

Research Report

on

Understanding the Status of Knowledge and Risk Perceptions about HIV Vulnerabilities of People with Disability in District Jehlum

March 2010

Under Joint Venture of



Table of Content

Section A: Quantitative Section	1
Chapter 1: INTRODUCTION.....	2
1.1 Introduction.....	2
1.2 Objectives of the Study.....	3
Chapter 2: METHODOLOGY.....	4
2.1 Study design and Setting.....	4
2.2 Case Definition.....	4
2.3 Sampling Technique.....	4
2.4 Study Tool and Key Variables.....	4
2.5 Data Management Plan.....	4
2.6 Data Analysis Plan.....	4
2.7 Ethical Approval.....	4
2.8 Consent Form.....	5
2.9 Development of Questionnaire and Translation into Urdu.....	5
2.10 Data collection.....	5
2.10.1 Hiring of Interview Teams.....	5
2.10.2 Training and pilot testing.....	5
2.10.3 Data collection procedure.....	5
Chapter 3: RESULTS.....	6
3.1 People with Disability.....	6
3.1.1 Socio-Demographic Characteristics.....	6
3.1.2 HIV knowledge.....	8
3.1.3 Vulnerability.....	10
3.2 Family members of People with Disabilities.....	11
3.2.1 Socio-Demographic Characteristics.....	11
3.2.2 HIV knowledge.....	12
3.2.3 Vulnerability of PWDs as perceived by Family Members.....	13
Chapter 4: DISCUSSION AND RECOMANDAION.....	14
Section B: Qualitative Section	16
B1. Background.....	17
B2. Methods.....	18
B3. Findings.....	18
B3.1 HIV Knowledge and Modes of Transmission.....	18
B3.2 Risk and Vulnerability Perception.....	19
B3.3 Specific Risks for PWDs.....	20
B3.4 HIV Information Needs and Preferences.....	20
B4. Discussion.....	21

Section A: Quantitative Section

Chapter 1: INTRODUCTION

1.1 Introduction

Approximately 650 million individuals worldwide or 10% of the world population have disability that affect their daily lives and this figure is increasing through population growth.¹. About 80% of these disabled live in developing countries². They are among the most stigmatized, poorest and least educated³ that make people with disability more vulnerable to HIV than non-disabled people. It is commonly assumed that individuals with physical, sensory (deafness, blindness), or intellectual disabilities are not at high risk of HIV infection. They are incorrectly believed to be sexually inactive, unlikely to use drugs or alcohol, and at less risk of violence or rape than their non-disabled peers⁴. In contrast PWD are more vulnerable to contracting HIV mainly because of poverty, poor access to information on sexual health, poor access to health care, sexual abuse and exploitation. Studies have shown that Disabled adolescents are indulging in risky sexual behaviours, and are at equal risk as their non-disabled peers of developing HIV^{5,6}.

The UN general assembly in May 2008 adopted the Convention on the Rights of Persons with Disabilities⁷ amending national laws and policies giving greater protection to human rights of people with disabilities. With this increasing number of programmes are being launched in view that disabled people be accepted as equals by the rest of society, and live, work and learn like everyone else does. With this PWDs are becoming more and more involved with the society making these Disabled individuals (both male and female) around more likely to be victims of sexual abuse and rape than their non-disabled peers. Factors such as increased physical vulnerability, the need for attendant care, life in institutions, and the almost universal belief that disabled people cannot be a reliable witness on their own behalf makes them targets for predators⁸

Despite the high number of PWD living with HIV and the fact that the risk factors associated with disability are similar to those leading to HIV/AIDS, PWD are generally not recognised as a target group among HIV/AIDS policymakers and organisations. Furthermore, HIV prevention does not reflect prominently on the internal agenda of disability organizations.

Currently very little is known about the prevalence and risk of HIV among disabled people. No prevalent data exist for any disabled populations from sub-Saharan Africa, Asia, Europe, Central and South America, or the Caribbean. HIV control programmes are also not tailored to provide access to HIV/AIDS information and services for PWDs. PWDs are regularly excluded from existing HIV/AIDS information and services, i.e. prevention, care and treatment that take account of their disabilities.

¹ Helander, E. (1993). Prejudice and dignity: an introduction to community-based rehabilitation. NY: UNDP.

² Mont D. Measuring Disability Prevalence, SP Discussion Paper No. 0706. The World Bank, March 2007, unpublished WHO document No A29/INF.DOC/1 Geneva, 1976.

³ DFID. (2000). Disability, poverty and development. London: DFID.

⁴ Fine M., Asch, A. (1988). Women with disability. Philadelphia, PA: Temple University Press. 2) Russo, H. (2000). Girls and women with disabilities. . Oakland, CA: World Institute on Disability/ NY: Rehabilitation International.

⁵ The sexual behaviour of physically disabled adolescents. [Maart S](#), [Jelsma J](#). [Disabil Rehabil](#). 2010;32(6):438-43.

⁶ Knowledge, personal risk and experiences of HIV/AIDS among people with disabilities in Swaziland. [Yousafzai AK](#), [Dlamini PJ](#), [Groce N](#), [Wirz S](#). [Int J Rehabil Res](#). 2004 Sep;27(3):247-51.

⁷ (Convention on the Rights of Persons with Disabilities, UN Doc. Doc.A/61/611 [<http://www.un.org/esa/socdev/enable/rights/convtexte.htm>]. (entered into force 3 May 2008)

⁸ HIV/AIDS and People With Disability By Nora Ellen Groce, Global Health Division, Yale School of Public Health, Yale University, New Haven, CT 06520, USA; June 2003

Pakistan has responded to this nascent HIV epidemic with a comprehensive multi-faceted programme. Advocacy, awareness and prevention programmes mostly focus on people with high risk behaviours. Prevention messages are mostly conveyed in print and radio which are not accessible to blind and deaf people respectively. Civil Society Human and Institutional Development Programme (CHIP) in partnership with National AIDS Control Programme (NACP) and Sightsavers International has ventured a research on “Assessment of the Risks and Vulnerabilities of People with Disability towards HIV/AIDS in District Jehlum”.

People with Disability (PWDs) in Pakistan are more likely than the general population to be illiterate, unemployed and impoverished, but little is known of their HIV risk. Furthermore, the public and private sector have led major interventions around HIV/AIDS prevention, treatment, care and support, but none of the interventions have encompassed disabled people as people with special needs or as a vulnerable group for HIV infection. PWDs’ equal access to HIV/AIDS information and services is a key factor in the fight against the pandemic.

Keeping in view the aforementioned considerations, the research in hand was planned. The research finding hoped to assess the HIV knowledge and vulnerability of PWDs in Pakistan and to guide the AIDS Control Programmes to design user-friendly interventions targeting the PWD as a special population at risk. It entails proper understanding of the HIV related risks and vulnerabilities of PWDs and their specific needs in order to plan disability-inclusive HIV prevention programmes in future.

1.2 Objectives of the Study

- a. To assess HIV/AIDS related knowledge and behaviours of people with disability in Tehsil Sohawa, District Jehlum;
- b. To assess HIV/AIDS related knowledge and behaviours of family members of people with disability in Tehsil Sanghoie , District Jehlum;
- c. To assess HIV risks and vulnerabilities of people with disability in Tehsil Sohawa and Tehsil Sanghoie, District Jehlum;
- d. To identify the needs and preferences of HIV related information and services of people with disability in Tehsil Sanghoie and Tehsil Sohawa, District Jehlum;
- e. To give suggestions/recommendations for designing disability inclusive HIV interventions in District Jehlum and Sohawa.

Chapter 2: METHODODOLOGY

2.1 *Study design and Setting*

A cross-sectional survey was conducted from January 2, 2010 to March 31, 2010 in Tehsil Sohawa and Tehsil Sanghoie, District Jehlum.

2.2 *Case Definition*

The study populations for this study were:

2.2.1 People with disability (PWD)

Inclusion criteria

A person ages 8 to 60 years who has any physical disability, complete blindness or low vision;

Exclusion criteria

Unable to speak, understand or communicate by speaking;

2.2.2 Family members of PWD

A family member who is responsible for looking after the PWDs most of the time. This includes mother, father, husband, sister, son or daughter others who can communicate verbally with the interviewer.

2.3 *Sampling Technique*

All subjects meeting the above case definition have been accessed and taken consent of to be part of the research using the sampling frame of all identified/registered PWDs and their families by CHIP in District Jehlum.

