express their opinions and to exercise choices. As for male respondents, accepting themselves as sexual beings seems easier. Sameed said proudly, “*Of course, I am sexual being, no matter what people say. I have a girlfriend now, even though we have not thought of getting*

married yet but I am happy with my life now, just as any normal people. [Are you confident to be a husband and a father later on?] my girlfriend's family is not really content of her having a boyfriend like me but I can do anything (Sameed, 20, male, personal communication, 2012)

"After my first sexual intercourse, I have not involved in any physical relation but I will find a girlfriend for me and eventually I may get married. [So you think you can do whatever a normal man can do?] I am sexual being, I know how to love a girlfriend and I know how to make children [laugh]) (Shivam, 22, male, personal communication, 2012)

The so-called dominated “boy” honor” (Foucault, 1984) are acknowledged as a privilege given to men in patriarchal society. And this advantage benefits more for males with disabilities rather than females. Therefore, ‘men with disabilities have greater access to health, education and employment opportunities than their female counterparts. They also find it easier to find sexual partners, both with and without disabilities. Indeed, being male shields them from some of the more dehumanizing consequences of being disabled that women with disabilities cannot escape (Addlakha, 2007:112). *“When I was so sick, I could not sit or walk, I just lied down on bed. My neighbors told my mother not to take me to the hospital for treatment because they say that I am useless, I am just a burden. No one will marry me and if there is someone marrying me. My parents have to pay a big amount of dowry since I am not normal”* (Amrita, 22, female, personal communication, 2012).

While the majority of male respondents are more confident of their sexual beings and connect it to their sexual activities, I found female respondents likely unsure and confused of which way would prove themselves as sexual beings until I commenced giving some hints. Later, it came to my realization that for females, being sexual is not necessarily associated with physical and intimate acts but the ability to get married and to bear children. For this reason, they tend to relate being sexual to reproductive capacity rather than explicitly accept themselves as sexual beings. This can be explained by the social and cultural notions that distinguish different roles and expectations between male and female and yet, according to Berner, this may influence them but not determine them (1998:4). *“I like having boyfriend [More than that, do you want to be loved, cherished, touched, taken care by a man?] yes, I do [shy] [Can you tell me more about that? What do you want from your boyfriend, your dream when being in a relationship?] I want to be a good wife and I want to have several children. I think I can do that. [That means you are sexual being right?] Yes, I am”* (Amrita, 22, female, personal communication, 2012). In spite of disability that may and may not greatly affect young people’s lives, the sexual desire goes beyond physical acts into a more stable desirable role of being a father and a mother.

However, one respondent refused herself as sexual beings given the fact that she is physically challenged. In this case, disability itself is the main factor that determines her conception of sexual beings, regardless of loneliness she has confronted. *“Sometimes, I feel so lonely, particularly when my friends go out with their boyfriends. I also want to have someone nearby to share everything with. [So do you also want to have a boyfriend?] My disability does not allow me to have a boyfriend [but your feeling is there, isn’t? that you feel lonely and you want to be loved?] Yes, I*

have those feelings but I don't think this will happen to me, you can see, no one will love and want to be with a person in a wheelchair like me [pointing at her wheelchair]" (Kavita, 20, female, personal communication, 2012). Since Kavita suffers from polio, which causes her legs to be paralyzed, the thought of disturbing her family continues haunting her, and this affects her sexual self-esteem and psychological well-being. Obviously, though, young people with disabilities consider themselves sexual beings and fully capable of a rich sex life, marriage and reproduction (Taleporos and McCabe, 2001 as cited in Remis, 2009:52); disability still heavily influences whether or not young people with disabilities perceived themselves as sexual beings and marriageable.

