

Disability and HIV & AIDS;

A participatory rapid assessment of the vulnerability, impact, and coping mechanisms of Parents of Disabled Children

on

HIV & AIDS.

Commissioned by;

Zimbabwe Parents of Handicapped children (ZPHCA),
Bulawayo Branch

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International cooperation for development (ICD)
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List of abbreviations

DPO	Disabled People's Organization.
HIV	Human immunodeficiency Virus.
AIDS	Acquired immunodeficiency syndrome
STI	Sexually transmitted infections
HBC	Home based care
MAC	Matebele land AIDS council
ZNNP+	Zimbabwe national network for people living with AIDS
NAC	National AIDS council
ZPHCA	Zimbabwe parents of handicapped children
ICD	International cooperation for development
PRA	Participatory rural appraisal
VCT	Voluntary counseling and testing
PMTCT	Prevention of mother to child transmission
TB	Tuberculosis
PSI	Population services internationaux
MDAZ	Muscular dystrophy Association of Zimbabwe
ASSOD	Association of the Deaf
NCDPZ	National council of the disabled of Zimbabwe

A participatory rapid assessment of the vulnerability, impact and coping mechanisms of Parents of Disabled Children on HIV&AIDS.

Background and Justification;

HIV & AIDS is a serious development issue in the world today that is threatening to reverse the development gains of the century. According to UNAIDS HIV& AIDS report December 2002, over 40 million people world over are living with the virus, out of which 28million people are in sub Saharan Africa. Southern Africa is the worst hit in the region and Zimbabwe is not exceptional, with over 30% of the adult population living with the virus, 30% of pregnant mothers are infected and about 75% of all hospital admissions are AIDS related.

The government of Zimbabwe, NGOs and the private sector have led major interventions around HIV & AIDS prevention, care, support and mitigation, but little or none has targeted the disabled people and parents of disabled children as people with special needs. Yet, according to information from the central statistics office indicate that, about 5%of the population in Zimbabwe is disabled in one-way or the other. Experiences from AIDS service organizations that offer home based care services have confirmed that HIV&AIDS is one contributing factor to disability.

For example, most of the interventions implemented to date are linked to behavior change, home based care, orphan care, VCT with a strong component of information, education and communication, however, they have not looked at the special needs of the visually impaired, the deaf and the dumb and the time requirements and workload of the parents of disabled children.

Given the above background, ZPHCA and ICD designed a participatory rapid assessment among ZPHCA membership to answer the following critical questions around HIV/AIDS and disability.

- > Does disability of children increase vulnerability to HIV&AIDS infection of their parents?
- > Is HIV&AIDS a concern to people who care for the disabled children?
- > What is the possible impact of HIV&AIDS on homes with disabled children?
- > How are the parents of disabled children and those who care for them coping with HIV&AIDS and disability?
- > What are the myths and misconceptions around disability and HIV&AIDS and their impact on the parents of disabled children?

The answers would then give ZPHCA information to design HIV & AIDS intervention programs for ZPHCA members.

Executive summary

The rapid assessment was commissioned by ZPHCA to assess the vulnerability, impact and coping mechanisms of parents of disabled children on HIV&AIDS and suggest strategies for developing a HIV and AIDS program for ZPHCA. The study used participatory methodologies of inquiry and involved 60% of ZPHCA membership from the Bulawayo branch sampling both male and female parents and guardians.

Among the many findings, the study found out that many parents of the disabled children were vulnerable and affected by HIV & AIDS. In homes of disabled children where one or two parents have AIDS, the quality of care for the disabled child is highly compromised especially if the person living with AIDS is the mother. In such instances, there is also double stigma and discrimination of parents of disabled children and at times the whole family is stigmatized for the disabled child and AIDS.

The study found out that having a disabled child increases vulnerability to STI/ HIV infection as all parents go out with other sexual partners to prove who was the source of the disabled child. In the process there is a high turnover of sexual partners to parents of disabled children leading to serial partners in a short period of time increasing the risk to infection

The study further found out that, having a disabled child in a home influences family planning behaviors and practices as parents hurry to produce another child to check whether it will also be disabled child. In some families they hurry to get another child to play with the disabled child as the community around would not allow their children to play with a disabled child, thus compromising the health of the parents and the child.