2.4 *Study Tool and Key Variables*

A structured questionnaire was designed including socio-demographic data along with other variables of interest like HIV related knowledge, vulnerability of PWDs and risk behavioral patterns. The main socio demographic variables included age, sex, type of disability, education, marital status, no. of children, social contacts and income. Other variables included modes of transmission, sexual abuse, drugs, injections use of therapeutic treatment, dental treatment, any surgery etc. The structured questionnaire was initially developed in English and later translated in Urdu after finalization by the technical experts. Urdu version of questionnaire was pretested and finalized to be used in the field.

2.5 *Data Management Plan*

At the field level two supervisors and four teams comprising each of eight interviewers were hired. Teams stayed in Jehlum and Sohawa to ensure evening sessions for corrections and adaptations. Supervisors checked the quality of data collection by daily checking all questionnaires. The questionnaires were further edited by an editor to eliminate any errors and to ensure the accuracy of the data being collected. Data entry was done using especially designed software in access. All analysis has been done using SPSS version 12.

2.6 *Data Analysis Plan*

Descriptive statistics were computed for socio-demographic variables and potential risk factors. Frequencies, Mean and their Standard deviation were obtained as appropriate. Where needed continuous variables were categorized through Quartile Analysis. Detailed description of results using tables and figures has been illustrated in the final report.

2.7 *Ethical Approval*

The research proposal was submitted to the National Bioethics Committee at PMRC, Islamabad, for ethical approval. Following will be ethical considerations for conducting the study:

2.7.1 Verbal consent and voluntary participation

Verbal consent and voluntary participation was obtained prior to recruitment. This was done through a standard consent form at the beginning of the questionnaire that was read out to the participant by the interviewer. The interviewer subsequently signed at an appropriate space on the questionnaire to indicate that consent was obtained before proceeding with data collection.

2.7.2 Confidentiality

Considerable efforts were being made to maintain the confidentiality of participation. All the questionnaires were anonymous and it was conveyed that no individual information will be disseminated, but the results will be disseminated in aggregated form.

2.8 Consent Form

A verbal consent form was developed in English and translated in Urdu. Urdu version of the consent form was used in the field. Consent was read out to the study subjects and after their approval the interviewer signed the form as an evidence of consent for the study participation.

2.9 Development of Questionnaire and Translation into Urdu

Two separate questionnaires for PWDs and their Family Members were developed as per requirements of the research. Initially the questionnaire was developed in English which was later translated into Urdu. The translated version was discussed amongst the members and unanimously agreed upon. Its validity and practicality regarding the nature of the study was looked into so that the transparent investigation could be carried out. Depending upon the feedback of the field staff and in result of the review meeting of the CHIP's officials at Islamabad a final draft was produced.

2.10 Data collection

2.10.1 Hiring of Interview Teams

A team of field researchers was hired after going through interviews and evaluation of the candidates. The field team consisted of community mobilisers a) One male community mobiliser b) one female community mobiliser who would visit various villages of Tehsil Sohawa and Tehsil Sanghoie to conduct the interviews. One male supervisor and one female supervisor were assigned the task of monitoring the activities of the community mobilisers who would support them during the activity if required. This would ensure the accuracy and the validity of the data being gathered from the respondents. After collecting the information from the community, the questionnaire was gone through by the supervisor for filtering the data. Editing of the collected data was further edited by for appropriateness of answers.

2.10.2 Training and pilot testing

The team assigned for the research was thoroughly trained prior to the execution of the activity. The training was conducted at the CHIP head office and the concerned field offices. The Research team was briefed about the understanding of HIV/AIDS: facts and myths, objection and methodology of the study, basic interviewing skills, and ethical issues including confidentiality. The participants were also made to deliver the questionnaire. The questionnaire was quite technical in nature and could not be progressed without complete understanding. As the introductory part of the questionnaire consisted of a consent form which required an effort to practice. The practice sessions were held to ensure complete understanding of the study and to avoid any mishaps during the activity. To gauge the accuracy and practicality of the questionnaires, each field researcher was asked to conduct mock interviews and fill-in the questionnaires. The filled questionnaires were assessed by the researchers and the team was briefed on the observations.

2.10.3 Data collection procedure

The study of the respondents was carried out in two phases. In the first phase the villages of Tehsil Sohawa were covered and in the consequent phase the villages of Tehsil Sanghoie were concluded.

Chapter 3: RESULTS

3.1 People with Disability

3.1.1 Socio-Demographic Characteristics

A total of 128 people with disability (PWD) were interviewed in the two Tehsils (Sanghoie and Sohawa). This section describes the key socio-demographic characteristics of the surveyed PWDs.

Table 3.1.1: Socio-demographic characteristics of PWD, 2010

Characteristics	Total %(n= 128)	Sanghoie %(n= 82)	Sohawa %(n= 46)
Gender			
• Male	55.5 (71)	64.6 (53)	39.1(18)
• Female	44.5 (57)	35.4 (29)	60.9(28)
Type of disability			
• Physical disability	79.7(102)	80.5 (66)	78.3 (36)
• Blind	4.7(6)	6.1 (5)	2.2 (1)
• People with Low vision	15.6(20)	13.4 (11)	19.6 (9)
Age			
• <19	25.8(33)	26.8 (22)	23.9 (11)
• 19 – 29	22.7(29)	22.0(18)	23.9 (11)
• 30- 44	24.2(31)	22.0 (18)	28.3 (13)
• > 44	27.3(35)	29.3 (24)	23.9 (11)
Mean age \pm SD years	32.4 \pm (15.8)	32.8 \pm (16.5)	31.7 \pm (14.5)
Marital status			
• Unmarried	55.5 (71)	51.2 (42)	63.0 (29)
• Married	33.6 (43)	36.6(30)	28.3 (13)
• Separated	2.3 (3)	1.2 (1)	4.3(2)
• Divorced	1.6 (2)	2.4 (2)	0
• Widowed	7.0 (9)	8.5 (7)	4.3(2)
Years of education			
• Quranic education	17.2(22)	19.5(16)	13.0 (06)
• Illiterate	25.8 (33)	23.2(19)	30.4(14)
• Up to 5 years	34.4(44)	31.7(26)	39.1(18)
• 06 to 10 years	21.1(27)	24.4(20)	15.2(07)
• > 10 years	1.6(2)	1.2(1)	2.2(01)
Having at least one child*	85.9(49)	87.5(35)	82.4(14)
Profession			
• Do nothing	42.2(54)	40.2(33)	45.7(21)
• Some profession	57.8(74)	59.8(49)	54.3(25)
Type of house			
• Pakka	25.0(32)	31.7(26)	13.0(6)
• Kacha	11.7(15)	12.2(10)	10.9(5)
• Semi-Pakka	63.3(81)	56.1(46)	76.1(35)
Share room with any one	89.1(114)	90.2(74)	87.0(40)
Mean \pm SD income/month(PKR)	1044 \pm 2273	1390 \pm 2600	423 \pm 13334

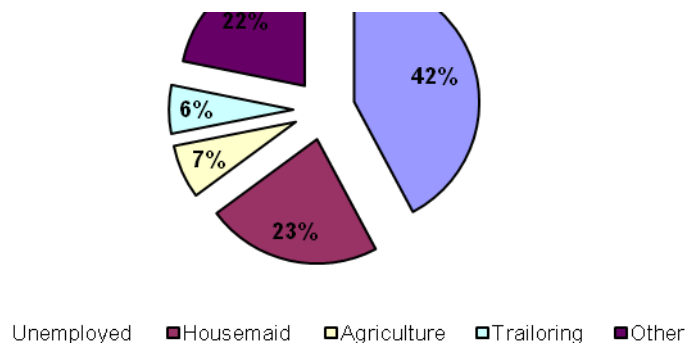
* Among those who were married

Out of the 128 PWDs interviewed 55.5% were male and 44.55% were females, however there were more females PWDs in Sohawa as compared to Sanghoie (table 3.1.1.). This does not reflect the overall proportion of disabled people in the two Tehsils.

Approximately, 80% were physically disabled, 15.5 % were people with low vision and 4.7% were people with total blindness. The overall mean age was $32.4 \pm (15.8)$, in Sanghoie the mean age was 32.8years and in Sohawa it was 31.7 years. Overall, 33.6% of the PWDs were currently married and 10.9% were ever married. The PWDs in Sanghoie reported more married than Sohawa (36.6% vs. 28.3). Segregated by type of disability, high proportion of physically disabled people tended to be more married as compared to those with low vision and complete blindness. High proportion (74.2%) of PWDs had received some education which was either formal or Quranic education.