3.2.2 They, themselves as Sexual Beings

With parents, when talking about their children's sexual related issues required more effort than young people themselves because the topic is, on the one hand, not commonly discussed among them, on the other it is considered as a personal and private matter only to be shared individually, not publicly. Despite that fact, respondents' parents accepted the sexual and reproductive capacity of their children. Amrita's mother talked about her daughter, "*no matter what people say about my daughter, to me, she is absolutely normal. [How do you deal with those comments?] I ignore [so this mean you accept your daughter as a normal person who have full function to get married? I mean to be able to become a wife and a mother?] Yes, she can do that*" (Amrita's mother, female, personal communication, 2012)

However, gender difference also plays an influential role in determining the parents' thinking toward their children's sexuality; and in building a greater expectation for sons to get married and settle down than for daughters. "*I hope my son will be better soon so he can take care of himself. [And get married too?] Yes [smile] [so you think your son can be a husband and a father?] Yes, despite the problem of his legs, I think he can do anything [smile] like getting married, having children and working.*" (Farhad's mother, female, personal communication, 2012)

Meanwhile, Kavita's father expressed his deep concern of his daughter's marital future, "*my daughter as sexual being? Actually I have not given it much thought. [Why?] I am so busy working and earning income to support my family. Also it is a women's thing. [So it is not a men's thing?]. [Have you thought of one day your daughter will get married?] I don't know because her situation does not allow her to marriage, except if someone wants to marry her. [Will you?] Yes [and you will have grandchildren?] Yes but I don't know if she can get married or not. [Have you started searching for a suitable suitor for her?] No*" (Amrita's father, male, personal communication, 2012). As argued by Addlakha, the normative feminine roles in Indian society where women are expected to fit into a category of ideal housewives; hence, girls with disability are often hidden and/or protected by their families (Addlakha, 2007: 112). This has unconsciously established the idea of girls with disabilities being firstly as patients of their own disabilities and secondly as passive patients whose lives and futures were determined by others.

For social workers, their viewpoint of young people with disabilities as sexual beings is clear. Ms. Vaidehi Subramani - Head of Social Work

Department shared her opinion: “*We know that they are human beings, just like anyone of us. They have sexual feeling and desire and we don't deny their sexual beings*” (Vaidehi Subramani, female, personal communication, 2012). With social workers directly working with young people with disabilities, sexual development is believed as a part of human growth, Aslam Khan said, “*I accept young people with disability in AP as sexual beings despite of their disabilities*” (Aslam Khan, male, personal communication, 2012). “*To me, they are sexual beings, which mean they can get married and have children. They have all the desire that we have. However, we don't talk about that.*” (Sweta Sah, female, personal communication, 2012)

Nevertheless, recognizing young people with disabilities as sexual beings mostly depends on individual opinions, which means social workers interviewed in the research view young people with disabilities in terms of sexual beings differently from other colleagues such as teachers and the management of the NGO. I heeded this divergence when a teacher who is in charge of a day-care group, stopped me from discussing with young people about their relationship with opposite-sex friends, suggesting that this topic should not be openly talked at school. Since social workers could not find a common voice on the issue of young people with disabilities as sexual beings, this leads to the constraints in implementing appropriate programs as well as the shortage of information given and/or inadequate sexuality education. Ms. Vaidehi revealed, “*Though I accept them as sexual beings, we don't have any particular program aiming to equip them with proper sexual and reproductive health information. Personally, I know young people with disability here at AP have these normal feeling and desire for others*” (Vaidehi Subramani, female, personal communication, 2012)

“*In my class, I've noticed several students who are interested in each other and I know it is quite normal – the chemistry between opposite-sex friends. However, I don't encourage that [which mean you don't accept them as sexual beings?], they are indeed but school is a place for knowledge not for students loving each other*” (Rupal, female, personal communication, 2012). How parents of young people with disabilities and social workers recognize them as sexual beings reflects the constraint between agency and social structure in which the norms still manipulates people's act of choices and expressions.

Concluding Points

Based on different experiences of sexual practice between males and females shown in my finding as well as their perception of sexual beings suggests that, though sexual desire exists in certain level it determines different sexual behaviors and expectation. As for males, being sexual is indicated by their leading roles in relationship but more importantly by their sexual activities. As for female, being sexual means marriageable. This conclusion may be inappropriate for women who have previous sexual experiences; however, since none of my female respondents had intercourse before, further relevant studies are strongly recommended.

Data collected also shows that agency as a conscious act of an individual to choose or to do something according to their will is indeed constrained by social structure with the component of many individuals' lives. In certain situation, social structure restrains and forces an individual to act accordingly.