Equally important, is the time requirements to care for the disabled child, the female parent gets highly occupied with caring for the disabled child that leaves no time for her to participate in programs that can help prevent HIV&AIDS infection in the home.

Other findings related to the above critical issues are.

- > Limited access to HIV & AIDS information and utilization of services like VCT, HBC and OVC by parents and disabled children due to lack of time on the side of parents.
- > Neglect for disabled orphans who are not taken to OVC programs due to their special needs.
- > A lot of myths and misconceptions that sex with a disabled female child cleanses HIV.
- > Defilement of disabled children especially the girl child by care givers and relatives.
- > Disabled children in a home are always blamed on the women and at times men run away from homes leaving many single mothers.

In conclusion, the study revealed that, the parents of the disabled children are at a higher risk of infection to STI/HIV and the risk increases as the parents try to cope with having a disabled child, therefore, a disabled child in a family act as one of the predisposing

factors to the parents infection and when an infection happens in a home, the quality of care for the very disabled child is compromised causing a vicious cycle of disability and HIV & AIDS at house hold level.

The study recommends that, a target specific interventions should designed and implemented for the parents of disabled children to address issues of HIV & AIDS and disability, empowerment & gender issues and sexual reproductive health.

Study objectives

Overall Objective; To assess the vulnerability, impact and coping mechanisms of parents of disabled children on HIV&AIDS and suggest strategies for developing a HIV and AIDS program for ZPHCA.

Specific objectives

- > Review existing policy framework on HIV&AIDS in relation to disability issues.
- > Review ZPHCA's previous work related to HIV&AIDS
- > Assess the knowledge levels, awareness, attitudes, behaviors and sexual practices of parents of disabled children
- > Assess the Impact of HIV&AIDS on the parents of disabled children and explore the current coping mechanisms to HIV&AIDS at individual and household level
- > Assess accessibility to services related to HIV&AIDS care and support including sexual reproductive health facilities by parents of disabled children.
- > Assess the vulnerability of the parents of/and disabled children to STI/HIV&AIDS infection
- > Assess the participation, capacity and potential of parents of disabled children to participate in HIV&AIDS prevention, care, support and mitigation programs.
- > Assess the capacity of ZPHCA to deal with HIV&AIDS among its membership and recommend possible approaches and networks for collaboration.
- > Provide options and recommendations on how to develop a program that can effectively contribute to tackling HIV and AIDS with full participation of all ZPHCA membership

Methodology;

The rapid participatory assessment took a qualitative approach, which used participatory tools and methods (PLA) to collect data. These include the following among others,

- > Focus group discussion by gender
- > Buzz Groups
- > Role plays to depict their situation and generate discussions
- > Risk factors analysis tree for secretariat
- > Field work
- > Matrices
- > Mixed group discussions
- > Semi structured interviews
- > Literature reviews

The choice of methodology was guided by the need to make the process participatory, interactive, learn from each other and give basic information about HIV&AIDS where necessary. For example where respondents indicated they had never heard of a female condom, the team demonstrated it.

SAMPLE SIZE;

The assessment involved a total number of 67 members, (10 men and 57 women) representing 60% of the membership of ZPHCA. 90% of the respondents were parents of

the disabled children; others were disabled youth and guardians. Members of the ZPHCA secretariat and committee who are also parents of disabled children were also interviewed separately.

