WATER FOOD ***DIABETES*** AYURVEDA ***GENETICS*** POVERTY ***YOGA*** STDS ***HISTORY*** SEX ***SOCIETY*** FAMILY PLANNING ***CASTE***
GENDER ***RIOTS*** RELIGION ***HEALTH*** DEMOCRACY ***FLOODING*** WASTE-MANAGEMENT ***UNANI*** PSYCHOLOGY ***FOLK***
MEDICINE AFFIRMATIVE ACTION ***GLOBALISATION*** BIOCHEMISTRY ***OLD AGE*** REPRODUCTIVE HEALTH ***MALARIA*** POLICY
HIV AIDS WHO ***MEDICOSCAPES*** COLONIALISM ***PHARMACY*** RELIGION ***LEPROSY*** BOTOX ***DEHYDRATION*** NGOs ***AYUSH…***

Experiences with HIV/AIDS and HIV/AIDS-related Stigma among Infected and Affected Children in India

by Ariane Petney

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Submitted by
Ariane Petney

Krokusweg 6

76669 Bad Schönborn

Supervisor:
Dr. Constanze Weigl
Prof. Dr. William S. Sax

Name, first name: **Petney, Ariane**

DECLARATION

For submission to the Examination Committee

Regarding my Master’s Thesis with the title

"Experiences with HIV/AIDS and the HIV/AIDS-related stigma among infected and affected children in India"

I declare that

1. It is the result of independent investigation
2. It has not been currently nor previously submitted for any other degree
3. I haven’t used other sources as the ones mentioned in the bibliography. Where my work is indebted to the work of others, I have made acknowledgement.

Heidelberg, 26.02.2010

Ariane Petney

Signature of candidate

I dedicate this Thesis to Maria, C. Joseph and Angel,

and to all those who have dedicated their lives to fighting HIV/AIDS and its related Stigma

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Abstract

India is one of the countries in the world that has been struck hardest by the HIV/AIDS pandemic and, based on the rising prevalence rates, it is likely that India will soon be the its new epicenter. Today India is already thought to have the largest number of AIDS-orphans worldwide, tendency rising. Not only the disease itself but also its social implications for the country and especially on the infected and affected people are tremendous. Whole families suffer as a result of social suppression and isolation as well as due directly to the medical consequences of the illness with children being especially vulnerable. Children infected, affected or even orphaned by HIV/AIDS experience a variety of social and emotional problems such as social isolation, denial of education, lack of love, care, affection, loss of self-esteem as well as various trauma related to the reduction of living standards, neglect by the extended family and friends and to illness and death of parents and/or siblings. This thesis deals with the experiences that children make and shows how they handle and perceive the situation they are in. It shows how they react to the traumas arising from the social implications resulting from the disease, how infected children deal with their own infection and how affected children react to the illness of their parents. Further it discusses the help provided by three organizations which have taken the challenge of addressing the topic of HIV/AIDS in India and the reactions of participants towards this help as well as their individual coping strategies and their opinions on what extra help or change would be needed to positively influence their situation. The findings out of one-on-on, open-ended and unstructured interviews with children, families and caregivers as well as of participant observation show a devastating picture of discriminations and big emotional problems especially in smaller children, on the other had it also shows the amazing ability of some children to adapt to their situation and to develop coping strategies that help them deal with their situation. Findings show that within this context public awareness campaigns play a role that is not to be underestimated, as a strong mode of stigma reduction as well as a coping strategy used by both infected and affected people to overcome the “felt helplessness” of their situation.

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Acronyms

AIDS	Acquired immunodeficiency syndrome
AICE	American-Israeli Cooperative Enterprise
ART	Antiretroviral treatment (or therapy)
ARV	Antiretroviral (or antiretroviral medicine)
AZT	Azidothymidine (zidovudine), which is one of the older ARVs
CHH	Child headed household
CSW	Commercial sex worker
CSI	Child Survival India (Name of a NGO)
FBO	Faith based organization
FSW	Female sex worker
HIV	Human immunodeficiency virus
IDU	Injecting drug user
MAC	*Mycobacterium avium* complex
MTCT	Mother-to-child-transmission
MSM	Men who have sex with men
NACO	National AIDS Control Organization (India)
NGO	Non-government organization
PCP	Pneumocystis pneumonia
PMTCT	Prevention of mother-to-child-transmission (of HIV)
STD	Sexually transmitted disease
STI	Sexually transmitted infection

TB	Tuberculosis
UNAIDS	Joint United Nations Program on HIV/AIDS
USA	United States of America
VCT	Voluntary counseling and testing
WHO	World Health Organization

Glossary

Acquired immunodeficiency syndrome (AIDS)

AIDS is an illness that was first described in 1981. It is characterized through a distinctively low cellular immunity of the body that is accompanied by a variety of opportunistic diseases.

Antiretroviral therapy (ART)

ART is the medical therapy which is given to HIV patients.

CD-4-cells

The CD-4-cells also called T-helper-cells are a subgroup of the lymphocytes, which belong to the white blood cells.

Human immunodeficiency virus (HIV)

HIV is a “retrovirus” that attacks cells belonging to the human immune system, the so called T-helper or CD4-cells.

Opportunistic diseases

Usually these are diseases that a healthy immune system could fight down without a problem but for people with a low CD-4-count, they can become life-threatening, especially if they are treated too late.

Retrovirus

A retrovirus is any virus belonging to the family of RNA viruses which uses an enzyme called reverse transcriptase to replicate within the host cell.

Serostatus

Condition of the blood serum (the liquid proportion of the blood) with regard to “having or not having antibodies[1] to a microbe[2] in the blood as a result of infection. One may have either a positive or negative serostatus (biology online, 2009).”

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[1] Any of the numerous Y-shaped gamma globulin proteins found in the blood or lymph, and produced by B cells as an immune defense against foreign agents (antigens). Each antibody has a region that binds specifically to a particular antigen which it neutralizes. It is typically made up of large heavy chains and small light chains. (biology online, 2009)

[2] A microscopic living organism, such as a bacterium, fungus, protozoan or virus. (biology online, 2009)

1. Introduction:

> "Sangeetha[3] got married to a police constable when she was 16 years old. Six months after the marriage her husband was found to be Human immunodeficiency Virus (HIV) positive. The constable consulted Child Survival India (CSI), where he received some counseling and was advised to also take his wife for testing. Sangeetha was accompanied to her test by CSI staff, and her serostatus was also found to be HIV-positive. One year after receiving the positive test results her husband passed away. Her parents in law, who had always been friendly to her, now totally changed their behavior towards her, they went around talking about her bad character and claimed that she was responsible for infecting their son with the virus. They told the neighbors and the family that it was Sangeetha who was responsible for the death of their son. When Sangeetha cooked the food, they would not eat and she was told not to touch anything they ate. The family secluded her totally. Though she should have inherited something as she was the wife, the family refused to give her her half of her deceased husband's property. "They were telling she is the one who gave the disease and she is a new member of the house, the family. Why she should get 50%." It took a long time till some sort of compromise could be found. Sangeetha went back to her native place where she lives of a monthly pension of 3000 rupees; "the in-laws did not want to give her more as she has no liability, no children." She finished 12th standard education but only got a 4th class job. She is 25 now."
>
> (Story told by: CSI program coordinator)

In the last decades the HIV/acquired immunodeficiency syndrome (AIDS) epidemic has had devastating effects on a global level (Piot et al. 2001: 968). Worldwide there are an estimated 33 million people who are infected with the disease and many more that suffer from its impact (Joint United Nations Program on HIV/AIDS (UNAIDS 2008: 32). India with 2.4 million infected people is the third most severely affected county in the world (ibid. 219), yet experts predict that with its "numerous predisposing and precipitating risk factors"(D'Cruz 2004: 44), it is the new epicenter of the pandemic (Radhakrishna et al. 2007: 865). But HIV/AIDS is not alone a medical problem (Beine 2003: 59), as it "affects

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[3] Names of all participants have been changed

all the dimensions of a person’s life – physical, economic, psychological, social and spiritual (International HIV/AIDS Alliance India 2009: 3)”. It is also considered to be a major social problem, especially in high prevalence countries. The recognition of the fact that “various types of illness are associated with stigma” within a certain social category has existed for a long time: the HIV/AIDS pandemic has also been accompanied by strong social implications for the infected and affected individuals from the beginning (Fife and Wright 2000: 50). As a result of this stigma HIV/AIDS infected individuals face severe discrimination within their social surroundings (Letamo 2003: 349). Yet it is not alone the infected individuals that have to face the negative social implications attached to the disease, in most cases it is the entire family that is confronted with the stigmatizing attitude of the public and the resulting discriminating behaviors (International HIV/AIDS Alliance India 2009: 3; Link and Phelan 2001: 363). Both infected and affected children are thereby especially vulnerable (D´Cruz 2003: 3-4). The psychological stress of children that are in any way affected by HIV/AIDS is severe. They include not only discrimination that adults also face, but they also undergo various traumas which result from their changing life situation (International HIV/AIDS Alliance India 2009: 3; D’Cruz 2003: 7). Even before the death of their parents “they often find themselves in circumstances,” that are difficult to handle, such as having to care for ill parents and sometimes siblings, decrease of living standards due to the fact that the family income is reduced as a result of job loss or the inability to work as a consequence of sickness, disruption or loss of relationships because of stigma and discrimination, educational hazards or school dropouts forced by the situation they are in. Thus, in many cases an HIV/AIDS infection of parents’ means the loss of childhood in the affected children (ibid.).

For the last four years, I have been working with HIV/AIDS affected and infected people, especially with children. During this time I have found that the experiences with HIV/AIDS and its resulting problems, as well as the related stigma and discrimination, have strong and often devastating effects on the lives of these children and their families. On the other hand, the hope and strength these children find for themselves, despite all the hazards, have often touched my heart. Viewing the literature about HIV/AIDS and its related stigma and discrimination I found that the stories of these children are almost never told and their perspectives and experiences are not taken into account. Within this thesis I attempt to give them a voice by telling their stories and by trying to see the topic of HIV/AIDS and the resulting problems through their eyes and the eyes of their care takers.

In chapter 2, I will begin explaining the research as well as its objectives and methods of both data collection and data analysis. Further information on both the field sites and the participants of the research will be provided in this chapter. Another section of chapter 2 will deal with my role during the field research, providing information on the difficulties and challenges I faced working with children on a highly sensitive and stigmatized topic, as well as the ethical issues that arose as a result of this. After this, in chapter 3, I will provide a short overview of the epidemiology of HIV/AIDS on the Indian Subcontinent. In chapter 4, I will introduce the theory of stigma, and then I will give a short introduction to stigma within its social context, before moving on to its effects. This will be followed by some basic information on the reactions of the Indian government to the HIV/AIDS epidemic. This part of the thesis will further include a short summary of the criticisms which have been voiced against the government's responses. In chapter 5 I will describe what I call the four spheres of experience with HIV/AIDS and the related stigma. This chapter will include all the experiences of children with the topic. The first subchapter, the inner sphere will deal with the individual inner emotions and psychological reactions towards the disease and its effects which were stated by the participants during the interviews or observed by their caregivers. It shows the inability to cope with these situations but also describes how children learn to handle and accept their illness and how they communicate this to others if there is the need to do so. Further this part deals with the reluctance and fear of status disclosure due to the fear of discrimination. In the next subchapter I will describe the outer sphere, the sphere of *enacted stigma* and negative effects on the overall life situation as a direct result of HIV/AIDS. I will attempt to show how difficult the situation is that families have to face during periods of illness and in the times following the diagnosis of HIV/AIDS. It also shows some of the different forms of discrimination of affected and infected people and reflects the suffering that arises from this. In subchapter three I will follow up on the helping sphere and give a short introduction to the help provided. Next I will describe how the participants of my research reacted towards the help provided to them; this will then be followed by the coping strategies that I found in my participants which were partly directly related to the help provided. Another aspect in this last chapter which shows the fourth sphere and is titled the future context will be the wishes that participants had towards the help provided to them, when they found that more help needed to be provided, as well as where they saw a need for action from the side of the government. Chapter 6 will provide a critical discussion of the field sites and the help provided there, including a basic comparison between the different settings. The concluding Chapter 7 will include a short discussion of the theory presented earlier in the thesis and my findings, pointing out the need of further research in this and related topics.

2. Research and research method

Stories like that of Sangeetha, in the introduction, are often to be found in the face of the HIV/AIDS pandemic. From the beginning, the HIV/AIDS epidemic has been "accompanied by an epidemic of fear, ignorance and denial, leading to the stigmatization of and discrimination against people living with HIV/AIDS (PLWHA)" (Letamo 2003: 348). There has been research done on the forms and effects of the HIV/AIDS-related stigma and discrimination on adults and on the way that they experience it and what influences it has on their lives. But though children and young people are not less affected by the stigma and discrimination than adults, their perspectives and experiences have been largely neglected (personal communication with HIV/AIDS Alliance India 2009). This study attempts to show which experiences children make when confronted with HIV/AIDS and with the HIV/AIDS related stigma and how strongly their lives are influenced by the experiences of discrimination and death. It will also show the ways in which professionals from non-governmental organizations (NGOs) and faith based organizations (FBOs) perceive and explain the situations which children and young people face due to HIV/AIDS related stigmatization and discrimination, as well as their responses. The research falls into the "realm of qualitative methods, which provide well-grounded, rich and contextualized descriptions and explanations of experiences and processes (D'Cruz 2003: 16)". These qualitative methods, as they are often more descriptive than quantitative analyses, help to understand the complexity of situations within a broader context and enable a clear chronology of happenings (ibid.). As Padgett (1998: 8) states they can help the reader understand the topic more easily, especially if the topic that is under study "is relatively unknown and requires sensitivity and emotional depth."

The most appropriate method of data collection for this research was found to be in-depth interviews, some of which resulted in detailed case studies. In-depth interviews were also made with the professionals working at the field sites. The in-depth interviews were unstructured, non-standardized, open-ended and face-to-face conversations between the participant, myself and a translator. This method was used as it enables the establishment of an initial rapport with people and it is easier to use in the case of children as it takes the formality out of the interviews. Conversations can be held more openly and there is less risk of interrupting the respondent's flow of information by straight away posing the next question (Russell Bernard 2005: 213). The aim was to understand the participant's situation and experiences, which had been expressed in his or her own words, and for such situations I found unstructured, non-standardizes and open-ended, face-to-face interviews the perfect method. Though at first standardized interviews were considered they proved to be of little use, as they limited the scope of the research and the possibility of gaining more in-depth knowledge about the participant’s real situation and experiences in an unnecessary way.

The topics covered by the interviews were the following: family structure and changes of such due to the diagnosis of HIV/AIDS, disclosure or non-disclosure of the serostatus, experiences of stigma and discrimination, reactions and feeling about discrimination and stigmatization as well as of disease itself and changes of such perceptions of the own situation, responses towards “care taking” institutions, attitudes of professionals within “care taking” institutions towards the topic of HIV/AIDS and towards the situations and experiences of participants.

In addition to the interviews conducted, the observations made within the institutions and during the interactions with the participants were noted down in detailed field notes.

As the study has a limited number of participants it cannot be seen as representative to the overall population of affected and infected children on the Indian subcontinent though findings show clear similarities in the experiences of children in all settings.

2.1. Study sites and participants

The research was conducted in three field sites. The first field site, CSI is an NGO in development that was first established in 1991. It is located in Khera Khurd, north-west Delhi. Its goal is “to help the marginalized and vulnerable sections of community to find new avenues and alternatives of development”. This is supposed to be achieved by “enhancing their knowledge, skills, capacities, access to opportunities and services, and their participation in life decisions.” The aim is to help people reach their natural potential to enable them to face the challenges of life with dignity and confidence, in other words to help people in need to help themselves. “Initially the organization started as a child focused organization. However over the years, through community feedback and grassroots experiences, there has been a change in the approach and strategic focus. Integrated approach to development with a prime focus on health and gender issues is now the basic theme" of the programs provided. These goals or aims are supposed to be achieved in the following ways: Firstly, by sensitizing and mobilizing "the communities towards social, health, education, and economic issues affecting their development. "Secondly, by increasing the overall capacities of the community and empowering the same, by providing information, training and technical support. And thirdly, by providing services, and develop referral linkages with government, non-government, and other concerned agencies for promoting physical, psychological, and socio-economic development of the community (CSI 2009). The second field site is St. Vincent's home within the Devine Retreat Center in Muringoor – Potta, near Chalakudy, Kerala. St. Vincent Home, which was opened in 1997, is a 100 bed after care centre and a home for AIDS patients. The home provides medical, educational, social and spiritual care for all its inmates. It has a special section for AIDS orphans and provides schooling to HIV-positive children within their retreat center school. The third and final field site was Jeevodaya, an institution lead by the Capuchin Social and Developmental Action Service Society (Caps & Dass Trust), which is located in Prathyasha Bhavan in Mele Chovva, Kannur. The institution has a total capacity of 70 beds for HIV infected people and AIDS patients. It provides medical, emotional, social and spiritual care for the inmates of the institution. HIV testing and counseling is provided at a different institution belonging to the Caps & Dass Trust (Fr. Palakudy 2009).

The study was conducted with thirteen children as participants, as well as seven professionals[4] from the three field sites. All children participating in the study where between the ages of four and eighteen years. It further included a twenty-three year old mother with her two months old son, as well as one combined family interview and five stories about children told by the professionals working at the field sites during the interviews. The combined family interview was conducted with the family of one of the participants after an invitation.

Of the children participating in the interviews five were orphans living within St. Vincent's home Muringoor – Potta, one of whom lived at the institution with his seropositve mother. The twenty-three year old mother with her son, as well as one other participating child were settled in Jeevodaya/Kannur. One orphan was living with the extended family, one lived with his mother and her new husband and four children still lived with their parents.