This issue is further analyzed in the next chapter. Through the eyes of young people with disabilities, I explore how they as agents and passive receivers handle and negotiate within the patriarchal structure.

Chapter 4

Growing up as Disabled and Sexual Beings

In this chapter, I focus on analyzing the interaction between bodies and context. Based on the viewpoints of young people with disabilities, I explore how they grow up within a patriarchal context, how the notion of masculine and feminine sexuality in patriarchal society and media, specifically the Bollywood film industry affect their perception as sexual being, sexual orientation, behavior, practice and education. I also attempt to answer the last sub-question *“Which factors greatly affect the conception of sexual beings accepted by young people themselves as well as by major actors i.e. their parents and social workers?”* In so doing, young people with disabilities have the freedom to talk about and share their sexual experiences during their growing up process and how they are coping with the changes of their bodies during puberty to try to fit themselves with the general norms and the way they respond within these norms.

4.1 The Norm - Sex in Patriarchal Society

In many Asian countries, sex is a taboo topic. Aggrawal, noted that adolescents therefore have little knowledge, limited attitude and sexual behavior (Aggrawal et al., 2000:226). Hence, ‘the sexuality concerns of people with disabilities are rarely acknowledged and therefore have not been considered an important area for study or research’ (TARSHI, 2010:6). This explains why, even though social workers comprehend the sexual development within young people with disabilities, openly discussing and solving sexual-related problems are likely avoided. *“We don’t discuss or talk about sex and sexuality in public. It is a cultural aspect which sex is considered as individual problems or privacy”* (Vaidehi Subramani, female, personal communication, 2012)

Furthermore, the chance for young people to have dialogues about sexual and reproductive health with their parents seems impossible. When asked if she asked her mother for any information about menstruation and pregnancy, Kavita immediately shook her head and responded, *“How can I ask my mother about contraceptive? It is impossible [Why?] we are not allowed to talk about that between a mother and a daughter”* (Kavita, 20, female, personal communication, 2012)

Not only is sex avoided for discussions, but also issues as having boyfriends or girlfriends are not encouraged for group discussions. More concisely, when I tried to gather young people with disabilities at AP together for a small group discussion about opposite-sex friends, by the time young people eagerly answered my question whether or not they had girlfriends or boyfriends, a teacher immediately said *“No, Madam. It is not suitable”*. Interestingly, young people stared at their teacher and asked *“Why?”* and the teacher replied that *“because school is not a place to talk or discuss about those things”* (Rupal, female, personal communication, 2012).

On the response of Rupal, Aslam Khan – a social worker shared, *“because of the socially constructed notion of sex as taboo in our society, we tend to solve all the sexual-related issues individually. [How?] Individual consultant [Could you be more*

specific?] Sometimes, we receive complaints of female students about inappropriate touches from male friends. We invite students to our department and explain why they should not do that. Sometimes, policemen come to our school and provide a short session for girls to protect themselves from sexual molestation. However, there is no formal sexuality education here at AP”(Aslam Khan, male, personal communication, 2012). The constraint between exercising agency and social structure is quite understandable and this leads to the temporary “informal” (individual) problem solving. However, providing short trainings or talks conducted by policemen to females implies the victimhood of young females with disabilities. They are still being treated as passive receivers; plus, it demonstrates the gendered vulnerability in the Indian context where women are believed to be more fragile and prone to sexual molestation than men. Hence, women with disabilities are undoubtedly more exposed to physical advance and abuse.

“We also want to have a sexuality education program here in our school. Indeed, we’ve planned for a program and yet we have not implemented that due to some consideration about cultural norms. And most importantly, we need evidence to prove that young people are really in need of these programs. Therefore, your study may help since young people may share with you information that they do not dare share with us” (Vaidehi Subramani, female, personal communication, 2012)

Sexuality may suggest a sensitive topic to be discussed, shared among generations yet such discourses tend to be a common ground for peers. Young people with disabilities even teach each other from how to successfully seduce a girl to how to use condoms and maintain erection. *“We discuss about sex with each other”* (Sameed, 20, male, personal communication, 2012); *“I teach my friend what they should do with their girlfriend and how to please them”* (Farhad, 21, male, personal communication, 2012). Unlike confident male respondents sharing their curiosity and discovery, female respondents just share issues related to their body changes and love stories with their peers. *“I listen to my friends sharing about her boyfriend. Sometimes they are in quarrel, so I suggest her what to do to maintain the relationship”* (Sumiran, 22, female, personal communication, 2012).