FINDINGS;

1. **Parent's knowledge on policies related to disability and HIV&AIDS;** 90% the respondents were not aware of the existence of policies on HIV/AIDS and disability. The 10% knew of the disability policy, but could not relate it to the national HIV/AIDS policy. This implies that parents could be vulnerable to abuse and violation of their rights and the disabled children.
2. **Basic Knowledge on HIV&AIDS;** All the respondents had heard of HIV and AIDS, they knew what HIV and AIDS is, the difference between the two, the modes of transmission, the signs and symptoms, current issues about treatment and methods of prevention.
3. Majority (75%) of respondents (males and females) perceived themselves and their disabled children at risk of HIV infection, with the girl child being at higher risk due to the belief in their communities, that, "*people with STI/HIV&AIDS get cleansed when they have sexual intercourse with a disabled girl child.*" However, the 25% of the respondents perceived themselves not at risk of HIV infection at all, giving reasons like old age, faithfulness, use condoms and sticking to one partner. This indicates that the level of sensitivity to HIV&AIDS still low despite the knowledge.
Respondents indicated that the vulnerability to infection of the disabled child was not influenced by location (rural or urban) but the literacy, nature of disability and age were believed to have a bigger influence. For example, the older illiterate, female children were perceived to be a higher risk, as the parents tend to reduce on the time they spend with them compared to very small children.
4. **HIV/AIDS prevention:** All the respondents recognized hetero- sexual relationships as the biggest mode of transmission of HIV&AIDS in the adult population, though they knew of others e.g. parent to child transmission and blood contact. The methods and efforts to prevention were linked to heterosexual relationships emphasizing safer sex practices e.g. condom use, faithfulness and abstinence. Although they emphasized condom use, over 95% of the respondents (male and female) had never seen the female condom. All the respondents had seen the male condom and had an idea of using it to prevent the spread of HIV. 95% of the women respondents preferred the male condom to the female one; this illustrates the power relations around sex and sexuality, and the dependency of women on male partners for HIV&AIDS prevention that increases the women's risk to infection.
5. 60% of the respondents said that, when a woman gives birth to a disabled child in most cases the men neglects the family, leaving the woman a single parent to look

after the disabled child. The majority of the members of ZPCHA are single mothers, with no stable incomes, some the methods of coping with the situation puts them at risk of infection.

6. **Basic knowledge on Reproductive health Issues;**

- **STI:** Respondents knew how STIs are transmitted, but they could only name two, that is Syphilis and Gonorrhea without differentiating them. However, they knew the relationship between STIs and HIV&AIDS because of the mode of transmission. Although there is knowledge about the relationship between the two, they could not link STIs/HIV to general reproductive health and reproductive health rights.
- **Family planning;** all the respondents knew what family planning is, and the different methods i.e. traditional, natural and modern methods of family planning. The majority preferred the traditional and natural methods to modern ones due to cost and side effects. However, a decision to initiate family planning and the methods is male partner's responsibility.

The respondents acknowledged that, having a disabled child in the family was a factor influencing the decision to family planning i.e. child spacing. Most respondents said, parents with disabled children produce a child immediately after a disabled child to prove whether they can be able to have an able bodied child, others due to stigma, that disabled child cannot play with other people's children, so the parent have to produce a child to play with the disabled child. In the process both parents engage in extra marital relationships to prove who is responsible for producing the disabled child, which may put them at risk of infection.

7. **Traditional practices and beliefs;**

- Most respondents acknowledged the existence of traditional and other practices that exposes them to the risk of infection as parents, these are inheritance of widows, polygamy, medicines for aphrodisiac, separation of husband and wife due to work, multiple partners, virginity test for the girls, father in-law to test newly married bride, circumcision etc
- Respondents also acknowledged that societal expectation, degree of wealth, relative social status, poverty, and alcohol influences the sexual behaviors and practices of parents of disabled children thus increasing the risk to infection. They further acknowledged that, their behaviors and practices at times put their partners and dependants at risk of infection too. Such behaviors relate to multiple partners, unprotected sex, serial partners and commercial sex work.
- Majority of the respondents were concerned about the origins of HIV which overshadowed their roles in protecting themselves and disabled children. The theories of origin centered on immorality i.e. people having sex with monkeys, Americans wanting to wipe out Africans and the punishment from God. These beliefs influenced the parents approach and thinking around HIV&AIDS for example,

those who believed in the punishment from God, have given up, that they cannot do anything about it.

IMPACT OF HIV&AIDS ON THE PARENTS AND DISABLED CHILDREN

- All respondents acknowledged the existence of HIV&AIDS among the parents and their communities, however, HIV & AIDS was perceived to have a lower impact on family resources, income and time at household level compared to having a disabled child. They perceived the impact to be more serious when there is both a disabled child and terminally ill person, and its worse if the terminally ill person is the mother and breadwinner.