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[4] 3 social workers (CSI/ Khera Khurd/ north-west Delhi), 2 nuns (1 from Potta and one from Kannur) and a priest (form Kannur), 1 project coordinator (CSI/ Khera Khurd/ north-west Delhi)

All participants originated from the lower or lower middle class[5]. All of the children participating from CSI were from a Hindi speaking background, but two of the elder children proved to have a very good knowledge of the English language. The children participating from both of the FBO settings in Kerala had Malayalam as their mother tongue. Regarding the economic status, all families[6] were stated to have an average monthly income of about 2000 to 3000 rupees. The overall proportion of the parents 95% were or had been workers for daily wages. In one case the child was the primary care taker of the family as both parents were ill. All participants in the school going age attended school with two children even visiting higher standards (above standard ten); one child was being taught at the institution due to health related problems. All children interviewed at CSI went to government schools, all children living in the FBOs attended a school run especially for children with positive serostatus within the Devine Retreat Center in Muringoor – Potta. Within four families there was a history of addiction, mostly alcoholism; in all cases it was the father who indulged in these activities. In one case the mother had worked as a commercial sex worker (CSW). In all except three cases the children originated from rural or slum areas. The other three came from lower-middle class urban surroundings. Of the seven children interviewed at CSI, six were from Hindu families and one child was a Panjabi Sikh. The five children at St. Vincent’s home where all indicated to be Roman Catholics by the sister superior of the institution; this has to be viewed in a critical light as the priest who functioned as a guide and translator during the interviews stated that most children were not originally Roman Catholic but were only baptized when entering the institution. With regard to one child this became very obvious as the boy was known by the priest to have been called Krishna when he entered the institution, which implies a Hindu origin, and was called Matthew when I came to know him. With regard to the one child participating from Jeevodaya little was known about her family of origin, but she had also been baptized to be Roman Catholic. The young mother and her son, living in the same institution, where Muslims. All children from the FBOs had tested seropositive, with exception of the two month old boy who was to be tested at an older age. At CSI, four of the seven interviewed children were seronegative. With the exception of three seropositive children at CSI none of the children participating in the research were being treated with antiretroviral medicine (ARV), although some of the

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[5] Lower class: houshold income Rs 2000 or less per month; lower middle class: household income Rs 2000-6000 per month; middle class: household income Rs 6000-12000 per month; upper class: household income Rs 12000 and above per month (D’Cruz, 2003: 23)

[6] For the orphans the researcher takes the family of origin into consideration

children seemed to be showing the first symptoms of AIDS or had already overcome an opportunistic disease.

2.2. The Process

With regard to the sensitivity of the topic and in expectance that it would be difficult to find participants, I contacted the International AIDS Alliance India, seated in Delhi, which established a contact between myself and the head executive director of CSI. Keeping within the ethical guidelines, I did not approach potential participants on my own. Participants were generally approached by CSI staff and informed about the purpose of research. Only after the participants and their care givers had agreed to take part in the research they were introduced to me. They were again informed in detail about the purpose of research by me; the respondents as well as one witness were asked to sign a consent form, which included all the given information on the research and on their rights. In case of underage children the consent form was signed by their parents. The interviews, with one exception, where done in the rooms of the CSI building in Khera Khurd, north-west Delhi. Only the family interview was conducted at the family's own home after I was invited to do this.

The interviews took place at CSI itself to ensure the anonymity and safety of the participants, as some of them had not disclosed their status to at their place of residence. Travel costs faced by the participants where paid for by me. The interview sessions took on average between one and two hours for each participant. The interviews where lead with the help of a translator in Hindi and English. All of the participants accepted the use of a tape recorder after its purpose had been explained. My observations were written in detailed field notes after the interviews had finished.

Due to unexpected expenses faced during the research, I had to shift my original plan of visiting an AIDS Alliance project located in Tamil Nadu to projects lead by FBOs in Kerala where expenses were considerably lower. I established contact with the managing Trustee of Caps & Dass Trust in Kannur, who helped to select the participants within the FBOs and accompanied me in the function as a translator for the interviews which were conducted within the organization in Malayalam and English. These were again tape recorded with participant consent which was given verbally by the care takers to the managing trustee. The data from St. Vincent’s home has to be viewed critically as the children were strongly influenced by the presence of the sister superior of the institution during the interview. All impressions made during the interviews and during the participant observation which enabled me to get a better insight of the situations were written up in detailed field notes.

2.3. The challenge of conducting research with children

Conducting a research project with children was a great challenge. Even though most of my work experience as a social worker was gathered with children and adolescents, the step to do anthropological research and collect qualitative data on the experiences of children with HIV/AIDS and its related stigma, was a big one. Which questions to ask in which way and why would have been challenging enough, but the mindset and psyche of children is quite different to that of adults and so would ask for very careful preparation, especially with regard to the sensitivity of the topic. I knew that with all likelihood I would be facing children who had been traumatized by their experiences and that they could be easily re-traumatize if I were to ask the wrong question. Also, I knew that it often takes a lot more time and intuition to obtain the relevant information from a child than it would to get the same from an adult.

Experience shows that children often have a tendency to try and tell what they think the person opposite to them wants to hear and the question of how to avoid this and obtain the information wanted as unbiased as possible was a further point to consider. Apart of this, gaining the trust of the children would be an unavoidable part of my work for it was essential to find a translator who would be able to understand the sensitivity of the issue and who would have the intuition to phrase my questions in the right way in the child’s native tongue. How important this was became obvious in more than one case when children or even parents started crying during the interview. From an ethical point of view these situations were critical and I found it very helpful that I had had basic psychological training and experience in counseling people. The knowledge that I had of phrasing and asking questions in a counseling situation was of great benefit, but not only that, being trained as a social worker, especially for family and child assistance, equipped me with a variety of different methods of questioning children in a very subtle and sensitive way.

Using “games”, family constellation[7] settings or “coin setting”[8], it was easy for me to find out about family structures and relationships as well as of problems existing within the family among certain members or in general. By using these games as modes of indirect questioning, especially with the younger children, it was easier to avoid pressurizing or re-traumatizing situations for the children as these had the feeling that they were playing, and the questioning was found only to be a secondary process during this game. During these games or painting pictures, which was another method I used to find out about the family structure, children would often open up and just start telling us about their families which made it a lot easier to start asking questions in a way that would not affect children in an emotional way.

2.4. Data analysis

All of the interviews where first translated and transcribed. I then read these transcriptions carefully and coded them thematically. Data that could be compared was put down in strategically sensible tables (Russell Bernard 2005: 456-462). By working in this way I was able to develop a detailed understanding of the life situations and experiences of the respondents. Data was compared to information available from literature reviews. The evaluated data was divided firstly into tables containing basic information on both participants and field sites, and secondly into eight categories[9] of experiences and information. [10] The eight categories then were summarized into four groups which were

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[7] Family constellation is a concept developed by the European psychotherapist Bert Hellinger. They are an effective way of revealing unconscious connections with the fates of family ancestors. Events such as the premature death of a parent or sibling, the exclusion of a family member, a murder of or by a family member, or victimization of others by a family member can all lead to "entanglements" which disturb one's life and relationships. Severe consequences may result, such as feelings of isolation, depression, mental and physical illness, accidents, financial or relationship issues and even suicidal thoughts or attempts. (Saunders and Malinak 2009). In most cases you use a so called family board, little wood figures with which one represents each member of the family.

[8] This is very similar to family constellations, just that there are no figures but coins of different sizes. The child is asked to choose one coin for each family member and to place his family on the floor. Subconsciously the pattern in which the children place the coins on the floor will represent the structure of the family and symbolize the relationship of the members to each other for example if coins are very close to each other there is a close relation between the people they represent etc.

[9] The eight categories: 1. Feelings related to the illness, disclosure and discrimination; 2. Inner attitude of participants towards HIV/AIDS; 3. Problems arising due to the disease related change in the life situations; 4. Stigmatizing attitudes and discriminating behavior through family and the public; 5.Experiances with stigma and discrimination in health care settings; 6. Wishes related to the topic of HIV/AIDS; 7. Reactions towards help and impressions of helping institution; 8. Coping strategies, future outlooks

[10] Please see Annex

defined as the four spheres of experience.[11] I could then identify linkages and patterns similar in the respondents and so was able to interpret behaviors and comments in meaningful ways.

During the time of research I spent a considerable amount of time both in CSI and in Prathyasha/ Jeevodaya which gave me the opportunity to engage in detailed participant observation, both of the patients and their behavior as well as of the staff working at the institutions. It was critical to make the respondents feel comfortable and establish their trust, which would help them share their stories which also allowed me understand their perceptions and experiences. Critical discussions with the staff of the institutions about the topic and the findings enabled me to further develop a deeper understanding of the situations and experiences as well as lives of the respondents.

A further significant point during the data analysis and interpretation, as well as during the research itself, was my engagement in voluntary work with HIV-positive people. All this, as well as discussions with colleagues and professors, helped me to develop the final data analysis presented in this thesis.

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[11] The four spheres of experience: 1. The inner sphere (categories: 1 and 2); 2. The outer sphere (categories: 3, 4 and 5); 3. The helping sphere (category: 7); 4. The future context/ sphere (categories: 6 and 8)

3. The epidemiology of HIV/AIDS in India

The epidemiological data on HIV/AIDS in India is an issue of controversy, as the existing estimates by the Indian government and the United Nations agencies vary in part considerably (Godbole and Mehendale 2005: 361)[12]. As in most countries of the world “the epidemiological data on AIDS in India has emerged ”mainly through a “network of sentinel surveillance, ongoing testing in antenatal clinics and blood banks, research studies, reporting of AIDS cases and information generated from mortality statistics (ibid. 356).” According to UNAIDS India in 2007 was inhabited by 2.4 million PLWHA, 2.3 million adults and 100.000 children; this implies that India is the third most heavily hit country in the world following South Africa with 5.7 million and Nigeria with 2.6 million infected people (UNAIDS 2008: 214, 219).

Based on HIV/AIDS surveillance data analysis from 2000 India has broadly classified it´s states and union territories into three groups: the first group “includes states such as Maharashtra, Tamil Nadu, Karnataka, Andhra Pradesh, Manipur and Nagaland,” in these states the prevalence of HIV/AIDS is over 5% in high-risk groups e.g. injecting drug users (IDU) or CSW and over 1% in antenatal women, which are used to represent the general female population. The second group “includes states/ union territories such as Gujarat, Goa, West Bengal, Delhi, Kerala, Mizoram and Pondicherry, where” the prevalence of HIV/AIDS is above 5% within high-risk groups but is still below the 1% benchmark within antenatal women. The third and last group “includes the remaining states”, which have a prevalence below 5% in the high-risk groups and less than 1% in antenatal women (Panda 2002: 24-25).

The measures of prevalence within high-risk groups and the benchmark of 1% among antennal women are important because in general the HI-virus has been found to “first affect populations with high-risk behavior or whose jobs put them at risk… such as female sex workers (FSWs), IDU and migrant populations such as truck drivers,” from these population groups the “virus then spreads to the general population,” usually via, sexual contacts, transfusions with contaminated blood, or mother-to-child-transmission (MTCT) (Narain 2004: 23). Only after the prevalence of the general population has reached the benchmark of 1% is the situation classified as a generalized epidemic (Weinreich und Benn 2005:21).

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[12] In this thesis I will mainly use the estimates from the UNAIDS 2008: AIDS-Epidemic update

The main mode of transmission in India is heterosexual contact (80-90%), IDU (5-10%) (Narain 2004: 24), which is especially prevalent in the north-eastern part of the county (Kaiserfoundation 2006:1), and MTCT (1-5%) (Narain 2004: 24). Transmission of the virus in health settings currently plays a limited role, although infections have been increasing among blood donators (Godbole and Mehendale 2005: 361). D'Cruz (2004: 44) comments that "a majority of women in India have no risk factor other than being married to their husbands". She also points out that the "increased HIV infections in young women is accompanied by an increase in vertical transmission and pediatric AIDS". Though the total percentage of cases of MTCT, as mentioned above, sounds low, one has to keep in mind that the likelihood of MTCT in India is still 36-48% and that a rise in the general HIV/AIDS prevalence includes a rise in the number of pediatric cases (ibid. 359). Going through the statistics, India has an estimated 100,000 HIV-infected children (UNAIDS 2008: 219), although the actual number of pediatric HIV-infections is not know. Besides the infected children, the World Bank states in a briefing paper of 2003: "India has the largest number of AIDS orphans of any country in the world. This number is expected to more than double in five years, and the proportion of orphaned children will remain exceptionally high until 2020 or 2030 (Children at Risk 2007: 5)." Although the exact number is not known (Crossroads international 2009), activists suggest a much higher number; they state that an estimated one million children in India under the age of fifteen years have already lost one if not both parents due to HIV/AIDS (Bharati 2009).

"The numerous predisposing and precipitating risk factors that either directly or indirectly facilitate" the transmission of HIV in India, are strongly likened to both social and cultural aspects of life within the society. Migratory patterns, increasing urbanization, poverty, illiteracy, subordinate status of women, high rates of sexually transmitted diseases (STDs) and intravenous drug use and wide spread practice of unsafe sex, are only a few of the risk factors facilitating the spread of HIV/AIDS on the Indian subcontinent. Further the "inadequate access to health information and service" has a severe influence on the ability of the population, especially on people with a higher risk factor (including women and adolescents) to protect themselves. Viewing the literature on HIV/AIDS in India, it becomes clear that most of the newly occurring HIV/AIDS infections are found in young people of the reproductive age[13], especially young women (Capoor 2006: 11). Further, considering the current and rising transmission rates and the fact that premarital sex in

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[13] Defined by Capoor as the age group between 15 and 40 years

India is no longer as uncommon as widely believed (Abraham 2002: 337), India could soon have the largest number of PLWHA in the world (D’Cruz 2004: 44).

4. Stigma and discrimination

The use of the term stigma according to Goffman (1967: 9) can be dated back to the times of ancient Greece where it was mainly used to point out a special sign on the body or a special physical characteristic of a person which was believed to be a hint towards an unusual or bad moral state in the carrier. The signs used to make such stigmatized people apparent were mostly burnt or cut into their skin (ibid.). As in the case of the Jewish star in Nazi Germany, these signs were used to identify their holders a belonging to a certain category of people (American-Israeli Cooperative Enterprise (AICE) 2010). Sign carriers in ancient Greece used to be slaves, criminals or traitors; in any case people who had been marked with the sign were seen to be immoral and impure. The sign gave the public the opportunity to identify and seclude the carriers of the stigma (Goffman 1967: 9).

Throughout the Christian period, the word stigma has also been used, although there are two new metaphorical meanings added to the original Greece meaning (ibid.). One of the new meanings refers to a physical sign which was awarded to the carrier by the grace of god and which pointed him out to be special or blessed, such as was said to be the case in St. Francis from Assisi, (Hellmann 1987: 43-44). These physical signs usually were found to be corresponding with those of the crucified Jesus Christ (Herek 1990: 2). The second was similar, it was used for physical signs which were thought to point out some ambivalence or negative source within its carrier (Kieckhefer 1996: 321), so called devils marks, which were used from approximately the 1450 - 1750 to identify witches (Levack 2006: 1, 30). Often the line between the two forms of stigmata, which made their carries either a “saint” or a “witch”, was very thin (Kieckhefer 1996: 321; Herzig 2006: 24)

Today, so Goffman (ibid.), the term stigma is used broadly in its original sense, which is strongly related to thoughts of impureness and dishonor with regard to it carrier. The term is not anymore so strongly related to the physical appearance of a person. Falk (2001: 11-12, 17-18) comments that in modern America both stigma and stigmatization refer to an invisible sign of disapproval, through which a line can be drawn between insiders and outsiders of a certain group. This demarcation that limits the inclusion into a group also permits the *insiders* to know who is “in” and who is “out”. Further, he says that it allows the group to maintain its solidarity by showing clearly what happens to people who deviate from the accepted norms of conduct. Scheyett (2005: 79-80) states that today stigmatization is an issue of disempowerment and social injustice.

4.1. The theory of stigma and discrimination

Emile Durkheim, the first scientist to explore stigma as a social phenomenon, stated in 1895:

> "Imagine a society of saints, a perfect cloister of exemplary individuals. Crimes or deviance, properly so called, will there be unknown; but fault, which appear venial to the layman, will there create the same scandal that the ordinary offense does in ordinary consciousnesses. If then, this society has the power to judge and punish, it will define these acts as criminal (or deviant) and will treat them as such." (Herman 1995: 39)

Durkheim's words imply that any behavior shown by a member belonging to the society in which this behavior is viewed as deviant, will lead to the stigmatization of this person. Goffman (1963: 13), contrary to Durkheim, focused on stigma not as a deviant and inherent behavior or attitude shown by a person but far more on the experiences and the meaning of difference. He considers that stigma is "the phenomenon whereby an individual with an attribute is deeply discredited by his/her society and is rejected as a result of this attribute. Stigma is a process by which the reaction of others spoils normal identity." Regarding the origin of stigma, Goffman (1967: 9-10) comments that through socialization people learn subconsciously to categorize others with relation to a complex of different characteristics which are seen as "normal" or "usual" within their own perceptions. These categories are so called norms of social identity. People belonging to a certain social identity are expected to behave and react within the boundaries defined by this identity (Goffman 1967: 9-10). Generally people are not aware of this fact; we automatically categorize people we meet into the categories of social identity known to us. We create a *virtual social identity* for the person, which might differ strongly from his or her *actual social identity*. If a person we meet for some reason does not fit into any of the categories we know, so Goffman, we are likely to perceive him or her to be dangerous, bad or weak. Through our inability to categorize this person he or she, in our point of view, is easily seen as an impure or handicapped person of less worth. The unknown characteristic becomes a stigma, evolving from the discrepancy between the *virtual* and the *actual social identity* of the person (ibid. 10-11). Such a discrepancy according to Goffman can also lead to us viewing a person as more positive, so upgrading him, but if we speak of stigma the negative interpretation is meant. In his book Goffman describes three different forms of stigma: *physical stigma*, which is characterized by any disgusting aspect relating to the physical appearance of a person, for example a physical deformity. Secondly, the *individualistic characteristic*, such as mental weakness or confusion, uncontrolled or unnatural passions, criminal ambitions or actions, addiction, homosexuality, joblessness, suicidal tendency, radical or dishonorable behavior. Finally, the *phylogenetic stigmata* such as race, religion or nationality. These forms of stigma are inheritable and generally affect more than one generation (ibid. 12).

These forms of stigma defined by Goffman were renamed into the following by Campbell and Deacon (2006: 412): overt or *external deformities*, *known deviations in personal traits* and *tribal stigma*. Goffman's definition of the three forms of stigma in make it questionable to link stigmatization to a deviant behavior or attitude shown by the stigmatized person as Durkheim does in his definition of stigma. The reason for questioning Durkheim after viewing Goffman's definition is simply that both his third and first form of stigma have nothing to do with deviance that is related to behavior or attitude. Neither race, religion and nationality nor physical deformations of a person necessarily have to do with his or her overall attitude or a deviant behavior.

Considering HIV/AIDS in Goffman's context the stigma imposed on HIV-positive people and their families would be a mixture of *individual characteristics* as HIV/AIDS is in public usually related to some immoral behavior of the infected person (Herek 1990: 1), and the *phylogenetic stigma*, as it affects not only the HIV-positive person but also his entire family which also includes children, and so more than one generation.

