ACKNOWLEDGEMENT TO CBM SARO (INDIA)

Study report on:
Issues of 'Disability and HIV/AIDS especially among Children.'

Research Documentation

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Submitted by:

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ACRONYM / ABBREVIATION

AFA	**:**	**The Action for Autism**
AICB	**:**	**The All India Confederation of the Blind**
AIDS	**:**	**Acquired Immunodeficiency Syndrome**
ARSH	**:**	**Adolescent Reproductive and Sexual Health**
ART	**:**	**Anti Retroviral Therapy**
ASD	**:**	**Autistic Spectrum Disorder**
Atlas.TI	**:**	**Statistical Software for Qualitative Research**
BSS	**:**	**Behavior Surveillance Study**
CBM	**:**	**Christoffel-Blinden Mission**
CBO	**:**	**Community Based Organization**
CD4	**:**	**Cluster Difference 4 (A glycoprotein on the surface of helper T cells that serves as a receptor for HIV**
CI	**:**	**Community, Institutional**
DNA	**:**	**Deoxyribonucleic Acid**
FGD	**:**	**Focus Group Discussion**
FSW	**:**	**Female Sex Worker**
FXB	**:**	**François-Xavier Bagnoud**
FXB India	**:**	**FXB India Suraksha**
GDP	**:**	**Gross Domestic Product**
GOI	**:**	**Government of India**
HIV	**:**	**Human Immunodeficiency Virus**
ICAD	**:**	**International Conference on Alzheimer's disease**
ICDS	**:**	**Integrated Child Development Services**
ICF	**:**	**International Classification of Functioning, Disability and Health**
ICTC	**:**	**Integrated Counseling and Testing Center**
IDU	**:**	**Intravenous Drug Users**
IEC	**:**	**Information Education Communication**
IPC	**:**	**Inter Personal Communication**
JSY	**:**	**Janani Suraksha Yojana**
KI	**:**	**Key Informant**

KII	**:**	**Key Informant Interview**
LCI	**:**	**Leonard Cheshire International**
MCH	**:**	**Mother and Child Health**
MoHFW	**:**	**Ministry of Health and Family Welfare**
MSM	**:**	**Men having Sex with Men**
NACO	**:**	**National AIDS Control Organization**
NACP	**:**	**National AIDS Control Programme**
NCR	**:**	**National Capital Region**
NDS	**:**	**The Noida Deaf Society**
NFHS	**:**	**National Family Health Survey**
NGO	**:**	**Non Governmental Organization**
NI	**:**	**The Naz Foundation (India) Trust**
NRHM	**:**	**National Rural Health Mission**
OI	**:**	**Opportunistic Infection**
OVC	**:**	**Orphaned and Vulnerable**
PCR	**:**	**Polymerase Chain Reaction**
PPTCT	**:**	**Prevention of Parent To Child Transmission**
PWDs	**:**	**Person with Disabilities**
RCH	**:**	**Reproductive and Child Health**
SACS	**:**	**State AIDS Control Society**
SARO	**:**	**South Asia Region Office**
SLF	**:**	**Stichting Liliane Fonde**
SPSS	**:**	**Statistical Package for Social Scientist**
SRH	**:**	**Sexual and Reproductive Health**
STD	**:**	**Sexually Transmitted Disease**
STI	**:**	**Sexually Transmitted Infections**
TG	**:**	**Trans Gender**
UNAIDS	**:**	**Joint United Nations Programme on HIV/AIDS**
UNCPRD	**:**	**The United Nations Convention on the Rights of Persons with Disabilities**
UNCRC	**:**	**The United Nations Convention on the Rights of the Child**
UNIASG	**:**	**The United Nations Inter-Agency Support Group**
UNICEF	**:**	**The United Nations Children's Fund**

UNMDG	**:**	**The United Nations Millennium Development Goal**
UR	**:**	**Urban, Rural**
WHA	**:**	**World Health Assembly**
WHO	**:**	**The World Health Organization**

The term 'Disability and Health' in this report adopted from WHO's ICF framework for measuring health and disability at both individual and population levels. The International Classification of Functioning, Disability and Health, known, more commonly as ICF was officially endorsed by all 191 WHI Member States in the Fifty-fourth World Health Assembly on 22nd May 2001 (resolution WHA 54.21).

EXECUTIVE SUMMARY

A cursory review of the literature by FXB India Suraksha reflected that while considerable attention was paid to the disabling effects of HIV/AIDS on previously healthy people, there was nearly no mention of the impact of the AIDS epidemic on people with a pre-existing disabling condition. Not only have there been few HIV/AIDS interventions for the disabled population, but also a rare evaluation of those few studies undertaken. FXB India Suraksha was contracted by CBM SARO (North) India to conduct a study on the 'Issues of Disability and HIV/AIDS especially among Children' in July 2011. CBM being lead development partner with technical and programmatic expertise on disability and FXB India Suraksha having a pan India work experience in HIV/AIDS and Child Rights partnered for a common cause to conduct this explorative research for generating knowledge base on the issues of 'Issues of Disability and HIV/AIDS. The main ***objective*** of this study is to assess the current gap in knowledge, policy and practice that exists in terms of the linkages between HIV and disability. 8 states were covered in this study. The states were selected based on high prevalence of HIV and high incidence rate of disable persons and where CBM SARO has existing implementing partners. Based on secondary data review and in consultation with CBM (SARO) the following states were covered under the study.

HIV High Prevalent State: Manipur, Mizoram and Andhra Pradesh based on (National AIDS Control Organization HIV Sentinel Surveillance data in India in 2003-2006, MoHFW 2007). **State with High incidence rate of Disability (and has CBM partners)**: Uttar Pradesh, Jharkhand, Gujarat, Madhya Pradesh, Delhi / NCR. One of the interesting finding is that, PWDs are often perceived to be 'asexual' by the general population which appears to be a myth as they are equally active sexually indicating their vulnerability to HIV AIDS as with other general population. Social discrimination, taboos and misconception exist among the PWDs and to some extent among their care givers. The research reflected a predominantly high risk behavior among classified category as they are occasional visitor to Female Sex Workers, engage into relationships often physical with friends and relatives, and few also engages in homosexual behavior without much knowledge of prevention or care. In the rural area, PWDs do not use condom during sexual intercourse. In Institutional set up in urban areas, respondents were more aware of HIV/AIDS and its related issues and harm reduction than that of rural community. Care givers in family, school teacher and vocational educators and effective source of mass media play pivotal role under this situation. The implementers of disability and HIV programs were also in favor of this approach and proposed to include 'Disability and HIV' in mainstream mass awareness programs by demonstrating case study, success or failure initiatives and suggested to introduce Interactive Teacher-Student Learning materials designed to address the needs for special category of disability. Practitioners in disability domain believe that all categories of disabilities are equally important to be vulnerable to HIV/AIDS. However, in the case of multiple disabilities e.g. autistic spectrum disorder (ASD) with mentally disabled and hearing with speech disabled and visual with mentally disabled were seriously exposed to greater risk and vulnerability. Among these special categories of disability ardent role of care givers as a torch bearer to whom they are dependent is a key concern. This research study established firm fact that HIV prevalence exist either with preexisting HIV infection or due to accidental disability. Abridge of required information and non-scientific knowledge on HIV/AIDS has created potential gap in perception, awareness and attitude impacting health seeking behaviors among study population. Agencies expressed there were lesser opportunity to share knowledge and their experiences to further build common understanding of the issues and to explore opportunities for collaboration to advance the rights of PWDs and PLHAs.

SECTION A: BACKGROUND

1. INTRODUCTION

HIV/AIDS is recognized as a global epidemic and has been receiving considerable interventions across the globe. Such interventions operate on the basis of identification of several high risk groups like IDUs, MSMs etc. While efforts directed towards prevention and awareness on HIV AIDS among the target population has been commendable, a certain set of population with considerable vulnerability like tperson with disabilities (PWDs) have been considerably neglected from the ambit of the HIV/AIDS global interventions.

Historically people with disabilities have largely been provided services that are more oriented towards segregating them from the mainstream population, such as residential institutions and special schools (Parmenter, 2008). However in the recent past, policies have changed and National and International initiatives like the 'United Nations Standard Rules on the Equalization of opportunities of Persons with Disabilities' have incorporated the human rights of people with disabilities, culminating in 2006 with the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The CRPD does not define disability, but instead describes disability as an outcome of the intersection between challenged person and the obstacles that limit full and active participation in society. This approach promoted the inclusion of all persons facing barriers and PLHAs are implicitly included in this definition since even they face obstacles as a result of impairments arising from the virus or from anti-retroviral treatment.

The inter-sectionality of HIV/AIDS and disability was discussed in the CRPD in terms of

- The value of defining or un-defining HIV/AIDS as a disability.
- The strategic advantages and disadvantages of the HIV/AIDS and disability movements working together and
- The integration of disability and HIV/AIDS at the programme level.

However although the CRPD talks about equal protection, in reality, people with disabilities have been majorly left behind from effective HIV/AIDS outreach programmes. While HIV/AIDS is included in the principle of the CRPD, the onus of its implementation for the rights of the disabled populations still remains a task largely undone. Further there is a double jeopardy experienced by people with both HIV/AIDS and disability. Fear of added discrimination by family, community and society is a barrier to openly sharing HIV/AIDS status or to self identifying as a PWD. Effort is thus required to combat this double stigma beginning with raising awareness and open communication. The shared experience of stigma and discrimination of PHAs and PWDs thus provides a strong foundation for collaboration and knowledge sharing. However, there is some resistance to defining HIV/AIDS as a disability, both within HIV/AIDS movement and in the disability movement itself.

2. GLOBAL CONTEXT – DISABILITY AND HEALTH

International Classification of Functioning, Disability and Health (ICF) in WHO's framework

The International Classification of Functioning, Disability and Health, known more commonly as ICF, is a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual's functioning and disability occurs in a context, the ICF also includes a list of environmental factors. The ICF is WHO's framework for measuring health and disability at both individual and population levels. The ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001(resolution WHA 54.21). Unlike its predecessor, which was endorsed for field trail purposes only, the ICF was endorsed for use in Member States as the international standard to describe and measure health and disability.

The ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus 'mainstreams' the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability. Furthermore ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. By including Contextual Factors, in which environmental factors are listed ICF allows to records the impact of the environment on the person's functioning.

Disability and Health

The International Classification of Functioning, Disability and Health (ICF) define disability as an umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports).

Over a billion people are estimated to live with some form of disability. This corresponds to about 15% of the world's population. Between 110 million (2.2%) and 190 million (3.8%) people 15 years and older have significant difficulties in functioning. Furthermore, the rates of disability are increasing in part due to ageing populations and an increase in chronic health conditions.

Disability is extremely diverse. While some health conditions associated with disability result in poor health and extensive health care needs, others do not. However all people with disabilities have the same general health care needs as everyone else, and therefore need access to mainstream health care services. Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disabilities to attain the highest standard of health care, without discrimination. There are diverse key issues so far identified in relation to health concern of person with disability. WHO details, people with disabilities report seeking more health care than people without disabilities (PWD) and have greater **unmet needs**. For example, a recent survey of people with serious mental disorders, showed that between 35% and 50% of people in developed countries, and between 76% and 85% in developing countries, received no treatment in the year prior to the study. Health promotion and prevention activities

seldom target people with disabilities. For example women with disabilities receive less screening for breast and cervical cancer than women without disabilities. People with intellectual impairments and diabetes are less likely to have their weight checked. Adolescents and adults with disabilities are more likely to be excluded from sex education programmes. People with disabilities are particularly vulnerable to deficiencies in health care services. Depending on the group and setting, persons with disabilities may experience greater vulnerability to secondary conditions, co-morbid conditions, age-related conditions, engaging in health risk behaviors and higher rates of premature death.

There are secondary conditions that occur in addition to (and are related to) a primary health condition, and are both predictable and therefore preventable. Examples include pressure ulcers, urinary tract infections, osteoporosis and pain. Co-morbid conditions occur in addition to (and are unrelated to) a primary health condition associated with disability. For example the prevalence of diabetes in people with schizophrenia is around 15% compared to a rate of 2-3% for the general population. The ageing process for some groups of people with disabilities begins earlier than usual. For example some people with developmental disabilities show signs of premature ageing in their 40s and 50s.

It is inevitable that **engaging in health risk behaviors** are also emerging trend among PWD. Some studies have indicated that people with disabilities have higher rates of risky behaviors such as smoking, poor diet and physical inactivity. **Mortality rates** for people with disabilities vary depending on the health condition. However an investigation in the United Kingdom found that people with mental health disorders and intellectual impairments had a lower life expectancy. People with disabilities **encounter a range of barriers** when they attempt to access health care including the following.

Affordability of health services and transportation are two main reasons why people with disabilities do not receive needed health care in low-income countries - 32-33% of non-disabled people are unable to afford health care compared to 51-53% of people with disabilities. The **lack of appropriate services** for people with disabilities is a significant barrier to health care. For example, research in Uttar Pradesh and Tamil Nadu states of India found that after the cost, the lack of services in the area was the second most significant barrier to using health facilities. People with disabilities were more than twice as likely to report finding **health care provider skills inadequate** to meet their needs, four times more likely to report being treated badly and nearly three times more likely to report being denied care.

In order to **address barriers to health care,** governments can improve health outcomes for people with disabilities by improving access to quality, affordable health care services, which make the best use of available resources. As several factors interact to inhibit access to health care, reforms in all the interacting components of the health care system are required. It is beneficial if **existing policies and services are reframed** to identify priorities to reduce health inequalities and plan improvements for access and inclusion of PWD in mainstream health care service delivery model. Thus government delegations and policy makers need to bring necessary changes to comply with the CRPD. This should establish health care standards related to care of persons with disabilities with enforcement mechanisms.

Where private health insurance dominates **health care financing**, ensure that people with disabilities are covered and consider measures to make the premiums affordable. Ensure that people with disabilities benefit equally from public health care programmes. Provide a broad range of modifications and adjustments (reasonable accommodation) to facilitate access to health care services. For example changing the physical layout of clinics to provide access for people with mobility difficulties or communicating health information in accessible formats such as Braille. Empower people with

disabilities to maximize their health by providing information, training, and peer support. Promote community-based rehabilitation (CBR) to facilitate access for disabled people to existing services. Identify groups that require alternative service delivery models, for example, targeted services or care coordination to improve access to health care.

Integrate disability education into undergraduate and continuing education for all health-care professionals. Train community workers so that they can play a role in preventive health care services. Provide evidence-based guidelines for assessment and treatment. Include **people with disabilities in health care surveillance**. Conduct more research on the needs, barriers, and health outcomes for people with disabilities.

Several international NGOs working on disability are currently looking at how to incorporate HIV into their programmes at an organisational level, including Christoffel-Blinden Mission (CBM), Stitching Liliane Fonde (SLF), Sense International and (LCI). In each case, the impetus was encountering people with disabilities infected and affected by HIV in projects they support in Africa. Debates are now centered upon the most appropriate way of addressing this, ranging from making HIV a cross-cutting strategy with dedicated staff, to deciding whether to access support on HIV externally or provide this directly. Within India, disability funder CBR Forum has also been exploring ways of how to encourage their partners to engage with HIV for the last two years.

WHO response on Disability and Health

In order to improve access to health services for people with disabilities, WHO:

- guides and supports Member States to increase awareness of disability issues, and promotes the inclusion of disability as a component in national health policies and programmes;
- facilitates data collection and dissemination of disability-related data and information;
- develops normative tools, including guidelines to strengthen health care;
- builds capacity among health policy-makers and service providers;
- promotes scaling up of CBR;
- promotes strategies to ensure that people with disabilities are knowledgeable about their own health conditions and that health-care personnel support and protect the rights and dignity of persons with disabilities.

Key facts on Disability and health - June 2011

- Over a billion people, about 15% of the world's population, have some form of disability.
- Between 110 million and 190 million people have significant difficulties in functioning.
- Rates of disability are increasing due to population ageing and increases in chronic health conditions, among other causes.
- People with disabilities have less access to health care services and therefore experience unmet health care needs.

3. BACKGROUND AND RATIONALE TO THE STUDY

A cursory review of the literature by FXB India Suraksha reflected that while considerable attention was paid to the disabling effects of HIV/AIDS on previously healthy people, there was nearly no mention of the impact of the AIDS epidemic on people with a pre-existing disabling condition. Not only have there been few HIV/AIDS interventions for the disabled population, but also a rare evaluation of those few studies undertaken.

The United Nations Conventions on the Rights of Persons with Disabilities (CRPD) states that people with disabilities have an equal right to social protection and special measures may be needed to ensure that safety nets are inclusive of disabled people. For safety nets to be effective in protecting disabled people, many public programmes need to be in place, such as health, rehabilitation, education, training and environmental access. More research is needed to better understand what works in providing safety nets to people with disabilities and their households. (Grosh, Ninni, Ouerhi, 2008; Marriott, Gooding, 2007).

Too often, individuals with disability have not been included in HIV prevention and AIDS outreach efforts because it is assumed that they do seldom engage in high risk behavior and are at less risk of violence or rape and hence are at little or no risk for HIV infection. However, the Global Survey on Disability and HIV/AIDS conducted by Yale University and the World Bank states that individuals with disability have equal or greater exposure to all known risk factors for HIV infection and hence must be incorporated in HIV outreach efforts (2004). Further there is also an apprehension that providing persons with developmental disabilities with information about sex will increase their vulnerability. This fear creates a major barrier to their access to information about sexual health and HIV/AIDS prevention.

Whether born with a disability or disabled later in life, PWDs are as likely to be exposed to all known HIV/ AIDS risk factors as the population at large. Unfortunately since most PWDs are denied formal education complemented with the inadequate awareness of sexuality of PWDs; it deprives them of formal and informal education on sexual and reproductive health. This leaves the PWDs in a vulnerable state, ill-equipped to negotiate safer sex. The Global Survey on Disability and HIV/AIDS conducted by Yale University and the World Bank states that there have been few HIV/AIDS interventions targeting PWD and almost none of these interventions have been systematically monitored and evaluated Further, the few studies carried out in the past like the DFID study mainly focuses on adult with disabilities and the issues and problems of children with disabilities are completely left untouched.

The already uncertain future of a child orphaned by AIDS is further compounded if he or she has a disability. Caregivers are in charge of multiple orphans and often lack the effective parenting skills to cater to the needs of a disabled child places thereby posing them at a higher risk of being neglected and abused, thus putting them at a higher risk of contracting HIV.

Over four decades, the United Nations has made a strong commitment to the rights of persons with disabilities which has been reflected in the 1971 Declaration on the Rights of Persons with Mental Retardation and now has culminated in the 2006 Convention on the Rights of Persons with Disabilities.