Findings demonstrate that in a typically patriarchal society like India, ‘men and women are bearers of polarized character types’ (Connell, 1999:67). The demonstration does not stop at how actively young people with disabilities are in expressing their sexual desires considering three male respondents revealed to have had sexual intercourse before and their confidence in marriage.

“Currently I am still in a relationship with my girlfriend. Her parents don’t like me much but we will try” (Sameed, 20, male, personal communication, 2012)⁵; *“I don’t think much of getting married at the moment but I will find a girl. It is just a matter of time”* (Shivam, 22, male, personal communication, 2012). Meanwhile no female respondents experience actual physical act beyond hugging, touching and kissing because being involved in relationship, for them, having unwanted pregnancy or simply having an opposite-sex friend would be negatively judged or deprecated by society. Plus the prospect of getting married is likely uncertain, *“I want to be loved but look at my situation [her wheelchair]. I don’t know if anyone love me and want to marry me”*(Kavita, 20, female, personal communication,

⁵In early September, I was advised from Aslam Khan that Sameed and his girlfriend had just engaged

2012); or the marriage will be decided by others, “*I am not sure about marriage; my parents may find one for me. [An arranged marriage?] Yes*” (Amrita, 20, female, personal communication, 2012)

As a result, the notion of feminine and masculine sexuality in patriarchal society determines how males and females should act in relationship. As Connell wrote “[power] relations: the main axis of power [...] and] gender order is the overall subordination of women and dominance of men [...] named] patriarchy” (Connell, 1999: 74). Furthermore, differences in feminine and masculine sexuality likely marginalize girls as passive patients to be protected. This is clearly shown in different sessions provided by local policemen to instruct young female with disabilities at AP on how to prevent “Eve Teasing”⁶

4.2 Mass Media and Sexual Behaviors of Young People with Disabilities

Today, people talk about mass media (magazines, television, the Internet, radio and etc.) and their ability in speedily spreading information from once place to another. One cannot deny the great influence of media on youth, particularly, ‘mass media serve as “super peer” as a source of information about sexuality that is unavailable in their peer group. In this way the media may serve as kind of substitute sexual peer’ (Brown et al., 2004: 420). Jane Brown especially mentions media as a frequent channel to provide portrayals of sexuality and as an increasingly accessible way for young people to learn and to see sexual behavior; firstly because they are on development progress of sexual beliefs and conducts, secondly because schools and parents remain reluctant in discussing sexual topics (Brown, 2002: 42). For young people with disabilities who are limited from sexual exposure and interaction, media even becomes more “a useful peer”.

In the society where sex and gender issues are taboo like India, the only way to experience the physical acts of sex is via media such as Bollywood movies. Furthermore, in the country with its more than 1 billion population, the impacts of Bollywood on people’s lives are tremendous. A volunteer at AP once shared with me “*In India, we don’t talk about sex but we know young people know about that [How do you know that they know?], we do know through newspapers, the Internet and Bollywood you know [Bollywood?] yes, Bollywood teaches them everything, everything*” (Pham, personal communication, 2012). According to a research done by WHO, young people are greatly influenced by movies and filmmakers (2003: 6). Thus, ‘the media are full of sexual information, and in some of the different kinds of media the portrayals have grown increasingly frequent and explicit’ (Brown et al., 2004: 421)

As I approached a journalist friend in the attempt to grasp the influence of Bollywood on young Indian people, he affirmed: “*You will never find any country where the people are so influenced by movies like India*” (Philip, personal communication, 2012) and found out that Bollywood movies also hold a main function of information provision for young people with disabilities to learn about sexuality. The reason for young people, particularly the physically and