According to UNAIDS (2007: 9), HIV/AIDS-related stigma and discrimination are defined as…"a process of devaluation of people either living with or associated with HIV and AIDS….. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status". Letamo distinguishes between *felt/perceived stigma* and *enacted stigma*. *Felt stigma* „refers to real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, disease (such as HIV) or association with a particular group"(Letamo 2003: 349), while *enacted stigma* is the real experience of discrimination. Discrimination is that behavior which results from stigma; it is "any form of distinction, exclusion, or restriction affecting a person by virtue of a personal characteristic" (Letamo 2003: 349; Goffman 1967: 13; Mawar et al. 2004: 474). Srivastav (2006: 359) considers that stigmatization describes a process of devaluation that is created by individuals and communities. As Mawar et al. (2004: 471) point out it can be conceptualized as a problem of "they" and "us". Srivastav (2006: 359) distinguishes stigma as "a complex, diverse and deeply rooted phenomenon that is dynamic in different cultural settings", so it can be seen as a collective process rather than as a "mere reflection of an individual's subjective behavior". Further he comments that it operates by "producing and reproducing social structures of power, hierarchy, class and exclusion" as well as by transforming differences such as class, race or health status into inequality (Srivastav 2006: 384). Goffman (1967: 11-12) points out the same but adds that what can be seen as a stigma within one special group of people or one society might be seen as a generally normal or even positive sign within another. Stigmatizing attributes according to Goffman cannot be generalized but have to be seen within a sociological context. Differently to Letamo (2003), Srivastav also distinguishes between *internal* and *external stigma*, "which is almost equivalent to the idea of the *dilemma of the discredited* and the *dilemma of the discreditable* mentioned by Goffman (1967: 12). Goffman adds that both dilemmas would be clearly known by any stigmatized person.

Srivastav's (2006: 384) internal stigma, just as Goffmans *dilemma of the discredible* (1967: 12) refers to a *felt or imagined stigma*; it is the shame that is associated with HIV/AIDS as well as "the fear of being discriminated against, which is felt by PLWHA (Srivastav 2006: 385). This form of stigma, so Srivastav, often causes a refusal or reluctance to disclose the HIV status or to a total denial of the disease. An example he gives at this point is the one of a mother who breastfeeds her child though knowing her positive status and the risk of transmission to the child because she is afraid of the social consequences if she does not breastfeed or if her status becomes known in public. He also states that this form of stigma in some cases seems to be a form of survival mechanism or a protection against *external or enacted stigma* (Srivastav 2006: 385). As also is the case in Letamos' definition of enacted stigma, and Goffman's idea of the *dilemma of the discredited*, Srivastav also defines external stigma to the actual experience of discrimination. He comments that:

> "This (external stigma) may include the experience of domination, oppression, the exercise of power or control, harassment, categorizing, accusation, punishment, blame, devaluation, prejudice, silence, denial, ignorance, anger, a sense of

> inferiority, social inequality, exclusion, ridicule, resentment or confusion" (Srivastav 2006: 385).

He further indicates that both *enacted stigma* and discrimination "have been described as a collective dislike of what is unlike", which means that which differs from oneself. This form of stigma is normally intentional, although people might sometimes not be aware of the fact that their behavior and attitudes are stigmatizing (Srivastav 2006: 385; Goffman 1967: 13-14).

If it comes to HIV/AIDS-related stigma, he states that as soon as stigma has been invoked it becomes easy to discriminate against PLWHA because in a sense stigma in public eyes removes the "qualities that make them worthy of respect and dignity", and as people act on a basis of their beliefs this often results in forms of active discrimination and human rights abuses (ibid.). Sharma (2007: 16) mentions that the widespread HIV/AIDS-related stigma results from various forms of misconception. He divides the HIV/AIDS-related stigma into the following three categories: first *instrumental AIDS-stigma* which is "a reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness" (Sharma 2007: 65). Second, *symbolic AIDS-stigma* which implies "the use of HIV/AIDS to express attitudes towards the social groups or lifestyles perceived to be associated with the disease" (ibid.); and third, *courtesy AIDS-stigma* which means the "stigmatization of people connected to the issues of HIV/AIDS or HIV-positive people" (Sharma 2007: 66). Sharma (2007: 66) further comments that: "often AIDS-stigma is expressed in conjunction with one or more other stigmas, particularly those associated with homosexuality, bisexuality, promiscuity and intravenous drug use." This would fit with the interpretation of HIV/AIDS in the context of Goffman's definitions of stigma.

4.2. The HIV/AIDS related stigma and its social context

Due to the relationship between HIV/AIDS and the social stigma related to it the disease cannot be seen solely as a biomedical problem Beine (2003: 59; Mawar 2004:471; Kleinman and Hall-Clifford 2009: 418); states that there also has to be recognition of the strong social implications which accompany the disease and that have severe negative effects on the lives of both infected and affected people. Farmer (1992: xi) mentions that "the world pandemic of AIDS and social responses to it have been patterned by social arrangements" and Herdt (2004: 39) claims that "culture shapes our responses to the disease". So cultural models of health are strongly influenced and shaped by cultural factors. AIDS in this context is no exception (Beine 2003: 59). Within this context Sahu (2004) further points out that "the rules of the game have changed with the advent of AIDS". As he puts it, long-standing practices such as unprotected casual sex suddenly become a deadly threat to communities but "encouraging safer sex practices means negotiating a path through the minefield of taboos, prejudices and inhibition that surround sexual activity in almost every society" (Sahu 2004: 49). Within societies there are social and cultural factors such as beliefs, myths and superstitions that are related to sexuality. These social attitudes and practices, so Sahu, vary within every society with relation to its traditional and cultural views on sexuality itself. Most of the time, certain sexual taboos and myths are important obstacles to sex education or the creation of a general understanding of the topic within a population. An example would be the attitude that sex is sinful unless it is meant for procreation. This can create a feeling of guilt if people are asked to use birth control measures such as condoms (Sahu 2004: 62). This again fits into Srivastav's concept of internal stigma (2006: 384) and Goffman's "dilemma of the discreditable (1967: 12)" described in the chapter above.

A problem with HIV/AIDS (and other STDs), and one of the reasons why it is so highly stigmatized, is that it is related to sexuality and the misconception that it only affects people from already stigmatized groups such as men having sex with men, sex workers and injecting drug users (Sharman 2007: 16, Sahu 2004. 156). The fact that HIV/AIDS is so strongly identified in public with stigmatized forms of sexuality or socially immoral behavior increases the amount of stigmatization and discrimination of people who are infected or affected by the disease (Sahu 2004. 156; Campbell et al., 2005: 808). Due to this fact HIV/AIDS infected individuals are blamed for causing their own condition through their immoral behavior, the illness thus is often stated to be a punishment by god for such behavior (Mawar et al. 2005: 472; Herek 1990: 5-6; Yang et al. 2007: 1527-1528). During the conducted research I found that infected men were often accused of drug use, homosexuality or of frequent visits to prostitutes and women who contracted the disease faced the accusation of being prostitutes or indulging in other sexually promiscuous behaviors. In any case people infected with the disease where accused to have contracted it by violating social and moral norms of society (Mawar et al. 2005: 472; Keusch et al. 2006: 525; Link and Phelan, 2001: 373) and as Kleinman and Hall-Clifford (2009: 418) put it the infected individual in this case has not meet its social obligations towards the society it lives in. This fits with Durkheim's definition of stigma which is related to deviant behavior of an individual and so with the violation of the norm mentioned above.

Due to the idea that HIV/AIDS is linked to forms of socially deviant behavior in which the infected person has indulged prior to his/her infection (Yang and Kleinman 2008: 6; Vanable, et al. 2006: 474; Herek 1990: 2; Mawar 2004: 471), and due to the fact that HIV/AIDS remains to be an incurable disease (Aggleton, et al. 2002: 1; Herek 1990: 9), infected people are perceived to be impure or untouchable (Krishnan 2003: 1). This can be related to the concept of impurity and untouchability which is deeply rooted within the Indian culture through the caste system (International Dalit solidarity Network 2009). In my research there was a clear distinction because infected people perceived their blood to be impure. Also health care staff were reported to show fear of coming into contact with what to them were impure and polluting body fluids. On the other hand, although one might think that stigma and the idea of impurity would be prevalent within the Indian context due to the existence of the caste system, this is not the case. Behaviors like those described above are a global problem (Yang, et al. 2007: 1528; Keusch, et al. 2006: 526) in the sense that can be no clear distinction made of an especially "Indian" form of HIV/AIDS-related stigma. In all of the field sites where my study professionals worked, questions about HIV/AIDS and caste elicited the response that HIV/AIDS related stigma is not related to the traditional caste concept, but in a sense it creates a new caste.

> "HIV makes one caste, even in the highest family HIV means rejection, stigma is not caste wise." (Nun, St. Vincent's Home Potta)

For HIV/AIDS within the Indian context there is not a increase in stigma with caste but with class. The problems increase the lower the living standard and economic background of the person.

> "Discrimination is put on all of the society but it is very less among upper class people. People in the slums face more stigmas." (CSI social worker)

These statements also support Paul Farmer's theory that HIV/AIDS related problems and stigma are strongly associated with structural violence, and that this increases exponentially the stronger the structural violence which an infected or affected person suffers (Kleinman 2009: 418; Castro and Farmer 2005: 54; Herdt 2001: 141).

4.3. The effects of the HIV/AIDS related stigma and discrimination

Addressing the discrimination resulting from the HIV/AIDS related stigma is of the greatest importance as it has severe negative effect on people's health seeking behaviors (Link and Phelan 2001: 363; Keusch et al., 2006: 525; Letamo 2003:348-349). Letamo states that "HIV/AIDS-related stigma and the resulting discriminatory acts create circumstances for spreading HIV. The fear of being identified as HIV-positive prevents people from learning their serological status, changing unsafe behavior, and caring for people with HIV/AIDS (2003:348-349). " Srivastav (2006) points out further that in India negative attitudes towards infected people can be found especially in health care staff. This increases the existing anxieties and fears of PLWHA with the result that they keep their status secret and don't seek help. In the majority of cases the denial of status or keeping it secret can be related to traumatic experiences made in health care settings (Srivastav 2006: 361).

HIV/AIDS-related stigmatization and discrimination not only have effects for the infected people themselves, but they almost always also play a major role in the individual lives of their family members. It is the families who have to take the responsibility of caring for and supporting their sick members. The four dimensions of stigma that Fife and Wright (2000: 50) identify are the following: social rejection, financial insecurity, internalized shame and social isolation.

Children in this context are especially vulnerable (D´Cruz 2003: 3-4) as we have already seen from the story of Sangeetha. Children[14], whose parents have AIDS and/or die from AIDS, for example, are impacted medically, psychologically, socially, and economically. AIDS orphans are often excluded from society, discriminated against, and left to fend for themselves. These children are generally psychologically distressed and do not have access to basic education and basic health care (Pandve et.al, 2008: 47). As in Africa, in India children are also often forced to care for their sick parents and even at young ages have to take up a job to be able to replace the parents' income and provide food and care for younger siblings (Sharma 2007: 130). D'Cruz (2004: 53) also addresses this issue of so

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[14] In the article by D'Cruz children are defined as persons under the age of 14 years. Article one of the United Nations Convention on the rights of children defines "children" as persons up to the age of 18. In this thesis I will use the later definition.

called child headed households (CHH) by stating the following: “When one parent dies in a nuclear family, there is usually no one to look after the other parent and siblings, and in that case, children assume adult roles,” she further points out that the number CHH in India is unknown but that there is estimated to be a significant number of such. Taking over the responsibility for the family’s wellbeing and providing care to parents and siblings strongly contravenes with the state of childhood. “Child caregivers experience burden on account of their role, but this is augmented by the psychological stress and trauma of watching parents and siblings deteriorate and die (D’Cruz 2004: 54).” The stress of the caring process and responses by the surroundings towards the family situations further threaten children in their psychological development D’Cruz (ibid.) which results from experiences of “exclusion, isolation and interference with education” as children care givers often miss school, cannot complete their homework and have no time for after-school activities. This overall strain could result in children suffering from mental ill health as a result of confusion, pressure and stigmatization (ibid. 55).

In Kerala, one study found that AIDS-orphans were banned from school after the parents of other children threatened to withdraw their children as a safety measure (Kumar 2004 and IBN Live, 2006). Due to the lack of support and care that affected and infected children experience, they face a higher risk of ill health and nutritional problems, and are easy prey to exploitation (e.g. prostitution, beggary, juvenile delinquency, and drug abuse) (Sen 2005). Srivastav (2006: 399) mentions similar situations as he states that affected or infected children face many forms of discrimination and violations of their human rights, such as: “being tested for HIV without their consent or the consent of their parents or guardians; being denied access to schools or being physically and verbally abused at school and denied access to adequate sexual and reproductive health information”. In addition, Sharma (2007: 129) points out that children who are affected often face lethal forms of discrimination and exploitation; as he puts it such children are not only turned away from schools but they are also turned away from clinics and orphanages because of the positive serological status of their family members. Especially the children of sex workers, street children or children from lower castes (such as Dalits) suffer even more as they also face other forms of discrimination (Sharma 2007: 130). Sharma also points out that many children, as well as the professionals who care for them, often do not have enough knowledge about HIV/AIDS to protect themselves or to be able to combat discrimination. He states that: “fewer than half of all secondary schools offer any AIDS education" and those "that do teach about HIV/AIDS do so at an age when children, especially girls, have already dropped out." The misinformation or lack of information that parents and caregivers have about HIV/AIDS often leads to the fact that families reject HIV-positive children or children who are thought to be HIV-positive (Sharma 2007: 130). Due to this AIDS-orphans often face a hostile environment which confronts them with neglect, stigma and discrimination. Researchers have found that being stigmatized can have strong long-term negative effects on individuals, such as loss of self-esteem and social rejection (Samules, et.al. 2006: 106). However, this reaction has been recognized and is beginning to be addressed:

> "Fundamental steps in building a supportive environment include involving children and families affected by HIV/AIDS in care and treatment strategies; increasing awareness of the impact of HIV/AIDS on children and families; and reducing fear, ignorance, denial and discrimination by increasing access to information, challenging myths and transforming the public perception about HIV/AIDS." (Pandve, et.al 2008: 48)

There has been little work done so far on HIV/AIDS-related stigma in children in particular; therefore it is of great importance to "disentangle all the various dimensions of stigma and discrimination in the special context of children living with and affected by HIV/AIDS" (HIV/AIDS Alliance India)[15].

4.4. Responses by the Indian government towards the HIV/AIDS epidemic

The first cases of HIV/AIDS were detected in CSW in Chennai in 1986; five years after the first cases of AIDS had been reported form the USA (Panda 2002: 15). Though there was a tendency towards a denial of the AIDS epidemic, from some influential leaders within the Indian parliament (Verma, et.al. 2004: 22), a "National AIDS committee was formed under the chairpersonship of the secretary of the ministry of health and family welfare" the same year. This committee was supposed "to formulate a plan and implement a preventive program (Sethi 2002: 37)" which it did. One year later the National AIDS Control Program was called to life, its goal was to establish "a central AIDS cell in the office of the directorate general health service in New Delhi and AIDS cells in each" of the Indian

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[15] Personal communication 01.07.2009

states. The states themselves were "encouraged to have their own plans for AIDS surveillance (ibid.)." In 1992 National AIDS Control Organization (NACO) was founded "as a central control agency for the AIDS campaign," with support of the WHO and the World Bank it was setup by the ministry of health and family welfare (Sethi 2003: 39; Verma et.al. 2004: 22). The program developed by NACO "involved all states and union territories in developing HIV/AIDS preventive activities, with a special focus on the major center of the epidemic (Sethi 2003: 39)". The five major components of the program are stated to be the following: "strengthening management capacity for HIV control; promoting public awareness and community support; improving blood safety and promoting rational use of blood; building surveillance and clinical management capacity and controlling STDs (ibid.)."

Despite the fact that the described actions look good at the first glimpse, the Indian government has been criticized sharply for slow, inadequate and poor executed actions (Verma et.al. 2004: 23). Verma et al. (ibid.) points out a number of criticisms. First, an excessive precedence to medical solutions (ibid.). This is relevant as it is clear that there is no cure for HIV/AIDS and scientists state that there is no hope of finding it anytime soon (Storad 1998: 19). Nonetheless most of the worlds antiretroviral medicines (ARVs) are produced in India (Westerhaus and Castro 2006), ironically most of them are exported to other countries and especially the newer ARVs don`t end up with the Indian HIV/AIDS patients at all (Bagla and Menon 2008: 57). With regard to my research this point becomes important as I was told that pediatric ARTs[16] especially those in syrup form were rarely available, and that children took the same ART as adults just in reduced doses. This is a problem as there is a high risk of over or worse under dosing children if the ARV is given in Tablet form. An exact dosage is only possible if the pediatric ART is given in syrup form and is measured by ml per kg of body weight (Nolen 2007: 246-248). Secondly he criticizes the "Absence of frank public discussions of the source of risk (Verma et.al. 2004: 23). Verma further states that there is little to no public discourse about sexuality in India. This can be seen in the fact that, though reproductive health and sex education for the adolescent age group, have been advised strongly by NACO, the fear of an increase of sexually related health risk behavior among adolescent populations has even lead to the fact that some Indian states such as Kerala and Goa have banned such education from their schools (Motihar 2008: 14). During my research both affected and infected people as well

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[16] ART = Antiretroviral therapy

as the professional working at CSI stated that the only mode of reducing stigma and discrimination as well as reducing the number of new infections in the long run is to create public awareness. Without opening a public discourse on the topic of HIV/AIDS and of reproductive health matters there can be no improvement of the situation in the long run. Further so Verma (2004: 23) there is a "failure to formulate an AIDS policy that integrates into more general public health and primary health care programs and HIV/AIDS prevention and care is not yet part of the mainstream social process (ibid.)." This is especially important considering that this also includes that there is a "major lack of attention to human rights and their violation (Sethi 2002: 58)." Though there was an early attempt to establish a subcommittee within NACO addressing such issues, it was never launched. With regard to the many cases of refused treatment, denied education and cases in which HIV-positive people were denied to rent a house or flat for themselves and their families (ibid.), it would be important to take action on this regard. Rajkhowa (2002:166-167) adds "law has an important role in complementing and assisting education and other public health measures to generate awareness. Legislation needs to provide for non-discrimination and privacy so as to facilitate full community participation and the integration of HIV-positive people in the society to secure their trust and cooperation, and not to compound the stigmatization and alienation of this group of people, whom the society has rejected by treating them in a negative, punitive way." Also this point of criticism is to be supported clearly by the findings of the research as children were banished from attending normal schools in Kerala, due to their positive status, and there were many experiences with the reluctance of doctors to treat HIV-positive patients in Delhi. Apart from that Verma (2004: 23) criticizes long delays for equipment and essential supplies for upgrading blood banks and other facilities. This might be especially important regarding the rising HIV/AIDS infection numbers among blood donors (Godbole and Mehendale 2005: 361). Two other points he Verma (2004: 23) mentions are: The lack of analysis and dissemination of important research results, which as a result remained unutilized and the lack of quality monitoring of prevention material, and lack of assessment with regard to different media and approaches (Verma et.al. 2004: 23). A further important point of criticism is that, although the threat of HIV/AIDS is no longer confined to "high-risk" populations such as truck drivers and commercial sex workers, and in fact there has been a dramatic rise within the general population, the Indian government allots 80% of their HIV/AIDS funding to prevention within these groups. This focus leaves only about 20% of the money for children and families living with HIV/AIDS (Pandve et.al, 2008: 48). It is obvious that this is not enough money, a fact that is underscored by India’s status as having one of the highest rates of AIDS orphans in the world (Sen 2005). This aspect together with the rising prevalence among the general population might in the long run turn out to be a fatal mistake considering the numbers.

