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**LUND UNIVERSITY**  
Faculty of Social Sciences

**Stigma and Challenges Faced by HIV-Positive Adolescents**  
*Through the Eyes of the Staff at Botswana Baylor Children's Clinical  
Centre of Excellence*

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Bachelor Thesis: UTKV03, 15 hp  
Spring Term 2012  
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## **Abstract**

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The aim of this study is to examine how the “empowering” strategies of Botswana Baylor Adolescent Programme (BBAP) are addressing problems HIV-positive adolescents are facing and how stigmatisation around HIV might be contributing to these problems. The main theories applied were “empowerment” and “stigma”. The study was carried out with a qualitative approach during a period of ten weeks at the Botswana Baylor Children’s Clinical Centre of Excellence (COE) in Gaborone. The research was based on key informant interviews and observations at four different branches of the BBAP. The results of the study show that many of the problems HIV-positive adolescents face are caused by stigmatisation in society. To “empower” HIV-positive adolescents, BBAP aims to improve the HIV-positive adolescents’ self-esteem and confidence by providing them psychosocial support, giving them vocational training and advice on how to disclose. However, empowerment is only limited to within the walls of COE, as COE does not challenge the norms and behaviour in society that are the root cause of stigma. The conclusions are that the BBAP is only “empowering” HIV-positive adolescents in certain dimensions, and to be able to challenge the norms in society, greater communication and involvement between the “disempowered” and the society is encouraged.

Keywords: Stigma, HIV, Adolescents, Empowerment, Botswana

## **Acknowledgements**

I want to thank and acknowledge my gratefulness to my local supervisor Tumani Malinga at University of Botswana, who unquestionably took her time to meet up with me to guide my research and thesis writing, Nunu Phaphe at the Botswana Red Cross Society for presenting me with vital information and contacts, Dr Maraphe Maraphe and Ntobelezi “B2” Boitumelo at Botswana Baylor Children’s Clinical Centre of Excellence for granting me access to the Botswana Baylor Adolescent Programme, and my supervisor at the Department of Sociology at Lund University, Lisa Eklund, who guided my thesis writing. I also want to thank my interviewees for their contribution to this paper as well as all Batswana who helped me during my ten weeks in the field.

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## **Abbreviations**

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
BBAP	Botswana Baylor Adolescent Programme
COE	Botswana Baylor Children's Clinical Centre of Excellence
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
MCP	Multiple Concurrent Partners
NACA	National AIDS Coordinating Agency
NGO	Non-Governmental Organisation
UNICEF	United Nations International Children's Emergency Fund

## 1. Background to the problem

*“The damage is done”* is not an uncommon perception in the Botswana society of HIV-positive young people. As a young HIV-positive person in Botswana you are one among the other 8.5% of the infected youth population between 15-24 years (UNICEF 2012<sup>1</sup>). Fortunately these adolescents (as the other HIV-positive age groups around the country) can be given medical treatment by the government, as the work to provide universal access to Anti Retroviral Therapy (ART) and Highly Active Antiretroviral Therapy (HAART) is being implemented on a national scale (NACA 2009:8). Some of the successes have been evident; between 2001 and 2007 HIV/AIDS related deaths declined from 16 000 people per year to 11 000 people per year (WHO, UNAIDS & UNICEF 2008:5). Medically, ART can successfully treat the disease and HIV is becoming less and less of a death sentence. But unfortunately ART cannot treat all aspects of the disease. The state institution National AIDS Coordinating Agency (NACA) describes ‘Stigma and Discrimination’ as one of the key determinants of the HIV/AIDS epidemic in Botswana, saying that “stigmatisation creates an environment of shame and loss”, “erecting and reinforcing social barriers inhibiting the most-at-risk population of health seeking behaviours”. If individuals choose not to find out about their status – thereby ensuring them the safety that no one else will find out about it – the potential for increased infections persists (NACA 2009:12, NACA 2003:16). Despite the fact that we are moving into a world where the first generation of individuals being born with HIV starts heading towards adolescence, they are still being stigmatised as ‘naughty’ and ‘irresponsible’ for a virus they caught from birth.