Disabled children like other children have important rights under the UN Convention on the Rights of the Child. They have the right to services to make it possible for their families to look after them, while those without families have the rights to special protection and assistance irrespective of ethnic, religious, cultural and linguistic background. (Morris, 1999)

The 1989 UN Convention on the Rights of the Child (UN CRC) is the first binding instrument in international law to deal comprehensively with human rights of children and includes an article specifically concerned with rights of children with disabilities. The implementation of CRC is monitored and promoted at the international level by the Committee on the Rights of the Child. The article 23 of the CRC refers to the obligations of States parties and recognizes that a child with mental or physical disabilities is entitled to enjoy a full and decent life, in conditions to ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

The British Government attempted to implement the UN Convention on the Rights of Child by drafting the Children Act 1989 which echoes the rights contained in Article 23 by requiring local authorities to provide services designed

(a) To minimize the effect on disabled children within their area of their disabilities.; and

(b) To give such children the opportunities to lead life as normal as possible. (Children Act, 1989)

However, although this act reflects the medical model of disability, it is incompatible with a philosophy of social inclusion, including disabled children as full members of our societies and communities. (Morris, 1999)

Further, while the CRC provides a binding implementation framework with implications for law, policy and practice with respect to children with disabilities, 'The Standard Rules on Equalization of Opportunities for Persons with Disabilities' was adopted by the UN General Assembly in 1993, and provides detailed guidance on its exact actions. Unlike CRC which is legally binding for all the states that have ratified or acceded to it, the Standard rules express a political commitment on the part of the States to adapt society to individuals with functional impairment. The rules cover four areas mainly, preconditions for equal participation, target areas for equal participation, implementation measures and monitoring mechanism. In October 2006 the Office of the UN Special Rapporteur on Disability published the results of a Global Survey on the Implementation of the Standard Rules, conducted by the South-North Center for Dialogue and Development, based in Amman, Jordon. The study concluded that although some progress had been made in recognizing the rights of persons with disabilities, there are more good intentions worldwide that are not necessarily backed by strong political will.

Over the years although risk factors for individuals with mental illness have received more attention, research or programming for this population still lags significantly behind that available for the general population. (World Bank 2004)

According to the report by 'Interagency Coalition on AIDS and Development', 2008; there is a growing need for increased collaboration in programming between the groups who advocate for the rights of people with disabilities (PWDs) and those who are involved in HIV education, prevention, care and treatment. This is mainly because Disability teamed with poverty and discrimination can make it difficult for the population to access health care. Further, widespread social perceptions that PWDs contribute far less economically and socially to a society causes devaluation of the PWDs in the eyes of the health care providers, which in turn contributes to unwillingness on the part of the PWDs to seek health care and testing for HIV. Greater incidences of sexual violence and victimization against PWDs also place them at higher risk of HIV infection. (ICAD, 2008)

In 2004, the Global Survey conducted by the World Bank and the Yale Public School, argued that the lives of individuals with disabilities are no less valuable than the lives of all other citizens and unless individuals with disability are included in HIV/AIDS outreach efforts, efforts to slow the spread of virus or eliminate it will be unsuccessful. Hence the study results strongly argued in favor of inclusion of individuals with disability in HIV/AIDS outreach efforts.

Often outreach workers and organizers believe that the integration of people with disabilities into their programmes will be unattainably expensive. However, emerging scholarship disputes this assumption. (ICAD, 2008) Groci, Trasi and Yousafzi (2006) propose guidelines for inclusion on a continuum mindful of the limited finances available to most outreach programmes. The continuum is divided into three parts.

Part one proposes the general inclusion of people with disabilities in outreach programmmes as part of society at large. Part two explores the possibility of minor to moderate modifications to existing material and programmes in order to facilitate accessibility and inclusion. Part three involves the development of disability specific programming and materials with specific focus on harder to reach individuals. While these suggestions operate on an escalating cost scale, all should be within the reach of HIV and AIDS outreach organizations. However, Groci, Trasi and Yousafzi importantly pointed out that people with disabilities are a diverse group and hence only a combination of these different suggestions is likely to facilitate inclusion rather than sticking to any one of them.

Keeping in mind the real need to understand the issue of HIV/AIDS among disabled people, and in particular among children, in India and to design and implement programs and policy in a more coherent and comprehensive manner, FXB India Suraksha was commissioned by CBM SARO (NORTH) to conduct a survey on the issue of Disability and HIV AIDS to understand and generate the baseline data about risks and vulnerabilities faced by the disabled population with special reference to the children. The two issues that this study would focus on includes, firstly, the impact and implications of AIDS epidemic on people with a pre-existing disabling condition and secondly, the disabling effects of HIV on previously healthy people .

4. RESEARCH METHODOLOGY

The present study exercised exploratory research design with survey method using predesigned study tools which were administered through partner NGOs working with CBM SARO (NORTH) across 8 selected states in India. Substantial proportion of primary research was carried out through direct semi-structured interviews with PWDs, key informant interviews with Program Managers, Research Directors, Project Coordinators and State and District officials from different stakeholders e.g. NGO, SACS, Special Educators in schools across 8 states covering 389 primary respondents distributed among 5 categories of disabilities (separate 20 samples in Delhi/NCR). While secondary research was conducted to explore existing interventions on Disability and HIV/AIDS, available knowledge resources , and existing integrated social welfare and public health services delivery mechanisms for Person with Disabilities. This study envisaged to provide directions to incorporate integrated approach in relevant child related and HIV/AIDS program and policies. The main ***objective*** of this study is to assess the current gap in knowledge, policy and practice that exists in terms of the linkages between HIV and disability.

In collaboration and consultation with the CBM SARO team, the following Research Questions were explored in the study

1. What is the current prevalence of HIV among people with disability?
2. Do people with disability have easy and customized access to information related to HIV?
3. Are people with specific disabilities more vulnerable to HIV/AIDS?
4. what kind of communication strategy on HIV/AIDS will works best to reach out to people with disability?

The ***main outcomes*** of this study would be:

- Assessment of gap in policy, programme and knowledge in the linkages between HIV and disability.
- Snapshots of the scale of incidence of HIV and disability
- Current level of awareness about HIV/AIDS among the disabled and level of awareness about disability among the HIV/AIDS infected.

- Different types of services in place and the vulnerabilities of the disabled to get infected with HIV/AIDS.

Definition of target group under study

Based on consultative discussion with CBM SARO (N) the target groups under were classified in five groups to be covered under the study.

Types of Disable persons under study

1) **Visual Disability**: Blindness refers to a condition where a person suffers from any of the condition like total absence of sight or partial. In this study we will cover only those who are completely blind.

2) **Speech Disability**: The impairment of speech articulation, voice, fluency, or the impairment language comprehension and/oral expression or the impairment of the use of a spoken or other symbol system. Here we will cover only those people who are not able to speak.

3) **Hearing Disability:** Means deafness with hearing impairment of 70 decibels and above in the better ear or total loss of hearing in both ears. We will cover those persons who have loss of hearing in both ears.

4) **Locomotors Disability:** Means a person's inability to execute distinctive activities associated with moving, both he/she and objects, from place to place, and such inability resulting from affliction of either bones, joints, muscles or nerves.

5) **Mental Disability:** Means a condition of arrested or incomplete development of mind of a person which is specially characterized by sub–normality of intelligence.

The entire respondents were categorized according to the above sub categories.. For doing this, WHO guidelines were also referred in addition to consulting CBM SARO. The WHO guidelines were also referred to classify respondents' age group who could participate and respond to this survey. As per the recommended WHO guidelines, for the purpose of this study respondents from age group 13 years to 60 years were taken as respondents to the survey. As per the WHO specification on research ethics, consent of respondents are important. Keeping this in mind children with disabilities above or equal to 13 years were only reached out.

Geographical Area for Study

The states were selected based on high prevalence of HIV and high incidence rate of disable persons and where CBM SARO has existing implementing partners. Based on secondary data review and in consultation with CBM (SARO) the following states were covered under the study.

HIV High Prevalent State: Manipur, Mizoram and Andhra Pradesh based on (National AIDS Control Organization HIV Sentinel Surveillance data in India in 2003-2006, MoHFW 2007).

State with High incidence rate of Disability (and has CBM partners): Uttar Pradesh, Jharkhand, Gujarat, Madhya Pradesh, Delhi / NCR.

Table 1 :Quick snapshots of the fitting of the above criteria is described below

Name of State	HIV High Prevalent State (NACO, MoHFW 2007)	State with High incidence rate of Disability	Urban – Rural (Program Intervention specific)	Community – Institutional (Client outreach perspective)
Jharkhand		✓	Rural	Community
Gujarat		✓	Urban	Institutional
Manipur	✓		Urban	Community
Andhra Pradesh	✓		Urban / Semi-urban	Community
Mizoram	✓		Urban	Community
Madhya Pradesh		✓	Rural	Institutional
Uttar Pradesh		✓	Urban	Institutional
Delhi / NCR		✓	Urban	Institutional

Methodology

The study is a mix of both quantitative and qualitative in nature and included the following method:

- Desk review of existing policies and programs of relevant Ministries, UN mandates, WHO guidelines
- Collection and compilation of secondary information on incidence of HIV/AIDS in people with disability
- At least 1-2 Focus Group Discussions with the disabled persons conducted in each state
- In-depth interviews with the Key Informants (KI) i.e. NGOs representatives working on HIV, Disability, Government officials involved in planning at district/state on disability issues, service providers like Hospitals, Schools and committed development professional working in special schools catering Blind, Deaf and Autistic population etc.

Sampling

Two stage sampling method have been adopted for the survey;

1. **Purposive Sampling**: - The selection of states has been made purposively according to high HIV prevalence of HIV as per NACO data and high incidence rate of Disability where CBM SARO has existing implementing partners.
2. **Representative Sampling**: - In each state approximate 50 people with disability have been selected on random basis and randomly 10 persons from each category of disabled persons elected for data collection.

Tool and Techniques

i. Semi-structured questionnaire: A sample of 389 PWDs (20 separate samples from Delhi) across 8 states has been selected with the help of local NGOs and CBM partners. An interview conducted along the semi structured questionnaire by field investigators among randomly selected samples from each 5 category of disables as mentioned above state wise.

ii. Focus Group Discussion (FGD): A homogenous group of minimum 8 to 10 disable persons have been selected randomly with the help of a local NGO and CBM partners for FGD with PWDs in different location, time duration of each FGD were around 60 minutes. The FGD will be facilitated by two research team members. A total of 20 FGDs were conducted among PWDs, NGOs working with PWDs and HIV affected population.

iii. In-depth Interviews with Key Informants (KII): A total of 10 In-depth interviews have been conducted with the key informants of local NGOs Managers, Government Officials and service providers like Hospitals and special schools to know their perception related to the services for Disable persons focusing on HIV/AIDS.

Analysis Tool and method

The following tools were used for the study analysis. A Written consent has been taken for all Semi-structured interviews, FGDs, KIIs and Group discussions. In order to ascertain answer to the research questions (refer methodology section), specific research tools were designed which includes semi-structured questionnaires for one-to-one interview conducted on frontline personnel of the organizations studies, Focus Group Discussion checklist for PWDs, staffs of disability and HIV organizations to assess subjective information on this issue of disability and HIV, In-depth interviews for of key informants were done with selected NGO Program Managers, SACS officials, Special Educators, Policy implementers.

Qualitative Data Analysis – Qualitative data was collected by FGD, KII and Group discussion, Case Study.

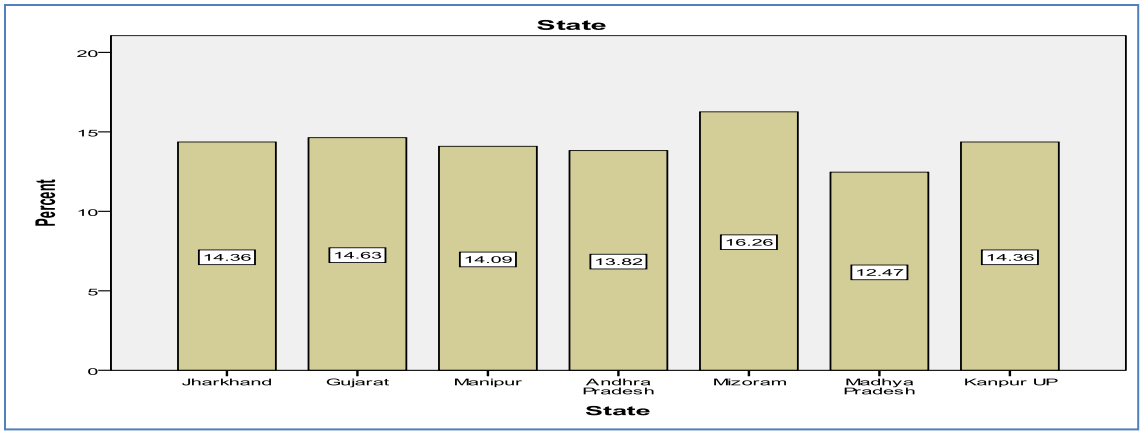
Quantitative data analysis was done using SPSS.19 for 369 samples across 7 states and MS-Excel analysis for specific 20 respondents from Delhi/NCR. Delhi interpreted separately and documented as case study. Both the quantitative and qualitative data are then analysed together for interpretation and report writing.

- **DEMOGRAPHICS: DEMOGRAPHICS PROFILE – GEOGRAPHIC SAMPLE DISTRIBUTION, SAMPLE CHARECTERISTICS**

Majority of the respondents belong to PWDs (369 individuals from 7 states, 20 PWDs from Delhi studying in special schools). Among the classified age group category from 13 to 60 years, visually and hearing impaired PWDs were only indirectly supported by their care givers for answering response as needed. In the following sections research findings are narrated on 369 analyzed samples along with qualitative information obtained through other sources of information. Rest of 20 sub-samples from Delhi/NCR are coded and analyzed in a case study mode explaining special schools' program interventions. In the following section, demographics profile – geographic sample distribution, sample characteristics are narrated to explain background and study outreach among the PWDs. The major responses are ascertained using quantitative data analysis which was further justified incorporating qualitative responses in all sections. Major proportion of qualitative responses is narrated in later part of study to specify Knowledge Attitude Practices (KAP) gap.

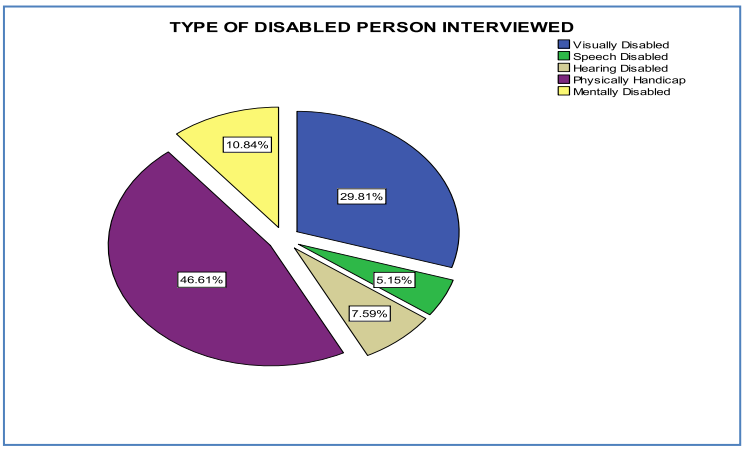
5.1 GEOGRAPHIC DISTRIBUTION

The geographic coverage for study is based on predefined inclusion and exclusion criteria suggested by CBM SARO. This includes CBM supported intervention sites, FXB India Suraksha's program operation and NACO classification of HIV high prevalent states and available information of high rate of resident disabled population. During this survey among 8 states, respondents were identified and surveyed in almost equal proportion from 7 states of Jharkhand (14.36%), Gujarat (14.36%), Manipur (14.09%), Andhra Pradesh (13.82%), Mizoram at highest (16.82%), Madhya Pradesh being lowest coverage (12.47%), Uttar Pradesh Kanpur (14.39%). In MP study area was in remote tribal coal mines area and due to seasonal migration, the study team could meet only limited number of respondents. The Delhi/NCR sample was separately analyzed as the target population belonged from specialized institutional care with very specific disabilities of Blind, Deaf and Autistic population. In Delhi total 20 samples interviewed along with FGDs and KIIs with disabled population and NGO staffs were carried out.



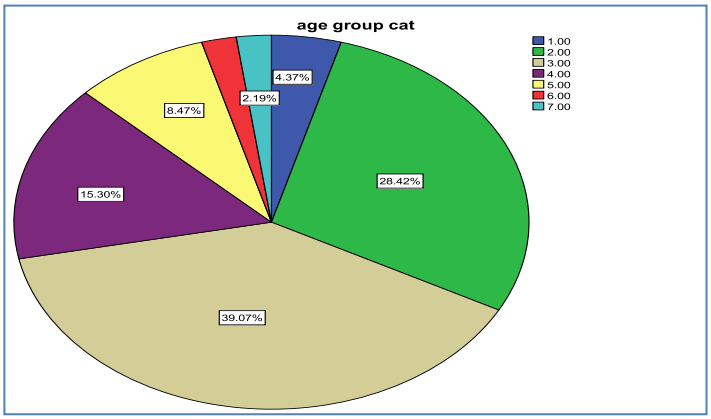
5.2 SAMPLE - SPECIFIC IMPAIRMENTS:

According to predefined criteria, 5 categories of disability were studied and responses documented from 7 states in addition to Delhi/NCR. Among these category, physical/locomotors disabled ranked highest (46.61%) followed by visually disabled (29.81%) and others respectively mentally disabled (10.84%), hearing disabled (7.59%), speech disabled (5.15%). In Delhi/NCR total 20 cases interviewed which includes visual, deaf and autistic population.