5. The four spheres of the experience with HIV/AIDS and the related stigma

> "Raju is nine years old, he is HIV positive he lives with his positive mother. His father has already died of AIDS. After the death of his father they suffered a lot under the pressure imposed by the family. The neighbors who know about the status though were very supportive. But as his father was dead the family suffered financially. His mother who works for daily wages got remarried to an HIV negative man. With him she has a daughter who is HIV negative just as Raju's two elder sisters. Raju's status, as well as that of his mother, was not disclosed to the new family out of fear of stigma and discrimination. Since September 2007 Raju is on ARV, when he started his CD-4 count was 752, now it is back up to 1.247. He knows about his disease and takes his own medicine. Asked if he is afraid he shakes his head and his mother tells me "No, he knows he can be a healthy kid through the medicines", but still he often suffers from pneumonia which worries his mother. A short while ago Raju had an accident while playing and he bled badly, but he will not let anyone except his new father or his mother touch his blood, he tells others to be careful because something is wrong with his blood. The neighbor children, though knowing his status, still play with him; they just run and get his father if something happens to him. In the school his status has not been disclosed out of fear of discrimination."
>
> (Interview with Raju and his mother at CSI, Khera Khurd/ north-west Delhi)

The experience with HIV/AIDS, and especially with its related stigma, affects all levels of an affected or infected person's life, as can be seen from Raju's story. Its effects are emotional, physical, economical, social and spiritual (International HIV/AIDS Alliance India 2009:3). In almost all of the cases, the diagnosis HIV/AIDS comes suddenly and unexpected to the families, after a long period of suffering.

> "Most of the family comes to know about HIV at the last moment, after suffering and treating so many diseases." (Renia 28, social worker at CSI)

I found families had been under pressure for a long time when they finally received the diagnosis of HIV/AIDS. Often the ill members of the family were pushed from one hospital to the other and had to undergo many medical tests before they were finally tested for HIV. The families stated that they sometimes had the impression that doctors were trying to get out of their responsibility if there was no clear diagnosis straight away and also as if the HIV-test was the last possible option to take if all other options and explanations failed. This attitude of doctors meant an immense pressure for the families both emotionally and financially. The mother of a participant stated:

> “Kisi ney nazar laga diya hai (Some has given us a bad eye). We went to many gods and goddesses, many temples in Pallavghar, Kutubghar. I also made many treatments and gave medicine to him. Our family lost money.… We went to the Muslim priest also to get holy water so that my husband can get well but nothing happened. We went to the Ambedkar hospital to other hospitals for various treatments; like this many months passed by. The doctors said to take him to a mental hospital… There they checked him and said he is not mad. Take him to a normal hospital. I again took him to a government hospital. There they did lot of tests, they did CT scan of head. They charged 2500 rupees…After a long time passed and we went to more hospitals they said he is positive with HIV.” (Mother of 4 children, CSI)

And another time I was told,

> “Her husband got ill and fever all the time, he was very thin. When she got pregnant they tested and she is positive.” (Nun at Prathyasha/Jeevodaya about Sita 23, Kannur)

Though the diagnosis itself in many cases brought clarity to the situation and enabled the families to seek an adequate treatment it was always bound to a number of new feelings and situations which the affected children and their families had never had to face before. The pressure of not knowing what was wrong with the ill family member was replaced by not knowing how to deal with the new situation and especially how to hide it.

> “Now we came to know he is positive, but we were afraid, what will happen to us now, what if people come to know?” (Sister 1 – now 20 –, CSI)

In the following four chapters I will describe the four spheres of experiences that I could identify during my research: the inner sphere thereby is related to the emotional and psychological reactions of each individual such as his or her feelings toward the disease and its effects, the outer sphere concerns the mostly negative influences on the individuals opposed on them from their surroundings such as the extended family, doctors or neighbors. Positive experiences and the reactions towards received help will be discussed in the chapter “the helping sphere”. This will be followed by the fourth sphere, the future context which will deal with coping strategies and wishes for the future, such as the opinions of the children on what has to be done to make their lives as affected children easier and what they wish from both government and society with regard to policy and attitude changes.

5.1. The Inner Sphere

> “Rishi is seven years old; his parents were both HIV-positive. His mother died first, a year later his father also expired, so he was taken to live with his maternal grandparents. Everything was okay in the family until they came to know that Rishi was also HIV-positive. His grandparents got scared and did not want Rishi to live in their house anymore. Rishi somehow came to know about the problem and could not cope with it at all, one day while playing with his cousins he bit one of them, his grandparents said he is dangerous and can infect others and can stay with them no longer. Rishi was taken to a hostel and admitted there. He could not cope with being sent away to the hostel “he is completely done, he did not cope with anything in the hostel. He was pushed around, first he was with his mother, then she died, then he lived with his father and also he died, and then he lived with his grandparents and they send him away to live in a hostel.” He could not cope, so on the first day in the hostel he takes a knife and tries to kill the ward because she was telling him to take breakfast, dinner and a bath, but he did not want to. He didn´t want anything, he didn´t even want to play. He is not interested in anything, he just sits there.”
>
> (Story told by: CSI program coordinator)

> “Sima is nine years old now; she is from the state of Haryana. When she was three and a half years old her father died of AIDS. The reason for his death was meningitis. Her mother is also HIV-positive. Sima herself is HIV-negative. Due to

> the meningitis her father used to have bad headaches and cried a lot. After his death whenever someone in the family complained about a headache Sima started crying. “She was toilet trained before his death but after his death she started bed wetting again. There are so many things that happened. We saw the child; she looked very beautiful and smart. After that her nature is different and everything is different. The child is changed, completely changed. Life is changed and walking style has changed. I think she was traumatized by her father’s death.” There were many changes in the family after her father’s death. The family of his father started putting a lot of pressure on her mother. Both Sima and her mother suffered a lot under that pressure. Finally her mother got married to a distant relative “a negative man”[17]. With the help of her mother and “new” father Sima took a year to recover from her trauma. (Story told by: CSI program coordinator)

Children that find themselves in extreme and emotionally pressuring situations such as Rishi are often unable to articulate their feelings properly. If this coincides with a lack of emotional backup for the child, due to the inability of the surroundings to handle the emotional needs of the child properly, maybe as a result of an inadequate knowledge on child psychology, it often leads to children compensating their feelings via extreme behavioral reactions (Kaminer et al. 2005:123; Greene 2007: 266-267; Brooks 2007: 201). The reactions that are often seen in children after the loss of a loved person are aggression, total ignorance or extreme clinginess towards other people that are of importance for the child or have the function as a caretaker (Greene 2007: 266-267; 447, 458). Feelings that are often compensated via this mode are fear, especially the fear of loss, emotional pain, helplessness and total frustration (Kaminer et al. 2005:123; Greene 2007: 266-267; 447, 458). Rishi’s reaction speaks a clear language, which becomes understandable if we look at its context. Both of his parents died within a short time period of each other and after a long and severe illness. Rishi has experienced all this closely, an experience highly traumatizing for a child. When Rishi finds out he is ill too, this knowledge, and the experience of seeing his parents die, will make him draw the conclusion that the same thing that happened to his parents might also happen to him (Subramanian and Kavitha 2007: 207). Such knowledge will lead a child to a feeling of fear, pain and hopelessness, a situation that is almost impossible to handle without emotional or psychosocial support

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[17] Referring to the HIV-status

(ibid.). Also in Sima’s case, the death of a parent had a great effect on the child’s emotional stability, yet through the help of her mother and her new father she was able to overcome the situation after a while.

During my time in Prathyasha/Jeevodaya, I met Maria, she was four years old and HIV-positive, her mother who had been a CSW had hanged herself after receiving the positive result of her own HIV-test.

> “The child was alone there, she was crying and called others, that time already her mother was gone (dead). She was only 3 years and then for her nobody was there and then this one NGO was there, they informed the court then first they found this place and we thought we will keep her in the Bala Bhavan (orphanage) then after that they said about this matter that her mother was affected by HIV we said “please then check it!” and they checked and she was also positive and then they brought her around 8.30 at night here (Prathyasha Bhavan).” (Nun, Prathyasha/Jeevodaya)

I spent a lot of time with Maria, but once I got ill and I could not go to play with her for three days as it would have been dangerous for her. When I came back to see her after that time she refused to even look at me, I sat next to her while she was lying on the bed turning her head away from me hitting me if I touched her. I sat and waited for a few minutes telling her I was sorry, and then I simply picked her up and went for a walk in the garden carrying her on my arm. It took about fifteen minutes till Maria put her arms around me and said “Ariana”. The reaction that Maria showed in this situation is typical for children that have had experiences with loss and it is often seen in orphans after adoption. The explanation is simple: she had been afraid I had left and left her behind.

Not alone, the experiences with the death of their parents was traumatizing for the children I spoke to. In addition the knowledge about the illness of their parents created a feeling of fear in the children, especially about the future. One girl told me:

> “I came to know about my parent’s illness with 11 years but only understood at 14 years and I had fear. Fear of who will see us if our parents die. If parents are not there, no one is there. Our future will be in trouble.” (Priya 18 years, CSI)

Another child stated:

> “I came to know about my parent’s infection when I was 13, I was afraid of what would happen in the future.” (Pratap 17 years, CSI)

Added to this comes the confusion that is created in children through behavioral changes in their parents, which are either related to the parent’s feelings regarding the disease, to the illness itself or to medical side effects. Pratap phrased his experiences and feelings in the following way:

> “We were very scared, because my father’s condition. It was a bit disturbing but we were prepared for it. There was a little satisfaction when at least there was some improvement in his condition.” (Pratap 17 years, CSI)

He adds:

> “We thought our father will die, so we took the family photograph. By seeing the family photograph we feel to cry. Our situation was so bad at that time.”

And his elder sister points out:

> “Looking at father’s activities we used to laugh but also cry as he is our father.” (Sister 20 years, CSI)

Both Pratap and his sisters mentioned that these aspects had been very difficult for them to handle at the time and that the situation had meant a lot of fear and insecurity for them. Priya, when asked about her feelings, is overwhelmed by them and starts crying for her it is very difficult as she has taken the role as a caretaker for her parents next to her responsibilities in school, where she attends the 12th standard. She says:

> “My mother takes very strong medicines and she becomes very angry and abuses me. I cannot listen to that. I tell my mother, you can slap me but don´t abuse me. She is my mother, she can hit me!” (Priya 18 years, CSI)

She adds that she tries not to let the pressure get to her and she tries to give her parents a good feeling and not to make them feel that they have a dangerous disease.

As we have heard in the introductory section on the effects of the HIV/AIDS related stigma it is not unusual that the eldest child in the family becomes the primary caretaker of parents and younger siblings, I was told by the CSI program coordinator that:

> “Like that girl (referring to Priya), so many children are doing care for the parents…” (CSI program coordinator)

The pressure of taking such a big responsibility is immense for children. Though Priya states that she lets no pressure come to her, her body language and the fact that her first reaction was to start crying speaks a different language. This is supported by her statement

> “I am doing a lot of effort but I didn´t find a good result in my school.” (Priya 18 years, CSI)

Also the CSI staff that spoke to me about Priya stated that she seldom complained and that she was very active in her work but that sometimes she would state that it is quite difficult.

The experiences with HIV/AIDS and the related stigma, as we can see especially from Rishi and Sima’s story, can have a severe traumatizing effect. The illness and death of parents as well as experiences of discrimination (discussed in the chapter on stigma and its effects) can have devastating effects on children’s psychological health. I found during my research that even children who were too young to really understand what they had or who had never been told by anyone had a feeling that something was wrong with them, or better, they even seemed to sense that it had to do with their blood. In the case of Maria I was told:

> “She feels something is wrong with her blood,….in her mind, there is something that she is having like that. When she got wound, when she fall down and got wound, then she will come only to me … she will say, don´t touch blood, don´t touch blood. She will say herself.” (Nun at Prathyasha, Jeevodaya)

Further I was told:

> “She will kiss only here (check), normally people kiss here (mouth) but she will kiss only here (check). She knows her mother sickness; something is there in that child!” (Nun at Prathyasha, Jeevodaya)

During my time in Prathyasha/Jeevodaya, I could experience many such incidences. One day while playing Maria slipped and she fell and when she noticed that she was bleeding she ran to the sisters, when I tried to clean the wound and help she started crying and hit me, she would not let me touch her blood.

Most children that I met did not react to the information that they were ill like Rishi; this might be the case because most of the others had not lost both parents to the disease. Krishna, who is HIV-positive and who lives with his brothers at his uncle's family as long as he can remember, tells me:

> "I don´t know what I have, I only know I am ill. They were saying I was sick and he can be alright but only if I take medicines. I was afraid when I heard that for the first time but when time passed and I took medicine it is okay. Now I am not afraid. I was afraid of injections and taking medicines. Not of the disease." (Krishna 14 years, CSI)

Krishna, did not know what he has, he cannot remember his parents as he was very small when they passed away, but like other children he was also afraid of doctors, injections and medicines. His fear only receded when taking the medicines became a routine and he noticed that nothing bad would happen to him because of them, but that in fact they made him feel better. Also Raju, a nine year old boy from CSI, who's father had died and who lived with his mother, his three sisters and her mother's new husband (a HIV-negative man), stated that he was not afraid of the disease and he takes his own medicine.

In case of Arun a fifteen year old boy who also knew about his disease I was told:

> "He is very successful and very positive. Other children with HIV are very irritated about themselves, but he is not." (CSI program coordinator)

She further tells me that many children, also non-infected but affected children, often seem to develop an inferiority-complex. They stay away from others, don´t want to play and become very closed up, almost as if isolating themselves. Within this context I was told:

> "They becoming introvert, develop an inferiority feeling, become pessimistic and react with fear, aggressions or depression." (Nun, St. Vincent's Home/ Potta)

> “Children develop loneliness; avoid talking to others due to insecurity about their behavior. They feel abandoned.” (Social worker at CSI, 29)

These descriptions and the reactions of children like Maria and Raju towards their blood almost make the impression of an *inner stigma* that children consciously or unconsciously inflict on themselves, or as Goffman (1967: 12) would put it, they show the *dilemma of the discreditable* (the stigmatized individual thinks that no one within his/ her surrounding knows about their stigmatizing attribute – Stigma is more internal). This self-stigmatizing behavior is also to be seen in Sita, a twenty-three year old mother in Prathyasha/ Jeevodaya.

> “Sita, cries a lot, she refuses food and sleep and does not wash herself or her and the childs clothes and she refuses all help offered to her. She even threatened to kill herself and the baby. At home she was yelling around that she is HIV positive and that she had AIDS” (Nun, Pratyasha/ Jeevodaya)

In Sita’s case, her behavior led from the *dilemma of the discreditable* straight to the *dilemma of the discredited* (The stigmatizing attribute is know by public or strikingly evident) showing that stigmatized people would inevitably have experiences with both (Goffman ibid.). In Sita’s case the *dilemma of the discredited* is shown firstly by the fact that her family brought her to Prathyasha/Jeevodaya together with her 2 month old son, as they felt that they were not in a position to handle her anymore. Apparently there had been a lot of trouble with the neighbors due to her behavior and maybe even more clearly in her negative attitude toward the institution and her frustration about being there which will be discussed in a later chapter.

In all cases of positive children that I spoke to in Delhi, the status of the child had not been disclosed out of fear of discrimination. Also in cases of positive parents, it was only disclosed in very few cases. Priya, when asked for the reason of not disclosing, says simply:

> ”They will make fun of us.” (Priya 18 years, CSI)

5.2. The outer sphere

In addition to the emotional difficulties the children face, which have been described in the previous chapter, there is also a sphere of *enacted stigma* or the actual experiences with discrimination. The outer sphere described in this chapter will deal with exactly these experiences of the *enacted stigma* as well as with situation or life realities that are a result of the HIV/AIDS infection of the parent or the children themselves. The situations of *enacted stigma* that the children face involved medical settings, social isolation, loss of friendship and/or exclusion from visiting normal schools. Life situations creating difficulties for children were financial problems, school dropouts and being forced to work at an early age to support the family, problems with finding marriage partners and experiences of physical abuse.

In Kerala, the HIV-positive children I met were not allowed to live in regular orphanages or visit a regular school. Although the Caps & Dass Trust, which was responsible for both Maria and Matthew, ran both an orphanage and a school, both children were separated from the other (HIV-negative) children and had to live in Prathyasha/Jeevodaya. When they reached the age at which they were expected to go to school they were sent to the St. Vincent's home in Potta and not to the school run by the institution that had the basic role of taking responsibility for them. When I asked about this topic I was told:

> "No school will accept them because they are HIV positive. If the school teachers accept that, then the parents will make problems. Even at our school, St. Francis School, the fathers have no problem, teachers also not, but the children will play together and then other parents will worry because a risk is there. They need special care and so… That's only the parents worrying; the children don't know about the sickness and they will play, and an injury or something might happen and the other children might also have an injury and that is why it will not work. The government is forcing to teach HIV-positive children in all schools but that is practically not possible." (Nun, Prathyasha/ Jeevodaya)

One of the boy's I met in Potta, who still had his uncle, had been sent there as he could not get an admission in any other school.