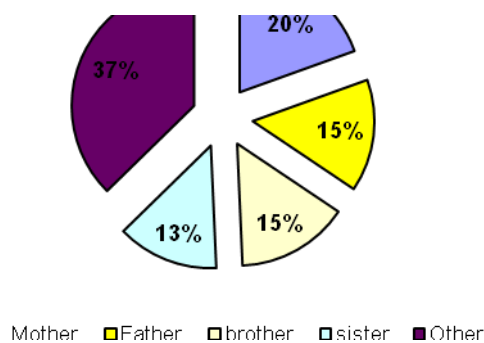
Overall more than half of the subjects (57.8%) reported being engaged in some kind of economic activity, 59.8% in Sanghoie and 54.3% in Sohawa. The more common professions reported were working as housemaid, involved in agriculture work, tailoring etc. (figure 1.1a). It was observed that 40 of 102 physically disabled, 10 of 20 people with low vision and 4 of 6 people with blindness were reported not being involved in any kind of work.

Figure 3.1.1a: Proportion of involvement of PWDs in some profession



Overall, 63.3% of the houses were semi Pakka, with 56.1% in Sanghoie and 76.1% in Sohawa. About 89% of the PWDs shared room with some other family members (table 3.1.1 and figure 3.1.1b) however only 2 physically disabled subjects reported that there are some cats and hens in the room where they sleep.

Figure 3.1.1b: Proportion of PWDs with whom they share their room



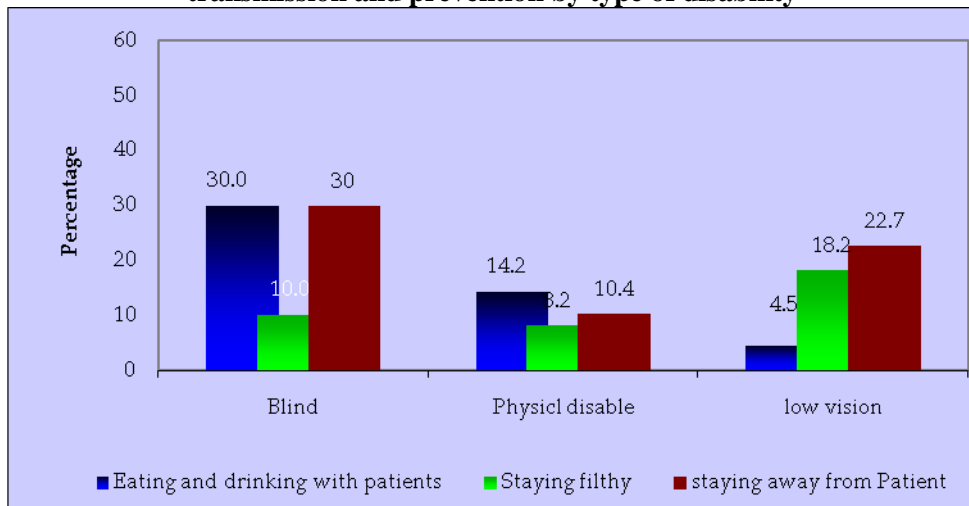
3.1.2 HIV knowledge

Table 3.1.2a: HIV Related Knowledge of PWD, 2010

Knowledge Area	Total %(n= 128)	Sanghoie %(n= 82)	Sohawa %(n= 46)
Ever heard of HIV and/or AIDS	41.4 (54)	40.2 (33)	43.5 (20)
Healthy looking person can have HIV / AIDS	42.2(54)	40.2 (33)	45.7 (21)
Is it curable	32.8(42)	26.8 (22)	43.5 (20)
Mode of HIV transmission			
• sexual intercourse	25.0 (32)	28.0 (23)	19.6 (9)
• sharp instrument/needle	15.6 (20)	9.8 (8)	26.1 (12)
• kissing, touching, hugging	5.5 (7)	4.9(4)	6.5(3)
• eating and drinking with patients	18.0(23)	18.3(15)	17.4(8)
• blood transmission	11.7(15)	11.0(9)	13.0(6)
• staying filthy	12.5 (16)	13.4(11)	10.9(5)
• through animals/insect	1.6(2)	2.4(2)	0
Mode of prevention			
• Condom	21.9 (28)	26.8 (22)	13.0 (6)
• Sexual abstinence	12.5 (16)	11.0 (9)	15.2 (7)
• Staying away from HIV patient	17.2(22)	15.9(13)	19.6(9)
• Staying clean	8.6(11)	8.5(7)	8.7(4)
Know where to receive HIV test	21.1(27)	19.5 (16)	23.9 (11)
Self perception of risk for HIV	35.9 (46)	34.1 (28)	39.1 (18)

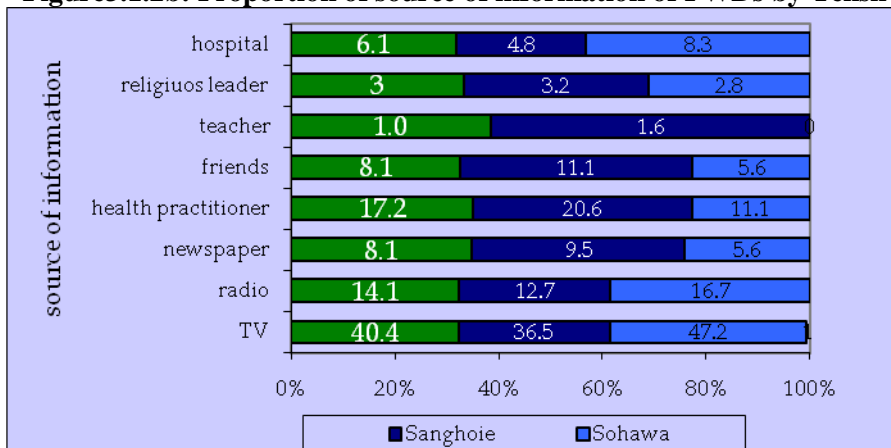
Approximately 41% had ever heard of HIV/AIDS. PWDs in Tehsil Sanghoie and Tehsil Sohawa reported approximately the same level of awareness. Forty two percent of the PWDs believed that healthy looking person can have HIV/AIDS (Table 3.1.2a). Knowledge of sexual intercourse as mode of transmission of HIV was prevalent among 25% of PWDs, but only 15.6% knew that HIV can be transmitted by sharp instruments/syringe/needle. The knowledge of blood transfusion as mode of transmission was still lower (11.7%), however substantially large proportion of PWDs also reported misconception on mode of transmission like eating and drinking with patients (18%) and staying filthy (12.5%). Approximately 22% of the PWDs knew that using condom is an effective method of prevention, 12.5% believed that sexual abstinence is effective (Table 3.1.2a). None of the respondents know using clean syringe as a mode of prevention from HIV/AIDS. The misconception of staying away from patient as mode of transmission was also reported by 17.2%. Among those who have heard of HIV/AIDS a very large proportion have false impression of mode of transmission and prevention of HIV (table3.1.2a). Only 21.1% of PWDs knew of a place where they could be tested, and about 36% perceive to be at risk of HIV/AIDS.

Figure 3.1.2a: Proportion of PWDs who reported the common misconception of mode of transmission and prevention by type of disability



Among those who have heard of HIV, the misconception on common mode of transmission and prevention of HIV/AIDS was reported to be substantially high among the people with blindness followed by people with low vision and physical disability (Figure3.1.2a).

Figure3.1.2b: Proportion of source of information of PWDs by Tehsil



Overall, among those who have heard of HIV/AIDS the common source of information reported are TV, health practitioner and radio (Figure 3.1.2b). The modes of information commonly reported by the respondents in both Tehsils were the same. Data was also analyzed for what were the common sources of information among different types of disabilities. Among the physically disabled, proportion of response for TV as source of information was 37.8%, health practitioner was 18.3% and radio was 13.4%. Among the people with low vision, proportion of response for TV was 53.8% followed by radio 15.4%.