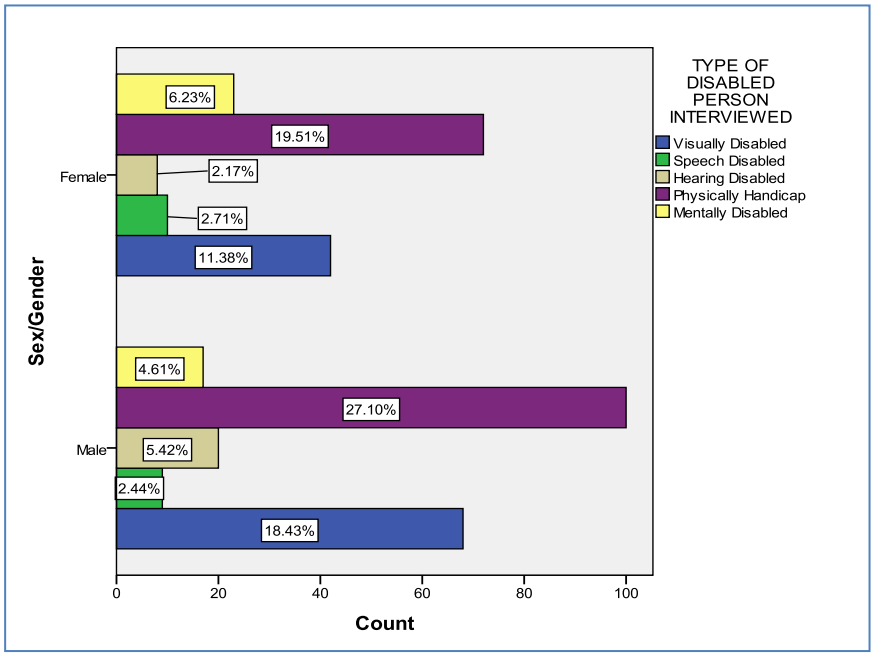
5.3 AGE GROUP CATEGORY

The entire study population covering 7 states were grouped and represented (refer research methodology) in different age Group Category. The respondents were categorized as < or equal to 13 years (Code 1),14-20 years (Code 2), 21-30 years (Code 3), 31-40 years (Code 4), 41-50 years (Code 5), 51-60 years (Code 6), < or equal to 60 years (Code 7). Among these category, highest proportion of the respondents were in the 21-30 years category representing youth group in reproductive age (code 3, 39.07%) followed by second highest in 14-20 years (code 2, 28.42%), while other are 31-40 years (code 4, 15.03%), 41-50 years (code 5, 8.47%), < or equal to 13 years represents early adolescent age (code 1, 4.37%), 51-60 years (code 6) and < or equal to 60 years (code 7) equally shares 2.19% represent geriatric age as lowest proportion of total respondents. In Delhi/NCR, entire respondents fall in 14-20 years (code 2), 21-30 years (code 3) represent entire adolescent and early reproductive age. This study established certain fact on issues of disability and HIV directly obtained from early adolescent age group category. Direct interview of children below the said age group had limitation in getting responses due to the topic of the study. However, efforts were made to understand risk and vulnerability related to HIV among children through interviewing their care givers and parents.



5.4 SEX/GENDER:

Efforts were made to select the respondents to ensure equal gender representaation in responses. Almost equal no of male and female respondents were included in the survey as depicted below across different types of disability..



5.5 URBAN-RURAL:

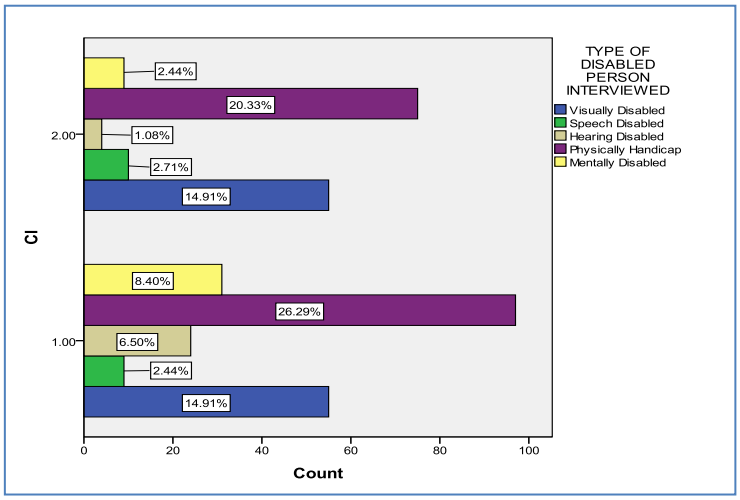
The study attempted to cover insights from both urban and rural program intervention sites. Thus primary data from 7 states were grouped in urban and rural sub category represented as U=Urban coded as (1) and R=Rural coded as (2). Among entire respondents of 7 states, physically disabled represented highest proportion in urban (31.44%) and rural (15.18%) while others were visually disabled in urban (24.66%) and rural (5.15%), mentally disabled in urban (8.40%) and rural (2.44%), hearing disabled in urban (4.61%) and rural (2.98%) and speech disabled in urban (4.07%) and rural (1.08%). In Delhi/NCR entire 20 (100%) respondents represented urban category studying in special schools.

5.6 COMMUNITY - INSTITUTIONAL:

The study also attempted to cover insights from different type of organizations. Two types of organizations were studies- some which are providing institutional delivery services and others that are community based. Primary data from 7 states were grouped in community and institutional sub category represented as C= Community coded as (1),

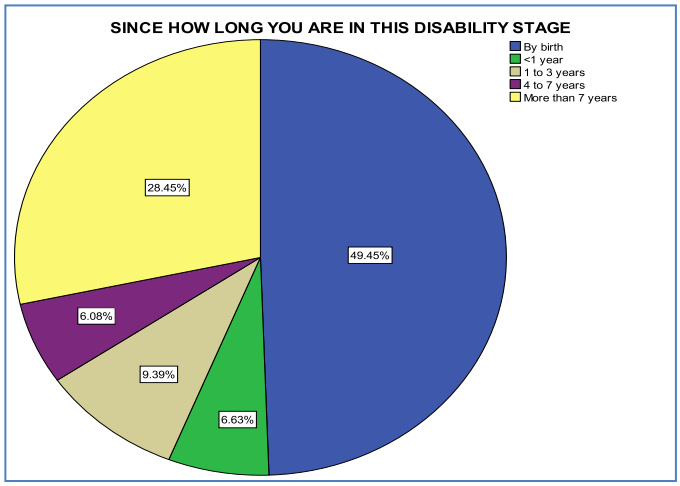
I=Institution coded as (2). These observations were to document difference in knowledge, attitude and practices under different set up. Majority of respondents fall in physically disabled category were from community (26.29%) and institutional (20.33%) and visually disabled represent equally in community and institutional (14.91%). While others fall in mentally disabled in community (8.40%) and institutional (2.44%), hearing disabled in community (6.50%) and institutional

(1.08%), speech disabled in community (2.44%) and institutional (2.71%). All the Delhi/NCR samples were from institutional set up.



5.7 STAGES OF DISABILITY

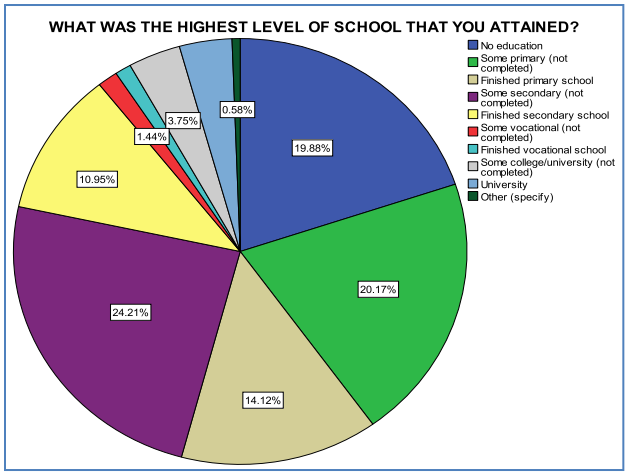
Respondents were also selected from different stages of disability. Majority of the respondents were from the ‘ By birth’ disability (49.45%) followed by more than 7 years disability in life span (28.45%). Less than 1 year of disabilitywere6.93%, 9.39% recorded 1 to 3 years of disability in life span and 6.08% recorded 4 to 7 years of disability in life span. In Delhi/NCR, respondent in blind, deaf and autistic category had by birth disability. By birth disability for majority of respondents depicted critical condition of social, physical and behavioral vulnerability in accessing health care services and social security schemes.

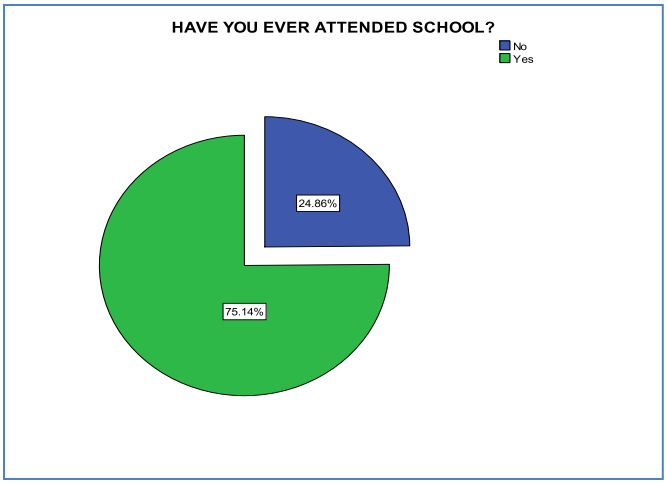


5.8 SCHOOL EDUCATION:

School Education is the second most important social institution where growing children are taught on various kinds of social norms, human behavior in addition to knowledge for education. Education helps develop strong personality traits for better decision making skill. Among the study population, 75.14% of respondents attended school and 24. 86% of respondents did not attend school. In-depth observation depicted 24.21% attended secondary (not complemented) as highest level of schooling at their early

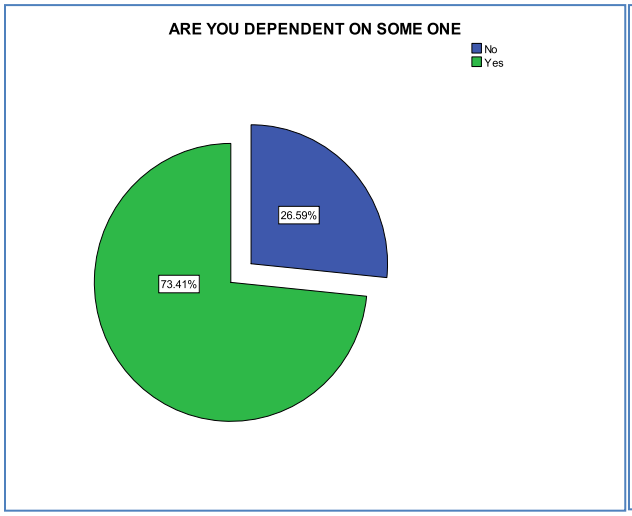
adolescent age, followed by 20.17% who attended primary school (not completed) while 14.12% finished primary school, 10.95% finished secondary school education. Interestingly 19.88% dropped out of school and have had no formal education. Very meager proportion of respondents comprised of attendees in vocational training courses, some finished or unfinished university education. In Delhi/NCR, majority of respondents attended school and completed secondary education and engaged in vocational course training for job.

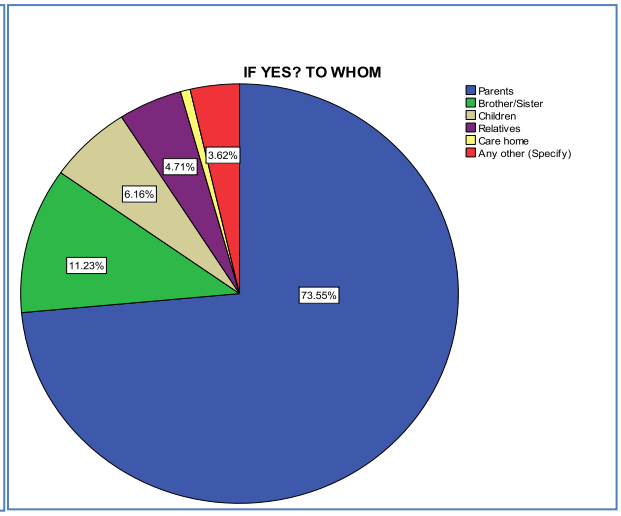




5.9 DEPEDNDENT ON CARE GIVERS:

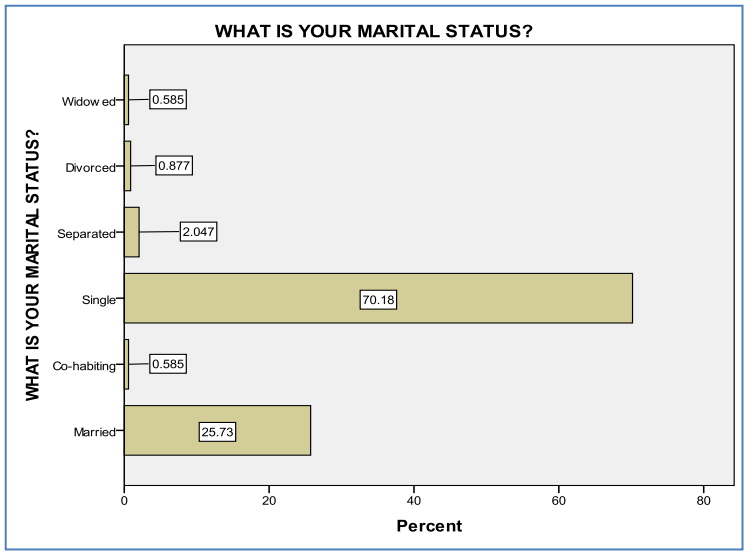
Since family is the first social institution for a growing child, it is expected that family provides them a sense of security and comfort. . In this study 73.41% of total respondents expressed their dependency on someone in the family and rest of 26.59% were either self dependant or not dependent on others. Among the dependents' category, majority mentioned that they were dependent on their parents (73.55%), 11.23% dependent on brother/sister, 6.16% dependent on their children and 4.71% dependent on relatives and 3.62% on care home others.





5.10 MARITAL STATUS and OFFSPRINGS:

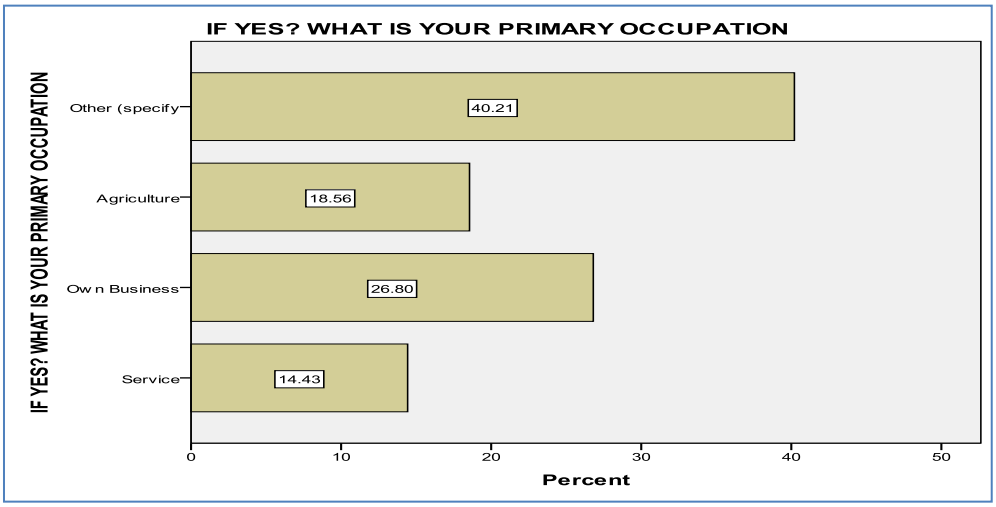
Marital status and having a child doubles the social responsibility for disabled population. Under this study, 70.18% reported to be single, while only 25.73% were married and others belong to separated (2.05%), divorced (0.88%), co-habiting and widowed (0.56%). Among the married category 54% had children and 46% had no children. Among them, majority had 2 children (38.0%), single child (23.9%) and 3 children (19.6%) in their family.



In Delhi/NCR, all were single and studying in vocational school but they fairly interact in heterogeneous group other than their family.

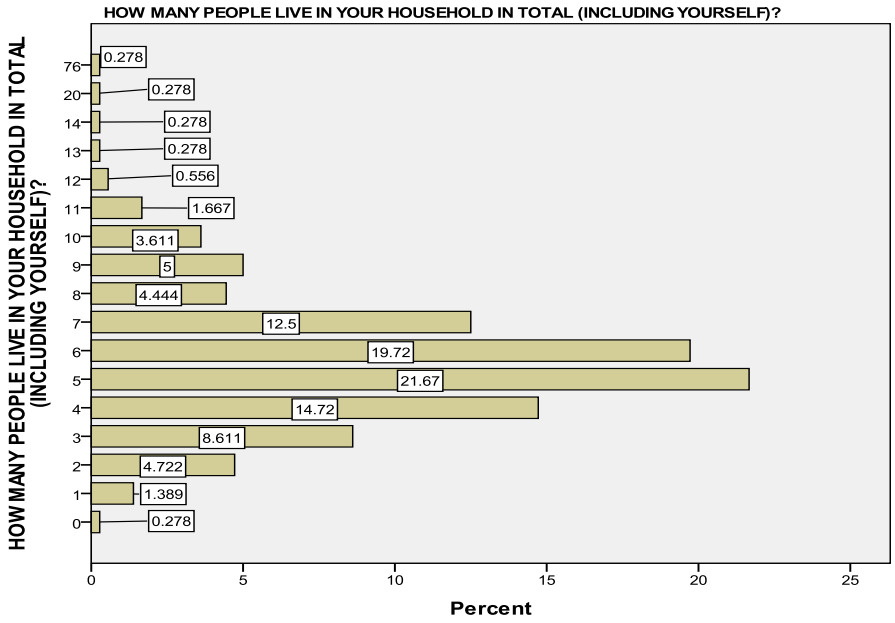
5.11 OCCUPATION AND EMPLOYMENT:

Occupation and employment ensures better economic stability to survive in society. It is quite detrimental fact that disabled people literally struggle to compete able bodied person on this ever changing world. In this study, it was observed that the employment status of disabled determines their health seeking behavior. Among the total respondents, 73% were unemployed and 30% were employed. While in detail, those who were employed were engaged in primary occupations like agriculture (18.56%), own business (26.80%), service (14.43%) and many had other sources of income (40.21%).



5.12 HOUSEHOLD INCOME STATUS and INHABITANTS:

Being employed determines the capacity to earn reasonable income and strengthens the ability to provide for basic needs of the household. In this study,, majority of the respondents who were engaged in some occupation or the other earned annually up to INR 50000 (80.5%), INR 50001 to 100000 (11.3%), INR 100001 to 150000 (2.6%) and INR 150001 to 200000 (4.1%) and only 2.0% could earn above INR 200000. While the number of household members varies, majority of households reported total of 5 members (21.67%), 6 members (19.72%), 4 members (14.72%) and 7 members (12.5%).