The individual responsibility is crucial for decreasing further spread of the virus, but individuals may find it hard to motivate themselves to find out about their status if they are going to face obstacles in their everyday life from a stigmatising society. So to help adolescents vulnerable to HIV, different strategies by actors such as the government, Non Governmental Organisations (NGO’s) and civil societies have been implemented towards eliminating stigma and denial. The Botswana Baylor Children’s Clinical Centre of Excellence (COE) is a clinic in the capital city of Botswana - Gaborone - focusing especially on ‘empowering’ adolescents in their

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<sup>1</sup> Latest number from 2009

<sup>2</sup> An organisation or industry that has some political authority and serves the state indirectly, esp. in

programme called Botswana Baylor Adolescent Programme (BBAP) that hopefully could lead to adolescents resisting being stigmatised and in the end helping to eliminating it.

## **2. Aim and Research Questions**

The aim of the research is to identify some key problems which adolescents living with HIV may encounter, examine some of the strategies of the COE's BBAP, critically examine what their views on empowerment are, how they work with it and how their focus on empowering HIV-positive adolescents may be crucial not only for easing some of the problems identified, but also for decreasing stigma around HIV-positive adolescents. The research question is:

*How is stigma contributing to the challenges of adolescents living with HIV and how is "empowering" these adolescents at the Botswana Baylor Adolescent Programme addressing these issues?*

This study is significant because the COE is a parastatal<sup>2</sup> organisation; practices and experiences drawn from their work are thus highly influencing national guidelines. This study is also important because lack of ethnographic studies that can help determining how to address local needs among people living with HIV/AIDS (NACA 2009:16).

## **3. The Botswana context**

### **3.1. HIV in Botswana**

Botswana, like many other countries in Sub-Saharan Africa, has a young population with 22% being adolescent (UNICEF 2012<sup>3</sup>) out of the total population of 2,09 million people (CIA 2012<sup>4</sup>). The country is one of the success stories of Southern African development with an economic growth rate that was one of the world's highest between 1966 and 2009 (CIA 2012). The population is fairly homogeneous

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<sup>2</sup> An organisation or industry that has some political authority and serves the state indirectly, esp. in some African countries

<sup>3</sup> Latest numbers from 2010 regarding adolescents between 10-19 years old

<sup>4</sup> July 2012 estimation



with 79 % being Tswana (ibid.). It has a well functioning government: half of the government revenues comes from the diamond industry (ibid.), used to improve the country's human capital, and the democratic regime is the least corrupted in all of Africa (Transparency 2012). Nonetheless, the country falls short of translating its success into the social aspects of development. Botswana is one of the worst HIV/AIDS affected countries in the world with a prevalence rate of 24.8% of the total population (CIA 2012), but has also come far in addressing the issue with public access to antiretroviral medicine. By 2007, about 82% of the population was covered (WHO 2008:8). Leading the work and holding the national financial power regarding the fight against HIV/AIDS is the state institution NACA, based in Gaborone. This is the main institution in the country that finances and arranges programmes to combat HIV/AIDS. Their work is mainly to lead and coordinate stakeholders to ensure effective management and control of the HIV and AIDS epidemic, letting the implementation go to local partners.

### **3.2. Why is the prevalence high?**

The latest National Strategic Framework available covering the years from 2010 to 2016, summarised the main problems that Botswana faces today. As mentioned previously, one of the biggest HIV related problems is stigma and discrimination about the disease (NACA 2009:12). The latest research based on national surveys available showed that only 41% of the respondents expressed an accepting attitude towards people living with HIV/AIDS (CSO 2008:51). The spread of HIV very much revolves around behaviours, and these could be rooted in the Batswana<sup>5</sup> culture. Although surveys on gender issues regarding safe sex show that 92.4% of the respondents<sup>6</sup> think it is okay for a woman to ask to use a condom during sexual intercourse, women still have a subordinate position in the society, especially being vulnerable in the position about deciding the practice of safe sex (CSO 2008:51). Even though the number seems promising, there are still around 51 out of 1000 adolescence births between the ages of 15 and 19 (UNICEF 2012<sup>7</sup>).