⁶A type of sexual harassment commonly occurred in public in New Delhi.

mentally challenged, subjected to the stereotype of asexuality, turning to the media is because it is relatively safe and less embarrassing way to be associated with. (Brown et al., 2004: 421)

Yet, 'the role of media influence is complex and does not involve simply 'absorption' or 'mimicry' (Kitzinger, 1999; Batchelor, 2003); however, several studies have shown that the media has an important part to play in shaping the knowledge and attitudes of young people, and can influence discussion around sexuality' (Davis and Harris, 1982; Thomson and Scott, 1991; Kehily, 1996; Currie et al., 1997; Forrest, 1997; Millwood Hargrave, 1999 as cited in Batchelor et al., 2004: 669). Sameed shared his experience; *"I learn what a man and a woman usually do in their bedroom by watching movies"* (Sameed, 20, male, personal communication, 2012)

"I love watching Bollywood and how actresses dance and move their bodies [Do you think it is helpful, I mean watching Bollywood?] I know what guys want from us, how to dress up and make ourselves pretty. I learn how to kiss a guy from Bollywood movies" (Sumiran, 22, female, personal communication, 2012)

Not only do young people admit the role of Bollywood in equipping them with information about sexuality, but also parents of these youngsters acknowledge this. Hence, they state confidently that they do not have to tell or teach their children about sex, even how to protect themselves because the children learn from movies and newspapers. *"You know, TV programs talk a lot about sex and contraceptive even on movie, our children watch these programs and understand better. [How are you sure that they know everything?] Because they mention everything [even how to have safe sexual intercourse?] I don't know but I think children know"*. (Farhad's mother, female, personal communication, 2012)

"I don't talk about sex with my daughter. [Why?] Simply we don't. Indian parents don't talk about that [so where does your daughter get information?] From TVs, movies [Bollywood?] Yes and schools [What makes you think school will teach your children about sexuality?] They teach about changes of body so I guess children know about that too. [When your daughter reached her puberty, did you instruct and explain your daughter why it happened?] I kept my daughter away from guys, I stopped her playing with boys. [Which reasons did you provide?] It was not safe. [Is that all?] Yes. [How about menstruation and the possibility of getting pregnant?] My daughter did not ask me about that, she just does it naturally." (Amrita's mother, female, personal communication, 2012)

Nevertheless, what has been shared among my respondents proves that they may know about sex and contraceptives, even how to seduce opposite-sex friends and maintain a relationship without any proper knowledge and information instructed to them. *"I know a lot about contraceptives [Can you share with me in details?] Like condoms, pills [Have you ever seen a real condom?] I saw TV advertises [how about in real life, do you know how it look like? No]"* (Amrita, 22, female, personal communication, 2012)

"I don't know much about pills, I hear people talking about it but I don't know how to use them [What if you have a boyfriend and you need to know how to use them?] I don't know, perhaps I will ask my friends" (Kavita, 20, female, personal communication, 2012)

“I have been using Stay-on for a year. [Do you have any idea of over-usage or side effect of it?] No, my friend just told me to use it because he uses it [...] I put condom on before penetration. [How about before that?] No” (Sameed, 20, male, personal communication, 2012)

Also, the gender roles, displayed in certain ways on Bollywood movies, characterize how typically men and women conduct themselves in relationships. Most importantly, this leads to dependent behaviors, “*Why I should have condom with me, that's what men should do*” (Sumiran, 22, female, personal communication, 2012). “*I buy condoms on my own [Are you shy?], at first I was then I watched a commercial ads for Cosmo, the guy went to a drug store and said Cosmo so I did the same.*” (Sameed, 20, male, personal communication, 2012)

Though, mass media play a crucial role as a source of providing information of sex for young people with disabilities. ‘The role of media in the development of young people’s sexual attitudes and behavior must be considered’ (Batchelor et al., 2004: 637 – 674). Furthermore, ‘it is important for health promoters to be aware of these mixed messages facing young people, and give consideration to the confusion and gaps in cultural representations from diverse sources’ (Ibid.)