➢ RESEARCH FINDINGS

In the global context, the draft policy brief on HIV/AIDS and disability from UNAIDS, the World Health Organization, and the Office of the High Commission for Human Rights discusses actions urgently needed to increase the participation of PWDs in the HIV/AIDS response. These actions include ensuring PWDs have access to HIV services which are both tailored to their diverse needs and are equal to the services available to others in the community. In order to advance disability issues within the UN system, the United Nations established the UN Inter-Agency Support Group (IASG) for the CRPD on the Rights of PWDs in 2007. The IASG supports State Parties within a framework of coordinated planning, and links to activities of other UN bodies such as UNAIDS. The IASG will work to raise awareness of the CRPD and its implications for advancing the rights of disabled persons, implement the CRPD, and providing training and capacity-building for using the CRPD. This has further conceptualized to promote the use of a disability lens to review current HIV/AIDS research, policies and programmes. Consequently this has envisaged having an immediate next step for organizations and networks to apply a disability lens to their HIV/AIDS work. Organizations or networks could assess the current level of activity and investment, and could identify next steps to improve inclusion of PWDs. The study team conducted interviews with relevant practitioners and policy makers from both the sector at national and state levels to understand the current practice of integrating HIV AIDS in the disability sector reflects the following:

- **HIV AIDS work does not specifically targets PWD as a separate category**

There are several national level technical research documented by NACO at regular interval viz. HIV Sentinel Surveillance study (2006), Behavior Surveillance Study (2006), HIV Fact Sheet and NACO-NACP III Annual Reports etc. But these fact sheets focuses on overall general population (including ANC mothers) and high risk group (FSW, MSM, TG, IDU, Truckers and Migrants) population only. In addition, National Family Health Survey 3 (2005-06) is focused on general population covering multiple socio-demographic, MCH and socio-economic indicators which doesn't include PWDs as a separate category of response. Therefore there seems to be a general inclination of including

- **Inadequate technical expertise on HIV AIDS amongst NGOs working for PWD to incorporate HIV AIDS in their priority program**

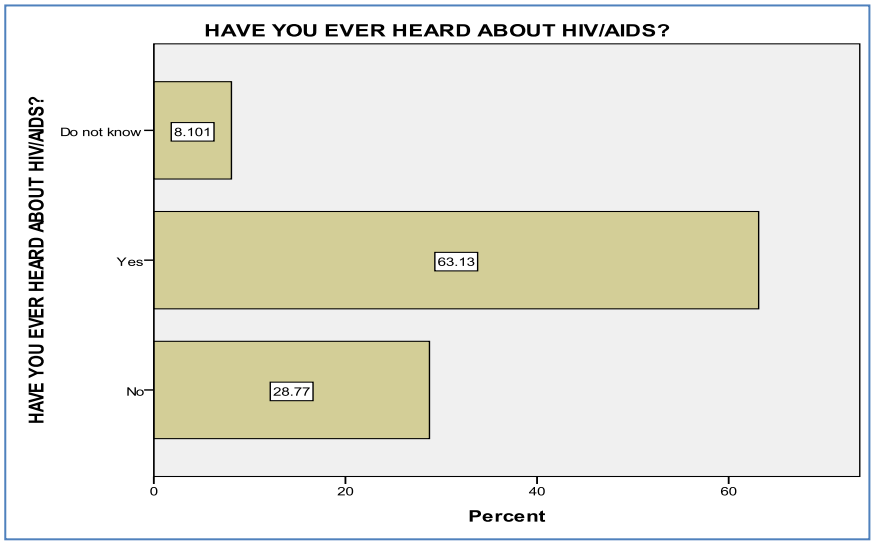
Individual Interviews and Key Informant Interviews were held with staff members of the NGO partners of CBM to understand their perception and practice on the study topic. Based on these discussions, it it appears that NGOs who are currently partners of CBM SARO (and were included in this study) are not executing any specific programs targeted at incorporating HIV/AIDS awareness generation among PWDs. Some staff of few NGO partners mentioned that they had explored options of incorporating HIV/AIDS specific services for PWDs but the program could not be conceptualized and implemented due to lack of technical competence on HIV AIDS amongst the staff members . A few NGOs mentioned that they had conducted brief and basic HIV/AIDS awareness program for the PWDs using user friendly language.. Examining this fact in detail and when discussed with the care givers and guardians of PWDs, they expressed that they do expect disability organizations to extend support for not only generic health care but also HIV/AIDS knowledge, sex education and Adolescent Sexual Reproductive and Sexual Health (ARSH) issues. Certain segment of policy makers and program experts of these organizations believe that, addressing issues of 'sexuality and HIV/AIDS' together could lead to obstacle for catering services to PWDs that might proliferate in-depth curiosity among PWDs for which organization will have to answer to their care givers. However, majority of the organizations stressed on the importance of introducing HIV/AIDS and ARSH as key area for this vulnerable group. They primarily emphasized the need for developing client friendly audio visual Information, Education and Communication (IEC) material in local brail and sign languages and other Inter Personal Communication (IPC) tools for assessing vulnerable and high risk behavior among PWDs. One of the strong findings of the study is the need to address this existing gap of lack of disability friendly communication strategy and related HIV/AIDS care and support programs for this special group who is vulnerable to HIV AIDS. This was clearly expressed by majority of the disability and HIV organization who proposed to include 'Disability and HIV' as part of mainstream mass awareness program

The study has explicitly explored issues related to potential of intersectionality of disability with HIV/AIDS with critical examination among the children and vulnerable age group with PWDs. Few interesting facts emerged contrary to popular belief about sexual needs of PWDs. It is interesting to note that, PWDs so often are perceived as 'asexual' by the general population, but in true sense they are equally active and have normal sexual desires. Social discrimination, taboos and misconception exist among the PWDs and to some extent among their care givers. General population usually treats PWDs as 'weaker section' for which they are socially secluded. In depth observation generate some interesting snapshots that, PWDs of both male and female category are equally attracted to both the heterogeneous and homogeneous social groups and explore opportunities to indulge in sexual fantasy. It was explored

that, there are high risk behavior predominant among them as they are occasional visitor to Female Sex Workers, are often engaged into extra martial affairs in community with friends and relatives, and often show homosexual tendencies. . The trend was found more in a community setting rather than in an institutional setup. Initially sexual fantasy urges them to explore essence of being in intimate relationship but later they indulge into abusing and high risk behavior. At rural community PWDs are more dependent on their friends and relatives to have sexual pleasure and in maximum cases they don't use condom during sexual intercourse. Unavailability of female partners was also reported as key reason why they choose to enter into homosexual relationship. These conditions enabling high risk behavior makes it all the more important that information and awareness on prevention of HIV AIDS be imparted to the. It is observed there were identified and unidentified HIV reactive (positive) cases exist in NACO classified HIV high prevalent states where this research survey were implemented. PLHIV-PWDs were only able to access ART treatment but ICTC outreach was reported to be inadequate.

Practitioners in disability domain believe that all categories of disabilities are equally important to be vulnerable to disabilities. However, in the case of multiple disabilities e.g. autistic spectrum disorder (ASD) with mentally disabled and hearing with speech disabled and visual with mentally disabled are more exposed to greater risk and vulnerability. Among these special categories of disability, the role of the care givers are important. They could play an important role in safeguarding or preventing high risks and creating an enabling environment where PWDs feel comfortable to share and access information.

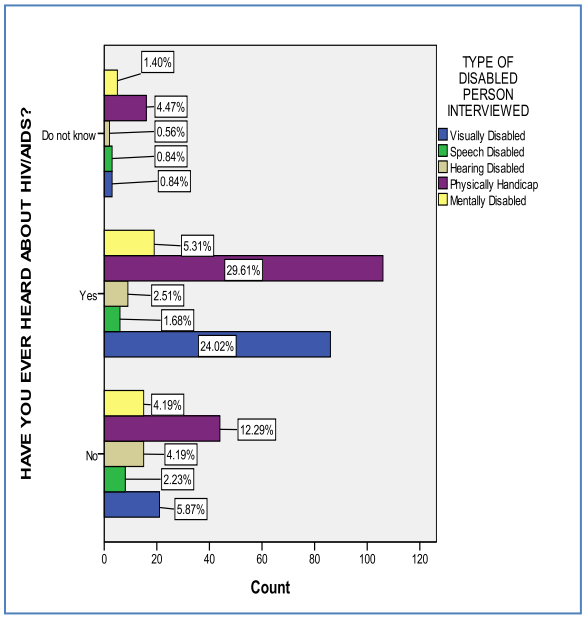
- **AWARENESS ABOUT HIV/AIDS AMONG PEOPLE WITH DISABILITY**

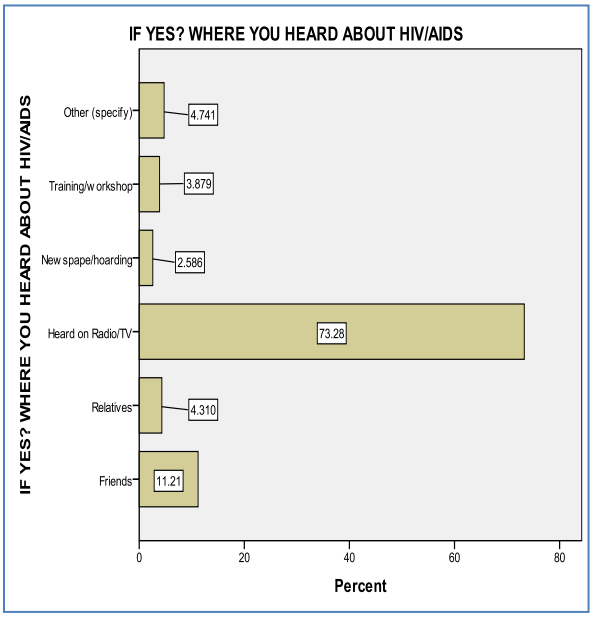


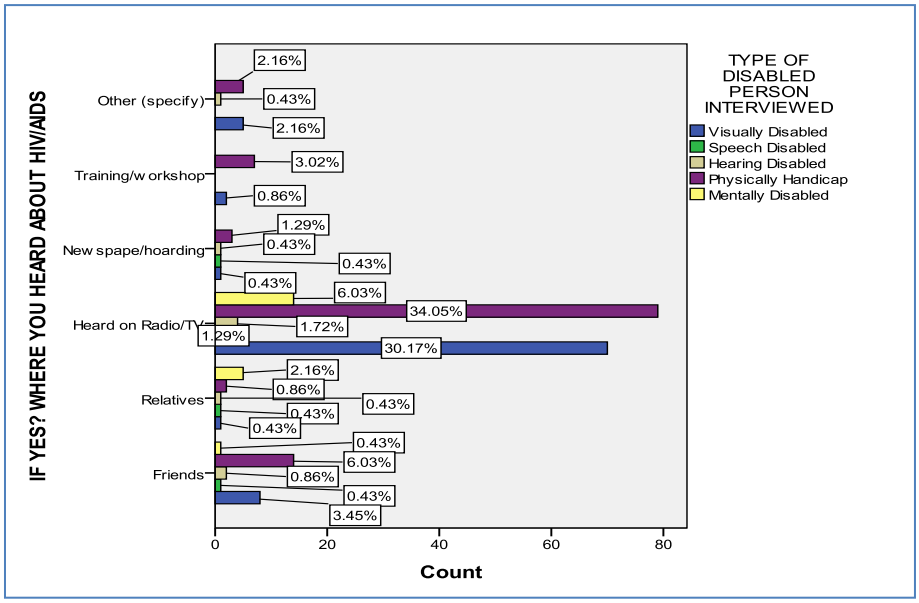
According to NACO-BSS 2006 study report, awareness of HIV/AIDS has significantly increased over the years (BSS 2001 - 67%, BSS 2006 - 80%). The proportion of respondents aware of HIV/AIDS was significantly higher in urban (92%) areas and among male (87%) respondents.. Except for Bihar (47%), in all other states more than 60 percent of the respondents had heard of HIV/AIDS. The awareness level was more than 90 percent in some of the northern states – Delhi, all north eastern states, southern states (Andhra Pradesh, Tamil Nadu and Puducherry, Kerala and Lakshadweep) and western states (Maharashtra, Goa and Daman and Diu) where the literacy level as well as the media exposure of the respondents was also quite high. There was a small but significant decline in the level of awareness about HIV/AIDS across all sub samples (rural-urban and male-female) in the states of Punjab and Jammu and Kashmir. The male as well as female respondents in both rural and urban areas were more familiar with the terminology "AIDS" (80%) than "HIV" (64%).

This was reflected in our study where of the 369 PWD respondents 63.13% mentioned that they have heard about HIV/AIDS, while 28.77% replied no and 8.1% do not know and unaware of this term. In-

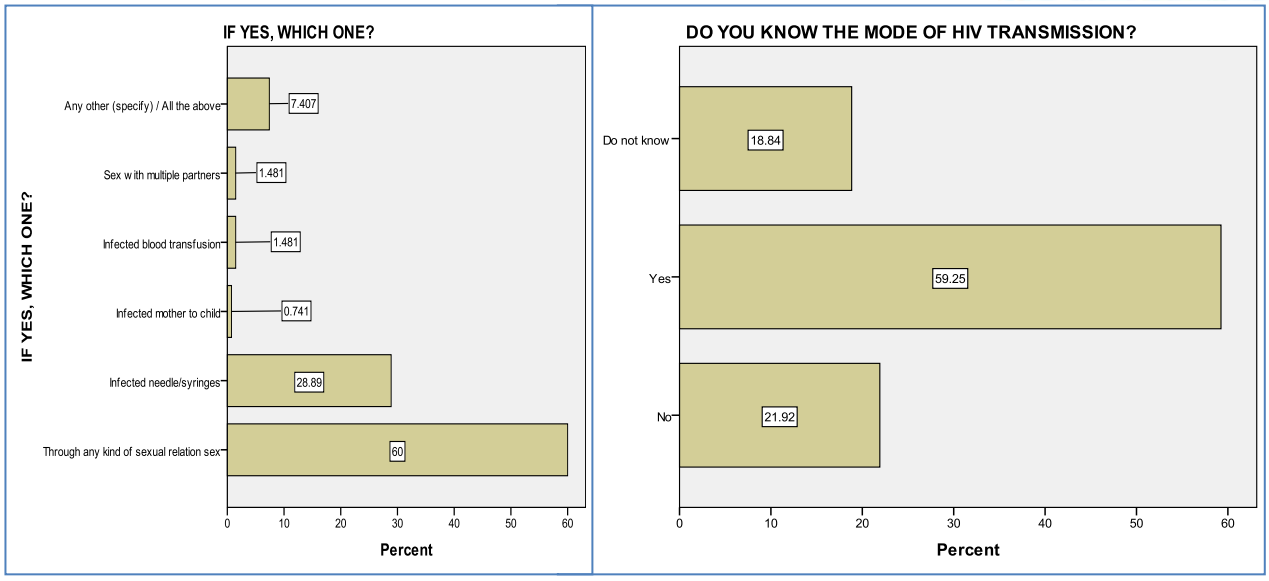
depth assessment showed that that the level of awareness is highest among those who are physically disabled (29.61%) and speech disabled had lowest level of awareness (1.68%). Majority of respondents about 73.28% have heard about HIV/AIDD on Radio and Television programs as these are only means to access public of communication. There is a clear need to develop different communication strategy to reach out to those from the special categories of disability mental, hearing and speech disabled who cannot access general source of information like TV, newspaper or Radio.





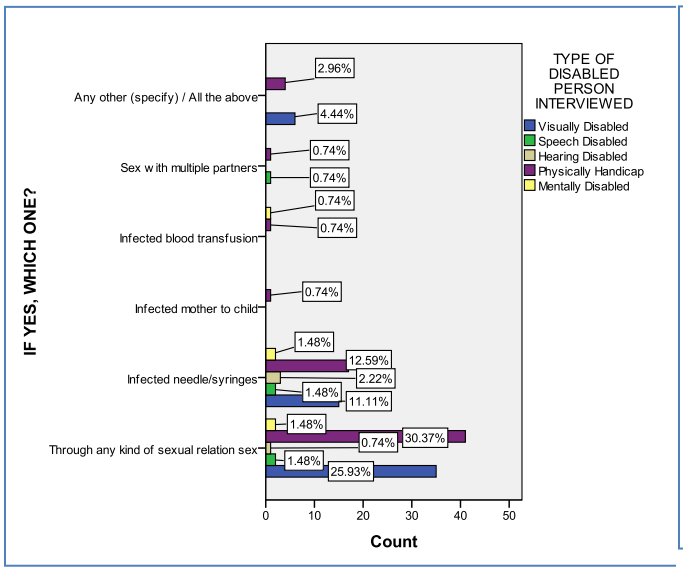


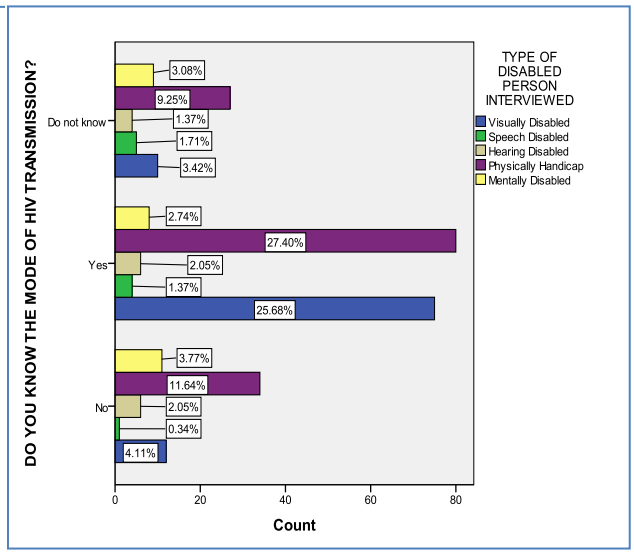
- **ACCESS TO INFORMATION AMONG PEOPLE WITH DISABILITY**



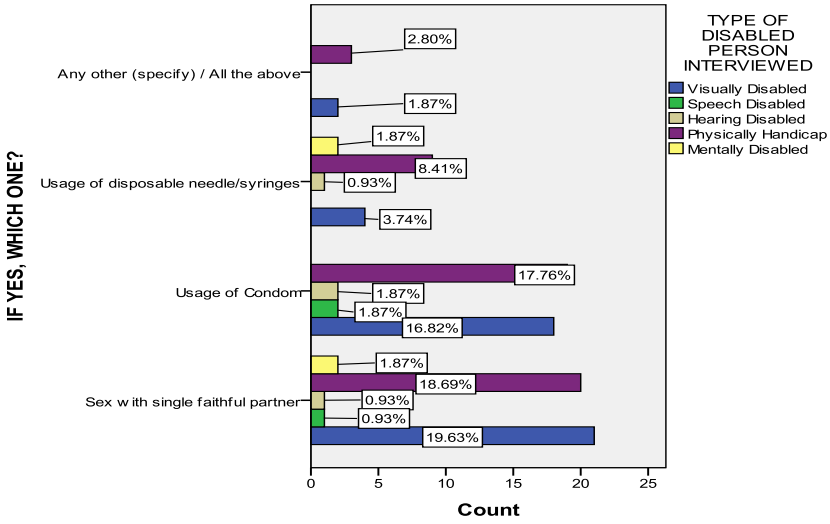
In National Family Health Survey 3 (NFHS 3, 2005-06) knowledge of HIV/AIDS among ever-married adults (of age 15-49), Women who have heard of AIDS were 57.0% of total population and among them 80.7% were in urban and 46.4% were from rural. Men who have heard of AIDS were 80.0% of total population and among them 94.2% were in urban and 73.0% from rural resident. NACO BSS 2006 study represents nearly three-fourths of the respondents in BSS 2006 were aware that sexual contact could lead to HIV/AIDS. This proportion has increased significantly since BSS 2001 (62%). Nine out of ten respondents in urban areas as against seven out of ten in the rural areas were aware of this aspect. Across both rural and urban areas, the awareness of HIV transmission through sexual contact was significantly higher in males (89% in urban and 78% in rural) as compared to females (82% in urban and 60% in rural). Four out of every five respondents reported that HIV/AIDS could be transmitted by infected blood during transmission, which was a significant increase from BSS 2001 proportion (three out of five). The awareness in the rural (71%) areas was significantly lower than the urban (88%) areas. The awareness was poorest in Bihar (44%) followed by Madhya Pradesh (59%). The proportion of respondents aware of two important methods of prevention of transmission i.e. consistent condom use and sexual relationships with faithful and uninfected partners has significantly increased from 39 percent in BSS 2001 to 57 percent in BSS 2006. There existed significant gender (male 67%, female 16%) and rural-urban (urban 65%, rural 49%) differences in this regard. The awareness level was very low in Sikkim (37%), West Bengal and Andaman and Nicobar Islands (37%), Bihar (40%), Karnataka (41%), Orissa (45%) and Madhya Pradesh (53%).