During a field visit to Emganwini Township, we observed a family of four; husband, wife and the two children aged 7 & 5 years. The 5 year disabled girl is blind, deaf, dumb and small for the chronological age. The mother is bed bound; the father has stopped work to take care of the family In his words, the family has no income, food and experiencing transport problems to hospital and the extended family is not supportive. The family is not part of the home-based care program, which would have otherwise supported the family.

- Respondents acknowledged the death of some of the parents leaving disabled children, who do not join the mainstream orphan care programs due to the degree of disability, stigma and discrimination. All respondents (male and female) acknowledged that in the event of the death of the mother, the disabled child is severely affected
- **Coping mechanisms;** Parents' coping mechanisms were linked to disability and other social problems like limited income and poverty in the homes than AIDS. The coping mechanisms of female parents were different from their male counterparts, for example, a female parent, would get another man to support her financially after the father of the disabled child has deserted the home. The way parents were coping to the effects of disability and other social problems were putting them at risk of infection.

However, during the field visit, the family with both disability and terminally illness was coping in different ways, e g. The man had left the job to care for the sick wife and is now self employed at home, he runs a gardening project to complement the family income and dietary requirements.

8. Access and utilization of HIV&AIDS services and facilities by the parents and disabled children;

- The majority of the parents acknowledged the existence of HIV and AIDS programs and facilities in their communities, though they were not clear about their operations. They named, National AIDS council, VCT centers, orphans programs, City health clinics and home based care.
- The utilization and access was limited because they were concentrating on disability rather than HIV Parents expressed a false confidence attitude about their HIV status, saying, " We have told our selves that we are negative" so that

we can continue caring for the disabled children, implying forgetting one problem and concentrating on the other.

- All the respondents said that parents of the disabled children do not participate in the existing HIV&AIDS programs in the communities due to time, stigma, self-discrimination, priorities and perception on vulnerability levels of their children. However, they expressed interest in joining HIV&AIDS programs that would benefit the disabled children.

9. **Access to information on HIV&AIDS;** Respondents indicated that they were accessing information, but there was no special package of information for the disabled children. Parents indicated that there should be HIV&AIDS information materials for the disabled children. E.g. brailled material for the blind and video cassettes for the deaf. They also indicated that the information centers are not accessible to the disabled children. This indicates that there is a misconception among parents of the disabled children that the existing information is not for them. It should be noted that the parents of disabled children are not all disabled, implying that they can access information without special packaging. The failure to read information and pass it over to the disabled children appears to be an issue of HIV&AIDS not being a priority to the parents and a perception that disabled children are at a lower risk of infection.

- **Media preferences:** The respondents indicated that they would prefer the following media: Posters, Health education talks, Radios, Print media, Cassettes, Films, Workshops, The school curriculum to include aspects of HIV&AIDS linked to behavioral change.

- **Health seeking behavior:** Using the curative matrix, different conditions related to AIDS and curative options were analyzed to understand the health seeking behavior and curative options. However, no unique health seeking behaviors were identified.

	Hospital	Traditional healers	Church	Private Doctors	Self Medication	Herbalist
Herpes	7	6	2	5	4	4
Gonorrhoea	8	7	0	7	5	9
Syphilis	7	9	0	7	7	6
TB	10	2	7	5	1	0
Diarrhoea	9	6	0	7	9	0
Skin Rashes	6	0	0	5	0	0
Swollen Legs	9	5	2	5	0	0
AIDS	10	10	7	10	0	10
Oral thrush	10	6	0	5	7	5
Total	76	42	18	49	33	34
Position	1	3	6	2	5	4

- Respondents indicated that parents always seek treatment from different sources however the majorities go to public hospitals. The analysis further indicates that although the majority of the parents go to public hospitals, simultaneously go to traditional healers and herbalists. With AIDS, the respondents said, the people are desperate for treatment hence they try everything.
- The discussion on self-medication generated very little information on home remedies to support positive living. Issues of nutrition couldn't come out as a therapy to some of the infections. This indicated that, there was need for educating parents on home remedies, nutrition for PLWAs to support the various curative options.