There was a similar reason for why HIV-positive children were not allowed in the orphanage belonging to the Caps & Dass Trust. This orphanage included a daycare center and parents would not let their children go there if there were also HIV-positive children present. This reduced the chances of Maria, who lived in Prathyasha/Jeevodaya at that time, to find friends. Though sometimes people came around with their children, they would not let them play with Maria most of the time, only the neighbor son's sometimes came over to play.

> "Some parents will bring their children but they will play with her (Maria) they don't allow their children. They will keep them at distance. Knowingly or unknowingly we cannot say. Only the boy's from the neighbors come, they are a little educated maybe that is why." (Nun, Prathyasha/ Jeevodaya)

In Delhi the picture was different as the status of the children was never disclosed in the schools; parents had no problem getting admission for their children. At CSI I found two cases of school dropout in higher standards which were directly related to the financial problem in the family as a result of the fathers HIV-infection. One girl told me:

> "Our education was stopped as we did not have money" (Sister 23, CSI)

The other added:

> "I was 13 and enrolled in a job, saying that I am 18. Our family needed money. So we all had to work. In our village no girl goes out of the home to work." (Sister, 20, CSI)

For the entire family this financial problem was extremely difficult:

> "Our emotional balance was gone. We had no money." (Pratap 17, CSI)

The family had to sell almost all of what they had to pay for the father's treatment. The children lived alone in a small house without doors or light for months while the mother was in hospital treating the father.

> "We felt very insecure and afraid." (Sister 23, CSI)

The situation got worse when one of the uncle's friends was sent to take care of the children.

> “Our uncle’s friend was staying with us but he was not a good man. His intentions were really bad…He knew that our father was ill, we were very young. If he did something to us we cannot do anything. He strangled me by the throat so badly that in my eyes blood came. For 2 months my eyes were not normal. I have to wear black goggles so no one can see my eyes. I was alone, he tried to grab me and convince me but I was running toward the door, he was trying to open the thread of my pant. I somehow threw him away but again he held me and strangled my throat. He was forcing me.” (Sister 23, CSI)

Also the second daughter talked about similar experiences to me. After these incidences, and with the knowledge that her husband might not recover, the mother decided that she had to get her two eldest daughters married. The problem was that because of the father’s illness she had no real option but to marry them to the first man available:

> “Two of our sisters married at a very young age, which was not the right thing. They both got married the same year. There is a lot of discrimination against them in their husband’s family because of our parent’s illness.” (Pratap 17, CSI)

This leads me to another aspect very prevalent in Delhi: discrimination by the own or extended family. Most respondents told me that their extended families stopped visiting them and some did not even speak to them anymore. These experiences were very difficult for all of them:

> “The attitude of our close relatives changed drastically. Except for one of my uncles none of the relatives would visited us and would make us feel bad and alienated from the mainstream relatives network. Not only did they stop visiting us but they also never invited us to their homes. Since we were under the supervision of this Christian missionary we never really felt alone and cut off from the society. But in the core of our heart we always regretted as to why we had such relatives in the family, it was a very bad experience and painful feeling. But not only family, also one of my friends has stopped seeing me.” (Pratap 17, CSI)

In cases where this did not happen, the extended family members stopped eating with the respondent’s family or brought their own food and water. The situation was different in some of the mentioned cases such as with Krishna who lived happily with his extended family. But often I was told of cases when the children were sent away to live in hostels by their extended family members, regarding one grandmother, who had sent her three grandchildren to live in a hostel, I was told:

> “We tried to speak to the grandmother, told her to leave the children live together but she doesn’t want it. She has a common job, she could afford the children but she doesn’t want them. “She is telling: Why should I take the headache? Why should I take the responsibility?” She says there are NGOs to do that job.” (CSI program coordinator)

With regard to the situation in Kerala I was told:

> “Most families accept, but neighbors treat them badly. Once they are positive they will not let them there. The society wants to isolate them. Rejection form school, then breakage of family.” (Nun, St. Vincent’s home/ Potta)

One other major aspect was the accessibility of adequate medical treatment for HIV-positive children and their parents. Many doctors and nurses in government hospitals showed a very strong reluctance to treat HIV-infected people:

> “The nurses where afraid that if they clean the blood, they will also be infected by the disease. They would not treat my father, my mother had to do it.” (Pratap 17, CSI)

> “My mom had to get a uterus operation. For the doctor’s safety I said about HIV positive. The doctor tried to avoid us, they were dragging her here and there and they were looking at the other patients but she was neglected all the time, but I was strong enough to fight with him and made him do the operation. Also the nurse who was treating her at that point (after the operation) was also showing discrimination. Illiterate people behave well, give respect to others. But people who study become proud of their study and degree.” (Priya 18, CSI)

One boy could only be treated within the CSI facility as other doctors refused to treat him. In this case it is also possible that financial reasons play a big role:

> “He does not go to local doctors, they do not check up well because of HIV, and in CSI it is free service.” (CSI program coordinator)

In the two FBOs that I did my research in Kerala things were a bit different, they had doctors who would come to the institutions and treat the people, and in case of the HIV-patients they relied on the Calicut (Prathyasha/Jeevodaya) and the Thrissur Medical Collage (St. Vincent’s Home/Potta). But despite the fact that the nuns knew who would be able and willing to treat the patients there were difficulties:

> “We are willing to do anything for them, but medicine, we cannot do anything here; because we rely on the government Calicut medical College and the team there, according to their advice only we can do something. More than Maria one cute girl was here when we took her to Calicut (to the specialist hospital) she passed away. On a sister’s lap she died.” (Nun, Prathyasha/Jeevodaya)

Problems with neighbors did not seem to be such a big issue in Delhi, as people did not disclose their status to them. Only in one case did the family report public repressions:

> “We had to go to the toilet outside in the jungle or fields, as we may spread disease. In jungle, so many insects were there, we had skin infections.” (Sister 20, CSI)

They also stated that neighbors talked badly about them when they found out about the illness of the father. The family had to relocate and to the new place; they did not disclose their status again:

> “We didn’t say anything about the disease. If they know they will ask to leave this house. They talk about my character and say that our family is polluting the society.” (Mother of 4 children –positive- , CSI)

Also in Sita’s case in Kerala it had been the pressure of the neighbors following her behavior, described in the last chapter, that finally made her family give up and take her to Prathyasha/ Jeevodaya:

> “Her neighbors got scared by her behavior and put pressure on the family; her family did not know what to do, so they brought her here.” (Managing Trustee Caps & Dass Trust/Kannur)

One of the nuns added:

> "Such reactions are normal, when we started taking in HIV-patients the neighbors made problems. They don't know much about this sickness, and it's spreading. They attacked the house threw stones on it and attacked the volunteers. More than one of them got beaten up." (Nun, Prathyasha/Jeevodaya)

It is evident from the experiences described in this chapter that there are severe social implications that result directly from the status of being HIV-positive or of being affected by the disease. Social rejection by the family (mostly extended family), the social surroundings, medical facilities and social institutions such as schools clearly became important. In many cases, this has led to complete or almost complete social isolation of the affected and infected individuals. This fits Goffman's idea of a spoilt social identity, which implies the inability of a person to meet the expectations for particular kinds of social interactions, or worse excludes them from participating in these completely (Herek, 1990: 1; Goffman 1967: 12-20; Major and O'Brien 2005: 394).

From all the stories in this chapter one thing becomes clear; fear and lack of knowledge are two of the main factors that lead to the stigmatization of HIV-positive people. It is therefore essential to provide help to stigmatized and discriminated people and to also raise public awareness on the topic in order to limit the risk of stigma resulting out of fear that arises from misconceptions or false knowledge.

5.3. The helping sphere

> "Good public awareness campaigns help and there is much support by the NGO". (Raju's mother - HIV-positive - , CSI)

Considering the problems of the HIV infected and affected children and their families that I have described in the last two chapters, it is essential that there are organizations that take up the challenge of helping these people. That this help is not always easy, and sometimes results in problems for the institution providing it can be seen in the example of Prathyasha/Jeevodaya where violent attracts by neighbors were experienced after they started taking in HIV-positive people. Nevertheless, there are many institutions, NGOs, FBOs and government facilities that have taken up this challenge. I will try to explain the help provided to the people using the examples of the three institutions at which I did my research. In this chapter I will give a short overview of the aspects of their work and the reactions that both affected and infected children show towards it, and in this and the following chapter I will also try to describe how and in which way the work of these NGOs shape the perceptions of infected and affected people towards the future and how they can change their lives and their wishes on a long term basis.

CSI is an institution that attempts to provide people with the necessary background that will enable them to help themselves. Deepa Bajaj, the president of CSI states:

> "I believe that people themselves have the power to bring change, to make a difference and create hope for life. We at CSI just act as catalysts and facilitators to help them take charge of transforming their own lives." (Deepa Bajaj, President, CSI)

Within their program „Community based care and support for affected and infected children and their parents" they provide nutritional, educational, psycho-social and medical support. They also have programs on drug adherence, life skill education, home based care and various awareness programs. All of the participants that I interviewed from the CSI setting were very positive about the help that they had received from the institution and pointed out how important it was for them. One respondent said:

> "I stay confident, feel better and get a lot of emotional and medical support from this organization. They provide us with a lot of medicines, care and support which is good for our mindset. My family was already with a Christian organization called "Naw Jeevan Sevan Mandal". The whole family feels quite united and confident because of this organization and CSI's selfless and continuous support. If the NGOs and organizations like "Naw Jeevan Sevan Mandal" and CSI were not there we would have been in a very miserable condition." (Pratap 17, CSI)

Another mentions:

> "CSI never let us feel that we are alone, everyone loves us, takes proper care of us. We never feel we are infected or affected people inside CSI. The people at CSI never make us feel as if we have any kind of big problem." (Priya 18, CSI)

Like Raju’s mother in her statement at the beginning of this chapter, all participants emphasized the importance of the NGOs and awareness campaigns strongly. In addition, the people working at CSI mentioned how important public awareness programs were, especially with regard to the reduction of stigma as its results mainly from a lack of knowledge and misconceptions broadly existent within the overall population (see the section on stigma theory).

> “Public awareness is important to make people understand; without this understanding there can be no change! There are still too many misconceptions and so much lack of knowledge.” (Deepa Bajaj, President, CSI)

Only in one case did I find a strong reluctance to accept help, due to the fear of stigma and discrimination.

> “When we wanted to visit the family at first the grandparents did not want that. So they spoke on the phone with us, we told them we are there to help the child. The grandparents were worried that someone will find out and the family will have problems. They are scared and don’t want anyone to know. After a while they allowed it. Still they are scared of disclosure because of stigma and discrimination. People might be rude, isolate them and not speak to him and he might lose friends.” (Social worker, CSI)

This is a wide spread phenomenon:

> “People are worried, they are scared that it will come out that they have this problem, but after some time they accept and are happy about the support.” (Social worker, CSI)

Within both of the FBO settings the picture was slightly different. Both of them provided nutritional, medical and spiritual support. Other than CSI they were closed institutions, and all of the infected people that were taken care of there lived there, despite the fact that some of them had a family elsewhere. The problems voiced by the children living there, in most cases, were that they were orphans or that there was no possibility of schooling for them outside of the institutions. The nuns and priest within the institutions were mostly loving to the children, although they were so overburdened with work that they had not much time to really do much with them.

> “We are ready to do anything for Maria; we are giving special care to her. Everyone here is already getting that medicine after you said[18], the sister went and bought it. Whatever we can do for Maria if she needs it we do if we can.” (Nun, Prathyasha/Jeevodaya)

Two nuns in Prathyasha/ Jeevodaya were especially caring with Maria; they took her with them on outings and played with her if they had the time and if I went out with the priest we also took Maria with us when we could, so that she would see other places as well.

It was different with Sita; she said she was scared of the place and that she wanted to go back home. It seemed to be very difficult for her to cope with the situation in the institution. She stated she found it was an impure place and very dirty and that she could not stay as she would get ill. Indeed she refused all help and became difficult towards the nuns if they tried to help her. One day she twisted a nuns arm so badly that she had to get it checked by a doctor. One of the nuns even had to threaten her to make her eat again.

It took Sita two weeks to adjust to her new situation and to permit the nuns and one of the other HIV-positive women in the institution to help her with her child. She was given psychiatric medicine to keep her calm, but still her attitude reminded of giving in to fate. Her son started putting on weight under the loving care of the nuns and by the time I left he was no longer the badly malnourished child he had been when he first arrived. As there seemed to be no public awareness campaigns or anything similar that I could find being done by the institution, I asked the managing trustee of the Caps & Dass about it and he answered:

> “We have a mobile service for providing information to the general public regarding HIV/AIDS and other topics of relevance. Wherever people gather in big numbers are made occasions to create awareness regarding these topics. I myself have played in street theaters to create awareness (not only about HIV/AIDS). I even wrote my BA thesis on the role of street plays in such contexts” (Managing Trustee Caps & Dass Trust)

Unfortunately there were no programs underway during the time that I was there.

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[18] I had asked a friend for advice on Ayurvedic medicines to support the immune system, and he spoke to the priest and gave him a prescription.

The St. Vincent’s home in Potta made a cold impression at first sight, but after going through the interviews in detail some of this first impression was changed. Before going there one of the nuns in Prathyasha/Jeevodaya, who had formally worked in Potta, told me:

> “Sisters are very good. Those sisters take good care and there are patients. Each Lady that is a little bit healthy will take care of one child as will the sisters also.” (Nun, Prathyasha/ Jeevodaya)

The children I met in the institution were all very quiet. Maybe this was related to my presence and the presence of the sister superior during the interviews. All children said that they liked the St. Vincent’s home and that they preferred it to where they had come from. One boy who went to live with his uncle during the holidays told me that he preferred to be here as he liked his friends here more than those outside, and that he preferred being here as no one could care for him properly at his uncle’s place; there all of them worked and had no time. Indeed the way the nuns spoke to the children was very loving and caring. Nevertheless, my data from Potta has to be viewed critically as the priest who accompanied me stated:

> “The children would have told us more if the sister had not been with us all the time.” (Managing Trustee, Caps & Dass Trust)

Generally, the help that was provided by both NGOs and FBOs was found to be valuable and needed by the participants of the study as it was the only real help provided. It was also clear that the open system provided by the NGO was especially valuable as people did not have to leave their own families and social surroundings and help was provided within the context of a “normal life situation”. The interviews with NGO staff showed that there was a perceived strong need for more public awareness and integration of the community to provide a more adequate and tolerant supportive system for the infected and affected people.

5.4. The future context

Normally, all help that is provided has the goal of archiving some positive change in people’s lives, if possible on a long-term basis. The challenge is to provide people with emotional support so that they can develop coping strategies which will enable them to face their situation with more courage and a positive attitude towards life itself. At CSI I found that many people who had disclosed their status started working there as volunteers doing public awareness campaigns together with social workers, such as Sima's mother.

> "She comes here whenever we call her and gives interviews and speeches for pregnant women. This helped both Sima and her mother; they now have a peaceful life. And also her new husband gives a lot of support." (CSI program coordinator)

Also Priya, whose parents are both infected, has become an active member of CSI and participates in street plays and awareness campaigns, she explains:

> "For me, due to the HIV of my parents, I have learned a lot so I am aware. Awareness has made the difference. I care for my mom and dad in a proper way; I give them medicines and good food and keep them out of tension. I know that everyone who is positive can live for a very long time, have a normal life; we just need awareness. I want to tell people that HIV-positive people can live normally in a society like other people. Every person has the right to live in this society, even if HIV positive, they should have equal rights. I want to change the misconceptions and misunderstandings of the society about HIV. Society needs to provide every opportunity to HIV people as are given to the normal people." (Priya 18, CSI)

And then she adds:

> "By doing this I have changed my life and I can change another person's life also, and I believe that everyone can live a very normal life." (Priya 18, CSI)

Working in the awareness programs helped her to tackle her own problems more effectively; it gave her a perspective of where to go and what to do. The feeling of being able to change ones situation through such campaigns has given her strength to face the future and it has given her hope that there is a possibility to change her life and create a better situation for children like her and HIV-positive people like her parents. She no longer feels that she is helpless; she now feels she is making a change for herself and others and this helps her a lot. But she thinks that more should be done to help, also from the side of the Indian government. Pratap has the same opinion:

> "There should be a law for HIV patients, that no one can discriminate and avoid HIV people like the doctors, who don't treat them or learned people who misbehave. They should lose their jobs if they do so." (Priya 18, CSI)

> "NGOs should particularly help the effected children in their day to day studies. In my case, although I'm getting some support from the organizations, but taking into consideration the high cost of tuition, I am not able to afford everything that should be termed as the basic necessity. Because our parents are also very poor affordability remains the big issue. In case of orphans, stronger support and care is needed, therefore there should be some government supported provision of certain basic benefits to these underprivileged children. Secondly it should be ensured that the affected children do not have to encounter any sort of discrimination at the workplace. These children should not be devoid of anything which can prolong and strengthen their career. In my case it is very sad that I have not been able to buy even the basic books for the education but I am trying to make the most of what I get from these NGOs and organizations." (Pratap 17, CSI)

Also for Pratap and his family the feeling of being able to do something actively about their situation helped.

In case of Sita there was no coping strategy visible and regarding her situation of not being able to actively do anything about her situation it is questionable if she will achieve anything except for an adjustment to her present situation. In the younger children, the coping strategy seemed to be not to let the situation get to close to them and to find contentment in the small things they had available. For Maria it was her ability to make good friends with the adults around her and to be caring towards Sita's baby. The other children engaged in plays and studies and one of the children said he enjoyed watching TV when he went to his uncle's place on holiday. It was found that the only coping strategies with expected long term positive effects were those that activated the affected and infected individuals, increasing their self esteem by making them feel useful. Especially training them to help implement the public awareness campaigns gave them the feeling of being "professionals" and individuals of worth who could contribute to society. Other coping strategies where not voiced or found during the research.

6. Discussion of research data

As my research was done in only three settings with a limited amount of respondents it can in no way be seen as representative for the overall population of infected and affected people on the Indian subcontinent. Nevertheless, there were no major differences in the inner sphere between the northern and southern Indian field sites. In all three institutions the children had undergone traumatizing experiences through the loss of parents. The types of stigma and experiences that I found were almost the same to those described in the literature and in the introductory parts of this thesis. It was prevalent though, that the status of HIV-positive children was not disclosed in schools and so did not create problems in that surrounding in the northern site. This was found to be quite the contrary in the south where HIV-positive children had to be sent to special schools. On the other hand, the findings might have been different had I done my research in an NGO in the south where children and their parents would go together and not an FBO that mainly cared for orphans. It might be that the picture would have been quite similar in the south then, as there is no law that forces the disclosure of the HIV-status in school going children in Kerala.