3.1.3 Vulnerability

Table 3.1.3a: Vulnerability OF PWDs

Vulnerability Area	Total %(n= 128)	Sanghoie %(n= 82)	Sohawa %(n= 46)
Therapeutic Injection usage on regular basis	39.8(51)	45.1(37)	30.4(14)
Consistent use of new syringe for therapeutic injections*	92.2(47)	94.6 (35)	85.7 (12)
Ever operated	25.8 (33)	24.4 (20)	28.3 (13)
Tooth extraction	25.8 (33)	23.2 (19)	30.4 (14)
Blood transfusion	13.3 (17)	11.0 (9)	17.4 (8)
Ever Arrested	9.4 (12)	12.2 (10)	4.3 (2)
Ever been beaten	20.3 (26)	15.9 (13)	28.3 (13)
Ever being sexually harassed	2.3 (3)	1.2 (1)	4.3 (2)
Taken alcohol in past 6 month	1.6 (2)	2.4 (2)	0
Taken any drug through injection	0.8 (1)	1.2 (1)	0

* Among those who responded positively to the initial question

Overall, approximately 40% of the PWDs reported regular use of therapeutic injection. Among those who inject, 92.7% reported always using new syringe for injections (Table 3.1.3a). Other risk factors which were reported by PWDs were ever operated and tooth extraction 25.8%, blood transfusion 13.3% and ever arrested 9.4%. The ever arrested was reported substantially high by the PWDs of Sanghoie as compared to those of PWDs (12.2% vs. 4.3%); all the PWDs who reported being ever arrested are physically disabled. Having ever been physically beaten and sexually harassed was reported by 20.3% and 2.3% PWDs respectively. Only one physically disabled PWD reported as injection drug user (Table 3.1.3a).

Table 3.1.3b: Sexual exposure of PWDs aged 15 years and above, 2010

Sexual exposure	Total %(n= 128)	Sanghoie %(n= 82)	Sohawa %(n= 46)
Ever had sexual exposure	51.0 (47.7)	51.5(35)	34.8(16)
Age at first sexual encounter Mean(± SD)	22.7 ±22.0	23.7 ±24.0	20.3 ±18.0
Sexual activity with spouse*	87.0 (47)	83.8(31)	94.1(16)
Sexual activity with other person*	9.3(5)	10.8(4)	5.9(1)
Use of condom during sex*	13.5 (7)	5.7(2)	29.4(5)
Ever forced to have sex	3.1 (4)	3.7(3)	2.2(1)

Due to the nature of the questions and social norms the risk of acquiring HIV/AIDS was inquired by those PWDs who were above 15 years of age. Percentage of subjects above 15 years was 84.4%. About half of the PWDs above 15 years reported ever having a sexual relation. The mean age of first sexual encounter was 22.7years. Sexual encounter was reported at a younger age group among PWDs in Tehsil Sohawa as compared to those in Tehsil Sanghoie. Eighty-seven percent of the PWDs reported having sex with their spouse while 9.3% reported sex outside the marital relationship. Of those who reported having sex with other person, 2 had sex with a male while 3 had sex with a female. Condom use was reported very low. Importantly, 04 physically disabled respondents also reported forced sexual encounters (Table 3.1.3b).

3.2 Family members of People with Disabilities

3.2.1 Socio-Demographic Characteristics

A total of 125 family members (FMs) of 128 PWDs were interviewed.

Table3.2.1: Socio-demographic characteristics of FM of PWDs, 2010

Characteristics	Total %(n= 125)	Sanghoie %(n=81)	Sohawa %(n=44)
Relation with PWD			
• Mother	15.2(19)	17.3(14)	11.4(5)
• Father	21.6(27)	14.8(12)	34.1(15)
• Sister	4.0(5)	1.2(1)	9.1(4)
• brother	16.8(21)	21.0(17)	9.1(4)
• Others	42.4 (53)	45.7(37)	36.3(16)
Age Mean age ± SD (median) years	38.8± 16.1 (37)	38.8± 15.2 (38)	38.8± 17.7 (35.5)
Years of education			
• Quranic education	20.8(26)	21.0(17)	20.5(9)
• Illiterate	25.6(32)	24.7(20)	27.5(12)
• Up to 5 years	18.4(23)	16.0(13)	22.7(10)
• 06 to 10 years	30.4(38)	34.6(28)	22.7(10)
• > 10 years	4.8(6)	3.7(3)	6.8(3)
Marital status			
• Unmarried	22.4(28)	23.5(19)	20.5(9)
• Married	65.6(82)	69.1(56)	59.1(26)
• Separated	0.8(1)	0	2.3(1)
• divorced	0.8(1)	0	2.3(1)
• Widowed	10.4(13)	7.4(6)	15.9(7)
More than one PWD in the family	12.8(16)	17.3(14)	4.5(2)
Profession			
• Some economic activity	87.9(110)	88.7(72)	86.4(38)
• No economic activity	12.0(15)	11.3(9)	13.6(6)
Mean ± SD income/month(PKR)	6206 ± 4404	5884 ± 4142	6750 ± 4815

Fathers were the most commonly (21.6%) reported relationship that were responsible for taking care of the PWDs followed by brothers (16.8%) and mothers (15.2%) (Table 3.2.1). Among the other relationships that took care of the PWDs were daughters, sister-in-law and cousins etc. However in Sanghoie the most common family members were brothers, mothers followed by fathers. The mean age of the FM was 38.8± 16.1 (median 37yr). Approximately quarter of the Family Members were illiterate, thus most of the PWDs were looked after by people who had some education. Overall, 66% of the family members were currently married but about quarter of the Family Members were also unmarried. Overall, substantially large proportion (12.8%) of the families reported that they have more than one disable person present at home. More than one PWD per house was reported in Sanghoie (17.3%) as compared to Sohawa (4.5%). About 88% of the family members who look after the PWDs reported being engaged in some kind of economic activity. The mean monthly household income was 6,206 PKR.

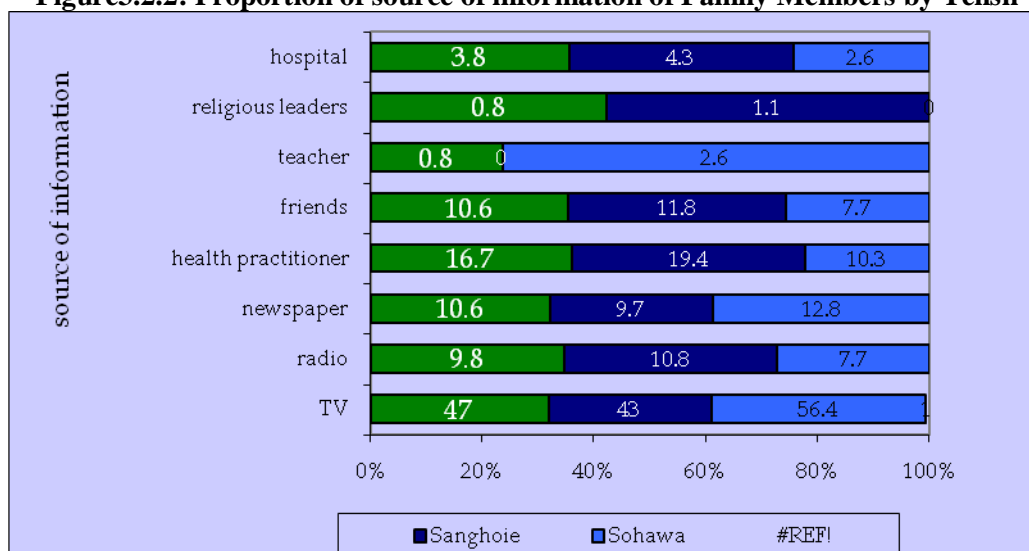
3.2.2 HIV knowledge

Table 3.2.2: HIV Related Knowledge of FMs of PWDs, 2010

Knowledge Area	Total %(n= 125)	Sanghoie %(n= 81)	Sohawa %(n= 44)
Ever heard of HIV and/or AIDS	60.8(76)	64.2(52)	54.5(24)
Healthy looking person can have HIV / AIDS	70.4 (88)	84.0(68)	45.5(20)
Is it curable	63.2 (79)	69.1(56)	52.3(23)
It is a serious disease	76.0(95)	88.9(72)	52.3(23)
Mode of HIV transmission			
• Sexual intercourse	45.6(57)	44.4(36)	47.7(21)0
• Sharp instrument/needle	2.4(3)	3.7(3)	0
• kissing, touching, hugging	25.6(32)	28.4(23)	20.5(9)
• Eating and drinking with patients	16.0(20)	19.8(16)	9.1(4)
• Blood transmission	16.0(20)	18.5(15)	11.4(5)
• staying filthy	0.8(1)	1.2(1)	0
• through animals/insect	14.4(18)	17.3(14)	9.1(4)
Mode of prevention			
• Condom	16.0(20)	18.5(15)	11.4(5)
• Sexual abstinence	47.2(59)	59.3(48)	25.0(11)
• Staying away from HIV patient	12.0(15)	12.3(10)	11.4(5)
• Staying clean	22.4(28)	24.7(20)	18.2(8)
• Using clean syringe	1.6(2)	1.2(1)	2.3(1)
Know where to receive HIV test	43.2(54)	48.1(39)	34.1(15)
Perceive risk for PWD	69.6(87)	80.2(65)	50.0(22)