CAPACITY OF ZPHCA TO ADDRESS HIV & AIDS AMONG ITS MEMBERSHIP

ZPCHA since its inception in 1987 has been pre occupied with disability because that was their main concern not HIV & AIDS. They did not perceive their children to be at risk of HIV & AIDS infection. To date, there are no tangible HIV & AIDS programs that have been implemented by ZPCHA.

ZPCHA as an organization has limited capacity in terms of skills, financial resources and manpower to implement HIV & AIDS prevention, care, support and mitigation programmes for its membership despite the expressed need. However, the committee and the secretariat said time could be made available for the HIV/AIDS programme.

Currently, ZPCHA does not have a HIV & AIDS policy framework that could permit the implementation of HIV & AIDS interventions within the organization; this partly explains why the organization has not done anything around HIV&AIDS.

The ZPHCA leadership (Committee and the secretariat) recognizes the existence of potential partners in the work against HIV & AIDS and the following were high on their priority list for possible networking and collaboration in case of starting up a HIV & AIDS programme.

- > Matebele land Aids Council
- > World Vision
- > PSI (New Start Center)

Vulnerability of ZPCHA staff and committee members to HIV & AIDS

All the respondents indicated that, they were at risk of contracting HIV & AIDS. ZPCHA secretariat is made up of mostly women within the age range of 25 yrs - 40 yrs that falls within the vulnerable age groups. Coupled with the nature of their work, such as traveling, interactions with other groups, being away from their families for some time, relative status, the secretariat was perceived to be more at risk than the committee. However, there were no workplace HIV & AIDS interventions for the secretariat and the committee.

Parent's expectations from ZPCHA to address HIV & AIDS among the members

- > The parents expect ZPCHA to facilitate HIV & AIDS information sharing, education, and communication (IEC) through drama, songs, TV programmes, posters, Braille, booklets for both the parents and the disabled children.
- > The parents expect training around home based care, systemic counseling, Income Generating Projects and HIV & AIDS prevention
- > The parents expect material support to the disabled orphans in the form of school fees, food, wheel chairs and other appliances.
- > The parents expect treatment in the form of anti retroviral drugs and treatment of opportunistic infections from ZPCHA.
- > The parents want a children center, where among other things they would learn about HIV&/AIDS.
- > The parents expect ZAPCHA to work with other partners in the area of HIV & AIDS and income generating projects.

Conclusions

- > Parents of the disabled children are at risk of HIV & AIDS infection due to pre occupation with disability issues of their children than HIV& AIDS prevention. The disabled children are equally at risk since their parents do not perceive them to be vulnerable to HIV & AIDS infection. Disabled children were at risk of defilement and HIV & AIDS infection because of the myth that you can get cleansed if you have sex with the disabled person.
- > There is relatively high access to HIV & AIDS information to the parents however this information does not trickle down to the disabled children because parents find no time to educate their disabled children as it is not a priority, some disabled children are visually impaired that they cannot read on their own. Parents have problems with the appropriate methods of teaching their disabled children on HIV & AIDS issues.
- > Parents of disabled children are not well informed on the policy issues related to disability, HIV & AIDS and reproductive health, hence they could be subjected to abuse and violation of their rights.
- > Although the parents knew the preventive measures of HIV & AIDS the majority of them had not seen a female condom in their lives, which implies that they are not in control of their sexual life.
- > Majority of the parents of the disabled children are not knowledgeable about sexual reproductive health issues which makes it difficult for them to effectively protect themselves against HFV & AIDS
- > Having a disabled child within the family increased the vulnerability of the parents to HIV & AIDS / STI infection
- > The parents were aware of the traditional practices that could increase their risk to HIV & AIDS/ STI infections but due to societal expectations, power relations, gender issues and poverty they did not have a choice. The parents knew the drivers of the epidemic in their locality, which are mainly poverty, alcohol, and

degree of wealth and gender relations, however, they didn't have the power to deal with the drivers of the epidemic.