4.3 Sexual Rights and Sexuality Education for Young People with Disabilities

Sexual health defined by WHO is a state which includes elements of physical, emotional, mental and social well-being in relation to sexuality, absence of disease and respectful approach to sexuality and the possibility of having healthy, enjoyable sexual relationship; however, to ensure the benefit of sexual health for each and every young people with disability, sexual rights should be protected and enforced (2012). Among the list of sexual rights claimed by WHO, I particularly take notice of the right to ‘seek, receive and impart information related to sexuality’ (WHO, 2012) as a guideline to reflect on how young people with disabilities at AP have handled with changes of their bodies.

Rhetorically, young people with disabilities are likely treated as right-holders and yet a loophole has been found in reality. *No one talks to me about how to protect myself or changes of my body.* [What did you do when you had your first menstruation?] *I was so scared, I almost cried because I did not see so much blood like this before.* [Why didn’t you ask your mother?] *I was not supposed to ask my mother. I ran to a friend of mine and ask her what was happening to me. Then she told me how to use pads.* [Did you know that since you start your menstrual circle, you could be pregnant?] *My mother did not explain to me in details how I could get pregnant, she just asked me to cover my body and use bras. She also did not allow me to play with boys but no explanation*” (Kavita, 20, female, personal communication, 2012).

“When I noticed changes of my body such as boobs growing, pubic hair. I did not ask my mother until I had my first menstruation. I told to my friends and they told me what to do [Did not you get these information from school? I mean through biology class?] No, it was not in details, we only learned about different organs” (Amrita, 22, female, personal communication, 2012)

"I wondered what was wrong with me, why so much blood. My sister told me to clean myself and that every girl has this period monthly" (Taran, 20, female, personal communication, 2012)

Even though the path is rhetorically open for everyone to know and/or improve knowledge of sexuality including young people with disabilities, young people are actually not well-equipped, even with the basic information such as personal hygiene for females during menstruation. Furthermore, not many of them are lucky enough to always have peers to share their concerns with. 'Regardless of the malfunctioning of certain abilities of the body, in most cases, adolescent girls will menstruate and boys will begin to have emissions. Again, regardless of disability, all people need to know how to keep themselves clean and safe from infection and consequences like unwanted pregnancies and have the right to a self-affirming sexuality' (TARSHI 2010: 32)

"I got up and found my pants wet. I thought I peed while I was sleeping. It happened regularly. I was embarrassed so I did not talk to anyone then when my friends talked about that. I only knew it was wet dream" (Farhad, 21, male, personal communication, 2012)

It is important to note that though female respondents revealed that they knew different types of contraceptives only one says she has seen it before. *"I watch condom ads on TV, I heard about pill but I never see them in my real life. [Do you have any idea how to use them?] No, because I don't think I need them now"* (Amrita, 22, female, personal communication, 2012). This shows that not only do young people with disabilities lack information of sexual and reproductive health but also they tend to become dependable on others that may be extremely dangerous for they could be easily seduced to sexual advances and deceived by others. *"I have know men using condoms [So women don't use condoms?] We have pills [smile] [So you think condom is only for men NOT women?] Yes* (Sumiran, 22, female, personal communication, 2012)

A lack of information about sex and sexuality also leads to several serious issues. For instance, sexual advance to one of my female respondent when her boy friend attempted to touch her body and convinced her as a way of affection expressed among couple. *"We went out together after several weeks exchanging SMSs to one and another, my mom did not know about that. She does not like the idea of me having a boyfriend. At first, he wrapped his arms around my shoulders then my waist and my bottoms."* (Amrita, 22, female, personal communication, 2012)

Shivam shared his heart-breaking sexual experience with his half-sister after watching a Bollywood movie, *"My sister and I were watching a movie, then it came a love-making scene. My sister who was 12 at that time turned into me and said, "let's play". At first, I was a bit hesitant but I was also curious how people have sex so I had intercourse with my sister. [Did you use a condom or any contraceptives?] I did not know about condom at that time, also we could not find one at home, we just did. [How many times did that happen?] Just once, later on, my sister insisted on me having sex with her but I got some information from my previous NGO about sex and I know it was not good. [How did you make sure that it would not happen again?] I told my sister that I would tell my dad if she kept asking me for sex"* (Shivam, 22, male, personal communication, 2012).