Approximately overall, 61% of the family members who take care of the PWDs had ever heard of HIV/AIDS, Family Members in Sanghoie reported to be better aware of HIV/AIDS as compared to Sohawa (64.2% vs. 54.5%). About 70% of the Family Members believed that healthy looking person can have HIV/AIDS; however there is a considerable difference in this perception among the Family Members in both the Tehsils. Only 45.5% of the Family Members knew that healthy looking person can have HIV/AIDS as compared to 84.0% in Sanghoie. Overall, 63% knew that it can be cured and 76% perceive it as a very serious disease, however this knowledge was reported very low by Family Members in Sohawa. Knowledge of sexual intercourse as mode of transmission was reported by 45.6%, but only 2.4% knew that HIV can be transmitted by sharp instrument/needle. 16 percent of Family Members knew that HIV can be transmitted through contaminated blood transfusion. Substantially large proportion of Family Members reported misconception on mode of transmission like kissing, touching, hugging (25.6%), eating and drinking with patients (16.0%) and through animal/insect bite (14.4%). This misconception was reported relatively lesser in Sohawa as compared to Sanghoie (table 3.2.2). 16 percent of Family Members knew that using condom is an effective mode of HIV prevention, 47.2% believed that sexual abstinence is effective. Very low proportion of Family Members (1.6%) knew that using clean syringe for injection can prevent HIV/AIDS. The misconception of staying away from patient was reported by 12.0 % and staying clean by 22.4%. Overall, approximately 43% of Family Members reported that they knew where the HIV test is done. Approximately 70% of the Family Members believed that a PWD was at an increased risk of acquiring HIV as compared to others.

Figure3.2.2: Proportion of source of information of Family Members by Tehsil



Overall, among those who have heard of HIV/AIDS the common source of information reported were TV, health practitioners, newspaper and friends (Figure 3.2.2). The modes of information commonly reported by the respondents in both Tehsils were the same.

3.2.3 Vulnerability of PWDs as perceived by Family Members

Table3.2.3: Vulnerability of PWDs according to their Family Members, 2010

Vulnerability area	Total % (n= 125)	Sanghoie % (n= 81)	Sohawa % (n= 44)
Therapeutic Injection usage on regular basis	32.8(41)	42.0(34)	15.9(7)
Consistent use of new syringe for therapeutic injections*	92.5(37)	100(33)	57.1(4)
Increase Physical vulnerability of PWDs	43.2(54)	40.7(33)	47.7(21)
Increase sexual vulnerability of PWDs	40.0(50)	43.2(35)	34.1(15)
Ever Left alone at home	68.0(85)	65.4(53)	72.7(32)
Ever go outside alone	71.2(89)	67.9(55)	77.3(34)
PWD physically abused by family member	20.8(26)	19.8(16)	22.7(10)
PWD physically abused by outsiders	9.6(12)	8.6(7)	11.4(5)
PWD sexual abuse by family member	7.2(9)	9.9(8)	2.3(1)
PWD sexual abuse by outsiders	4.8(6)	7.4(6)	0

* Among those who respond positive to the initial question

Approximately 33% of the Family Members reported that PWDs use therapeutic injection on regular basis, a much higher proportion of therapeutics injection use was reported in Sanghoie (42.0%) as compared to Sohawa (15.9%). Among those PWDs who use therapeutic injection, 92.5% of Family Members reported that they ensure that for all injection a new syringe was used. This was consistent with what was reported by PWDs (Table 3.1.3a). A considerable proportion of Family Members believe that people with disability are more vulnerable both physically and sexually (43.2% vs. 40.0%) as compared to others. A very large proportion of PWDs was either left alone at home or had gone out of the house unattended. 68 percent of Family Members reported that they had ever left the people with disability alone at home and 71.2% reported that PWDs had gone out alone, which shows a very high risk of both physical and sexual risk for PWDs. About 21% of the Family Members reported that PWDs were more physically abused by them and 9.6% reported being abused outside home. Overall, 7.2% of the Family Members reported that PWDs had ever being sexually abused by a family member and 4.8% reported being sexually abused outside. The sexually abused were reported more by Family Members of Sanghoie as compared to Sohawa.

Chapter 4: DISCUSSION AND RECOMANDAITON

This study is the first among PWDs and their family members in Pakistan which has assessed the knowledge and vulnerability of HIV/AIDS. It shows that the situation in Pakistan is not much different from other countries regarding disability and HIV/AIDS. People with disabilities are a 'forgotten' group within our HIV related development programmes and government policies.

The overall economic condition of Pakistan is poor. 45% of the people are living below the poverty line; the majority of this proportion is residing in rural Pakistan. The people with disability are future compromised in term of economic opportunities. This is reflected in the finding of the studies as the mean income of the PWDs is very low.

The study showed that large percentage of PWDs above 15 years of age are sexually active and some also are engaged in sexual relationship outside marital relationship which is consistent with findings from other studies. Family Members of the PWDs perceive that they are more prone to physical and sexual abuse. Due to increasing efforts of NGOs for including PWDs in the society and encouraging them in their contribution to household income, the PWDs are becoming more and more economically independent thus increasing their normal biological desires like marriage, relationships etc. Their movement within the society makes them more vulnerable to HIV without proper sexual education and protective measurements. Their vulnerability in future increases due to lack of knowledge and their efforts to become more society expectable. PWDs can be an easy target for sexual abuse and rape. A study from India⁹ showed that large percentage of women with physical and mental disabilities have been subject of abuse. Men often promise to marry a woman with a disability, but sleep with her and walk away again. Another group of disabled persons are in prostitution, because it is the only way in which they can make money to survive.

The data from the study shows that although substantial proportion of both PWDs and their Family Members has heard about HIV, they still have misconception on mode of transmission. They believe that transmission is only through sexual contact and lack of knowledge of misuse of syringe in an environment where unsafe therapeutic injection is very high^{10, 11, 12} puts them at higher risk of HIV. This risk increases also due to PWD's inability to express themselves encouraging the so called health providers for this criminal act.

TV remains the most powerful media of communication to all the PWDs including for blind which shows that the messages are either heard or watched with care. Even full message is not being communicated to both the PWDs and their Family Members. NACP have a well established advocacy and communication department which have produced material for parliamentarians, uniformed personnel (including police), media personnel, educationists, religious leaders, civil servants and others. There are no messages developed keeping in consideration the different disabilities. The low literacy rate of the Family Members further makes the communication of messages about HIV/AIDS more difficult.

Based on the finding of the studies the following recommendations are made:

Organizations working with people with disability should sensitize the AIDs control programmes to include HIV/AIDS and disability issues in their advocacy programmes e.g. advocating for HIV and

⁹ Mohapatra and Mohanty (2004) Orissa,

¹⁰ J Coll Physicians Surg Pak. 2006 Sep;16(9):622-4. *The cost of unsafe injections in pakistan and challenges for prevention programme.* Altaf A, Janjua NZ, Hutin Y

¹¹ J Ayub Med Coll Abbottabad. 2004 Jul-Sep;16(3):35-8. *Determinants of therapeutic injection overuse among communities in Sindh, Pakistan.* Altaf A, Fatmi Z, Ajmal A, Hussain T, Qahir H, Agboatwalla M.

¹² Int J Infect Dis. 2005 Jan;9(1):52-9. *Long-term improvement in unsafe injection practices following community intervention.* Luby S, Hoodbhoy F, Jan A, Shah A, Hutin Y.

AIDS information written in brail, counseling in sign language at VCT Centers and Hospitals and disabled people to be part of the advocacy teams for funding rising for HIV and AIDS programmes.