- > Parents perceive the impact of having a disabled child in a home as being more serious than the impact of HIV & AIDS however where both are found in the same home i.e. the disabled child and the chronically ill person the impact is worse.
- > Parents of disabled children have experienced a number of deaths and their disabled orphans have not joined the mainstream orphan care programme because of the nature of disability, stigma and discrimination and there are no facilities to cater for the disabled children in those programmes.
- > Due to stigma, self-discrimination and time, parents of disabled children do not participate in other development programmes including those related to HIV&AIDS, which leave them out of the mainstream development programmes.
- > Parents coping mechanisms are centered on disability than HIV & AIDS however those coping methods increase their vulnerability e.g. when a man deserts the wife because of a disabled child the wife copes by getting another partner.
- > There are different HIV & AIDS services in the community however they were not being utilized by the parents because of the preoccupation with the disabled child and that they were not addressing the need of the disabled child.
- > The preferred media for HIV & AIDS messages targeting the disabled children and parents are posters, health education talks, radios, print media, cassettes, films, and workshops.
- > ZPCHA has not implemented any HIV & AIDS intervention for their members, disabled children and the secretariat due to lack of skill, resources, policy framework and man power to implement the programme.
- > Awareness and knowledge level on HIV & AIDS among parent is relatively high although it has not matched behavior change due to a number of social, economic, and cultural factors.

Recommendations

- > ZPCHA should initiate a HIV & AIDS and reproductive health programme that looks at issues like STIs, Family planning, prevention, care, support and mitigation for the parents and the disabled children. As the organization is looking for resources, ZPHCA should be supported to main stream HIV&AIDS.
- > There should be a professional Cadre within ZPCHA secretariat who should coordinate and implement HIV &AIDS programmes within ZPCHA.
- > Given the capacity and ZPHCA's level of organization, to effectively implement HIV&AIDS activities among its membership, its important that efforts should be geared towards main streaming or integration of HIV&AIDS to into already existing activities.
- > ZPCHA committee and secretariat should formulate a HIV & AIDS policy that will enable the implementation of HIV & AIDS programmes for its membership and secretariat.

- > There is need to implement empowering processes for the parents to enable them to deal with social, economic and cultural factors that predispose them to HIV & AIDS infection, we recommend ZPCHA to implement the STAR (stepping stones and reflect) programme to empower the parents.
- > ZPCHA to mainstream HIV & AIDS and disability issues in their advocacy programmes e.g. advocating for HIV & AIDS information written in Braille, counseling in sign language at VCT Centers and Hospitals.
- > ZPCHA should initiate and facilitate training of parents on HBC, counseling, peer education and orphan care. However, ZPHCA should not start a parallel HBC program for the parents and disabled children, parents should be encouraged to join the existing HBC programmes in their communities. ZPHCA should work with existing programs to integrate issues of disability care in Home based care programs.
- > ZPCHA should facilitate the inclusion of disabled orphans into mainstream orphan care programmes, where it is not possible ZPCHA should offer material support in form of school fees, food, etc.
- > ZPHCA to source information, education and communication materials that are target specific to the needs of the parents and the disabled children. ZPHCA can facilitate the translation of the materials to local languages.
- > ZPCHA to use the information of this study to design an operational document on how to involve the membership in the fight against HIV & AIDS.
- > ZPHCA secretariat should try to find out the feelings of disabled children on HIV& AIDS as this study could not capture the views of disabled children.

Checklist of issues- for the parents of disabled children

1. Policy issues;

- Existing policy frame work on HIV&AIDS and disability
- National HIV/AIDS policy
- Statutory instrument 202 of 1998

2. What has ZPHCA done in the field of HIV&AIDS?

- Has ZPHCA done anything on HIV&AIDS? If yes, what is it? How was it done and when. If not, why?