Sameed who has low IQ (75% - Medical record from AP) shared with me his sexual "adventure" with his girlfriend and how they have ended up having

protected sex. ‘*We did not use condoms when we first had sex. [Why?] We heard about it but having sex without condom made us feel at ease. [So nothing unusual happened to your girlfriend?] No [I mean, pregnancy?] There was once she was late along with tiredness and nausea, we went to a hospital. [Did she get pregnant?] I don’t know, a doctor did not say anything to me, she kept her in her room for a while and then asked us to use condom whenever we have intercourse*’(Sameed, 20, male, personal communication, 2012).

Their striking stories raise the same issue of information shortage for people with disabilities, which make them become more vulnerable to defend themselves and easily to be deceived and made use of by others. This problem demonstrates a profound gap to be critically looked at when recognizing the right of people with disabilities, to require adequate, accurate and appropriate sexual and reproductive health information. ‘*If there is a training or session that teaches us about our bodies and pleasure [laugh out loud], I will definitely join it*’ (Shivam, 22, male, personal communication, 2012). ‘*I need the information about sexual and reproductive health*’ (Kavita, 20, female, personal communication, 2012). ‘*Why don’t people talk to us about that, we also need these information*’ (Amrita, female, 22, personal communication, 2012).

Concluding Points

Chapter four further explores how young people with disabilities think and cope with societal factors. Besides the issue of norms and the impact of media, I particularly highlight sexual rights and sexuality education. To me, it is time to seriously look at the consequences that lacking of such education may bring. An Indian colleague of mine once argued, ‘*if sex education is introduced at schools, parents will not allow their children to go to school*’ (Pham, personal communication, 2012). I argue sexuality education is not merely to teach children and young people about sex and how to have sex but also to let them know and understand their bodies. In fact, young people with disabilities are in need of the information.

The actual existence of the sexual desire in young people is undeniable, irrespective of their disabilities. Whether we accept its existence or not, the sexual desire, demands to be released and satisfied, still, in an appropriate, safe and enjoyable way. Nevertheless, without access to accurate instruction and adequate knowledge, young people with disabilities become more vulnerable to sexual advances. It may lead to inappropriate sexual behaviors, which is not accepted socially in terms of morality.

Chapter 5

Conclusion and Recommendations

The whole research has brought up the issue of youth agency in which youth refers to young, disabled and sexual people who are described as “invisible population”. Through the eyes of young people with disabilities, I started a journey to explore how they perceive and experience themselves as sexual beings and the process of their growing up, socializing and negotiating their agency within a patriarchal society via factors influencing their sexual behavior, thinking, experiences as well as their parents and social workers. This research attempted to fill the gap in study about youth, disability and sexuality by identifying the voices and having them voice out, showing their vulnerability as well as demands for an acknowledgement of their capability.

Hence, the findings have verified three important points to answer research questions. Firstly, young people with disabilities consciously perceived themselves as sexual beings. Nevertheless, sexual conduct and experiences differ between males and females. While men actively express their sexual desire in actual solo or partnered sexual acts, the women find themselves sexually aroused in a psychological and sensual way. Being sexual for men is linked to actual sexual activities while for female is linked to marriage and children. This is caused by gender differences, which determine specific gender roles that shape the social constructed notion and expectation of being a boy and being a girl. As a result, it influences esteem and self-confidence among the researched through body – image. The severity of disability may not affect young male with disabilities in forming relationship and experiencing sexual intimacy and sexual well-being, however the same may not apply with their female counterparts. Plus, the role of partners also help boost self-esteem and sexual – esteem among young people with disabilities. Though young people with disabilities are recognized as sexual beings by social workers and parents, contextual factors including norms and values restrain them in transforming their thoughts into action. This results in the acceptance of young people with disabilities as sexual beings to be limited within individual levels.