NGO need to work closely with NACP to develop special package of information materials which are target specific, for example, more sign language programmes on Television. Seminars for the disabled people, AIDS information in Braille and dramatizing HIV and AIDS information through street theater for the deaf and singing. NGOs should also educate the public on issues related to people with disability with reference to HIV/AIDS.

Through a participatory and consultative process involving organization working with people with disability and AIDS control programmes should formulate HIV/AIDS policies that will enable the implementation of HIV/AIDS programmes for PWDs, their family members and staff.

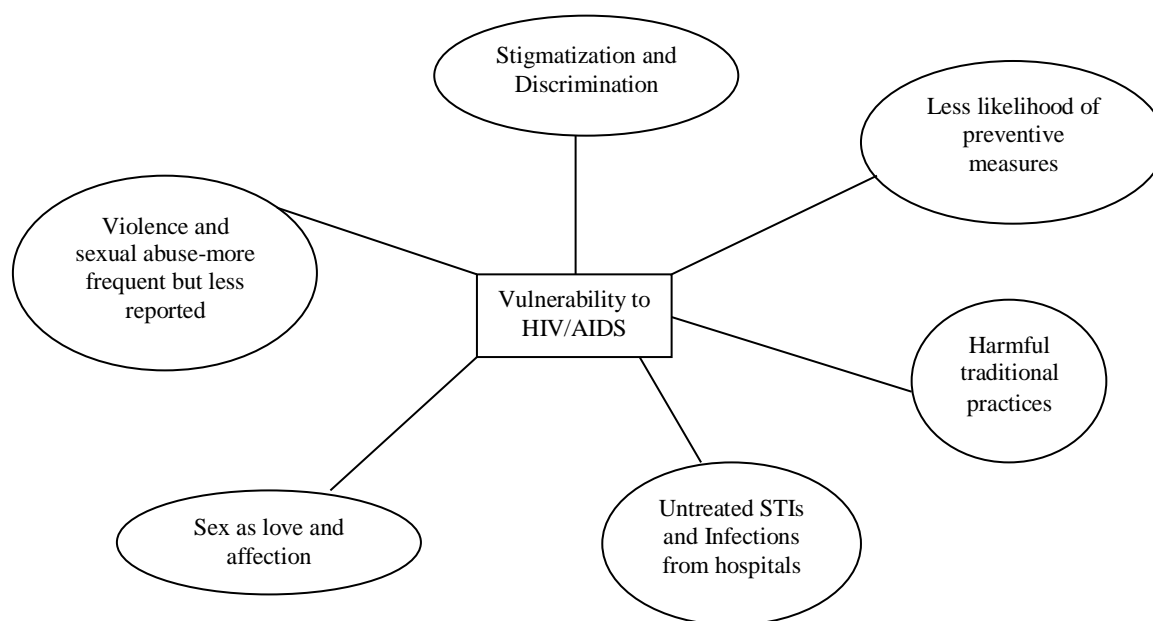
While developing empowering programme for people with disability special emphasis should be made to develop mechanism for the disable person to enable them to deal with society, economic and cultural factors that pre dispose them to enable them to HIV/AIDS.

Since this is the first time that HIV/AIDS issue was raised among the disable people, due to lack of trained personnel to communicate with deaf they were not included in the quantitative survey. However separate FGDs were held with deaf person and their families to understand the vulnerability and knowledge of HIV/AIDS (See section B). Furthermore this report can be used as starting point into further understanding of issues of disability and HIV/AIDS.

Section B: Qualitative Section

B1. Background

HIV/AIDS poses one of the most daunting challenges of developing countries today. Around 33 million people live with HIV⁴, and over 20 million people have died from AIDS since the first cases were diagnosed in the early 1980sⁱ. It is estimated that approximately 10% of the world's population live with a disabilityⁱⁱ, of whom the overwhelming majority live in low-income countries. There is little in-depth knowledge of the sexual health of PWDs in developing countries, but the existing evidence indicate that the following aspects increase the risk of PWD contracting HIVⁱⁱⁱ:



A pilot survey of HIV/AIDS knowledge among deaf population in Swaziland^{iv} identified significant knowledge gap between disabled and non disabled respondents. People with disability used to believe in incorrect modes of HIV/AIDS transmission and prevention. 99 % deaf population was facing problems in interpersonal communicating with health care facilities. As a result they were not able to use testing facility and voluntary counseling facility. Disabled people in many countries are generally excluded from HIV/AIDS prevention interventions with a belief that disabled people cannot catch HIV/AIDS infection assuming that disabled people are not sexually active and therefore they are at little risk of infection^v.

Moreover, a matter of even greater despair is that disabled people are not reached by HIV and AIDS prevention, treatment and care programmes. Prevention messages are mostly transmitted in print and radio which are not accessible to blind and deaf people respectively. Service points without wheelchair ramps do not accommodate people with physical disabilities. Fortunately, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has entered into international law and it requires that all governments ensure that the human rights of people with disabilities are realized including the right of information.

People with disability (PWDs) in Pakistan are more likely than the general population to be illiterate, unemployed and impoverished, but little is known of their HIV risk. There is dearth of evidence on HIV related knowledge and risk perceptions of people with disability with almost no qualitative or quantitative study conducted on the issue. Furthermore, the public and private sector have led major interventions around HIV and AIDS prevention, treatment, care and support, but little or none has targeted the disabled people as people with special needs or as a vulnerable group for HIV infection. There is a dire need to guide the AIDS Control Programmes to design user-friendly interventions targeting the PWD as a special population at risk. It entails proper understanding of the HIV related risks and vulnerabilities of PWD and their specific needs in order to plan disability-inclusive HIV prevention programmes in future.

In seeking to understand the level of HIV awareness and vulnerability of people with disability and their information needs in Pakistan, the present study addresses the research question using an anthropological perspective. With the immediate aim to provide empirical evidence for formulation of targeted HIV prevention interventions for PWD, the research explored through the family members of PWD: (1) The knowledge on HIV and understanding of modes of transmission, (2) Their perceptions of the risks and vulnerabilities of PWD to HIV, (3) Their needs and preferences for HIV related health communication as well as prevention and treatment services.

B2. Methods

This study was undertaken as part of the larger quantitative study to document the HIV knowledge and behaviors of PWD, their risks and vulnerability perceptions and their needs for relevant services. The quantitative study included all people with physical disabilities and people with blindness or low vision registered with the CHIP along with their family members in Tehsil Sohawa and Tehsil Sanghoie of District Jehlum. The people with hearing and vocal disabilities and their family members were thus studied through qualitative research methods based on focused ethnographic approach were used. A focused ethnographic approach allows an exploration of a distinct subject (HIV knowledge and risks) from a broad cultural perspective. Data was collected from rural village of Tehsil Sohawa, District Jehlum, Rawalpindi. The respondents included both male and female family members of the people with hearing and vocal disability who were also the primary caretakers of the people with disability. Men and women aged 18-65 years, of all socio-economic classes and levels of education were included in the sample. A total of two focus-group discussions were held, one with 10 men and other with 12 women. They ranged in age from 18-65 years. The focus group discussions were conducted in Punjabi and Urdu, digitally recorded and later translated and transcribed and using a social constructivist, interpretative approach, and the data was coded and domains were developed. The results of this study are specific to data from the rural population of District Jehlum, Rawalpindi.

B3. Findings

B3.1 HIV Knowledge and Modes of Transmission

Male Family Members of PWDs were mostly aware that infected syringes or blood from drug addicts can lead to spread of a number of diseases including TB and cancers. Only one respondent knew that AIDS is transmitted through sexual contact. Almost all of them had heard about HIV/AIDS and the sources mentioned were other patients and their relatives and talk shows on TV. Most of the respondents thought AIDS as a serious disease leading to death. They said that the patients become extremely weak and get detached from the routine life. They were also of the opinion that a healthy looking person can get HIV/AIDS and if it is diagnosed early, it can be controlled. The patient has to get himself tested and then take full course of medicines. However, some of the respondents said that AIDS cannot be completely cured. If one is taking medicines, he will be fine but if he stops the therapy, the disease will erupt again. One of the respondents shared that he has seen some patients of AIDS in Rawalpindi General Hospital, Fauji Foundation Hospital, Combined Military Hospital and Civil Hospital. He described the patients being very weak, with blackened skin and face and skeletal legs and arms. The patients can manage to walk around and take food but the appearance is very scary.