The reactions towards the help were very different between the NGO and the FBOs, but this must be related to the very different setups and approaches by the institutions. Whereas CSI had the aim of enabling people to remain in their normal social environment and to equip them with the ability to help themselves, Prathyasha/ Jeevodaya was a closed place caring for people within the boundaries of the institution with little or no option for the people to leave and spend time outside, “in means in, no way out.” Surely the inmates who had a family outside had the option to visit it, but this was done very rarely. Sometimes inmates would receive visitors at the institution, but generally the stayed within the grounds of Prathyasha/Jeevodaya. Once the managing trustee of Caps & Dass Trust told me:

> “Sometimes I wonder if we are doing the right thing locking these people in here, but if we don´t care for them, who will?” (Managing Trustee of Caps & Dass Trust)

In fact I found that most of the institutions caring for HIV/AIDS affected and infected people were related to the Christian church in one way or another, in Kerala. In St. Vincent’s Home there was a similar picture with children remaining within the grounds of the Devine Retreat Center; some children that had family left would receive visitors or go home on a holiday but generally they remained institutionalized. Regarding HIV-negative AIDS-orphans I was told that there was the option of adoption, and in fact I was told about three children who were waiting for their adoption by an Italian family. There was no case in which an HIV-positive child had ever been adopted. The sister superior at the St. Vincent's Home told me:

> "If the children are positive we could think they are positive. But for the negative children, it is more difficult, because they have a future to care for. Will anyone come forward to adopt them, knowing their history?" (Sister superior St. Vincent's Home/Potta)

At CSI there were no incidences of children being adopted by foreigners. The four orphans that CSI had in their program were all taken care of by their extended families. The statement of the nun above is highly questionable, as it implies that children that are infected with HIV/AIDS have no future. It is true that the life expectancy of a child born HIV-positive is estimated to be a maximum of 15 years and most of them die before their first birthday (Nolen 2007: 241-253; Avert 2009; India Together 2010) as there is no adequate pharmaceutical treatment available, but if an HIV-positive child were to be adopted into a western country, the life expectancy would be considerably higher through the right medication and sufficient medical care. HIV/AIDS in Europe has become a chronic disease with the same average life expectancy as a child born with diabetes which is exponentially higher to the life expectancy of children born with the disease in developing countries (Adler[19], personal communication). It should be strongly emphasized that HIV-positive children should also be given the chance of adoption, as for them this opportunity is a matter of life or early death, and it appears that this statement in a way shows a discriminating attitude. Obviously it is understandable what the nun means, and generally speaking, if we take only the situation in India, she is absolutely right, but blocking out this option for HIV-positive children is a form of discrimination.

The medical care within CSI was purely biomedical with a strong focus on ART, TB-programs and vaccinations. Drug adherence was also checked critically. In Prathyasha/Jeevodaya, ART was given to the adult patients in addition to Ayurvedic medications and vitamins, Maria was mainly treated with vitamins and various traditional (mostly Ayurvedic) medications, such as application of nim leaf paste on her skin against

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[19] Head of „AIDS und Kinder e.V." Heidelberg

rashes. Nevertheless, the HIV/AIDS patients, including Maria, lived directly next to people suffering severe diseases among other of the respiratory tract or even TB, which are major health risk factors especially for a child with a strongly reduced immune function. Further it is critical that fevers and coughs affecting the child were often not taken seriously and there was absolutely no specialized knowledge about HIV/AIDS visible at all. On the other hand, it is important to keep in mind that this situation might arise due to a lack of resources, as there is no money to establish a proper care center only for HIV/AIDS infected people. In Potta the treatment was a mixture of biomedicine and Ayurveda, whereas for children the Ayurvedic treatment seemed to be used most often. Amazingly the priest accompanying me asked the nun if the children in St. Vincent's Home did yoga; this showed a strong reliance on traditional Indian healing systems in the face of HIV/AIDS. The nun replied that there was no yoga but that the children did the rosary prayer and that they also had a special prayer only for them. The integration of Ayurvedic medications into the therapy for HIV-patients is a positive thing for various reasons; firstly some of the Ayurvedic medications have been scientifically proven to have an antiretroviral effect (Vermani and Garg 2002: 50, 62-63; Kusumoto et.al, 1995: 180), which means they can reduce the viral load in the blood, and secondly this can expand the time that patients have before the first AIDS symptoms appear and so can prolong the time without the need of ART, which again extends life expectancy. Nevertheless, it is important to monitor both the viral load and the CD-4 count very carefully and in children to give special attention to the appearance of opportunistic diseases. The guidelines for adults are not applicable to children (Avert 2009), and first signs of AIDS in children are often overlooked or not taken seriously as they might mistakenly be thought of as regular childhood illnesses (Nolen 2007: 246-248).

A further interesting aspect was that whereas in CSI and Prathyasha/Jeevodaya there was a very clear distinction used between affected and infected, there seemed to be no awareness or consideration of these biomedical terminologies in St. Vincent's Home, as there was no differentiation between affected and infected in their terminology, as one can see in the following example:

> "There are children here who are in plus two, but they are not "affected". Among the "affected" children highest is 8th standard." (Sister superior, St. Vincent's Home/Potta)

St. Vincent’s Home also kept no statistical data on the children living there, and there was great confusion about the numbers of patients when I asked for them during my research. This was also different in both of the other institution that had very clear lists of the people they cared for or supported.

7. Conclusion

Relating the data collected from New Dehli and Kerala back to the types of stigma mentioned in the introductory part of the thesis, a very strong *internal* or *felt stigma* was found (Letamo 2003 and Srivastav 2006: 359), which influences the feelings towards oneself and the surrounding and which led to the fear of disclosure. This also fits clearly with Goffman's (1967: 12) *dilemma of the discreditable.* This fear has been shown to be realistic, as there is a high incidence of partly severe *external* or *enacted* stigma. Thus people who are affected develop a state of insecurity and a sense of shame. They then attempt to move back into themselves; in some cases like in that of Maria's mother the fear of this *enacted stigma* led to a strong suicidal tendency. This relates to Goffman's (1967: 12) *dilemma of the discredited*. To escape the vicious circle of *self-stigmatization* or *internal stigma* and to limit the effects of *external* or *enacted* stigma I have found it is essential to provide the kind of help that will take the affected people out of their submissive role and that will show them that they are not helpless, that there are ways in which they can help themselves and others. This was the case with many of my respondents in CSI such as Priya or Sima's mother. For the reduction of fear in public it is further essential to facilitate and increase public awareness campaigns on HIV/AIDS.

Although the forms of stigma described by my respondents were basically the same as those described in the existing literature, their experiences and life realities were not. The ways in which the children handled these situations and the influence these had on their life and their surroundings opened a window to a field barely explored so far. My findings show that the pressure on both affected and infected children and their families, induced through experiences of HIV/AIDS and the related stigma, are extreme. It is important to gain more knowledge on this subject so as to enable NGOs and FBOs to establish projects even more suitable to address the needs of both infected and affected children. Further, it is necessary to educate the people caring for HIV/AIDS infected people in such settings on the health risks of the children and the modes of transmission, so that they can provide better treatment and care for the people in need of it. It would be interesting to find out more about the primary health seeking behavior of infected people, as in more than one case I found that such individuals went to religious healers after the medications given by doctors had failed before seeking help in hospitals.

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9. Annex

9.1. Explanations of specific terminologies

Acquired immunodeficiency syndrome (AIDS)

AIDS is an illness that was first described in 1981. It is characterized through a distinctively low cellular immunity of the body that is accompanied by a variety of opportunistic parasitic and other infectious diseases as well as specific malignancies such as Kaposi's sarcoma. The disease is the result of an infection with the human immunodeficiency virus (HIV). Generally the diagnosis of AIDS is given to an HIV-positive person if his CD-4 (see below) count is below 200/µl and/or when the first opportunistic diseases appear, in children this can also be the case when the CD-4 count is still a lot higher, as the number of their cells is generally higher than that of adults. The time from HIV-infection to the outbreak of AIDS can vary largely depending on the type and subtype of the virus but also on the infected person himself and his/her life situation. On average, a HIV-infected person develops AIDS after 8-10 years if he does not receive antiretroviral therapy. The incubation time in both babies and children is a lot shorter (Weinreich and Benn, 2005: 14).

Antiretroviral therapy (ART)

ART is the medical therapy which is given to HIV patients, it is generally required when the CD-4-count falls below 350 cells/µl blood, but the guidelines for ART vary greatly between the countries: in most high prevalence and low income countries ART is started if the CD-4-count falls below 200-250 cells/µl blood. On the other hand not only the CD-4-count is relevant when it comes to the recommendation of starting a therapy with ART; just as important is the viral load[20] in the blood of the infected person and the occurrence or non-occurrence of opportunistic diseases. The World Health Organization (WHO) has developed a method of describing the different stages of HIV disease based on clinical symptoms. In children HIV is also monitored through the viral load and CD-4-count, but as

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[20] The amount of virus present in the blood serum (the liquid in which the blood cells are found). Tests that measure viral load are being used to help decide when to start therapy against HIV and when a therapy is no longer working well (The Body, 2009).

the levels of both CD-4-cells and viral load levels vary strongly in children, especially between the ages of one to four, they must be treated on a very individual basis. Guidelines on when to start ART in adults do not apply for children as their CD-4-count is generally a lot higher than that of adults. “Before a person starts treatment it is recommended that a basic clinical assessment should be carried out. This should include determination of existing medical conditions (such as hepatitis, tuberculosis, pregnancy, injecting drug use and major psychiatric illness), assessment of current medications (including traditional and herbal medications), as well as weight measurement and assessment of patient readiness for therapy. If AZT (azithromycin) is being considered then a hemoglobin measurement should be taken, and a pregnancy test should be taken (Avert, 2009).” The treatment with the antiretroviral medicines (ARV) needs a lot of commitment from the patient and, in the case of children, from the caregiver as medication must be taken 2-3 times a day always at the same time so as to reduce the risk of a viral resistance towards the medications which is of great importance as HIV is a very mutogenic virus and develops resistance very quickly. ART is a way to keep the effect of the virus within the body stable, to increase or stabilize the CD-4-count and to reduce the viral load. It is given as a triple combination therapy containing three different types of medicine: nucleoside analog reverse transcriptase inhibitors[21], non-nucleoside reverse transcriptase inhibitors[22] and protease inhibitors[23].

CD-4-cells

The CD-4-cells also called T-helper-cells are a subgroup of the lymphocytes, which belong to the white blood cells. The number of these cells in the human blood is used to measure the immunological reactivity of the human organism, which implies the advance of the HIV-infection. The so called CD-4-count, the number of CD-4-cells per µl of blood helps to monitor the antiretroviral therapy given to HIV patients. The value of CD-4-cells in a

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[21] Drugs that limit HIV's ability to make new copies of itself by interfering with the HIV enzyme reverse transcriptase. Often simply called nucleosides. They differ from the group of drugs called non-nucleoside reverse transcriptase inhibitors in how their molecules are linked together and in how they interfere with reverse transcriptase. (The Body, 2009)

[22] Drugs that limit HIV's ability to make new copies of itself by interfering with the HIV enzyme reverse transcriptase. Often simply called non-nucleosides or NNRTIs. They differ from the group of drugs called nucleoside analog reverse transcriptase inhibitors in how their molecules are linked together and in how they interfere with reverse transcriptase. (The Body, 2009)

[23] Drugs that limit HIV's ability to make new copies of itself by interfering with the HIV enzyme protease. (The Body, 2009)

healthy adult person is 600-1.300 cells/µl in the blood (Weinreich and Benn, 2005: 14; Avert, 2009).

Human immunodeficiency virus (HIV)

HIV is a “retrovirus” that attacks cells belonging to the human immune system, the so called T-helper or CD4-cells. The virus integrates its ribonucleic acid (RNA) into the deoxyribonucleic acid (DNA) of these cells and blocks their function; it further uses the host cells to duplicate itself and then destroys them. As a result the virus blocks the function of the CD4-cells and in this way steadily decreases the capacity of the human immune system to defend the body against pathogens. We distinguish two virus types HIV-1 and HIV-2, whereby HIV-1 is globally the predominant type. It is further divided into subtypes A-D, F-H, J and K that occur in different regions of the world (Weinreich and Benn, 2005:13-14).

Opportunistic diseases

With the increasing damage that HIV causes to the immune system it becomes more susceptible to a variety of different diseases, so called opportunistic diseases. Usually these are diseases that a healthy immune system could fight down without a problem but for people with a low CD-4-count, they can become life-threatening, especially if they are treated too late. Unfortunately many opportunistic diseases are not recognized early enough in children as they are similar to normal childhood illnesses. The most common diseases, other than diarrhea and various skin rashes that belong to the category of opportunistic diseases are bacterial diseases such as tuberculosis, MAC[24], bacterial pneumonia and septicemia (blood poisoning). Secondly, protozoan diseases such as toxoplasmosis, microsporidiosis, cryptosporidiosis, isopsoriasis and leishmaniasis can

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[24] *Mycobacterium avium* complex, or MAC, is a serious bacterial infection that can infect HIV+ people. MAC is related to tuberculosis. It is also sometimes called MAI, which stands for *Mycobacterium avium* intracellulare. MAC infection is usually found only in people with under 50 T4 cells. The symptoms of MAC can include weight loss, fever, chills, night sweats, swollen glands, abdominal pain, diarrhea and overall weakness. MAC usually affects the intestines and inner organs first, causing liver marker levels to be high. Swelling and inflammation also occur. (HIV/AIDS treatment Data network, 2006)

cause fatal disease as can fungal diseases such as PCP[25], candidiasis, cryptococcosis and penicilliosis. Further, a variety of viral diseases such as those caused by cytomegalovirus, herpes simplex and herpes zoster virus and also different HIV-associated malignancies such as Kaposi's sarcoma, lymphoma and squamous cell carcinoma are also important (Avert, 2009; HIV/AIDS treatment Data network, 2006; The Body, 2009).

Retrovirus

A retrovirus is any virus belonging to the family of RNA viruses which uses an enzyme called reverse transcriptase to replicate within the host cell. “The genetic information of the virus is stored in a molecule of single-stranded ribonucleic acid. After entering the target cell, the virus uses reverse transcriptase to direct the cell to make viral DNA. The DNA becomes integrated into the DNA of the host cell. Retroviruses are enveloped and assemble their capsids in the cytoplasm of the host cell. Retroviruses are used in laboratory research to import foreign DNA into a cell. They are transmitted by sexual contact with an infected person, through exposure to infected blood or blood products, and perinatally from an infected mother to the child. Human immunodeficiency virus (HIV1, HIV2), which causes acquired immunodeficiency syndrome, is a retrovirus. Other retroviruses include members of the Oncornaviridae family, such as human T cell lymphotropic virus type 1 (HTLV-1) and human T cell lymphotropic virus type 2 which cause adult T-cell leukemia, hairy cell leukemia, tropical spastic paresis, and HTLV-1-associated myelopathy (Mosby's Medical Dictionary, 2009).”

Serostatus

Condition of the blood serum (the liquid proportion of the blood) with regard to “having or not having antibodies[26] to a microbe[27] in the blood as a result of infection. One may have either a positive or negative serostatus (biology online, 2009).”

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[25] Pneumocystis pneumonia (PCP or pneumocystis) is the most common opportunistic infection in people with HIV. Without treatment, over 85% of people with HIV would eventually develop PCP. It has been the major killer of people with HIV. (The Body, 2009)

[26] Any of the numerous Y-shaped gamma globulin proteins found in the blood or lymph, and produced by B cells as an immune defense against foreign agents (antigens). Each antibody has a region that binds specifically to a particular antigen which it neutralizes. It is typically made up of large heavy chains and small light chains. (biology online, 2009)

[27] A microscopic living organism, such as a bacterium, fungus, protozoan or virus. (biology online, 2009)

9.2. Basic information on children

Case-number	Child	Age	Location	Serostatus	Live with	Religion	Economic Status of family, area	School	Risk factor in family
1	Maria	4	Jeevodaya/ Kannur	Positive/ no ART	Institution	Roman Catholic	Low, suburban	Not yet	Mother CSW
2	Sita	23	Jeevodaya/ Kannur	Positive/ ART	Institution	Muslim			non
3	Priya	18	Khera Khurd/ north-west Delhi	negative	Parents	Sik	Lower middle class, suburban	Yes 12th standard	Father alcoholic
4	Pratap	17	Khera Khurd/ north-west Delhi	negative	Parents	Hindu	Low, slum	Yes 11th Standard	non
5	Sonia	10	Khera Khurd/ north-west Delhi	negative	Parents	Hindu	Low, slum	Yes	Not known
6	Shri	11	Khera Khurd/ north-west Delhi	Positive/ ART	Uncle and grandparents	Hindu	Low, slum	Yes	Not known
7	Krishna	14	Khera Khurd/ north-west Delhi	negative	Parents	Hindu	Low, slum	Yes	Blood transfusion
8	Raju	10	Khera Khurd/ north-west Delhi	Positive/ ART	Mother and new Husband	Hindu	Low, slum	Yes	Father truck driver, Addict
9	Rishi	7	Khera Khurd/ north-west Delhi	Positive/ ART	Institution	Hindu	Low, slum	Yes	Not known
10	Mohan	12	Muringoor – Potta	Positive/ no ART	Institution	Roman Catholic	Low, rural	Yes	Not known
11	Vina	11	Muringoor – Potta	Positive/ No ART	Institution	Roman Catholic	Lower middle class, suburban	Yes	Not known

12	Juliet	11	Muringoor – Potta	Positive/ No ART	Institution	Roman Catholic	Low, rural	Yes Homeschooling due to bleeding	Not known
13	Johnson	14	Muringoor – Potta	Positive/ No ART	Institution	Roman Catholic	Low, rural	Yes	Father alcoholic
14	Matthew	7	Muringoor – Potta	Positive/ No ART	Institution	Roman Catholic	Low,	Yes	Father alcoholic
15	Sister 1	23	Khera Khurd/ north-west Delhi	negative	Married	Hindu	Low,	No, stopped in 12th standard	None
16	Sister 2	20	Khera Khurd/ north-west Delhi	negative	Married	Hindu	Low,	No, stopped in 9th standard	None
17	Sister 3	13	Khera Khurd/ north-west Delhi	negative	Parents	Hindu	Low, slum	Yes	None
18	Sima	9	Khera Khurd/ north-west Delhi	Positive/ ART	Parents	Hindu	Low,	Yes	Father was truck driver and addict
19	Sangeetha	25	Khera Khurd/ north-west Delhi	Positive/ ART		Hindu	Middle class,	Completed 12th standard after death of husband	Husband was police man
20	Arun	15	Khera Khurd/ north-west Delhi	Positive/ ART	Mother and maternal grandparents	Hindu	Low, slum	Yes	Not Known
21	Three Orphans	?	Khera Khurd/ north-west Delhi	negative	Institution				
22	Three Orphans 2	?	Kannur	negative	Institution				