The Botswana AIDS Impact Survey from 2008 tried to examine the nation's

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<sup>5</sup> Batswana = People from Botswana in plural (singular = Motswana)

<sup>6</sup> Aged 10 to 64

<sup>7</sup> Between year 2000-2010

reproductive age group's<sup>8</sup> behaviour of condom use. In spite of the vast HIV epidemic in the country, the population's general condom use is low both among regular and non-regular sexual partners. During the past 12 months, 27.7% of the respondents reported always using a condom with regular sexual partners while 39.6% reported always using a condom with non-regular sexual partners (CSO 2008:50). Hence, the practice of unprotected sex might be a leading cause of the spread of the virus.

Another factor related to the spread of HIV is multiple concurrent partnerships (MCP), also further increasing the spread of HIV/AIDS. Interestingly it seems to be more common for men to have fewer MCPs, while few women have a lot of MCPs. The statistics show that at least 23% of the males on a national scale in the reproductive ages between 15 and 49 years of age have had more than one sexual partner the last year, a number that is represented by 10.4% of the women (CSO 2008:49). Statistics show that the HIV-prevalence is peaking between the ages 30 to 45 (CSO 2008:45). If the HIV-prevalence continues to be steady, the number of people being able to work will decline over the next 5-10 years (NACA 2003:15). Good news is that so far, the lowest rate of new infections is actually the age group of 15 to 19 year olds, with an incident rate of 0.7% (CSO 2008:45). Institutions such as the COE are therefore focusing on 'empowering' this particular group to minimise the infection rates even in the coming ages.

### **3.3. Why adolescents?**

Adolescents are specifically addressed because they are in a period of individual characteristic transition in life and starting their sexual life (Lottering 2010:37). The transition from being a child to becoming an adult could involve risky behaviours (COE 2011:21). Consequently, the importance of addressing adolescents became more emphasised in the last National Strategic Framework by NACA, for example stressing the dire situation of adolescent girls today. They are especially vulnerable to sexual exploitation as research show they are less able to negotiate condom use, are more involved in intergenerational sexual relationships with older men, combined with the social acceptance of male partners having more than one relationship (NACA 2009:11,12). The vulnerable position of adolescent girls not only increases the risk of transferring the virus to the girls, but also of transferring the virus from HIV-positive

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<sup>8</sup> Aged 15 to 49

adolescent girls to other partners. Nevertheless, adolescents seem to be careful in the beginning of their sexual life. According to the latest national statistical survey, adolescents between 15 and 19 are out of the whole population most likely to use condom at the sex debut as 91% of them reported doing so (CSO 2008:49).

### **3.4. The Botswana-Baylor Children's Clinical Centre of Excellence**

The private-public funded Botswana-Baylor Children's Clinical Centre of Excellence (COE) in Gaborone, Botswana established 20 June 2003, is one of the first in the country to fight HIV/AIDS not only through comprehensive care and treatment, capacity building and clinical research, but also through addressing the psychosocial issues of being HIV-positive (COE 2011:3). One of COE's programmes is the BBAP that deals with clinical and psychological management and support of adolescents. The BBAP has many different branches dealing with different aspects of adolescence empowerment, but only a few of them were observed in this study: The Teen Club, the Teen Mothers Support Group, the Adolescent Forum and the Teen Leaders.