“Mareez laghar ho jata hai, kisi kaam ka naihn rehta, bahar say theek ho ga laikin andar say khokhla ho jata hai” (Man, aged 35 years, Brother of a PWD)

Female Family Members of PWDs did not know of any disease that spreads through blood. They opined that use of infected syringes can spread many diseases like cancers, fever, cough and flu. They also referred to spread of germs through towel, soap and brush but did not know the diseases. Regarding sexually transmitted infections, they were of the view that sexual contacts can lead to spread of TB and hepatitis. They had mostly heard of HIV/AIDS and the source mentioned was TV commercials. They were of the opinion that it is a dangerous disease and can be transmitted to others very easily. They thought that AIDS is a fatal disease and there are medicines to treat it but some patients get better with the treatment and some do not. If one gets AIDS, the symptoms would include cough with bloody sputum, fever, body aches and many such ailments. Most of the respondents

thought that a healthy looking person cannot have AIDS and AIDS patients are usually very weak; he would have consistent cough and would also have fever; so by the look of that person one would know that he is an AIDS patient. They were mostly of the view that if AIDS is diagnosed at an early stage, it can be completely cured with treatment.

B3.2 Risk and Vulnerability Perception

Male Family Members of PWDs while responding to the likelihood of HIV transmission from one person to another, a couple of respondents said it was not for sure. In their opinion, the patients of TB are asked to be kept in isolation from day-to-day utensils, food etc but for AIDS patients they have not heard of such preventions. However, the rest of the respondents said that AIDS can be spread through sexual contact, eating, drinking in same utensils, meeting each other in routine etc. They said that if there is a patient of HIV/AIDS in the house, his room should be separated and also his utensils soap and towel. The care taker should use gloves while caring for the patient. The patient should not keep a contact with others because it can lead to the transfer of germs.

Female Family Members of PWDs were of the view that their grandparents never caught any germs like this. In this new era, the germs are also very different from old times. One of the respondents mentioned that she did not complete the EPI vaccination course for the newborn because she thinks it is useless and the baby would not get any disease. She further elucidated that no one of their forefathers ever caught any disease but in today's world the germs readily affect people. Another respondent narrated the problem of epistaxis of her boy as being a disease spread by blood. Majority agreed that in this modern age, the adolescents and young girls are having many problems in their monthly periods as well. They have some issue with their blood, every girl complains of pain during menstruation, and leucorrhoea and backache. Diseases like hepatitis B and stomach problems are quite common in the present era. One of the respondents showed concern over very little girls of 8-9 years having leucorrhoea problem.

“Is dor main bemarian bohat hain, her bachchi ko dard hota hai” (Woman, aged 50 years, Mother of a PWD)

“Jaraseem ho saktay hain, door rehna hi achcha hota hai” (Woman, aged 55 years, Sister-in-Law of a PWD)

Regarding risk of HIV transmission, the majority thought that AIDS germs can be passed on through social contact with patient like sitting with him and using same utensil to eat or drink. Some of them recommended use of gloves while taking care of such patients. One respondent negated this by saying that she had looked after her mother who had cancer and people used to advise her to stay away to avoid the germs. She said that she used to give her bath and feed her and take all the necessary care before her death and yet she was free of any germs from her mother.

“Hota wohi hay jo Allah ka hukam hota hai, aur yeh kisi ko bhi ho sakta hai” (Woman aged 27 years, wife of a PWD)

One of the respondents shared that a woman in their village died of cancer which is also a deadly disease. Another woman had a wound on her leg and she died. Also one woman had put henna on her head to dye hair and she got paralysis and died of that just in two weeks time.

“Mareez tau pait key dard say bhee mar sakta hai.” (Woman, aged 55 years, Mother of PWD)

While responding to the methods of prevention of HIV transmission, many of the respondents opined that prevention is necessary. The patient should have separate bed, and utensils and clothes. Patients should also take their medicines regularly and always use new syringes. None of the respondents had ever heard of HIV test and they did not know of any place where to get tested for HIV.

B3.3 Specific Risks for PWDs

B3.3.1 Male Family Members of PWDs

The respondents were of the opinion that it is not common to physically torture the people with disability. Rather they take good care of people with disability in the family.

“It is a matter of fear from God. We take extra care of the PWD in family. We give them food before anyone else in the house because they are disabled and cannot say anything to explain their feelings” (Man, aged 50 years, Brother of a PWD)

The respondents were of the view that sexual abuse of PWD has been heard frequently and it is quite possible that they suffer from sexual harassment.

“It happens, it happens. Just two months back a little girl of 03 years age who was disable had undergone such kind of abuse” (Man, aged 45 years, Father of a PWD)

B3.3.2 Female Family Members of PWDs

Female Family Members of PWDs agreed that PWDs are more exposed to physical and sexual abuse than the other people of their age. Regarding risk of PWDs to be more prone to physical torture, the respondents mostly agreed that being less mature and less sensible; the PWD kids usually are more exposed to physical beating by family members than the other kids. Some of the respondents who were mothers of PWDs shared that these kids are naughtier and they ask for many things to be bought for them. The parents have to meet their demands of food, clothes and shoes etc. in their limited resources. If their demands are not met, they get irritable and then the parents have to discipline them by beating.

“Hamari bachi hai, hamain pata hai, her cheez kehtey hai mujhay bhi do. Na ho to kahan say do? Sahee bachay ko samjha saktay hain, laykin in ko nahin.” (Woman, aged 30 years, Mother of a PWD)

“Aisa bacha bay samajh hota hai, shararatain ziyada karta hai, tang ziyada karta hai” (Woman, aged 40 years, Mother of a PWD)

Answering the question on PWDs having higher risk of sexual abuse; the respondents opined that the risk is surely higher for PWD since they are deaf and dumb and cannot communicate their feelings easily and clearly. If any such event happens, the family would certainly be in anger and they would blame the PWD for the mishap. Therefore, the risk of being abused and tortured is great. Also the PWDs may get scared and refrain from sharing the problem with the parents so even the parents may remain unaware. If the PWDs are disturbed due to any stress and become irritable, the family members may understand his or her condition but the others would never understand. They referred to a recent incident when a deaf and dumb mother went to a well and was trying to commit suicide and also threw her infant into the well when a villager saw her and brought her back home. They further added that the deaf and dumb mother also used to beat her mother and sisters and quarrel with them but the family understands her problems.

“Ghar waley tau samajhtay hain, bahar waley tau nahin samajhtay” (Woman, aged 33, Sister of a PWD)

B3.4 HIV Information Needs and Preferences

B3.4.1 Male Family Members of PWDs

Male Family Members of PWDs think that PWDs usually do not have any information about such diseases because they are deaf and dumb. They do not have the opportunities to access the knowledge. The villagers are anyway not very literate. One of the respondents added that in those families where the girls are educated, they might be having some idea about these diseases. This thing is very uncommon in the villages as compared to the cities. It happens more often in the cities.

“Yeh tau na boltay hain na suntay hain, in ko kiya pata hai kay HIV kiya hai” (Man, aged 35 years, Brother of PWD).

Only two of the respondents mentioned receiving an information leaflet about HIV through a lady health worker in some health facility but no one ever opened that to read and understand. They also agreed that the PWD should be tested for HIV being at higher risk than others. However, majority of the respondents had never got any information or education material on HIV. Only one respondent had watched a television talk show by a doctor regarding HIV.

Their opinion about HIV information needs and preferences was that the government should develop information material in Urdu and there should also be more frequent TV commercials to raise HIV awareness. For the deaf and dumb people, the family members were regarded as the best source for communicating with them. They added that the literacy levels are generally low, and the deaf and dumb people are not taught the sign language, it may not be very helpful to have HIV information in sign language on TV commercials. They referred to some efforts by local NGOs to enhance literacy of PWDs which should also be a channel of information on HIV for them.

B3.4.2 Male Family Members of PWDs

Female Family Members of PWDs were never provided any information, education material on HIV by any health worker. However, they agreed that the PWDs should get HIV tests as well as the basic HIV information. They preferred TV commercials as channel of information since the PWDs like watching TV and learn many things from that. The female family members added that they themselves are not literate and may not benefit from any written information so TV and radio are better media for raising awareness. The respondents referred to the lady health workers and also some volunteers from NGOs who also frequently provide them with information on health issues. They added that being caretaker of the PWDs, have good communication with them and continuously convey information to them as they get it.