9.3. Basic information on field sites

	CSI	**Jeevodaya**	**St. Vincent´s home**
Location	Khera Khurd/ North-west Delhi	Kannur	Devine Retreat Center/ Muringoor – Potta near Chalakudy
Project	Community based care and support for affected and infected children and their parents.	____________	___________
Number of children	143	1	33
Positive Children	35	1	16
Negative Children	108	____	17
Orphans	4	1	30
Help Provided	- Nutritional support(also toilet material and toothpaste) - Educational support (material) - In winter warm clothes for children - Psycho-social support - Medical support (basic medicines, regular health checkups, home visits on a regular time, vaccinations) - Drug Adherence - Raising life skill education (workshops etc.) - Home based care ●	- Nutritional help - Medical support - Spiritual support	- Schooling - Nutritional support - Medical support - Spiritual support
How many children care for parents	25	_________	_________
Schooling	Most children go to governmental schools	Will go to school in Potta	Retreat Center school with 20-25 children
Medicine	Biomedicine ART also for children	Biomedicine and Ayurveda No pediatric ART	Biomedicine and Ayurveda No pediatric ART

9.4. Sorted data 1/ Information given my professionals

Location	St. Vincent`s home	Kannur	Kannur	Delhi	Delhi	Delhi	Delhi
Age	41	?	38	?	28	29	29
Sex	Female	Female	Male	Female	Female	Female	Female
Job	Nun - Sister Superior	Nun – Medical work	Priest – Managing Trustee of Caps & Dass	Project Coordinator at CSI	Social Worker	Social worker	Social Worker
Opinion on HIV/AIDS	It is a big problem because the stigma is still continuing. The very existence of this institution shows that there are problems within the community. It is a financial problem to treat HIV+ people in the own house, many fears about the risk of infection… no knowledge about transmission modes. Comparing to the situation 5 years ago there are changes but not so much. The scene changes are	Now also with HIV here people have fear, then when they heard that we were going to keep HIV patients here then around 30 people thought that they will also get HIV , they don´t know much about this sickness, and spreading how it is spreading and all things. Like that only they attacked	It is a big social issue in India. The stigma and discrimination against HIV positive people is very strong. And awareness is low.	It is a big medical and social problem and should be taken care of more.	AIDS is disease which remains incurable so far.	AIDS is a disease which has no cure so far. Most of the patients with us are poor.	It is a big problem as there is no cure and there is a lot of stigma.

	that people come to visit (at least a few) or take the children home for 2 or 3 days. Some families have started to support not all but few.	the house threw stones on the house and attacked the volunteers, Robin and all enough and more they got beaten and all things and first we called police but first the police also did not come because also they don´t know what happened when we are here also we are going to start then what is going to happen, like that. That time I think nobody in this area nobody here had this HIV that one fear is there, you know, from outside from					

		out of India this sickness only is in everybody's imagination but in India and even Kannur town these HIV patients are there, they heard and now it is all gone (attacks). Like that it did happen.					
Problems of patients	Patients react psychological problems (depressions, inferiority complex, suicidal tendency) due to isolation. Fear of touching their children.	Regarding Children: No, nobody accepting that because he is HIV positive, because the school teachers accept that or not then the parents will make a problem here even our school, St. Francis School,	HIV patients have no social acceptance in the Indian society and the life of their children is still worse.	They face many problems socially and financially.	We have mostly poor patients, who have no income sources. These people have to quit their jobs to get treatment facilities and they have to suffer most of the time. We try to help such people but sometimes it is beyond or reach. Some people hide them disease	These people do small time jobs to manage their life, home expenses, selling eggs and vegetables are such jobs. Children of the poor people are not to complete basic education. These poor people are psychologically weak. We help such people by providing them medicines and	HIV+ people have several problems like he/ she has to go for CD4 every six months. They fall sick time and again and their economic condition gets badly affected. If the husband and wife both are HIV + the children get affected by it. Such couples can neither take

		Fathers not any problem, teachers also not but children will play together and all that and then other parents and all one risk is there anyway, they need special care and so… That’s only the parents the children do not know about the sickness and all they will play, and that time some injury or something happens and the other children will also have some injury and that is somewhere that way the thing will go but the			and some people can´t afford diagnostic test for AIDS and they also don´t have any job. Such people suffer more than others. They have limited opportunities. We want them to get financial help and job-concerning help.	books for their children.	care of themselves nor of their children. The situation gets even worse it the children are also positive. In such cases those couples can’t even take their children to hospitals because of lack of traveling expenses. We feel very sorry due to all this.

		government is forcing to teach HIV positive children in all schools but that is practically not possible.					
On awareness programs	Awareness programs are conducted. There are also interactions with schools where children can share their experiences.	_________	“We have a mobile service for the concientization of the general public regarding HIV/AIDS and other topics of relevance. Wherever people gather in big numbers are made occasions to create awareness regarding these topics. I myself have played in Street theaters to create awareness (not only about HIV/AIDS), I even wrote my BA –Thesis on the role of street plays in such	We do a lot of different awareness Programs, that is very important.	We conduct various types of awareness programs like positive speaking sessions, community meeting etc.	Sometimes we conduct one-on-one awareness programs as well.	Awareness camp, health camp, positive speaking sessions, Community meeting for HIV/AIDS, stigma and discrimination & community mobilization, local service provider by HIV session.

			contexts"				
Doctors and discrimination	Special doctors that treat the children also special pediatric treatment. No negative or discriminating experiences. Specialists at Thrissu Medical collage	Some places there is here this time Maria got a sickness and we took her to this hospital and one doctor S. is there she is ready to treat her, and others. Sometimes and all this year once I had to take a patient to a government hospital for an endoscopy and then we asked one hospital and the doctor agreed, she said she was having but the doctor did not follow then we took the patient there	I have heard of such incidences.	A lot of discrimination, That is why we have a doctor at CSI.	Not all doctors will treat HIV patients there is a lot of discrimination. We have a doctor at CSI who is a specialist. HIV + people face a lot of discrimination here	Not all doctors will treat HIV patients there is a lot of discrimination. We have a doctor at CSI who is a specialist. There is a lot of discrimination and so there is no equal for HIV+ people.	Not all doctors will treat HIV patients there is a lot of discrimination. We have a doctor at CSI who is a specialist. People are discriminating they fear they will also get HIV.

		and he was put on the table and all and then only she understood what is this and that he was an HIV patient and she refused to do that. We had paid for it already but they did not do it, that day we felt very bad. It is a mental problem they are afraid of the infection and getting it too.					
ART	No ART in syrup form	ART yes, but not special medicines for children.	____________	We also help with that and the adherence.	ART is given to children as well but in tablet from.	ART is given to children as well but in tablet from.	ART is given to children as well but in tablet from.
Ranking of transmission modes	MSM (6) Injecting drug use (5) Heterosexual contact between	_________	Heterosexual contacts	Most of the cases are heterosexual contact	60% heterosexual contact	60% heterosexual contact	60% heterosexual contact

	partners (4) MTCT (3) Heterosexual contact in extramarital relationships (2) Prostitution (1)						
Types of Stigma	Mistreatment by community and family: alienated from society, other partners are not even willing to marry someone from the family, access to public well denied, children rejected from school (public schools – that is why we have a separate school here).	Socially neglected.	Neglect by family, children are not allowed to go to school, social isolation, there are many.	Family neglect, seclusion and isolation of positive people and their family, refusing of treatment by medical staff, los of job etc.	To stigmatize, discriminate and hate HIV + people. They are hocked down as inferior and down-graded people in the society.	Not eat together, to hate, to stigmatize, to hate their children.	Stigma, what else can be worse than having physical relationships with no one. To hate, to treat badly, to take drugs.
Stigma and children	Children above 15 years can grasp the problem faster and they can relate it to the situation. Children above	Can´t go to normal schools, parents of other children won´t accept that.	If the parents die many are not accepted by the family. Many cannot go to school that’s why we have St.	In Delhi nobody discloses the status of children, so that in school level there is no experiences of discrimination,	Children of the age 5-8: “They don´t have any problem, there is no discrimination by society, because the	13-16: Children don´t like sitting and playing together, they develop an inferiority complex.	13-16: During this time children learn about HIV and understand new things about the disease.

	15 are affected the most. As soon as the community comes to know about a positive status children are very much ill treated regard less of their age. Mostly school rejection and breaks in family relationships, nonaccessability to the public forum		Vincent´s home.	that is with family and neighbors mostly.	society is probably unaware of all this.” 9-12: “There is not much problem in this age” 13-16: Children who know about their disease feel abandoned from the society and if other people come to know about them a lot of discrimination is made on them.		
Stigma most for men	Social alienation	__________	____________	____________	No one likes to mingle with a HIV + person and he is too much worried about his /her disease. No one eats with them. He remains alone in the society and stigmatization comes to him.	Don´t eat together, don´t like living together, don´t like to walk together, they will hate.	People will not talk with such a person and call him an addict.

Stigma most for women	Rejection from the family	__________	____________	____________	Women are not allowed to attend any awareness programs. They are ill treated and all suffer severe discrimination.	Told to have the bad eye on females, to hate, to not allow sitting together.	She is said to have physical relations with other men, be a prostitute and is looked upon as an inferior person.
HIV and caste	HIV makes one caste, even in the highest family HIV means rejection. Stigma is not caste wise.	No caste in HIV. HIV is one caste.	There is no caste in HIV.	____________	Stigma is the same with all casts but people in the slum area have to face it more than others and they are looked upon as inferior people.	Children living in the slums are considered inferior; Addicts are also seen as inferior; upper class people are not considered inferior.	Discrimination is put on all of the society but it is very less among upper class people. People in the slums face more stigma.
Stigma and economics	Earlier mostly truck drivers running national permit trucks got it but now it affects all also normal houses. Stigma is not due to economics only that they can afford better treatment and life situation, if richer.	__________	Upper class can hide it more easily. Get better medicine and treatment.	_____________	Lower and middle class are more affected by this stigma because of money problems.	Lower and middle class are more affected by this stigma because of money problems.	Lower and middle class are more affected by this stigma because of money problems.
Where does stigma show most?	Community, public life	__________	In community and in families too.	Seclusion and isolation	Extended Families, neighborhood,	Extended Families, neighborhood,	Extended Families, neighborhood,

					medical facilities, Nuclear family	medical facilities, workplace (of parents), schools	medical facilities, workplace (of parents)
Emotional disturbances in children	Becoming introvert, inferiority feeling, pessimistic views develop, fear of people, aggressions, depression etc.	They feel sad. It is hard if parents die. They also scene that something is wrong with them, something is in their mind.	Children suffer if their parents die a lot.	Yes many, but psychosocial support is difficult, children psychology is different.	Children get hurt on knowing about their own or their parent's disease. They feel insecure about their future.	Children get too much worried knowing about their parent's disease.	Children develop loneliness; avoid talking to others due to insecurity about their behavior. They feel abandoned.
More emotional disturbance in special groups of children	___________	__________	____________	____________	Four children live with their grandparents and other children live with parents. There are some single parent orphans and these children are so much worried about the disease.	Four children live with their grandparents and uncle; children who live with their parents are much more worried about their sickness.	All children live with their families if single parent or otherwise. We have only 4 children who are totally orphan and they live with grandparents.

9.5. Sorted data 2/ Information given on/ by the children in the interviews

Name of child	Age	Serostatus	Serostatus of parents /siblings	fieldsite	Internal experience / Attitude	Negative experiences within the family	Negative experiences in surroundings	Positive Experiences	Coping strategies
Maria	4	Positive CD4 (550) Had abdominal TB Skin rashes Coughs fever No ART (pediatric ARVs not available) Septran Tabletts and Vitamins Nimleaf past for her skin “their life most of the time we see will be up to twelve very rare, so many children were here,	Mother was positive (dead/ suicide) – sex worker	Kannur/ Jeevodaya	Senses something is wrong with her blood “Ariana in her mind there is something that she is having like that” “When she got would, when she fall down and got wound, then she will come only to me,… she will say don´t touch blood, don´t touch blood, she will say herself.” Hits when you try to touch her blood and cries “She will kiss only here (check), normally people kiss here (mouth) but she	________	Could not stay in a normal orphanage (Bala Bhavan) Because of her positive status Adults will not let their children play with her, the only children who play with her are the neighbors sons “Some parents will bring their children but they will play with her but they don´t allow their children. They will keep them at distance. Knowingly or unknowingly we cannot say.”	“We are ready to do anything for Maria, we are giving special care. Everyone is already getting that medicine after you said, the sister went and bought. Whatever we have to do for Maria if she needs. But medicine, we cannot do anything here; because all is the government Calicut medical College is one team,	She is tremendously strong in her will and stubborn. Makes good friends with adults. Is happy with small things. Is very loving towards Lila’s Baby boy. Sometimes makes the impression of being a small adult.

		one child was about 7, 8, then 10, 11, 12 Passed away. That´s why this Maria, we cannot think about that. More than Maria, one cute girl was here when we took her to Calicut (special hospital) she passed away, she died on sisters lap.			will kiss only here (check). She knows her mother sickness, something is there in that child”		“Yes but the other side, some boys are there in that house, they are coming and playing. I think they might be a bit educated children that´s why.” Will have to go to school in Potta as no school will accept her due to status “very difficult, we are sending these children to school, in st.Vincent home” “It is like a district school for patients… At the divine what happened is that school is a retreat center school nothing more ten 20-25 children, the	according to their advice only we can do something.”	

							sisters who are with the children teach in that school, they will take care of the children, they will not allow them to play with others like that.” “Sisters are very good. Those sisters take good care and there are patients, each Lady that is a little bit healthy will take care of one child and plus the sisters also.” Have Dr. R. and Dr. S who are willing to treat the child People visiting are afraid of visiting the house of the HIV positive		

							sometimes. “They are getting afraid, that is why they don´t go inside there.		
Three children	________ _	negative	Both positive (dead)	Kannur	___________	Neglected by family, sent away, grandparents did not want to keep them.	___________	Waiting for adoption by Italian family.	___________
Matthew	7	Positive No ART Upper Kindergarten In Potta since 3 Months (July 2009) Was brought to Jevodaya by his mother	Both positive (dead) Mother died in Jeevodaya/ Kannur Child said mother died of fever Father used to drink	Potta	He knows what he has He tells people “I am having this sickness, that is why don´t touch my blood”	____________	___________	___________ _	Seems happy to see the father. When asked what he does here except for studying he remains silent the father must ask further to her something else. Looks not so well, has herpes in his lip
Johnson	14	Positive No ART	Both positive (dead) Sister also in institution also positive	Potta	___________	Was brought her by uncle (maybe he was also the neighbor)	__________	___________	Says he is happy here, he does not want to go back

			From Kodagu/ Karnataka Father was an alcoholic; he used to torcher the mother. Mother was taken to Potta that is why the children were brought here. Daily wage worker Thinks his mother died of skin disease			When both parents fell ill, children were taken away by one of the family From their house.			
Juliet	11	Positive No ART Cannot go to school due to bleeding, so she studies in the home (2^{nd} Standard)	Mother dead Father no information he came to visit once and never again	Potta	___________	___________	___________	___________	____________

		There since 6 years (2003) Was brought to Potta by her parents, her mother was very ill at that time. Remembers a loving father.							
Vina	11	Positive No ART 2 elder sisters (negative) Attends 5th standard Here since 2007	Father positive (dead/ suicide) Was an alcoholic Mother positive and in the institution too Origin Kannur/ but parents worked as tailors in Hyderabad	Potta	Prefers to be here as mother is here	___________	___________	Prefers her friend here, they are better	___________
Krishna	12	Positive No ART	Both positive (dead/ Father TB/	Potta	Isolates himself at his uncles place prefers to	Can´t take care of him properly as all	Can´t get him admitted in normal school.	Goes home to uncle for Holidays.	___________

		5th Standard Here since 2005	both suicide) Comes from Munnar /Idukki district/ Kerala Father was a taxi driver Mother sprayed pesticides in a cardamom plantation Sister negative (lives with uncle)		watch TV. But no evidence that it has to do with the disease	work. Feels alone when home on holidays.		Likes his friends here more than outside.	
Priya	18	Negative 11th grade	Positive and alive and on ART Mother is ill and Jessy takes care Takes her to the doctor, gets her ARV form the hospital if she can´t go herself.	Khera Khurd / north-west Delhi	Came to know about parents' illness with 11 year but only understood at 14 years her reaction was fear. "Fear that who will see us if our parents die. If parents are not there, no one is there. Our future will be in trouble."	"My mother takes very strong medicines and she becomes very angry and abuses me. I cannot listen to that. I tell my mother, you can slap me but don´t abuse me. She is my mother, she can hit me!"	"I am doing a lot of effort but I don´t find a good result in my school." – If her mother is very ill she never attends classes. "I faced such kind of pressure when my mom had a uterus	About the institution: "CSI never let us feel that we are alone, everyone loves us, takes proper care of us. We never feel we are infected or affected people	Does awareness campaigns. – Reactions: "Some people are not interested; some are, if they understand they get afraid." "For me, due to the HIV of

			2 sisters and 3 brothers (all negative) 2 are married Brother 11th and 8th standard Sister 10th		“I never let any pressure come to me. If someone does bad to us, they will also suffer. God looks at everything.” “Every person has the right to live in this society, even if HIV positive, they should have equal rights.” She tries to give her parents a good feeling and tries not to make them feel that they have a dangerous disease. “I want to change the misconceptions and misunderstandings of the society about HIV. Society needs to provide every opportunity to HIV people as		operation. For the doctors safety I said about HIV+.The doctor tried to avoid us but I was strong enough to fight with him and made him do the operation. Illiterate people who don´t study behave well, give respect to other. But people who study become proud of their study and degree.” The father’s boss and one aunt and uncle know about the illness, the others don´t. She also did not tell friends: ”They will make fun of us.” Problems with	inside CSI” “The people at CSI never make us feel as if we have any kind of big problem.”	my parents I have learned a lot, so I am aware” Awareness has made the difference. I care for my mom and dad in a proper way, I give them medicines and good food and keep them out of tension. I know that everyone who is positive can life for a very long time, a normal life, we just need awareness.” “I want to tell people that HIV+ people can live normally in a society like other people.” “By doing this she thinks that she has

					the normal people get.” “There should be a law for HIV patients, that no one can discriminate and avoid HIV people like the doctors, who don´t treat or learned people who misbehave. They should lose their jobs if they do so.”		her mother when she had to go for an operation “they were dragging her here and there and they were looking at the other patients but she was neglected all the time.” “The nurse who was treating her at that point (after the operation) was also showing discrimination.”		changed her life and she can change another person´s life also and she believes that everyone can live a very normal life.”
Pratap/ family interview		Negative (all children)	Both parents positive and alive (health not good. – father worse than mother)	Khera Kurd/ North-west Delhi	“There were no doors in the house. We are 4 young girls alone. We felt very insecure and afraid.” (2nd) “Looking at father’s activities we used to laugh but also cry as he is our father.” (3rd)	“Children were separated, some used to stay with grandmother.” (2nd) “Our uncle’s friend was staying with us but he was not a good man. His intentions were really	School dropout (one in 12th standard) of the 2 eldest sisters due to lack of money for education (expenses of treatment) “Our education was stopped as we did not have money” (2nd)	“There was no food, no water. Our neighbors helped us a lot. Some gave us wheat flour, some gave vegetables. Our parents were in hospital. Alone in	“When I used to go for work, my neighbors used to say that I go for sex work. If I was a sex worker, I should have all the luxury. I used to go for tuition, going to teach small children.