Among the study group under this study, 59.25% replied ‘yes’ they knew mode of HIV transmission but 21.92% said ‘no’ and 18.84% replied they ‘don’t know’ the mode of HIV transmission. 60% of respondents mentioned sex as main mode of HIV transmission and 28.89% mentioned infected needles/syringes as second most highest mode of HIV transmission. Again, physically and visually disabled categories were found to be more aware of sexual contact and use of infected syringes as major route of HIV transmission.

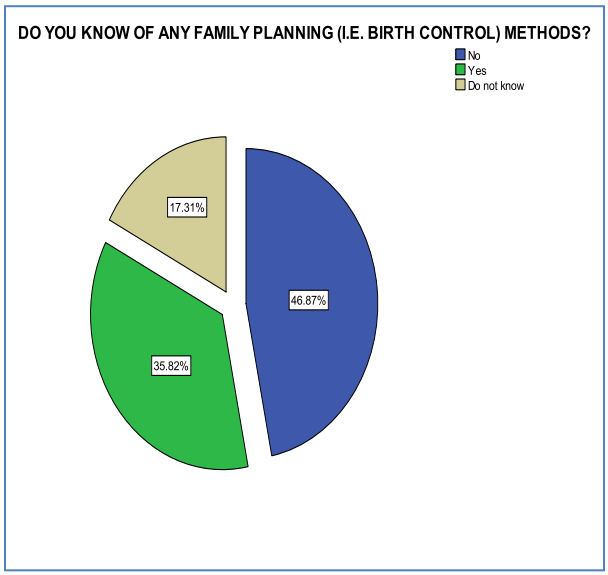


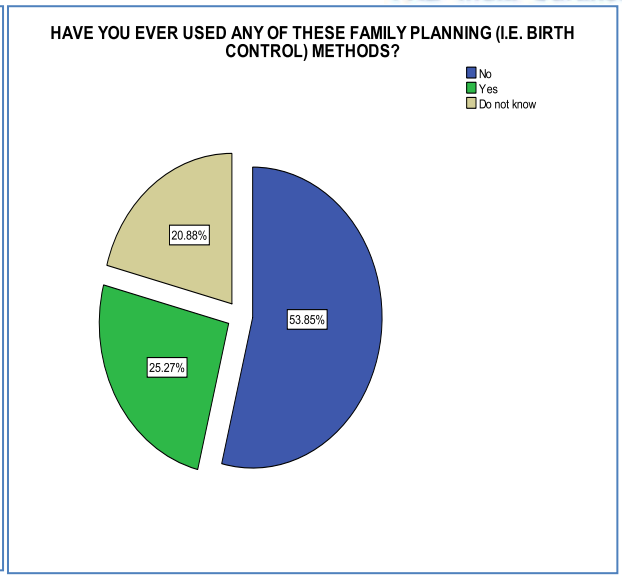


Regarding knowledge on method of HIV prevention, respondents mostly replied sex with faithful partners; consistent condom usage and regular use of disposable syringes are the best choice. But interestingly, there were huge gap in individual knowledge amongst the respondents from the special category of disabled



Certain segment of this study population was married and had children and a few others had personal relationship. Our survey revealed that only 36.82% of respondents 'knew' of any family planning methods while 46.87% replied 'no' and 17.31% were not aware of such method. In contrast, those who ever knew of any family planning methods, only 25.27% ever used any of family planning method and 53.85% didn't use and rests of 20.88% were unaware of family planning method.

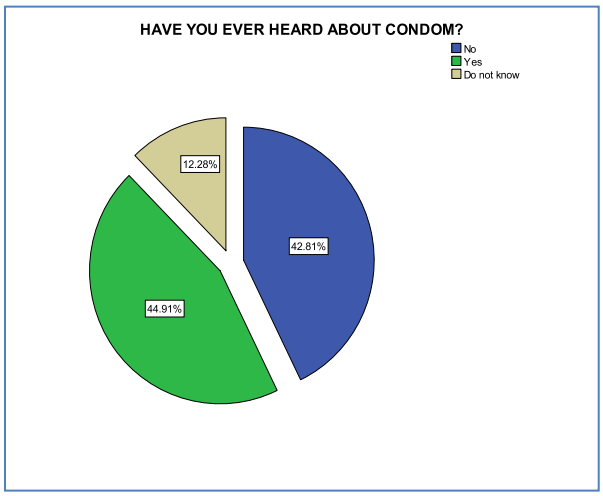


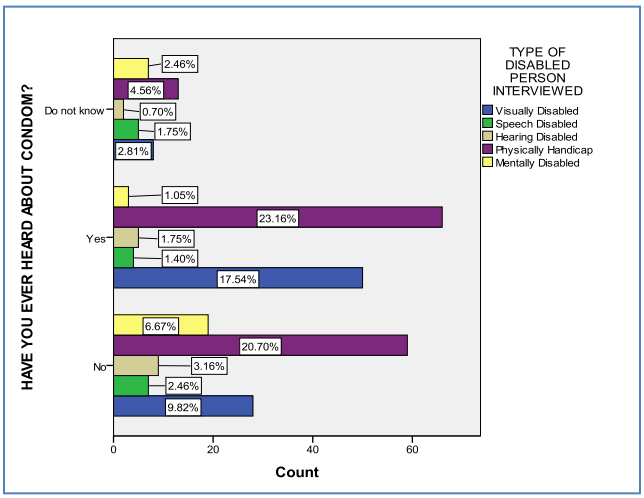


- **AWARENESS AND ACCESS TO CONDOM AND CONDOM USAGE**

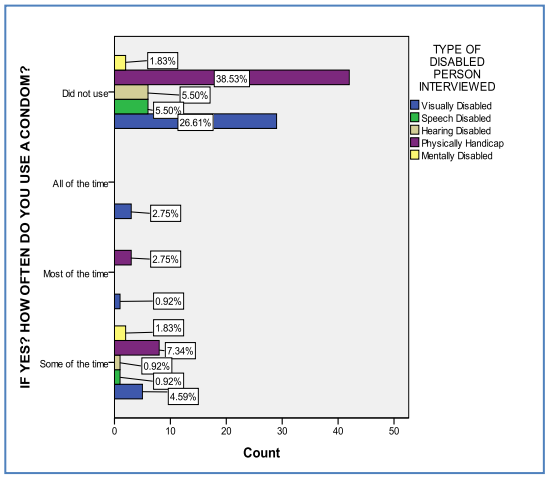
In this study it is evident that, among the total respondents only 44.91% ever heard of condom and 42.81% answered 'no' and 12.28% said 'don't know'.. Among specific category of disabled, only 20.70%

of physically disabled and 9.82% of visually disabled have ever heard of condom and its usage whiles other were not aware at all. Often unmarried disabled were informed about condom and its use by their married friends or in-laws. Drugstores and chemist shops were mentioned as other important source of information on condoms

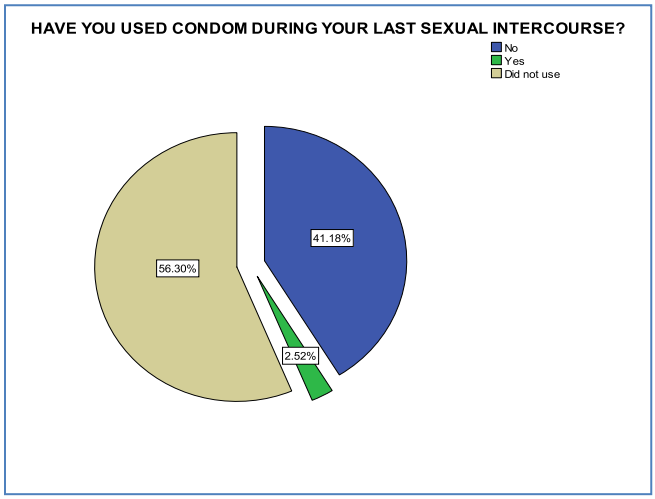


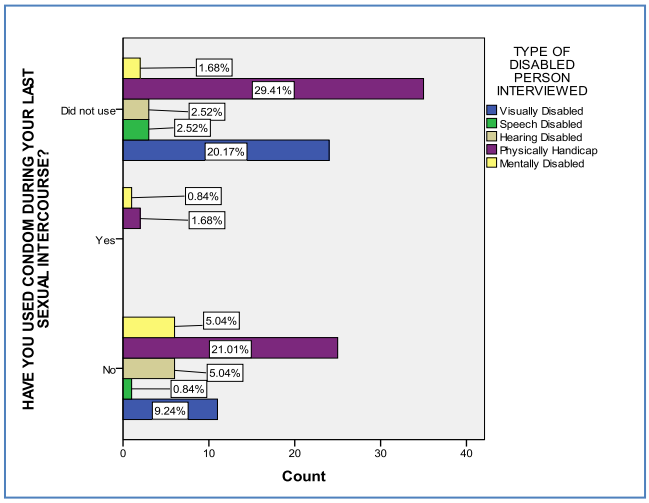


Even lesser percentage of disabled population heard of condom, but majority of 77.98% did not use it while 15.60% have used it some of the time. In detail classification, 7.34% of physically and 4.59% of visually disabled have used condom some of the time.



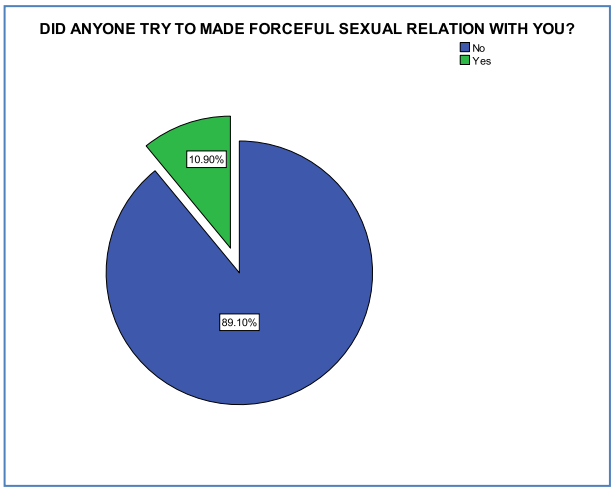
These above fact aptly justify that lower level of awareness on condom and inconsistency in regular condom use can make PWDs more vulnerable and susceptible to acquire greater risk of HIV infection and sexually transmitted diseases. Though physically disabled displayed highest level of knowledge on condom and its usage but in reality they reported not to use during their sexual intercourse. This reflects huge and prominent gap existing on sexual and reproductive health seeking behavior among the entire disabled community. This also correlates gap in policy advancement not reaching to invisible disabled population at high risk among the general population.

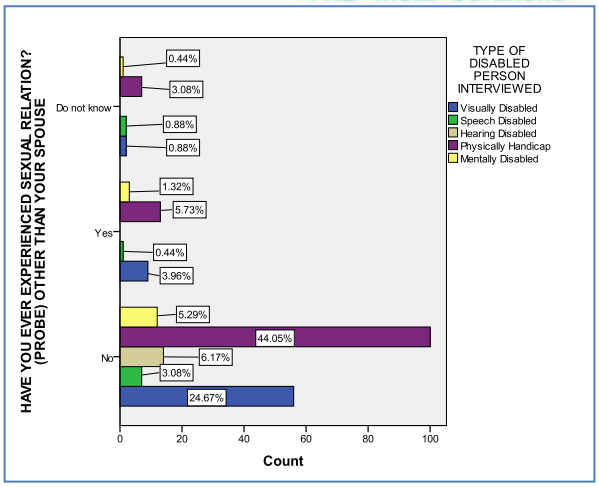




➢ SEXUAL BEHAVIOR AND HEALTH OF PEOPLE WITH DISABILITY

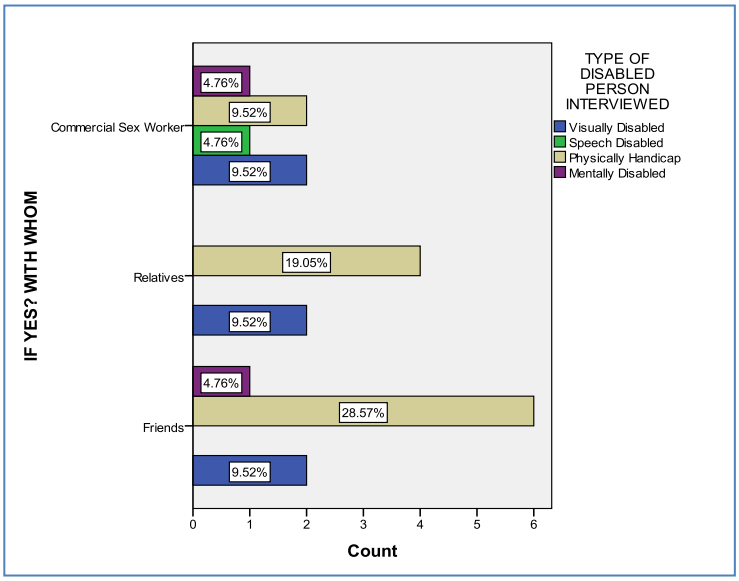
Though the care givers and general population endorsed a perception that disabled are 'asexual- or do not have normal sexual desires' but interaction with the PWD community reflected that in reality they were equally active and engaged in sexual activities. In such an instance, sexual abuse and exploitation can always be a big threat for these entire categories of disabled population. 89.10% of study population mentioned that they never felt threatened sexually, yet 10.90% of respondents mentioned that in one and many cases they were forced in sexual relation and were sexually abused. In specific category, 5.73% of physically disabled and 3.96% of visually disabled were reported as main victims of sexual abuse.





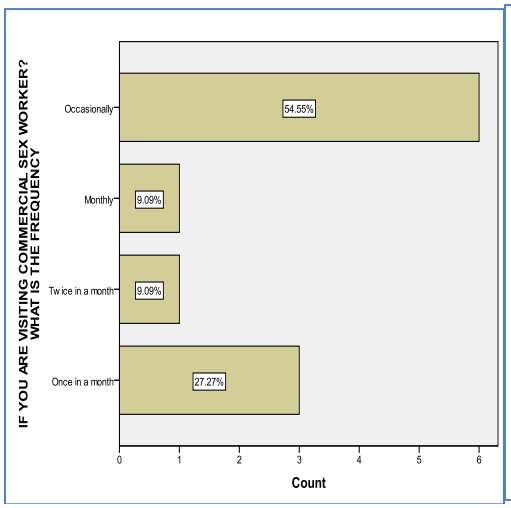
Previous literatures on disability and HIV/AIDS infer that there are factors that increase the person with disabilities chances of contracting HIV. Some of the factors discussed include sexual violence, wife sharing, stigmatization, poverty, traditional faith healing and failure to get the husband of choice. (Mulindwa, I.N. 2003, Groce, E.N. 2003 Munguti K.,Yousafzi.A, 2004). In majority of cases it was reported that friends and peer group, relatives and commercial sex workers were the main sources of extra marital or undefined sexual relationship. The trend is clearly visible among the physically and visually disabled. Often able bodied male or female offer sex to these so called 'asexual' group assuming that they are out of risk and often driven by sympathy and indulge in un-protected sex.

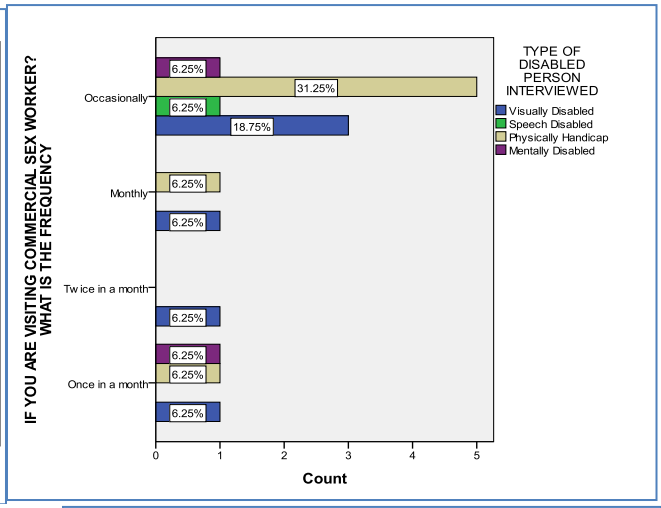
➢ HIGH RISK ACTIVITIES AMONG PEOPLE WITH DISABILITY

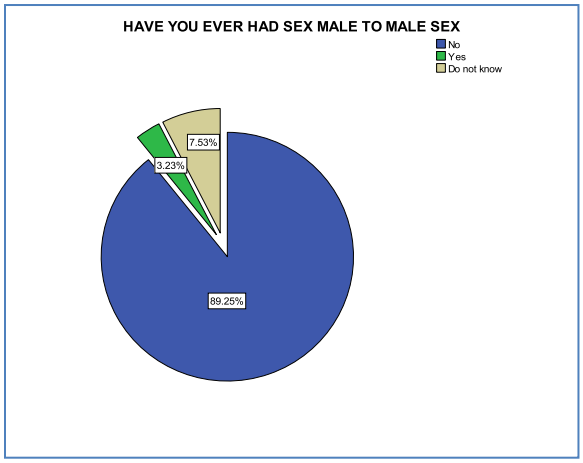


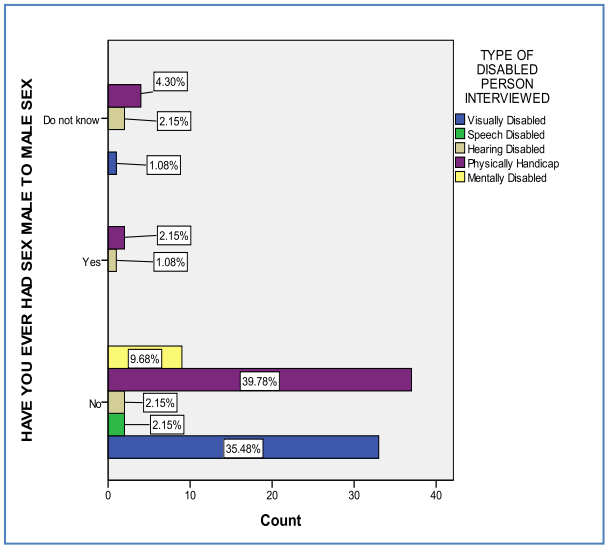
High risk and its vulnerability are only narrated by NACO for specific vulnerable groups in India. As a matter of fact, HIV surveillance for general population overlooks the disabled community within its reporting. Social discrimination, stigmatization and taboos have already made disabled community self centered and prejudiced. But, biological sexual drive urged many of them to indulge in high risk activities which could be risky and harmful for their health. Amongst the entire study population, it was observed that 54.55% occasionally visits commercial sex workers and 27.27% used to visit regularly once in month. Among the occasional visitor at brothel or flying CSWs, physically (31.25%) and visually (18.75%) reported the highest while a significant proportion of speech and mentally disabled (6.25%) also reported to visit these places for sex.