The Teen Club, which is one branch of the BBAP, has proven to be one of the most successful ones. Their mission is "empowerment" through "*building positive relationships, improve self-esteem and acquire life skills, ultimately improving clinical and mental health outcomes as well as a healthy transition into adulthood*" (COE 2011:22). UNICEF has also recognized this Teen Club on a global level for Best Practice in the field of adolescent support (COE 2011:23). The outcomes of this club have shown to be positive, making the teenagers better at coping with the disease in the daily life, with their families and friends, giving them incentives to study, practicing life skills and increase their hopes for the future (Pettitt 2010:80).

The Teen Mothers Support Group exists for teens that are or have been pregnant and, as a consequence, do not feel confident enough to join the regular Teen Club because of fear of stigma. The Teen Mother Support Group meets monthly with a group of Teen Club, psychology and social work staff to discuss topics that are specially relevant for teen mothers such as "*safe sex, parenting skills, adherence, taking care of babies, relationships as well as feelings and emotions around motherhood*" (COE 2011:22). The people involved in the Teen Mothers Support Group also ask the teen mothers how they became pregnant in order to see if any patterns can be identified to the root cause, and then use that information to address these issues.

The Adolescent Forum meets twice a month with the adolescent related personnel such as nurses, psychology, social work and auxiliary work staff. The meetings highlight cases focusing on care, treatment and psychosocial issues of challenging adolescent patients. Furthermore, the forum functions as an updating apparatus for the personnel at COE to enlighten them about the latest news in the BBAP, such as the results of the latest Teen Club (COE 2011:21).

The last branch observed was the Teen Leaders meeting, a meeting where five girl- and five boy teen leaders between 15 and 19 years of age meet two weeks before the Teen Club is carried out, to discuss their perceptions and opinions on the program of the upcoming Teen Club. This meeting is solely for the teens, and the adults don't necessarily need to attend the meeting.

#### **4. Theoretical framework**

Below I will account for some of the key theoretical concepts used for this study, namely stigma and empowerment.

##### **4.1. Stigma**

In Goffman's work from 1971 he explains that people in society automatically categorize people, even strangers, at the very sight first of them (Goffman 1971:11). These first impressions shape our expectations about the "stranger". Typically, these demands may be implicit for us until we notice whether they have been fulfilled or not. This first impression creates a "*virtual social identity*" about the individual that does not necessarily confirm with the individuals' "*actual social identity*" (Goffman 1971:12). The "*normal*" person is the one not deviating from our shaped expectations about them (Goffman 1971:14).

When the stranger is in your presence, some undesirable attributes about the stranger may be identified, thus reducing the stranger from being a whole and unified person to a tainted and ostracized human being. To be branded like this is an example of *stigma* (Goffman 1971:12). Stigma is an attribute that is deeply discrediting, although it needs to be clarified that the real context of stigmatisation revolves not around attributes, but rather around relations between the "stigmatised" person and the "normal" person (Goffman 1971:13). Because "the stigmatised" are not seen as

fully humane people, “the normal” takes, not always intentionally, discriminating actions reducing the life possibilities of the stigmatised (Goffman 1971:14).

What then, is “normal”? The norms and values in a society are the ones upholding the notions of what “normal” is. It is then up to the citizens to follow these norms; those who do not deviate from the norms we are expected to follow are what we call the “normal” (Goffman 1971:14). Stigma is rather a societal function, a process which occurs where identity norms exists (Goffman 1971:135). Norms are also attached to sexuality and sexual behaviour, which is highly relevant to HIV. Becoming a teen mother is one of the actions deviating from the norms, confirmed by NACA that tries to minimise teenage pregnancies around the country (NACA 2003:60).

Previous research that has been made about HIV related stigma defines some typical characteristics around HIV stigma. Although written seventeen years ago, the description of HIV related stigma discussed by Alonzo and Reynolds (1995:305) is still very applicable in the case of the HIV/AIDS situation in Botswana. They suggest there is stigma around HIV because it is: “1) associated with deviant behaviour, both as a product and as a producer of deviant behaviour, 2) viewed as the responsibility of the individual, 3) thought to be contracted via morally sanctionable behaviour and therefore thought to represent a character blemish, 4) perceived as contagious and threatening the community, 5) associated with an undesirable and an unaesthetic form of death and 6) not well understood by the lay community”.