					“Our family needed money. So we all have to work. In our village no girl goes out of the home to work.” (3rd) – *was also repeated often by the other women, seemed to be a big pressure issue.* “I was 13 and enrolled in a job, saying that I am 18.” (3rd) – “They don´t give us money and we cannot say this to our parents that we did not get our money, they will get more stress.” (2nd) No light in the house and no fan and landlord raised the rent. (Krishan) “For my father’s illness we to sell	bad…” – *raped girls (2nd and 3rd daughter)* “He knew that our father was ill, we were very young. If he did something to us we cannot do anything. He strangled by the throat so badly that in my eyes blood came. For 2 monthes my eyes were not normal. I have to were black goggles so no one can see my eyes. I was alone, he tried to grab me and convince me but I was running toward the door, he was trying to open the thread of my pant. I somehow through him away but again	“The nurses where afraid that if they clean the blood, they will also be infected by the disease” (Krishan) “I used to clean my husband and bandage him.” (mother) “Public and neighbors told bad about me. They used to say “dhanda karti hai” I do body business.” (2nd) “We had to go for toiltet outside in jungle or fields. As we may spread disease. In jungle, so many insects were there, we	home. (3rd) – *trauma of being alone*	My husband’s family member also used to say bad words: I used to endure it for first then I learned to fight. “ (2nd)

					our home articles. Or mental balance was not there, no money.” (Krishan) “We thought our father will die, so we took the family photograph. By seeing the family photograph we feel to cry. Our situation was so bad at that time.” (Krishan)	he holded me and strangled my throat. He was forcing me. One woman was coming to our house. I run towards the door. Still he tried to grab me. The door opened and there were public. Lot of neighbors were looking at us.” (2nd) – *public reaction was none at the time but they stared speaking badly about the girl.* “He tried to give me sleeping tablets, he was also trying for me.” (3rd) “At first when relatives come to know about the disease,	had skin infections.” (2nd) *Marriage issues:* “We went to see a boy, we asked verbally, does he work, if he takes alcohol or not. At that time they said no but actually this man now sometimes also beat my daughter.” – *Could not be selective.* Problems in Husbands family after the marriage. “Due to fathers HIV they torture us, discrimination is there.” (1st) *With relation to neighbors:* “We didn´t say anything about		

						they stopped to come to our house. Then they use to come they do not eat our food." (mother) "they don´t drink our water." (2nd) "They bring water from their home" (Krishan)	the disease. If they know they will ask to leave this house. They talk about my character and say that our family is polluting the society." (2nd)		
Pratap	17	s.o. 12th standard in a governmental school Smart boy, ever adult.	s.o	s.o.	Came to know about the parent's infection when he was 13, and he was afraid of what would happen in the future then. "It was a bit disturbing but we were prepared for it and also a little satisfied because at least there was some improvement in his condition."	"Two of our sisters married at a very young age, which was not the right thing. They both got married the same year." "At that time we were living alone in the house when my parents were in hospital, they came back home only for	"We had to sell of a major part of our land." – *financial problems after diagnosis seem a big issue in the family* *Regarding neighbors:* "No they had no idea about the condition of my father. They always had the impression that my father had	*About Institution:* "I stay confident, feel better and get a lot of emotional and medical support from this organization. They provide us with a lot of medicines, care and support which is good for our	*NGOs and their help is a give a way of coping with the surrounding issues but also makes him think about others:* "NGOs should particularly help the effected children in their day to day studies. In my case

					“Separation from my friends is something I am always scared of. I always have this feeling that if one of my friends tells other people about our problem, some more people will stop talking to me and my family members.”	the marriage of their daughter, one sister was age 19 and the other was near age 18 at the time of marriage. We were living alone in a small house at that time. A house without any door and we had no idea what was happening in the hospital, but of cause we were very scared, because my father’s condition.” “The attitude of our close relatives changed drastically except for one of my uncles none of the relatives would visited us and make us feel	some kind of mental problem, some sort of fever in the head. And even now though they are a little suspicious but still quite unsure about the actual problem of my father.” “One of my friends has stopped seeing me, while the other two meet me from time to time but one of these two is really good. He visits me on a regular basis and supports me all the time. The attitude of people scares me but I don´t know why it happens like that.”	mindset.” Before the family had been with a Christian organization called “Naw jeevan sevan mandal”. He states that: “The whole family feels quite united and confident because of this organizations selfless and continuous support.” “If the NGOs and organizations like naw jeevan sevan mandal, was not there we would have been in a very miserable condition.”	although I´m getting some support from the organizations but taking into consideration the high cost of tuition I am not able to afford everything that should be termed as the basic necessity, because our parents are also very poor affordability tremens the big issue. In case of orphans stronger support and care is needed therefore there should be some governmental supported provision to provide certain basic benefits to

						bad and alienated from the mainstream relatives network, since we were under the supervision of this Christian missionary we never really felt alone and cut of from the society. But in the core of our heart we always regretted as to why we had such relatives in the family, it was a very bad experience and painful feeling. " "Not only did they stop visiting us but they also never invited us to their homes. During the time of my father's hospitalization			these underprivileged children. Secondly it should be inshore that the affected children do not have to encounter any sort of discrimination at the workplace those children should not be devoid of anything which can prolong and strengthen their career. In my case it is very sad that I have not been able to buy even the basic books for the education but I am trying to make the most of what I get from these NGO s and organizations.

						all 4 of us used to live in separate locations and wherever we lived people stopped meeting us. There was a total negative attitude towards our family.”			”
Raju	10	Positive On ART since 2007 (Lamivudine Zidovudine, Nevirapine) start CD4 count 752 now 1.247 often pneumonia	Mother positive Father positive (dead)- was a truck driver and addict Mother (daily wage worker) remarried to a HIV negative man 2 elder and one younger sister negative	Khera Khurd/ Delhi	He knows about his disease and takes his own medicine He is not afraid, his mother says that he knows that “He can be a healthy kid through the medicines” Will not let anyone except his new father or his mother touch his blood, he tells others to be careful because something is wrong with his	suffered a lot under the pressure and discrimination imposed by the family After her relatives knew, they stopped coming to their place. They also don´t eat together, they just stay away. Rajus status, as well as that of his mother were not disclosed to the new family	In the school his status has not been disclosed out of fear for discrimination	The neighbor children though knowing the status still play with him; they just run and get his father if something happens to him. The neighbors who know about the status though were very supportive.	“Good public awareness campaigns help and there is much support by the NGO”

					blood.	out of fear of stigma and discrimination.			
Rishi	7	Positive	Both positive (dead)	Khera Khurd/ Delhi	came to know about the problem and could not cope with it at all He could not cope with being sent away to the hostel “he is completely done, he did not cope with anything in the hostel. He was pushed around, first he was with his mother, then she died, then he lived with his father and also he died, and then he lived with his grandparents and they send him away to live in a hostel.” He could not cope, so on the first day in the hostel he takes a knife and tries to kill the ward because she	Used to be taken care by his maternal grandparents after the death of his parents. “Everything was okay in the family until they came to know that also Rishi was HIV-positive” His grandparents said he is dangerous and can infect others and can stay with them no longer. Rishi was taken to a hostel and admitted there.	-----------------	---------------	

					was telling him to take breakfast, dinner and a bath, but he did not want to. He didn´t want anything, he didn´t even want to play. He is not interested in anything, he just sits there.”				
Sima	9	Negative From Hariana	Both positive Father (dead / meningiti) – truck driver, addict Father used to suffer heavy headaches and cry a lot Mother remarried to a HIV negative man. New husband/ father is very supportive	Khera Khurd/ Delhi	After father’s death whenever someone in the family complained about a headache the girl started crying. She was toilet trained before her father’s death but after his death she started bed wetting again. “There are so many things that are happened. We see the child; she was looking very beautiful and smart. After that her nature id different and	There were many changes in the family after her father’s death. The family of his father started putting a lot of pressure on her mother to marry again.	-----------------	---------------	Her mother disclosed her status and is now an active member of CSI, “she comes her whenever we call her and gives interviews, and speeches for pregnant women.” This helped both Sima and her mother; they now have a peaceful life.

					everything is different. The child is changed, completely changed. Life is changed and walking stile has changed. I think she was traumatized by her father's death." Sima took a year to recover from her trauma.				
Three Children (2)	Oldest 14	Negative	Both positive (dead) Grandmother is care giver.	Ibid.	The eldest boy keeps running away from the hostel and coming back home, he does not want to stay there but she keeps sending him back. The whole life is running away. The children miss their family. They do nothing, no school.	Grandmother sends the children away to different hostels, she does not want them with her. We tried to speak to the grandmother, told her to leave the children live together but she doesn´t want it. She has a common job, she could afford the	____________	___________	_____________

						children but she doesn´t want them. “She is telling: Why should I take the headache? Why should I take the responsibility?” She says there are NGOs to do that job. Children are separated because of that.			
Sonia	**------------**	negative	Mother positive Father positive 2 sisters negative Younger brother positive (4) – *very sweet child* “Is a 4 years kids and first time he come here	Ibid.	______________	_______________	_____________	She does not want to go, every time	______________

			the children, that time he was 2 and a half years old and he is very weak like this, no talking, no walking, like this. Very lazy and after they start treatment and everything he is very charming, he didn´t still two minut, he´s moving moving moving.”						
Mohan	------------	negative	Mother positive “She delivered forth baby, a boy, he´s also infected; right now he is 7 years	Ibid.	______________	______________	______________	______________	______________

			old. The delivery was caesarian so three units blood is transfused in the government hospital. After the blood transfusion she is not well, not well, something here and there and after 4 years the child is also not well. So after 4 years a HIV test is done and status positive. She know that she´s positive status, and after that only her status is positive, husband negative and						

			husband is come in our office and told me my wife is positive, I’m negative and my son is also sick but I don´t know the status. Day second after the, day second he come here, so I advised everything and again and he tested as it was done in private ward, we don´t believe in private, so we accompany again in government hospital husband and wife and husband again is negative she is positive.						

			She is very ill that time. 2007, end of 2006 maybe.” Father is sick (pilia = jondis) Younger brother positive (7)						
Sita	23	Positive Test was done during pregnancy. Even before that she had suspected that her husband had it as he was very thin and used to suffer from fevers all the time. She says that she told him “You have AIDS; you get fever all	Husband positive Son 3 months (status unknown) After finding that she was positive her husband ran away, maybe out of fear from her family. She is told by the doctor to give the baby 2 spoons of	Jeevodaya / Kannur	She was complicated and made trouble for the family at home. She said she was scared in this place and she wanted to go back home. Cries a lot, she refuses food and sleep and does not wash herself or her and the Childs clothes and she refuses help. cut on my hand	Was brought to Jeevodaya because her family could not care for her and the baby. The family did not know how to handle her. She was yelling around that she is HIV positive and that she had AIDS, so the family secluded her and brought her here, as the neighbors	-----------------	---------------	She is depressive. It is not easy for the sisters to cope with her, one day she hurts the one sister’s arm badly by turning it. It takes about a week to calm Laila down, she takes the medicine and she washes and cares for the baby who is making

		the time.” went through the PMTCT pogram, she took the ARV, had a caesarian section and does not breast feed, the baby boy was also given medicine for one month after delivery	Milk a meal, which she did; as a result the baby is badly malnourished. He is so weak he can barely suck the bottle the sister gives him.		and when she saw that she looked frightened and pushed me away from her pointing at the cut, shaking her head, but I told her that it was okay, that nothing could happen to me. She looked confused but then permitted me to hug her again and gave in to crying. Threatened to kill herself and the baby. Does not let anyone help her with the baby in the beginning and she says it is not clean and it is impure here and she cannot stay. After Sister Mary told her: “If you don´t eat, I will put a pipe in your	where also getting upset and worried. She did not get much help at home or and advise on how to treat and nurture her son. She speaks to her family but every time she yells and the cries.			good progress under the loving care of the sisters. He is putting on weight and starts smiling, he almost looks like a normal and healthy child now. Lila herself still looks sad but somehow she has arranged herself with the situation that she is in. She starts permitting help and lets one of the other positive women who also cares a lot for Maria take care of her son.

					stomach though your nose and give you food in that way”, Laila starts taking food again				
Arun	15	Positive On ART Was very sick when he came to CSI, weak and not tall enough for his age. He used to get infection very easily. When he came he was not aware of the disease, his mother did not tell him. Very sentive	Both positive father (dead) Stays with maternal grandparents together with mother and sister (negative)	Delhi	Very successful and very positive. “other children with HIV is very irritated about themselves” but he is not.		Does not go to a local doctor, they do not check up well because of HIV. And in CSI it is free service.		
Vishnu	14	Positive On ART (since he was 3 years old) He is very	Parents positive (dead) 2 elder brothers (negative)	Khera Kurd/ North-west Delhi	If he could choose to do something he really wants to do, he would want to see America.	When the CSI staff wanted to visit the family at first the grandparents did not want that. So they		Family cares for him very well. He likes to go to	Hope given by his family.

		healthy He knows that he is positive since he is 7 years old and is really responsible about taking his medicine. Comes to CSI since 2 years. He likes the place. His status has not been disclosed outside of the family out of fear of stigma and discrimination He plays cricket.	Lives with his grandparents and uncle (main care taker/ unmarried) Paints his uncles family, and his family. His mother died 10 years ago and father 8 years ago.		He is not afraid of the disease or the situation, his family gives him a good backup. “I am not afraid of anything; I used to be afraid of ghosts but not anymore.” His uncle told him about his disease not directly but he heard them. “They were saying I was sick and he can be alright but only if I take medicines.” “I was afraid when I heard that for the first time but when time passed and I took medicine it is okay. Now I am not afraid.” “I was afraid of injections and taking medicines.	spoke on the phone and the CSI staff said they are there to help the child. The grandparents are worried that someone will find out and the family will have problems. They are scared and don´t want anyone to know. After a while they allowed it. Still they are scared of disclosure because of stigma and discrimination. People might be rude, isolate them and not speak to him and he might lose friends.		school, everyone is friendly. “I like living with my family very much. I have been with my uncle always.”	

					Not of the disease.” *Does he know what is wrong with him?* “I don´t know, I only know I am ill.” My favorite God is Kali. But if I could have one power it would be Shiva’s, because he is good, he takes care of everyone and he can heal.				

9.6. Example of a Consent form

International
HIV/AIDS
Alliance
in India

Consent form for In-Depth Interview (IDI)

Informed consent for people participating in IDI for an Operations Research on "The effects of the HIV/AIDS-related Stigma on children affected by the disease"

Purpose of the study

(Greet the man/woman). My name is Ariane Petney. I am a student at the University in Heidelberg /Germany, together with the HIV/AIDS Alliance (or, Alliance India) I am trying to find out more about the effects of the HIV/AIDS-related Stigma children who are affected by the disease, which includes both children who are infected themselves and children who are affected through the presence of an infected Person in their closer family. The study should show what forms Stigma takes and what psychological effects it has on the affected children. Also we are trying to find what the perceptions of the children are regarding their situation and what coping mechanisms they develop to face the stigma and decimation in their day to day life.

Procedure

You will be asked to participate in an interview today. You will be asked questions about your perceptions and experiences with stigma and the resulting discriminating acts, as well as developed coping strategies. You will not be required to provide contact information as no follow-up discussion is intended. We would like to ask for your consent to be interviewed now on the topic by me or by one of our trained interviewers.

Benefits and Risks

If you agree, your participation will help develop new and better modes of psychosocial support for children suffering under stigma or the resulting discriminating acts. Although we have taken full care not to discuss any issue or question that are insensitive or questions that may make you uncomfortable but if at any time during the process, if you

feel so, you may directly convey your views candidly. The interviewer will not insist on your views or perceptions or experiences.
Although we have taken full care not to ask any questions that are insensitive or questions that may make you uncomfortable but if at any time during the process, if you feel so, you may directly convey your views candidly. The interviewer will not insist on answers to such questions.

Compensation
You will not receive any monetary or material compensation for participating in the research process.

Offer to answer questions and freedom to withdraw from the study:
You can refuse to respond to any issue and can stop the discussion process at any time. There will not be any consequences if you decide to drop out of the study. The discussion will take approximately between 50 - 60 minutes. Participation is completely voluntary.

Confidentiality
Everything that you report during the interview will be kept strictly confidential and your name will neither be recorded on the questionnaire nor divulged in any manner. All records of your interviews and data collected during the research process will be kept in a safe and secure place.

Participant's Statement
I have read the consent document regarding my participation in the study / the consent document regarding my participation in the study has been read out to me. I have been given a chance to ask questions and my questions have been answered to my satisfaction.

I understand that all records will be kept confidential and that I can leave the study at any time. I have also understood that my decision not to be in this study or to leave the study will not affect the services I receive under the CHAHA programme.

I agree to be in this study as a volunteer.

Name of the respondent__________________

Signature of the respondent:_________________ Date:________________________

Name of witness:

Signature of witness:_________________
Date:________________________

Name of Facilitator:

Signature of Facilitator:_________________
Date:________________________