“Hum in bachoon ko achi aur buri batain bhi batatay hain takay wo khud be samajhdar banain” (Woman, aged 55 years, Mother of a PWD)

B4. Discussion

This qualitative research study was conducted to explore the understanding of HIV and its risks and vulnerabilities among the people with disability (deaf and dumb) and their family members in Tehsil Sohawa, district Jehlum. Selection of this study site was to minimize the potential challenges in identifying, locating and reaching PWDs; since CHIP has already had a long-standing respectable repute among the PWDs and their families on account of their socio-economic and rehabilitative interventions with the community in this district.

While designing the research, it was planned that experts of sign language would be engaged for the interviews with deaf and dumb people in order to get the first hand knowledge of their understanding about HIV as well as their perceived risks and information needs and preferences. However, while in the field, it was realized that the deaf and dumb people in Tehsil Sohawa, district Jehlum were not well versed with sign language and it was very difficult to communicate with them about such a sensitive topic as HIV/AIDS. An attempt was made by the researchers with support from the field staff members from CHIP who were very experienced in sign language and have been communicating with deaf and dumb people in routine. The staff members found it impossible to make the PWD understand the exact questions or its meaning. Therefore, it was finally agreed that the qualitative survey would only focus on the male and female family members of the deaf and dumb people.

The key findings from this research are as follows:

B4.1 The male and female family members of PWDs (deaf and dumb) have heard of HIV/AIDS but the knowledge of modes of transmission and prevention is not accurate. Not a single respondent mentioned use of condom as a preventive method. Also they mostly referred to TB and Hepatitis as diseases communicable through blood and infected syringes.

B4.2 The risk and vulnerability perceptions of both male and female family members of PWD were quite alike. Social contacts, sharing of utensils, clothes, food etc were mentioned as modes of spread.

B4.3 Referring to the specific risks for PWD, the female family members admitted that if the PWD does not behave properly, they beat him physically, whereas, the male family members said that PWD in a home is always given special attention and never beaten. Both male and female family members of PWD agreed that PWD being unable to defend themselves may be at higher risk of sexual abuse.

B4.4 HIV Information needs and preferences cited by both male and female family members included TV and radio, health care workers and NGOs. While male family members wanted information materials in URDU, the female members did not prefer that due to their low levels of literacy.

While the next step will be to use this information for advocacy with the HIV/AIDS prevention and control organizations in both public and private sector in the country in order to promote the rights of people with disability with regard to HIV prevention education as well as interventions. At present, the HIV prevention messages and interventions do not address the specific needs of the people with disability. As evident from this research, the knowledge of HIV among the rural community, from which the family members of PWDs belong, is profoundly limited with various prevailing myths about the modes of spread and prevention. Particularly among the female respondents, the majority had not heard of HIV/AIDS which is consistent with the PDHS 2006-07^{vi} findings where only a third of rural women had ever heard of HIV. It needs to be highlighted that children with disability and their families face many barriers to their full participation in society which limits their capacity both to contribute towards and access community resources and services, including preventative services^{vii}. Moreover, some regional evidence^{viii} shows that many PWDs remain housebound and thus less likely to access mainstream programmes or services due to reasons like the difficult terrain, lack of mobility aids; being single and female in a traditional setting; and fearfulness prompted by experiences of stigma or harassment.

Another key finding is regarding the specific risks for people with disability; physical torture was reported by the female family members on account of the sub-optimal behavior of PWDs which is rather due to their disability. On the contrary, men had this perception of PWDs having preference over others in the family because of their disability. This difference in opinion might be because the females take care of the PWD throughout the day and get exhausted by the demanding care taking process, while men come to homes in the evening and out of their concerns, they give extra attention to the PWD in the family. However, the responses on risk of sexual abuse were affirmative by both male and female family members. Despite there is little evidence from the region or the country to support the finding of higher risk of physical and sexual abuse, there is some research that supports these findings. Sullivan et al^{ix} found that disabled children were 1.8 times more likely to be neglected; 1.6 times more likely to be physically abused and 2.2 times more likely to be sexually abused. Crosse et al^x found that disabled children were 2.8 times more likely to be emotionally neglected; 2.1 times more likely to be physically abused; 1.8 times more likely to be sexually abused and 1.6 times more likely to be physically neglected. Overall they were 1.7 times more likely to be abused or neglected than non disabled children.

Finally, the HIV information needs and preferences identified by the family members largely indicated mass media and interpersonal communication by health workers or local NGOs. The existing efforts by health workers or NGOs for HIV awareness raising were regarded as very occasional as if the PWDs and their families are invisible to the outreach health service providers^{viii}. Being housebound most of the time, the use of disability-friendly messages (tailored to the needs of deaf and dumb people through formative research) should be delivered via TV, Radio and Information leaflets. Use of sign language for imparting HIV knowledge will be only effective when the PWDs have been trained in sign language by parallel public or private sector efforts.

As an impact of this and similar endeavors will be to have disability-inclusive HIV prevention and control efforts in the country; one would like to have the PWDs recognized as a vulnerable group in the National Strategic Framework of HIV/AIDS, as has been done in South Africa in 2007^{xi}. It goes

without saying that effective mainstreaming of disability into the HIV/AIDS response must be context-specific and relevant; built on accurate understanding of the epidemic and how it affects PWD; address the root causes and also safeguard the rights of individual PWD^{xii}.

Acknowledgments

We would like to thank the members of the research team, Dr. Tahira Ezra Reza, Dr. Qudsia Uzma, Ms. Lubna Hashmat, Mr. Imran Ahmad, Ms. Madiha Ehsan, Ms Ambreen Yousaf, Ms. Shehar Bano, Ms. Shmaiza Majeed, MR. Pervaiz, Mr. Naeem Younas and Mr. Asjad for their valuable contribution in data collection. I would also like to extend special gratitude to our research participants who volunteered for the focus group discussions and shared their time and experiences with us. And indeed acknowledgment of the support by DFID, Sightsavers International and CHIP for making this research initiative a reality with the financial and technical assistance in collaboration with the National AIDS Control Programme, Pakistan.

REFERENCES:

- ⁱ UNAIDS. 2007 Epidemic Update,
http://data.unaids.org/pub/EPISlides/2007/2007epiupdate_en.pdf
- ⁱⁱ Mont D (2007). Measuring Disability Prevalence. SP Discussion Paper No 0706. Social Protection World Bank. Available at:
<http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf>
- ⁱⁱⁱ Østergaard L (2007). People with disabilities confronted with HIV and AIDS – A desk study of project experiences from Africa and Asia. Study commissioned by DPOD.
- ^{iv} Groce N, Yousafzai A, Dlamini P, Zalud S, Wirz S. “HIV/AIDS and disability: a pilot survey of HIV/AIDS knowledge among a deaf population in Swaziland” *Int J Rehabil Res.* 2006 Dec;29(4):319-24
- ^v Available at:
http://www.awid.org/eng/layout/set/print/Issues-and-Analysis/Library/AFRICA_07/13/09.
- ^{vi} National Institute of Population Studies (NIPS) [Pakistan], and Macro International Inc. 2008. Pakistan Demographic and Health Survey 2006-07. Islamabad, Pakistan: National Institute of Population Studies and Macro International Inc.
- ^{vii} Miller D. “Disabled Children and Abuse”. Report of National Working Group on Child Protection and Disability. 2002 www.nspcc.org.uk/inform
- ^{viii} Morrow M, Arunkumar MC, Pearce E, Dawson HE. “Fostering disability-inclusive HIV/AIDS programmes in northeast India: a participatory study”. *BMC Public Health* 2007, 7:125 doi:10.1186/1471-2458-7-125
- ^{ix} Sullivan, P. M. et al (1997) Maltreatment of children with disabilities: family risk factors and prevention implications. *Journal of Child Centred Practice*, 4(1): 33-46.
- ^x Cross, S. B., Kaye, E., and Ratnofsky, A. C. (1993) *A report on the maltreatment of children with disabilities*. Washington, D.C.: National Center on Child Abuse and Neglect.
- ^{xi} HIV, AIDS and Disability in South Africa -“Nothing about us..... without us!” Available at www.heard.org.za/.../nothing-about-us-without-us-hiv-aids-and-disability-in-south-africa.pdf
- ^{xii} Aidsnet (2006). Making a Difference: An NGO Guidebook for Facilitating the Involvement of PLWHA. Aidsnet –The Danish NGO Network on AIDS and Development. Available from: www.aidsnet.dk