Because the HIV stigma is in few cases revealed from the first sight, the HIV-positives are “*discreditable*” as they can choose when and to whom to reveal their stigma to (Goffman 1971:50). The “discreditable” then have different ways of controlling information about their “stigma” and dealing with stigma. One way for discreditable to deal with stigma is to put lots of personal efforts in an act to behave just like anybody else, such as performing activities usually excluded for the stigmatised (Goffman 1971:19). Controlling information about yourself and your stigma is described in Goffman simply as “*information control*”. One way to control information about ones “stigma” is by not revealing certain symbols that have become related to the stigma. Goffman talks about these as “stigma symbols” (1971:52). These stigma symbols can take many forms, such as taking medicine, socialising with some certain people and visiting some certain institutions. If a discreditable is seen associating with any of these, their stigma is at risk of being exposed.

During the socialisation process the “stigmatised” learns its roles in society. Some of those born with a stigma attached to them have to adapt to their situation all the way from birth while they learn what the society expects and does not expect from them (Goffman 1971:40). In some cases the family and the closer neighbourhood can help controlling information about a stigmatised person by creating a protective environment where stigmatised are shielded from the knowledge that they own a stigma. However, it comes to a certain period in life where family and neighbours cannot protect the stigmatised anymore. This period occurs at different stages in life depending on each individual, but usually it is when stigmatised children starts school they have to realise their stigma (Goffman 1971:41). This realisation starts a moral transformation for stigmatised when they realise their belonging to another “group”. Goffman further argues that in those cases where stigmatised children manage to pass the early school years without the moral transformation, they might encounter problems later in contacts with the opposite sex and when applying for jobs. Adolescence is the stage where stigmatised individuals seem to experience a shift in identification. Consequently, the stigmatised teens identify themselves less and less with their own stigmatised group and prefer to be identified with the “normal” (Goffman 1971:42).

Stigmas become evident when groups from the “normal” and the “stigmatised” are mixed in different social situations. Some of these situations can be predicted and consequently avoided by the stigmatised. Hence, this can lead to great consequences, as the “stigmatised” might force themselves into isolation (Goffman 1971:21). An isolated person is spared the healthy stimulation of socialising with people different from us, which can lead the isolated to be more suspicious, depressed, anxious and confused when being around people. The realisation that the stigmatised is inferior to the “normal” consequently leads the stigmatised never to feel accepted in the presence of the “normal” (Goffman 1971:22). Amongst their “own” the stigmatised can build their lives in spite of their stigma, but have to adjust to the ‘half world’ they have to live in (Goffman 1971:29). Thus, this creates a situation where the “stigmatised” need to live in a “double world”; one where people *believe* they know the stigmatised person and one where they *actually* know the stigmatised person. The risk of living in a double world is that people that *do* know about the person’s stigma can threaten to reveal the stigma to those unknown to it (Goffman 1971:85). When the discreditable gets into a situation where they are forced to reveal

information about their stigma, they either have to reveal their “stigmatised identity” or be forced to further commit to their “normal” identity if their “stigmatised identity” is to be kept (Goffman 1971:90). This is the reality many non-disclosed HIV-positive adolescents have to deal with.

Some stigmas are more prevalent in some societies than in others. It may seem self-evident that societies where one certain stigma is more familiar, the less the “normal” are bothered about it. Although, it can be argued that some certain stigmas are more welcoming and less contempt in societies where the stigma is unfamiliar, just because society does not have to deal with the stigma on a constant basis (Goffman 1971:61). When a stigma seems to be more evident in a society, groups or institutions are sometimes shaped to “help” the stigmatised. Both stigmatised people and “normal” people can be the ones shaping these. The “normal” people who works with people attached to a certain stigma, or in any other way are related to the stigmatised and are aware of their situation, are called the “wise” (Goffman 1971:37). Most of the “discreditable” living with a stigma that is easily concealed – such as the HIV-positive adolescents visiting COE – and do not often have to worry about concealment around strangers and temporary contacts, but instead have to deal with this among their closest (Goffman 1971:62).