This clearly indicates the high risk and vulnerability to getting infected with HIV and other allied causes of infection among the general population.

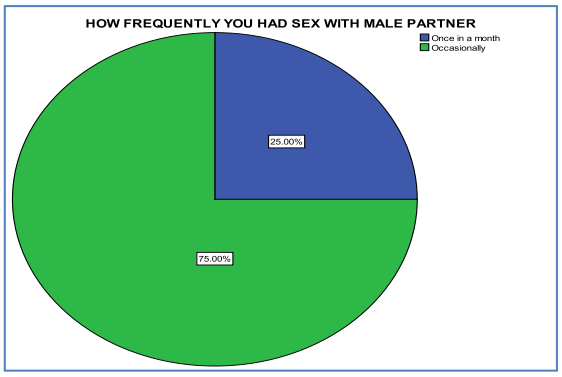


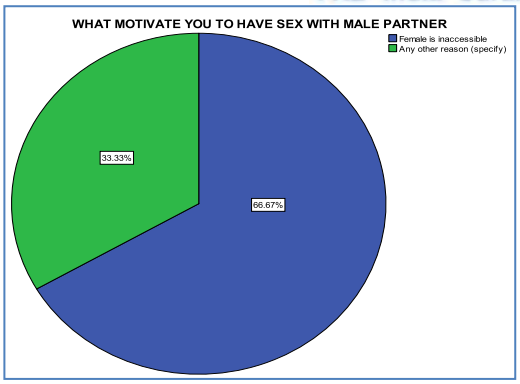


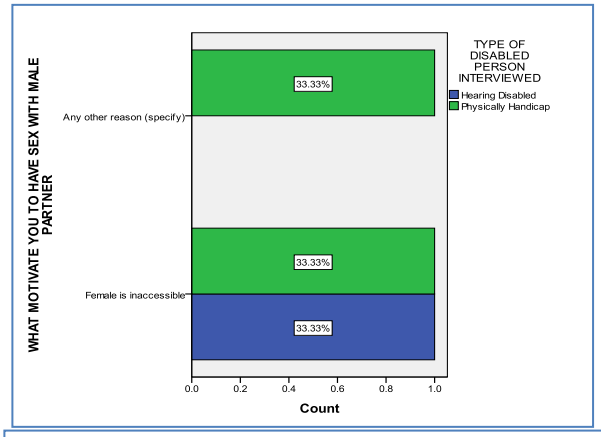


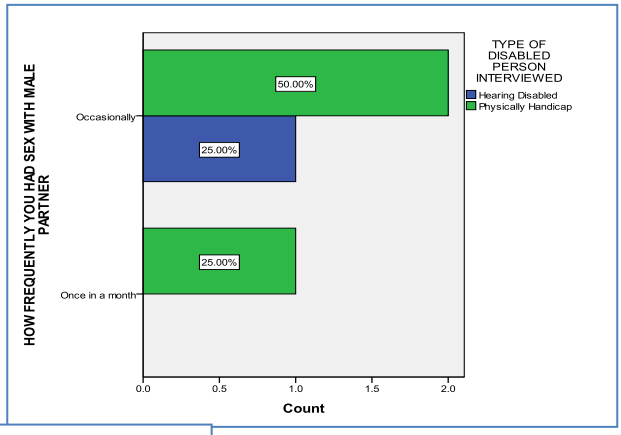


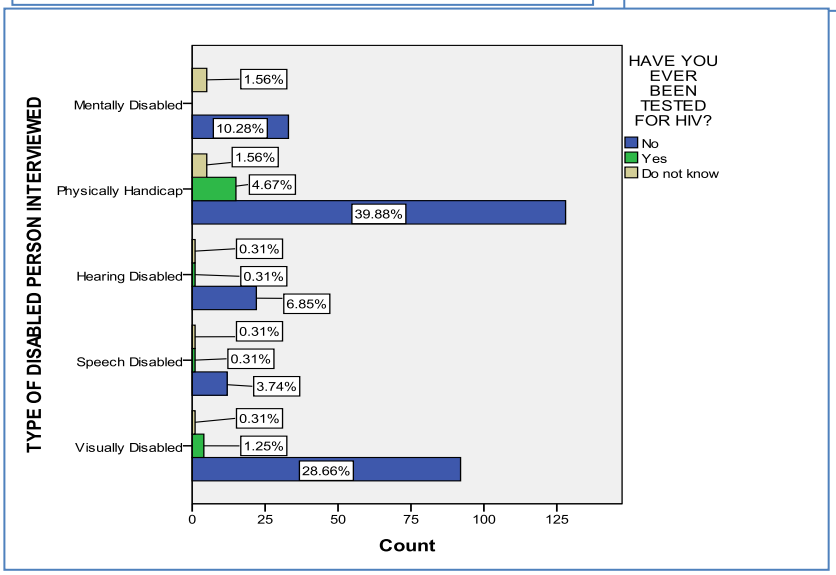
Even if male to male sex was very less in response but still, they reported occasionally to have had experienced homosexual activity. In major responses among physical and hearing disabled population it was evident that, inaccessibility of female partners were the main reason to have occasional sex with their male partners.





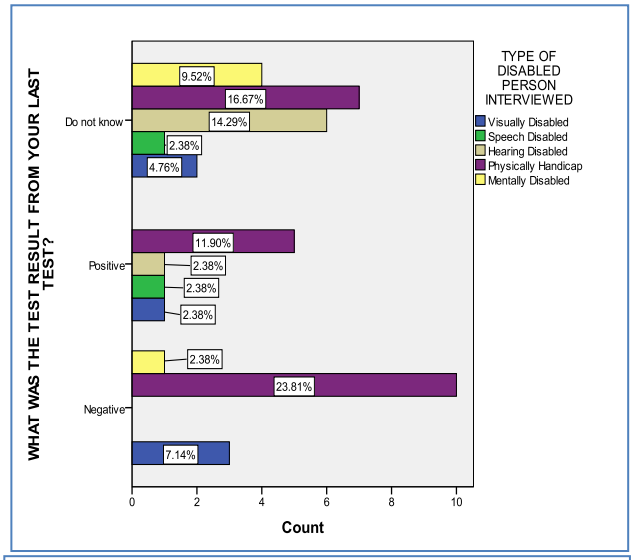


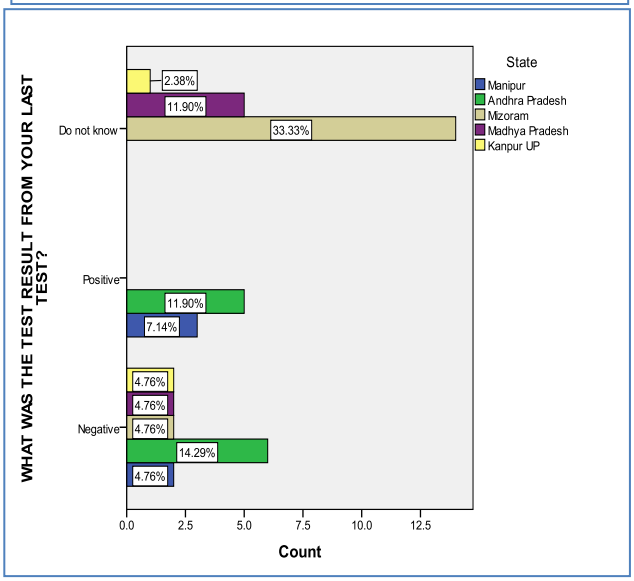




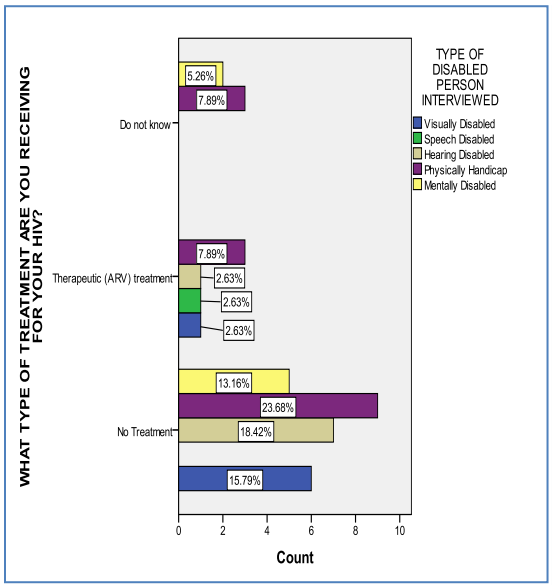
Considering these issues of risk and vulnerabilities, further analysis were done to capture t sero-positive rate and accessibility to existing HIV/AIDS health care and treatment either in government or private setup. Among the all 8 study states, Mizoram, Manipur and Andhra Pradesh were classified as HIV high prevalent states with category A and B districts approved by NACO. During this research, it was recorded that only physically disabled (4.67%), visually disabled (1.25%), hearing and speech disabled (0.31%) respondents were tested for HIV but mentally disabled were completely missed out.

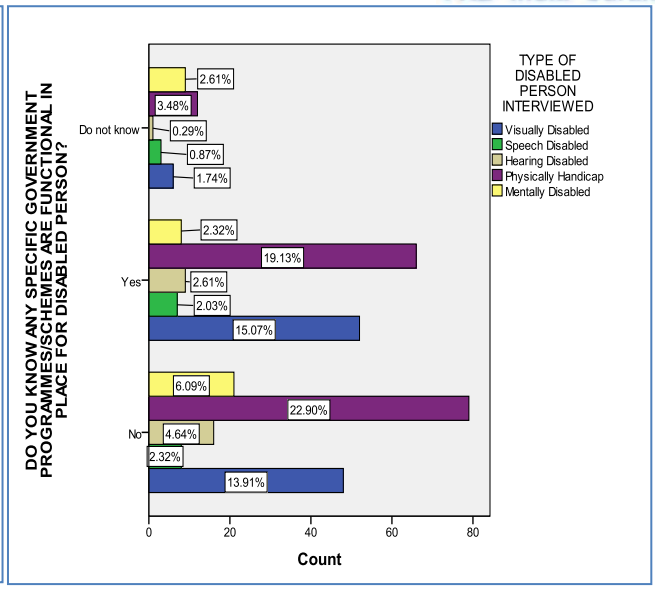
Among the study states, in Andhra Pradesh (11.90%) and Manipur (7.14%) PWDs were found HIV positive, while in Mizoram (33.33%), Madhya Pradesh (11.90%) and UP Kanpur (2.38%) didn't know about their test results. Those who had HIV positive results, physically disabled (11.90%) had highest response followed by visual, speech and hearing disabled (2.38%). This filed data raised enough opportunity for debate whether these PWDs had acquired HIV infection due to their high risk sexual behavior or they would have pre existing HIV prevalence plunged them into disability. During the field level investigation this was a limitation to enquire in detail case analysis. However, only ART report card from District/ States level ART centers revealed that they had CD4 count in a range of lowest 92 up to 860.





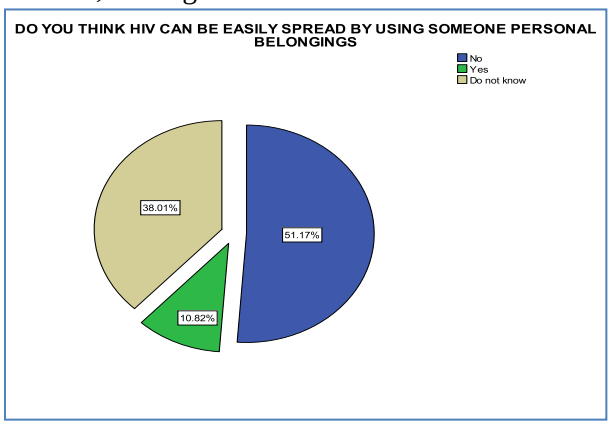
Once PWDs were disclosed about HIV positive status most of them kept it secret in fear of getting socially excluded and discriminated. Physically disabled (7.89%) followed by visual, speech and hearing disabled (2.63%) received therapeutic (ARV) treatment while physically disabled (23.68%) followed by visual (15.79%), hearing disabled (18.42%) and mentally disabled (13.16%) were untreated by the time of research study. Respondents had information on availability and accessibility to any specific government programs / schemes those were functional. Physically disabled (19.13%) and visually disabled (15.07%) acquired maximum source of information on social welfare and social protection schemes.

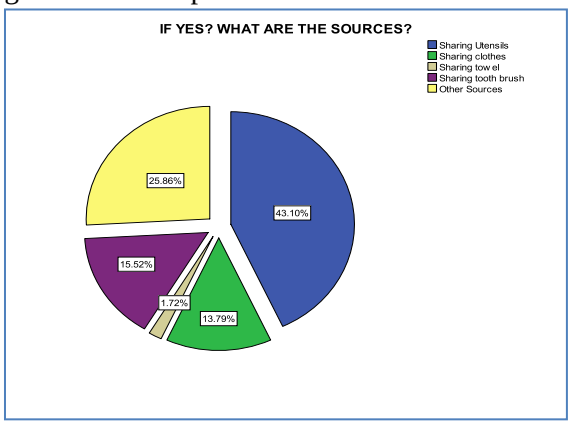




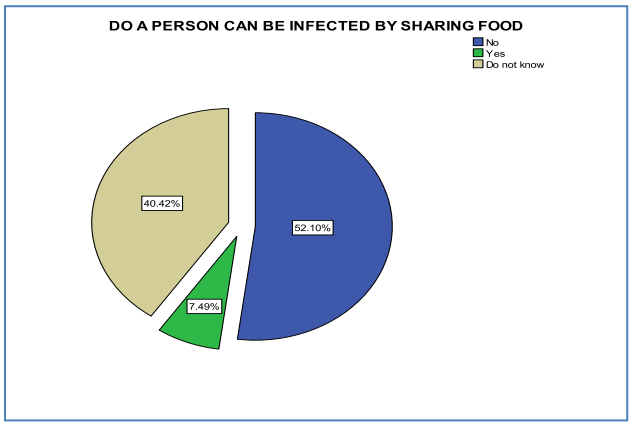
- **PERCEPTIONS ABOUT HIV/AIDS AMONG PEOPLE WITH DISABILITY – MYTHS AND MISCONCEPTIONS**

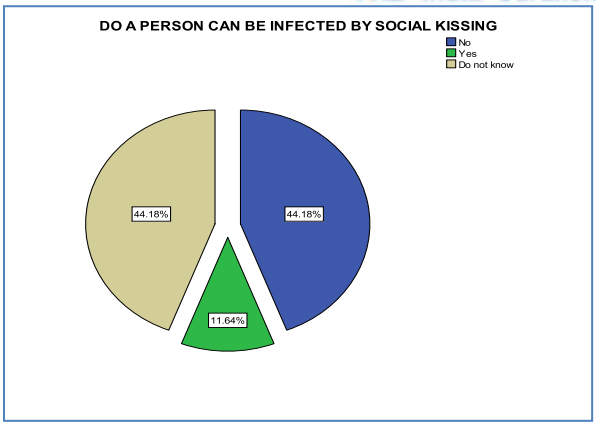
NACO HIV surveillance data explored factsheets about knowledge and perception of general population along with high risk group but overlook level of understanding of PWDs at a great extent. Under this mid-scale study, multilayer information related to myths and misconceptions on HIV/AIDS were explored. 10.28% of respondent answered that HIV can be spread by using someone's personal belongings while 52.17% replied 'no' and 38.01% were completely unaware of the fact. Interestingly, those who admitted this fact, sharing utensils were the main reason through which HIV spread.





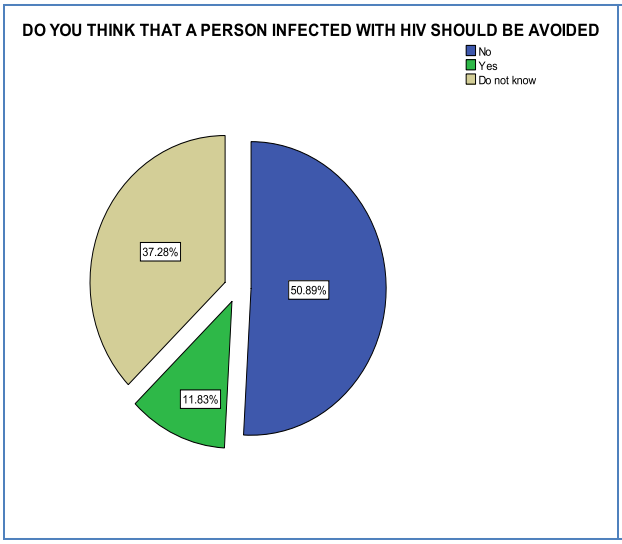
Sharing food (no 52.10%, yes 7.49%, don't know 40.42%) and social kissing (44.18% for both yes and no, 11.54%) were also low level of myths and misconception perceived by PWDs.

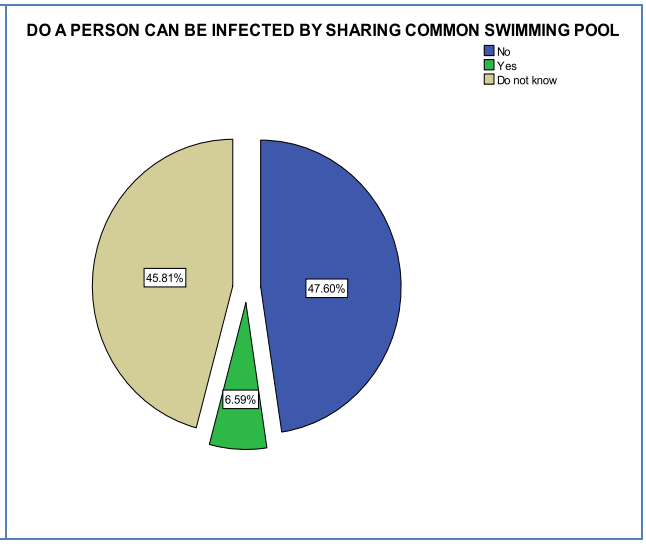




Sharing common swimming pool (no 47.60%, yes 6.59% and 45.81%) were other type of responses as perceived by PWDs. To understand PWDs' individualistic opinion about avoiding HIV infected people, 50.80% replied 'no' and only 11.83% said 'yes' while 37.28% didn't able to understand the issue and remain unanswered. So it was evident that, by virtue of HIV/AIDS awareness campaign or mouth to mouth public communication PWDs were educated on marginally on myths and misconceptions on HIV/AIDS.