3. Assessment of knowledge, attitudes, practices (behaviours) of the parents on HIV&AIDS.

- Knowledge (facts and misconceptions about HIV and AIDS)
 - What is HIV? And what is AIDS?
 - Can a person be HIV+ with out AIDS or the reverse?
 - What are the modes of transmission of HIV?
 - What are the methods of prevention of HIV?
 - Is the there HIV & AIDS Treatment
 - Issues of sexual reproductive health rights- STDS, Family planning etc
- Attitudes and Values

- o Traditions around sex and sexuality that may pose a risk to HIV infection
- o Which practices do you feel should be carried forward or negated?
- o Safer sex practices-Condoms,(female and male condoms), abstinence, faithfulness, delayed sex
- o Beliefs around HIV/AIDS
- o Hopes and fears around sex and reproduction
- Practices
 - o Why we behave the way we do? Influencing factors- social, economic, cultural and religious factors. Focus Group discussion by Gender
 - o How does your behaviour or practices affect people around you and those who depend on you?
 - o Issues sex practices-
 - Consistent and proper use of condoms.
 - Multi partners
 - Virginity test
 - Circumcision etc

4. **Vulnerability/ risk factors assessment of parents of parents and of disabled children to HIV&AIDS/STI infections**

- Perception analysis of vulnerability to infection with HIV/ STI- parents themselves and their children
- Analysis of vulnerability in relation to Gender, rural/ urban/ age/ literacy.
- Following the given risk factors, how do you protect your self and the disabled child⁹
- Vulnerability assessment tree for ZPCHA secretariat

5. **Impact of HIV&AIDS at individual, household and organisational level.**

- o Impact analysis; What are the observable impact of HIV/AIDS the parents
 - **As a disease-** Analysis of issues of stigma and discrimination, costs for treatment, time, family resources, etc (a Comparative income and expenditure pattern analysis of two house holds, one with a disabled and the other with both AIDS client and disable child)- *Further study/ research can be done to quantify actual expenditure*
Comparative analysis of time allocation to the care of the disabled child versus HIV/AIDS patient in the home... what if it's the parent is ill, what happens?
 - **Death due to AIDS;** impact of death and bereavement to the family and the disabled child-
 - Impact of HIV&AIDS at ZPCHA level-
- Analysis of coping mechanisms of the parents to the Impact of HIV&AIDS
 - o What are the current coping mechanisms to HIV&AIDS at individual, household level and organisational levels?
 - o Advantages and disadvantages of the coping mechanisms (short and long term implications)

- o Which coping mechanisms do you feel should be carried forward or negated?

6. Accessibility to services

- Knowledge of existence of services and facilities related to HIV&AIDS.
 - o VCT, PMTCT, HBC, COUNSELLING, OVC, STI clinics etc
- Accessibility and utilisation of the available services and facilities
- Health seeking behaviour- *Disease Curative matrix*
- Access and utilisation of information (Details refer to preparatory notes)
 - o Media preference to access information

7. Assess the participation, capacity and potential of Parents of and Disabled children to participate in HIV&AIDS prevention, care, support and mitigation of HIV and AIDS

- What are the existing HIV&AIDS programs in your community
- How many are participating (why) by gender
- How many are not participating (Why) by gender
- Are you willing to initiate HIV&AIDS programs and participate in future?
What are the programs that you are interested in, why, (by gender).

8. Assess the capacity of ZPHCA to a deal with HIV&AIDS among its membership and recommend possible processes, approaches and networks to collaboration.

- Staffing levels
- Skills on HIV&AIDS/ STI/ reproductive health
- Financial resources
- Time
- Potential partners working on HIV&AIDS with in the locality
- HIV and AIDS work place Policy- issues for ZPHCA and the secretariat

9. Concluding questions;

- What should ZPHCA do to effectively help you as a parent to deal with HIV&AIDS at individual and house hold level for the disabled children.
- What are the achievable, high priority steps for near term improvement of HIV&AIDS prevention, care, support and mitigation among ZPHCA members?
- What partners/ networks should ZPHCA enter into to deal with HIV&AIDS among its members
 - o With whom
 - o Level
 - o Roles of ZPHCA
 - o ZPHCA's expectations from partners
- How should HIV&AIDS activities in ZPHCA be coordinated to effectively have an impact on the membership?