## **4.2. Empowerment**

The concept of empowerment is used in this paper as a theoretical approach because the COE is using “empowerment” as a strategy in the BBAP. Below, a theoretical concept of empowerment is described by my own definitions.

The COE’s definition of empowerment is emphasised on change. This is very much related to Kabeer’s (2005:13) talk about empowerment as a process. She says that the disempowered are the ones being denied the ability to choose. “Empowerment” then, is the process where the disempowered acquire the ability to make choices. Thus, “empowerment” in that sense means change (ibid.). The different changes desired can take various kinds of forms, but the most suitable for the case of BBAP is *human and social empowerment*. Page and Czuba (1999) in Luttrell et al (2009:1) describe the definition of human and social empowerment:

“Empowerment as a multidimensional social process that helps people gain control over their own lives. This is a process that fosters power (that is, the capacity to implement) in people, for

use in their own lives, their communities and their society, by being able to act on issues that they define important”.

This seems to be the most suitable definition since the COE is focusing on empowerment at the grassroots level, originating from the HIV-positive adolescents themselves to be able to make life choices, such as whether or not to disclose their status to people.

The question is then, how is change brought about in society? A discussion within the empowerment paradigm is whether *change* is pushed or generated by forces beyond peoples’ control or through individual and collective action. In Luttrell *et al* (2009:9), the former type of change is called “structure” while the latter is called “agency”. The term “agency” is referred to as:

“The capacity of individuals to act independently and to make their own free choices” while the term “structure” is covering “the rules and social forces (such as social class, religion, gender, ethnicity, customs, etc.) that limit or influence the opportunities that determine the actions of individuals” (ibid.).

Since stigma is the focus in this study, I am including stigma to the social forces that “structure” is shaped by. Some people argue that individuals have a great capacity for acting freely, whereas other people argue that the social systems are the ones determining the actions of individuals (ibid.). By these definitions, the work at COE is operationalized through “agency” because they are working with empowerment at the individual level (COE 2011:22).

Because “empowerment” is used very diversely in different contexts, the concept of “empowerment” is very contested. In her conceptual framework of “empowerment”, Mayoux (2003:16) defines different dimensions of empowerment. Her definition, not unlike Kabeer’s, is that empowerment is a “multidimensional and interlinked process through which people work towards a society where all people are able to make and realise free and informed life choices”. For people to be able to make these choices, the society has to have an environment where it is *equally* possible for all its inhabitants to make choices. To be able to achieve this it is important to address the “agency” among the disempowered, but *also* transforming the “structure” to change the attitudes and behaviour of those in position to deny people their choices (ibid.).



“Empowerment” comes in different dimensions that can be operationalized through “agency” or “structure”. In Mayoux (2003:16) the dimensions are defined as: “power from within”, “power to”, “power over” and “power with”. According to this model, the most applicable dimensions for BBAP are “power from within” and “power with”. “Power from within” is operationalized through “agency” by increasing awareness of possible choices, boosting confidence and self-esteem and by aspiring dreams. If change is wanted in the “structure” it is required to change attitudes, stereotypes and encourage engagement (ibid.). “Power with” is operationalized through “agency” by organising the disempowered to together (with their own abilities) challenge existing power relations and increasing participation in local institutions. Also to achieve “power with” the “structure” needs to be challenged by *“supportive organisation of those with power to change inequality and injustice”* (Mayoux 2003:16). The patterns operationalized here by “agency” can be identified by the work of the BBAP. The question is however, are they challenging the “structure”?