Secondly, as part of their growing up and socializing process, mass media play a crucial role in providing some basic information that helps young people know how to maintain their social relations. Due to the limited accessibility and privacy that young people with disabilities may have, media, especially Bollywood movies may be a rich channel where young people have themselves exposed to different social relations and sexual behaviors. However, because of the mixed, yet diverse, sources of information of sexuality as well as contents shown on different media channels, a significant gap is found in differences between accurate knowledge and the copying practice which young people actually have not even experienced what has been talked on TV or newspaper. Furthermore, parents of young people with disabilities tend to acknowledge the information provided on media channels and expect their dependent attitudes, thus leads to serious lack of knowledge on issues related to sexual and reproductive health.

Finally, as agency is constrained by the social structure – the patriarchal society, sex and disability are not viewed compatible. Hence, young people with disabilities are still treated as patients who need to be sheltered and protected but not to be guided properly. Data showed that shortage of sexual and reproductive health knowledge leads to severe consequences such as child right violation and making young people with disabilities even more vulnerable. Though sexual rights are made as legislation to enhance and ensure the life of people with disabilities, young people with disabilities are somehow socially excluded while their body changes and sexual development are undeniable.

Although the research does not aim at proving that young people with disabilities are sexual beings, data obtained through the field research substantiated the fact that young people with disabilities are indeed involved in different forms of sexual activities in both conscious and unconscious ways. Therefore, based on the research findings, some recommendations need to be considered by social workers, development practitioners and policy makers. Firstly, participation of young people should be enhanced by opening more space for them to get involved and to share their concerns in order to inform suitable and effective programs; by doing so the role of young people with disabilities could be confirmed as right-holders. Given that ‘sexuality is an area of distress, exclusion and self-doubt for persons with disabilities, at its core, sexuality is essentially about the acceptance of self and acceptance by others’ (Addlakha, 2005). Thus, once young people with disabilities “accept” themselves as sexual beings, there should be no reason that others would not accept that fact. Hence, development practitioners and policy makers need to focus on awareness building through combining both “school-based initiative” and “community-based intervention” (Paiva et al., 2004) to call on for holistic cooperation.

Furthermore, intervention in enhancing their sexual lives should clarify the difference between sex and sexuality and take into consideration the issue of age and contextual factors so that appropriate programs can be implemented for different ages and levels. Last but not least, official documentation and legislation should be specific in indicating and recognizing young people with disabilities as a group and therefore, not generalize as people with disabilities as a whole. Also sexual and reproductive health schemes should not only focus on women with disabilities but men too, since they are also exposed to vulnerability, though in a male-dominated society, women tend to face more inequality.

The bottom line is selecting such a topic for researching, at some points challenged my will, determination, patience and passion for knowledge. Not only is this research a professional journey but also personal one that gave interesting experience in different places, going through a number of situations. In my opinion, social justice will become an endless and meaningless fight unless voices of young people with disabilities are attentively listened to. Dignity and well-being of young people with disabilities would never be achieved without serious recognition of them as right-holders, specially sexual rights to deserve a good, healthy and active sexual lives and these rights should be acknowledged and respected.

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Appendix 1: The List of Interviews

1. Group A

No.	Interviewees (Pseudonym)	Sex/Age	Date	Positions/Occupations of Interviewees
1.	Amrita	F/22	9 July 2012	Student at Day-Care Group Center
2.	Farhad	M/21	24 July 2012	Student at Day-Care Group Center
3.	Kavita	F/20	10 July 2012	Student at Vocational Training Center
4.	Taran	F/20	12 July 2012	Student at Vocational Training Center
5.	Sameed	M/20	17 July 2012	Employee at AP
6.	Shivam	M/22	19 July 2012	Student at Day-Care Group Center
7.	Sumiran	F/22	30 July 2012	Student at Vocational Training Center

2. Group B

No.	Name	Sex	Date	Positions/Occupations of Interviewees
1.	Aslam Khan	M	18 July 2012	Social Worker
2.	Sweta Sa	F	2 August 2012	Trainee
3.	Rupal (Pseudonym)	F	26 July 2012	Teacher
4.	Vaidehi Subramani	F	3 July 2012	Head of Social Work Development
5.	Amrita's Mother	F	2 August 2012	
6.	Farhad's Mother	F	6 August 2012	
7.	Kavita's Father	M	3 August 2012	