- **STIGMA AND VULNERABILITY**

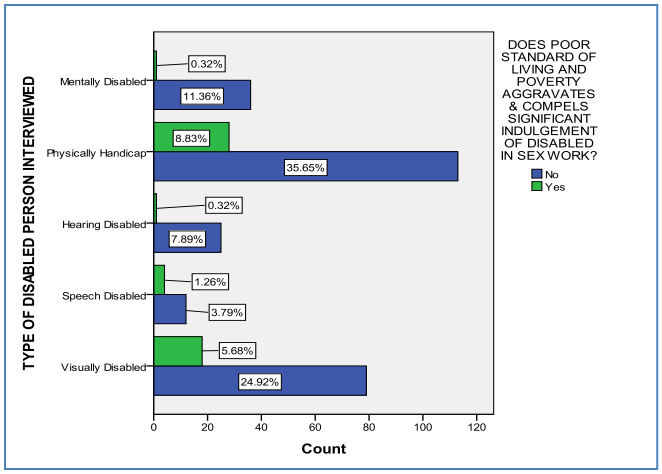




Among the study population social stigma, discrimination and potential vulnerability exist. There were series of causality effects of stigma opined by respondents that had aggravated risk and vulnerability of HIV among PWDs and their families. Among others 30.62% respondents felt 'situation is really perplexing and government should focus on their issues and 25.75% of respondents believed if national level attention is not given with immediate effects then situation will deteriorate further. There were significant similarities noticed in NACO-BSS 2006 study report in relation to the present research that, stigma and vulnerability were bipolar conflict that either of one contradicts. Stigma and vulnerability though equally exist in all set up like rural and urban and community and institutional but PWDs living at rural set up and under major threat and still many of them unidentified and unreached.

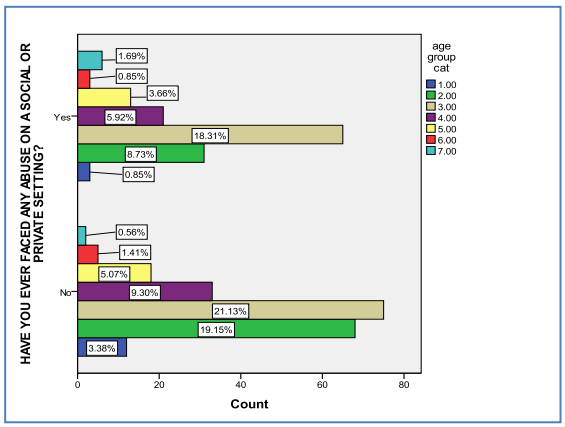
➢ RISKS AND VULNERABILITY TO HIV/AIDS FOR ESPCIALLY FOR CHILDREN WITH DISABILITY

Health is a fundamental right of people and bridges inextricable link to human rights addressing immediate needs to survive on Earth. Standing on 65th National Independence, India has been experiencing bouquet of Public Health challenges in different dimensions. Those are poverty, malnutrition and poor sanitation, lack of quality education, inadequate housing, unemployment and working condition, migration and practice of high risk behaviour, socio-cultural inequity and failure in public health delivery, epidemiological disease transmission fuels to ill health. Among these, poverty, malnutrition and inadequate public health care and service delivery count for major concern and if adequately addressed can control crucial epidemiological disease transmissions through HIV particularly among Women and Children. This sound phenomenon continue to be a devastating vicious cycle and today we have about AIDS Orphan in India which is estimated about 1500000 [UNICEF Study at UNGASS 2010 India Report].



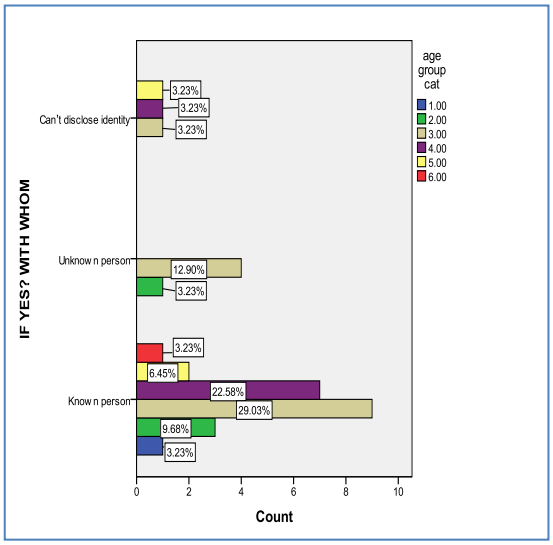
In this context, during this study, attention was given to understand the socio-economic and demographic distribution of respondents and risks to getting infected to HIV AIDS or its treatment. Majority of respondents are employed with an average gross income of INR 50000 only which clarify them in BPL category. The study had equally focused to documenting information from both male and female respondents. Among the target population under this study, physically disabled (8.83%), speech disabled (1.26%) and visually disabled (5.68%) had responded that their poor standard of living and poverty aggravates and compels them to indulge in sex for money.. While in contrast, physically disabled (35.65%), speech disabled (3.79%) and visually disabled (24.92%), mentally disabled (11.36%) and very less of hearing disabled (0.32%) didn't support this statement.

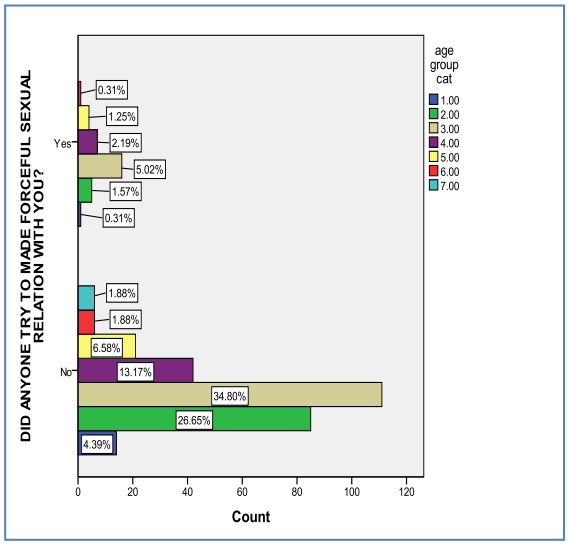
The entire respondents were categorized in sub categorise to ease research analysis and interpretation. For doing this, WHO guidelines taken in forefront consulting CBM SARO for considering minimum age of respondents at early adolescent of reproductive age of 13 years was taken as the ground rule to participate in survey and able to answer by self up to geriatric age group of 60 years. **Classification of Age Group Category in range and corresponding codes are to be read as : > or equal to 13 years (code 1),14-20 years (code 2), 21-30 years (code 3), 31-40 years (code 4), 41-50 years (code 5), 51-60 years (code 6), < or equal to 60 years (code 7).**. Attempts were mad to include equal number of male and female respondents to maintain gender balance.



The national launch of India's pediatric HIV/AIDS initiative by the Government of India, through NACO in collaboration with the Indian Academy of Pediatrics, UNICEF, WHO and the Clinton Foundation, on the eve of World AIDS Day, 2006 was a reflection of the Indian Government's commitment to reversing the HIV/ AIDS epidemic and ensuring that it does not devastate the socioeconomic fabric of a nation that is on a fast growth trajectory. HIV Prevalence amongst Children in India is estimated to be 202,000 children who are infected by HIV/AIDS (UNAIDS 2004). Using a conservative transmission rate of 30 percent from an infected mother to child, approximately 56,700 HIV infected children are born every year (NACO, 2005). Global experience shows that 25 – 30 percent children, who acquire HIV from their mothers die before their first birthday. Most of them (50 – 60 percent) develop symptoms early in life and, in the absence of timely diagnosis and ART and general HIV care, progression of HIV infection is usually accelerated. All children exposed to HIV will be tested for infection. A CD 4 cell estimation test will be performed to assess the stage of disease progression and treatment will be advised. Since September 2006, children across five states (Tamil Nadu, Andhra Pradesh, Maharashtra, Karnataka, and Delhi) have been mobilized, screened and put on treatment. Presently, the number of children on ART is 3600 and access is being further stepped up to cover remaining states. Besides providing drugs, early diagnosis of children up to 18 months will also be done using DNA-PCR. The importance of the initiative is to diagnose HIV in infants and provide treatment. Now this test can be done on newborns, as early as 6 weeks after birth.

Children of today are the youth of tomorrow. HIV affects this very precious generation and bear grave

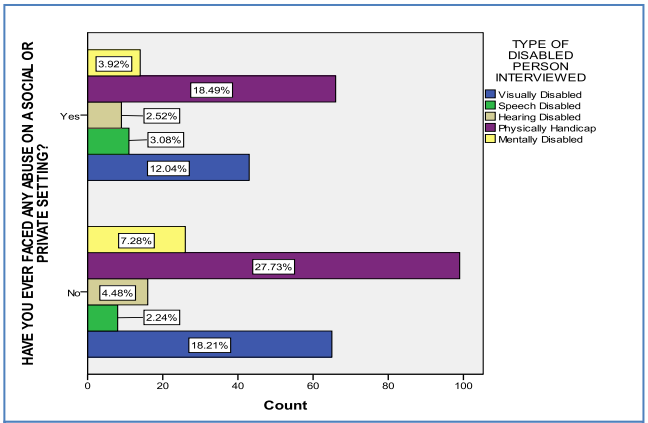


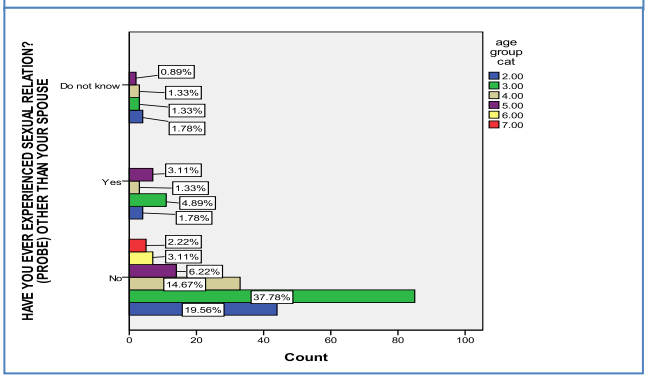


consequences to our future, our nation, the continent and the world at large. It will adversely impact the health statistics, economic growth and above all the morale of nations. Although children represented only 6% of all people infected with HIV/AIDS as of December 2005, they accounted for 18% of the 3.1 million AIDS deaths in 2005. Only 40,000 or 4% of the one million people now on antiretroviral treatment are children. This means that one in every six AIDS deaths each year is a child, yet children represent less than one of every twenty-five persons getting treatment in developing countries today. There are 2,300 children, who are currently receiving ART in India (NACO Oct, 06) however; half of

HIV-positive children die undiagnosed before their second birthday. The reasons for lack of access for treatment of children with HIV/AIDS are manifold and include among others, issues of diagnosis in infants (early diagnosis), lack of clear guidelines for the treatment of children, lack of access to appropriate pediatric ART formulations, inadequate capacity and knowledge of service providers in clinical management of Pediatric HIV/AIDs, lack of surveillance and data in this age group (<15 years), nutrition in young infants, inadequate follow up of infants born to mothers from the PPTCT programme and other programmatic issues such as convergence with RCH services and the lack of a minimum package for care and support of children affected and infected with HIV. Enhancement of health care systems' ability to address health needs of infected children, resulting in effective management of common childhood illnesses and prevention and treatment of opportunistic infections. Children have specific needs for growth and development, and of early diagnosis of infection besides needing a strong family support. Orphaned and vulnerable (OVC) children, both uninfected and infected add to the complexity of the issue in terms of vulnerability, social security, livelihood, poverty etc.

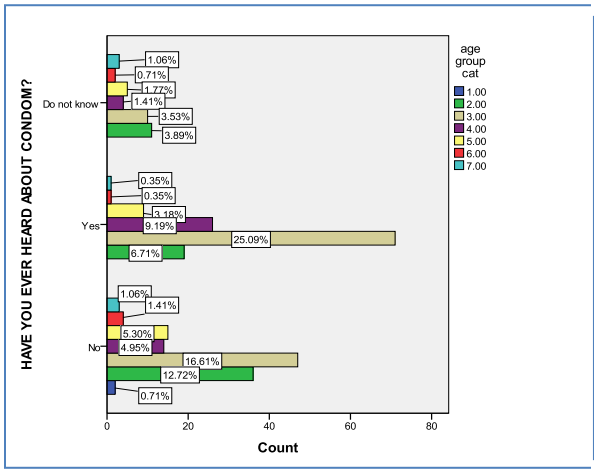
An important aspect of this study was also to explore issues of HIV/AIDS affecting Children, however during this study lowest age group that we were able to interview was 13 years and above to capture potential risks and vulnerability of children to HIV AIDS It was clear and evident that, almost equal proportion of all categories of disabled have had ever faced any form of abuse on a social or private setting, among them physical and visually disabled reported the most. Most of the adults replied that children were also equally thrashed by common abusers while engaged in begging and earning food against petty work. However analyzed data reflects, only 0.85% of just 13 years teenagers and 8.73% of teen agers at 14-20 years have had any abuse on a social or private setting.

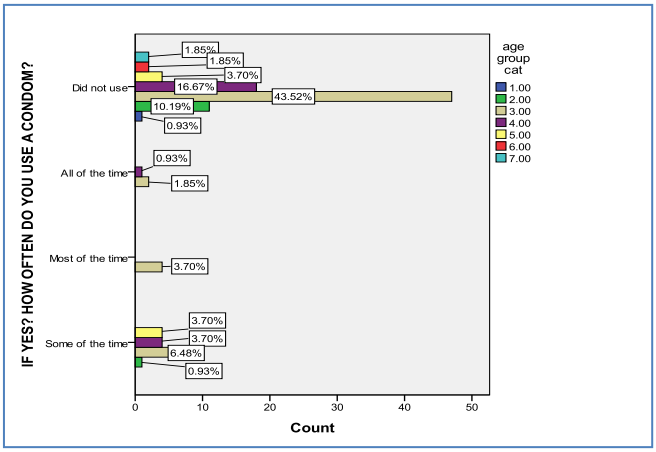




Almost each category of disabled population have had faced such exploitation at public place (about 64%).

Other than physical or social abuse, our study found that children and adolescents were also sexually abused in different set up. Though the reported figure is less among 13 years of teenagers (0.31%) and 14-20 years (1.57%) but still it represents potential for risk and high vulnerability. Upon in-depth interaction it was shared that, in majority of cases known family/peer group person tried to establish sexual relation with PWDs (13 years 3.23%, 14-20 years 9.68%). Knowledge on mode of HIV prevention among the target population for study was noticed. Early teen age group have never heard or seen condom. But significant proportion of respondent in age 14-20 years (6.71%) knew the word 'condom' and has seen also at medicine shop and among the peer friends. While answering on use of condom, only 0.93% of respondents in 14-20 years said that they had used condom some of the time but 10.19% of respondents in same age group category didn't use at all despite having knowledge of it.


HAVE YOU EVER HEARD ABOUT CONDOM?
Do not know
Yes
No
1.06%
0.71%
1.77%
1.41%
3.53%
3.89%
0.35%
0.35%
3.18%
9.19%
25.09%
6.71%
1.06%
1.41%
5.30%
4.95%
16.61%
12.72%
0.71%
0
20
40
60
80
Count
age group cat
1.00
2.00
3.00
4.00
5.00
6.00
7.00


IF YES? HOW OFTEN DO YOU USE A CONDOM?
Did not use
All of the time
Most of the time
Some of the time
1.85%
1.85%
3.70%
16.67%
43.52%
10.19%
0.93%
0.93%
1.85%
3.70%
3.70%
3.70%
6.48%
0.93%
0
10
20
30
40
50
Count
age group cat
1.00
2.00
3.00
4.00
5.00
6.00
7.00

- **NEED FOR SPECIALIZED CARE FOR PEOPLE UNDER SPECIFIC CATEGORIES OF DISABILITY:**

Case Study of Premier Special Schools in Delhi/NCR

BLIND - All India Confederation of the Blind (AICB)

All India Confederation of the Blind (AICB) is a body of blind persons working for and with its blind brothers and sisters. It is made up of grass-roots and State-level Associations/Organizations working with the blind. It has 22 affiliates across the country. The Confederation has now completed 30 years of its existence. AICB derives some satisfaction from the fact that have traversed quite a long distance--from a small rented office to its own premises housing a variety of services; from just one part-time employee to the present number of over 100 staff members; from a meager fund of just a few hundred rupees to the present budget of over 25 million rupees; from hardly any activity to over 20 projects and services.

The Confederation's work has been receiving appreciation and commendation from various quarters. It has been adjudged the Best NGO in the disability sector for 2006 by the Government of India and presented the corresponding National Award by the President of India on December 3, 2006. During the current year the Confederation's Braille printing press was adjudged the best in the country and was awarded a Citation and cash Award of Rs. One Lakh on the occasion of 200th birth anniversary of Louis Braille in a grand function organized by the Government of India on 4th January, 2009.

Vision Statement: While the exact number of visually impaired persons in India is not clearly established, yet there is no doubt that we have a sizeable section of sight-impaired children and adults--male and female--across the country. These vision impaired persons possess immense potential and skills. No talk of total national development can be worth its while without taking on board all of these teeming millions. Our blind brothers and sisters are invaluable treasures and have immense capacity to contribute their mite towards the overall socio-economic flowering of the country's multi-dimensional growth and development. All that we need is to put our shoulders to the wheel, pool our resources together and make a determined and continuing dent on the prejudices and misconceptions in society, which impede the development of the blind, here. This is the underlying philosophy and conviction of our Confederation.

Mission: AICB has a dream. Like the World Blind Union, it, too, seeks to strive ceaselessly towards changing what it means to be blind. It wishes to take one and all with it in the challenging task of bringing the blind of the country out of the present generally miserable state of ostracisation, deprivation and neglect to genuine inclusion, acceptance and development. Towards this highly humane and stimulating endeavor, AICB calls upon all like-minded individuals and organizations within and outside the country, to lend a helping hand and come together with us. We cannot stop until we are able to reach out "unto the last" individual with visual impairment.

Priorities: AICB has a clear mandate. It seeks to reach out into areas hitherto untraversed or scantily attended. Thus, visually impaired children, women and the elderly are our primary target groups. Opening

up of new vistas of opportunities for the neglected segments of our blind population residing in rural areas is our major concern. On the other hand, facilitating access to information and harnessing appropriate technologies for improving the quality of life of our blind friends is a matter of faith with us. Seeking out new and challenging work-opportunities commensurate with the interests and capabilities of our blind youngsters is yet another challenging task before us. We have to make our programmes and services consistent with the daunting demands and realities of the twenty-first century. That is the volume and magnitude of work for which we strive to design and develop our future strategies and approaches.

AICB at work: School Education: A highly progressive special school for blind children in a typically rural environment; a Resource Center with a Science Lab, a Touch-and-tell museum and a Geography room so rare elsewhere in the country; a wealth of cultural and co-curricular activities. "AOF-AICB Centre of Excellence" (Computer training for children); Access to knowledge and information: A high-speed state-of-the-art Braille Press established with support from NABP, with the capacity to produce Braille at the astounding rate of 1200 characters per second through 3 computerized high power Embossers; provision of textbooks to all blind children in a number of States either free or at highly subsidized costs; a recording studio-cum-cassette library providing books to college students on easy to operate cassettes; publication of 4 magazines in Braille and on cassettes; production in Braille of three reputed children's print journals; a wide range of reports on various research projects completed by the Confederation; production into Braille of a wide array of general knowledge books, stories, drama and novels in English and Hindi; bringing out into Braille textbooks in Hindi, English, Sanskrit, Punjabi, Malayalam and Kannada; Training and Employment: Braille Stenography and Computer Training courses; Crisis Management Unit for helping recently blinded persons to overcome the retarding effects of their visual disability; O. and M., ADL and Home Management training; placement of over 325 ex-trainees of Stenography courses in various government departments, banks and public sector undertakings; placement in industrial and other forms of employment; Rehabilitation: CBR projects in a number of States; provision of financial assistance to blind persons to enable them to start income-generating activities in rural areas; providing pensions to elderly blind persons; a Day-Care Center for the geriatric group of blind persons; Prevention of Blindness and Eye-Care: Eye screening for thousands of school children and adults; providing free eye glasses to the poor and the needy; IOL surgeries; Women Empowerment: A hostel for College-going blind girls providing free facilities and reading materials; merit scholarships to blind girls studying at post-graduate level; intensive leadership training and personality building programmes; Other services: Braille Equipment Banks in many States; judicial activism through an Advocacy Cell to facilitate redressal of grievances of individuals and securing the rights of the blind by filing petitions in various Courts; a wide range of professional conferences and consultations from time to time.

AICB in the context of 'Disability and HIV/AIDS': AICB being a reputed national level institution for blind express an interest on mainstreaming the 'issues of disability and HIV'. The current institutional set up is more focused on providing vocational education, computer learning and livelihood generation for blind students. Generic health checkup and soft skill training with adult education is a combined approach that enables AICB students to learn many skills. Special educations of this institution believe quite often they organize health awareness discussion and train senior students to be peer leaders to teach others on adolescent health issues. But they believe, there are gaps in program conceptualization to integrate proper adult education among the disabled. Possible reasons are the policy of the AICB is specific to enable blind students with vocational skill training and computer literacy education which are more of demand driven and need based. Proper strategic approach with HIV/AIDS awareness and information sharing on STD/STI risk have never been a part of their initiative to safeguard late adolescent and youth residents. Focus group discussion with both male and female blind students expressed their interest to understand of

the issue of HIV/AIDS and STD/STI awareness and other complexities in body. However, the institute believes for blind disabled category, IEC material and demonstration in brail language to be produced. Voluntary HIV testing for new entrants or residents in AICB appeared to be difficult in particular to integrate the approach in organization policy. However, there will be possible scope for HIV/AIDS organizations to approach and work together with accessible communication materials.

DEAF - Noida Deaf Society

"Every one of us is different in some way, but for those of us who are more different, we have to put more effort into convincing the less different that we can do the same thing they can, just differently." Marlee Matlin (Deaf American Actress).

The Vision of Noida Deaf Society is to mainstream the Deaf people into the community through specialized vocational programs leading to gainful employment. NDS has mission to focus not on the disability but the ability of the Deaf! For NDS believes that the Deaf can do everything except hear. We provide vocational training to the Deaf to enhance their employability quotient and enable them to become contributive partners of society.

Objectives of NDS are as following: Develop Life skills amongst the Deaf, Build employability skills for Deaf youth, Provide Education to Deaf Children, Create a pool of Deaf trainers, Develop teaching and learning resources for the Deaf community.

Noida Deaf Society in the context of 'Disability and HIV/AIDS': Transition in at late childhood to adolescent and there after adolescent to youth stage multiplies social and behavioral risk. Focus group discussion specify that all students are enrolled in different course work and undergoing vocational training e.g. Computer aided graphics design and DTP works, English language etc. They all enjoy NDS platform as convenient and safe place for learning knowledge and enabling environment for personal development through soft skill training. Teachers are the best enablers for them and participants are attending different course work 3-5 days/ week for 6 months to 2 years of course duration. Participants have knowledge on general health but most of them are unaware of HIV/AIDS. Only 2/3 of them heard of HIV from School Teacher and The Deaf Way Club for Hearing Impaired. Small proportion of them have functional understanding of mode of HIV transmission only by Blood and Injection but none of them are aware of unsafe sex and MTC mode of transmission. About mode of prevention, boys are little aware of condom use while girls are completely unaware of any preventive procedure. Both boys and girls are aware of basic sexual health and hygiene. None of them have heard of Sexually Transmitted Infection as their parents haven't also detailed them on this issue. Deaf being in crucial category of disability are at risk of sexual or physical violence. Peers in deaf category and their guardian community haven't yet seen any disabled person with HIV. In NDS most of the participants were unmarried hence they don't have fair understanding of sexual and reproductive health. But often boys have seen condom from their married friends and condom demonstration at The Deaf Way society; while girls have seen used condom thrown at garbage pit and they have seen oral contraceptive pill strips from their female relatives. Increased school sex education with condom demonstration, initiate dialogue with married friends and family members on safe sex, condom box available at hospital, distribute IEC materials in local language etc. could effective way to prevent from communicable diseases. 'Girls

said only self protection and adopt the principle of abstain from unsafe sex'. 'Boys opined better level of group education through inters agency knowledge dissemination and workshop would be best possible way to spread info on communicable disease prevention'.. They are completely unaware of services related to SRH as a consequence they are indulged into unsafe sexual relationship. As part of best practices, NDS register cases for Inter Personal Counseling both for boys and girls who have suffered though relationship problem and provided need based general health check up and free medicines on quarterly basis. Health care service providers play sensitive role to support disabled population but it may not be the same everywhere. NDS has specific confidential record maintained about no. of married or sexually active clients for whom they maintain high end confidentiality. In their support system they organize special session with girls and boys on SRH and RH, about how to main safe sexual relationship. Within their outreach capacity no cases were found or identified as PWD with pre-existing HIV.

Twice yearly HIV/AIDS awareness session in general is a part of their annual activity but that seems to be not detail effort. Since this institution does not have formal structure of education system for PWDs which could directly link them with HIV/AIDS awareness, they suggested counseling strategy – Interpersonal Communication, Social Group Work, Parent Counseling covering issues of SRH, HIV/AIDS would be promising effort. Majority of cases lack awareness on government or civil society linked HIV/AIDS programming. Program implementers of NDS expressed there is urgent requirement of equal and accessible information linked to IEC. This will explain the cause and effect of HIV/AIDS among vulnerable PWD population and peer groups. Efforts to be given at maximum to prepare documentary film on all perspective of HIV/AIDS, SRH, RH and Communicable diseases in Integrated Sign Language demonstration, this will be sustainable.

AUTISTIC - Action For Autism, The National Centre for Autism

Action for Autism (AFA): the pioneering, national and non-profit autism society of India. We provide support and services to persons with autism and those who work with them in South Asia. Founded in 1991, we are a parent organization began with the goal to "put autism on the Indian map." Awareness of autism in India has grown tremendously in the past decade, and our activities have also changed to meet current needs in India. We work through direct services, advocacy, and research to improve the lives of children with autism and their families. We are an Indian organization, and our efforts are focused on the needs of those in India. We are also committed to assisting other countries in South Asia achieve legal recognition of autism and develop services for children and families. To more effectively orchestrate national activities for autism, we relocated to the AFA National Centre for Advocacy Research and Training in 2006.

Vision of AFA:
A society that views the interdependence of people of every ability as valuable and enriching and seeks to provide equal opportunities for all.

Mission of AFA:
To facilitate a barrier free environment; to enable the empowerment of persons with autism and their families; and to act as a catalyst for change that will enable persons with autism to live as fully participating members of the community.

Action for Autism in the context of 'Disability and HIV/AIDS': Autism is a special category of disability and many of its aspect is still unexplored. With the advancement of scientific research and emerging vocational education skill to bring behavior modification and social skill learning, now a day there are other allied social health issues are also coming on face. This is a true and complex fact that autistic person in particular who are affected by Autistic Spectrum Disorder (ASD) do highly require systematic effort to be mainstreamed in regular care and support for PWDs. This kind of support only be possible within an institutional setup and requires intense effort to convince the parents community of autistic person. Development of work skill and behavioral modification among the autistic child and adolescents are the bottle neck to measure success. In this situation, active parent training could play crucial role in understanding the need for discussion on the issues of sexual and reproductive health and integrated concern of HIV/AIDS. Certain segment of staff in AFA had a belief that introducing sex education and HIV/AIDS would contradict and may not counter balance the agenda of supporting ASDs but the policy makers and research professional opined in favor to examine the fact and have in-depth understanding primary perception of ASDs on HIV/AIDS with the possible response by their care givers only. It was well captured that, ASD being sub-classification in PWDs also bear significant proportion of social health risk as in some cases they physically assault their care givers with a drive of undefined sexual urge. Psycho-social atmosphere in and out of the family and special educational institution / schools for ASDs alarms exceptional threat for high risk behavior. Overall, it was summarized that, active parent counseling and privacy treatment for preventing sexual health could be a close fit for autistic person in special category.

SECTION D: NGOS VIEW POINTS

➢ VIEW POINTS OF ORGANIZATIONS WORKING ON HIV ABOUT DISABLED POPULATION

About Naz India: The Naz Foundation (India) Trust (NI) is a New Delhi based NGO working on HIV/AIDS and Sexual Health since 1994. Through the years, Naz India has evolved and implemented a holistic approach to combat HIV, focusing on prevention as well as treatment. Their focus is on reaching out to marginalized populations infected and affected by HIV. They also aim to sensitize the community to the prevalence of HIV, as well as highlight issues related to Sexuality and Sexual Health. The organization believes in providing quality care and support to people living with HIV unbiased factual information on sexual health and HIV to the public and in a rights-based approach.

Major focus of NAZ India has been on high risk groups. They have both institution based care and support and community based outreach services in Delhi/NCR. Key functionaries of this organization were interviewed and their views on the critical issues of disability and HIV were explored. The major highlights of their views are:

- NAZ India promotes strengthening health system and is working in close coordination with NACO and Delhi SACS for ART and PPTCT support and follow-up. As of now they have not yet worked with disabled PLHIV as a focus, but have handled cases and come across PWDs who have in many cases been infected with HIV AIDS due to negligence and lack of awareness.. They mentioned that those disabled with pre-existing HIV are regularly attending for ART at the government run ART Centers. Upon discussion it was evident that PLHIV with extra burden of disabled status feel similar level of social stigma. It is well understood and observed that all categories of disabled are equally vulnerable to acquire HIV infection. In fact in many cases they are more vulnerable to sexual exploitation due to their disability. The team of the organisation mentioned that in entire history of program operation on HIV/AIDS issues, team members have never seen or attended any workshop or program initiatives that specifically facilitated needs of PWDs infected with HIV. They participatory training, workshops in schools as best method introduce HIV subject among PWDs, while parents counseling and home based outreach as other alternate ways to reach larger population.

SECTION E: CONCLUSION AND RECOMMENDATIONS

The intersectionality of HIV/AIDS and disability has emerged as an important area of global policy development. This research established firm fact that HIV prevalence exist either with preexisting HIV infection or due to accidental disability. Abridge of required information and non-scientific knowledge on HIV/AIDS has created potential gap in perception, awareness and attitude for health seeking behaviors among study population. Agencies expressed there were lesser opportunity to share knowledge and their experiences to further build common understanding of the issues and to explore opportunities for collaboration to advance the rights of PWDs and PLHAs. Specific disabilities like visual, deaf and autistic population are at higher risk and extent of vulnerability. Implementation of next strategy will require thorough brainstorming to arrive at decision for providing future opportunities for networking. It is highly recommended that, user friendly IEC and audio-visual aid in brail or sign languages in local dialect would be best media for ensuring active knowledge on HIV/AIDS among each category of disability. Mainstreaming of HIV programming among the disabled population would be a promising effort.

Based on the study findings the following broad recommendations are suggested that will help incorporate and focus on the needs of integrating HIV AIDS and Disability as a theme

- ***HIV/AIDS, DISABILITY AND LAW:*** UNAIDS's mandate for positive reinforcement of legal instrument-CPRD among the member countries (India among others) is highly mandated as this will help address this gap well. The Government of India needs to allocate resources in 12th five years plan for making apt use of this legal instrument for ratification and effective implementation of CPRD at pan India level.

- ***INVESTMENT IN PUBLIC PRIVATE PARTNERSHIP:*** Lack of technical and methodical research in interdisciplinary approach in the arena of public health and social sciences merely overlook aspect of visibility of invisible PWDs reeling under threat of poverty, health and human rights. In India, major proportion of specialized agencies working for PWDs are of mostly private and non-governmental set up. Government set of specialized care are placed in central locations or at periphery of regions which already overcrowded. Hence, role of ICMR (being apex medical research institute in India) and MoHFW along side with Planning Commission plays an ardent role for conceptualizing pilot initiative to venture with private hospitals and non-governmental organizations with repute and work on 'Issues of disability and HIV'.

- ***NETWORKING AND PARTNERSHIP:*** Nurturing and building the technical capacity of PWDs and those organisations working for the disabled people to facilitate meaningful ***delivery of*** HIV/AIDS education/awareness is required. For this case, promoting partnerships for knowledge sharing between organisations working for disabled people and those working for HIV AIDS should be encouraged. Knowledge societies/platforms on disability and HIV AIDS should be set up which will help understand both perspectives and therefore promote effective linkage.

- ***User Friendly knowledge Kit:*** Knowledge material on the subject to specific disability and health related issues like general health , HIV/AIDS, reproductive health, sexual health etc. needs to be prepared in user friendly languages e.g. brail, sign language, audio-visual films and documentary etc. to create long term impact among the PWDs to safe guard them from risk of HIV/AIDS.

1. ANNEXURES : LIMITATION OF STUDY, BIBLIGOGRAPHY, STUDY TOOLS (ATTACHED)

Limitation of Study

This study has established couple of interesting facts related to knowledge, awareness and attitude of PWDs on disability and HIV. Risk of HIV in children among the infant, early and late childhood category were not possible to examine. Unwillingness of special institutional in Delhi/NCR to refer and allow resident disabled students at respective institutions was a major hindrance in collecting authentic source of information. There were lesser respondents as planned to be interviewed from NACO or SACS who expressed their consent. Qualitative information was not possible to analyze in Atlas.TI software instead SWOT and Gap analysis represented. Despite of numerous approaches to apex institutes and research body, Ethical Clearance couldn't be ensured in for this research. However, Institutional Review Board of Action for Autism have thoroughly reviewed and furnished necessary inputs subjected to be justified enough having ethical consent.

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Name of the Organizations covered under 'Study on Disability and HIV' in 8 States of India	
Mizoram Dr. Vanlalrutta, Ophthalmologist Durtlang Presbyterian Hospital Willow Mount, Durtlang Mizo ram Phone: 2361222/2362241, Fax: 0389-2361185 Email: synodhospital@gmail.com	**Gujarat** Dr. Bhushan Punani, Executive Director Mrs. Nandini Rawal, Project Director, Blind People's Association Jagdish Patel Chowk, 132 Ft. Ring Road, Vastrapur, Ahmedabad-380 015, Gujarat, India Tel: Direct: 91-79-26306432 EPBX: 26305082, Fax: 91-79-26300106 Email: bpaiceviad1@sancharnet.in or nandinirawal@bpaindia.org Website: (BPA: www.bpaindia.org) (ICEVI: www.icevi.org)
Jharkhand Mr. Satish Girija At – Amrit Nagar, PO - Korra, Hazaribag Hazaribag District, Jharkhand Phone/Fax: 06546 - 263332 Cell: 9431140385, 9431141147, 9431140508 Mail: nbjkco@gmail.com; satishgirija@gmail.com Website: www.nbjk.org	**Madhya Pradesh** Ms. Silvia, (Project Manager, CBM projects) Evangelical Lutheran Church in Madhya Pradesh Luther Bhavan, P.O Box. 30 Madhya Pradesh 480001 Chhindwara / Madhya Pradesh, INDIA Mobile number- 09424666676 Email address: elc.cbmscr@gmail.com
Delhi/NCR 1. **All India Confederation of the Blind (AICB)** Mr. J. Kaul (Secreatry General) Near Rajiv Gandhi Cancer Hospital, Sector-5, Rohini, Delhi-110085. Phone - 91- 27054082 Fax - 91-27050915 Mobile - 091-09810684208 Email - aicbdelhi@yahoo.com Website - www.aicb.in 2. **Action For Autism (AFA)** Dr Nidhi Singhal Director (Research and Trainings) Anvay Research and Trainings The National Centre for Autism, Pocket 7 and 8, Jasola Vihar, New Delhi 110 025 Tel: +91 11 4054 0991-92, +91 11 6534 7422 Mob: +91 98113 32254 Email: <dr.nidhisinghal@gmail.com> Website: http://www.autism-india.org AFA's Vision is a society that views the	**Manipur** Ms. Y. Durgabati, Head Mistress Mr. B. Brajalala, Asst. Teacher Government Blind School, Takyelpat-Imphal West, Manipur – 795001 M: (+91) 8974053382

interdependence of people of every ability as valuable and enriching and seeks to provide equal opportunities to all. 3. **Noida Deaf Society (NDS)** Ms. Preeti Dhingra, Program Manager C-4/194 Sector 36, Main Road Noida 201301 U.P Phone: 0120-4245061, 9310640348 Email : ruma_roka@hotmail.com, info@noidadeafsociety.net Website: www.noidadeafsociety.net	
Andhra Pradesh Organization for Rural Reconstruction (ORRC) Mr.Ramesh, Program Coordinator Chodavaram Village, Visakhapatnam District, Andhra Pradesh	**Uttar Pradesh - Kanpur** St.Catherince Hospital Dr.Neena Lyaal and Mr.Himanshu Lyaal St Catherine Hospital Address: 63/8 M G Road, Kanpur, Uttar Pradesh, India Postal Code: 208004 Kanpur, UP

Deliverables As Per Action Plan And Method Note			
KEY TECHNIQUES	**NUMBER OF STUDIES TO BE CONDUCTED**	**PROPOSD TOTAL SAMPLE SIZE**	**FINAL STUDY SAMPLE COVERED**
Focus Group Interviews	2 each in 8 states	16	20
Administering Semi Structured Questionnaires	50 in each of 8 states	400	369 sample from 7 states 20 samples from Delhi/NCR
KII with NGOs	1 in each of the 8 states	8	8
KII with SACS	1 in each of the 8 states	8	4
Study of premiere special schools	3 in any of the 3 states	3	3 in Delhi/NCR