## **5. Methodology**

### **5.1. Methodological approach**

This study was conducted with a qualitative approach during a time span of ten weeks. As described by Punch, a qualitative approach attempts “to capture data on the perceptions of local actors ‘from the inside’, through a process of deep attentiveness, of empathetic understanding and of suspending or ‘bracketing’ preconceptions about the topic under discussion” (Punch 2005:141). To achieve this, I believed it would be best to retrieve data from few sources that could provide in-depth data instead of referring to statistics or similar – therefore a qualitative approach seems most suitable. Because of the interest of the work done by a certain institution – i.e. the COE – the research was narrowed down to a case study of that certain clinic. As described by Punch, the objective of a case study is to develop as full an understanding of the particular case as possible. The study is aiming to recognize the context of the case in its natural setting: for the key informants at their workplace and for the adolescents at one of the Teen Clubs, a Teen Mothers Support Group and a Teen Leaders meeting. It also has a holistic focus that is aiming at understanding the wholeness and unity of the

case. The specific type of case study in focus here is, according to Stake in Punch, “the intrinsic case study”, which is conducted by the researcher when he/she wants a better understanding of one particular case (Punch 2005:144).

The sampling technique is of non-probability sampling. Two strategies were used, *convenience* which means that the sample was chosen by virtue of its accessibility (Bryman 2008:183) and *snowball sampling*, which in certain aspects is a form of convenience sampling with the difference that other groups relevant to the topic are presented from the convenience sample (Bryman 2008:184). With these sampling strategies, the study is not aiming to give a generalized overview of the overall situation in Botswana, just the case of the COE. Some conclusions drawn from this case study might be useful for other contexts, but the findings are not generalizable.

This research was inspired by an inductive theoretical approach, with an iterative strategy where, rather than being strictly inductive, the data and theory was weaved back and forth during the analysis, inspired by grounded theory (Bryman 2008:12). This means that the research was conducted with an open mind towards the data collected, rather than testing theories.

## **5.2. Ethical considerations and biases**

During the correspondence with the COE before leaving Sweden some problems were accounted with conducting research at the COE; they required anyone wanting to collect data from their teens to get an ethical approval from both the National Ministry of Health and from the COE itself. The time it would take to receive the permit would be around three to six months. After the initial meeting with Dr Marape, the director of research at the COE, the agreement lead to the possibility of observing the activities of the BBAP, thereby getting an overall observation that could be used as data, instead of retrieving data directly from the teens themselves.

The nature of the study could be, as the nature of much qualitative research is, very intruding if interviews were going to be conducted with the adolescents themselves. As this study deals with the most sensitive, intimate and innermost matters about difficulties living with HIV, ethical issues inevitably will accompany the collection of such information (Punch 2005:277). Furthermore, the direst ethical issues raised during the pre-face of the study are described in Punch as “Harm and Risk” and “Privacy, confidentiality and anonymity”. The “Harm and Risk” describes

the concern about what the study could do to hurt people, in this case psychologically hurt the adolescents interviewed. Would it be worth to ask fragile teens very private questions about their chronic disease to acquire data for the study? As described about “Privacy, confidentiality and anonymity”, the study would definitely intrude and come closer to people than they wanted, if adolescents were to be interviewed directly (ibid.). This became very evident when two interviews were conducted with two HIV-positive people<sup>9</sup> outside the COE, at “Tlamelong Rehabilitation Centre” through the Botswana Red Cross Society. These interviews were focused on their own perceptions of living with the virus. During the interview it became evident that the informants were very uncomfortable talking about their disease, both in the way they answered the questions and in the way they behaved. It became very evident for me that it would not be worth going through the same procedure with maybe 10-15 more adolescents. In the end, it was more suitable for me to do a study based on key informant interviews.

Since the data was retrieved with a great deal of help from the people at the COE, the data from the organisation and the people interviewed needs to be treated as it was intended to be, keeping the level of reciprocity balanced and not making them feel exploited. This also leads to the issue of biases. What most importantly needs to be stressed is the fact that this field study was conducted in the context of COE and only focused on the thoughts and interpretations of people working at COE.

Moreover, I was influenced from the very beginning during information collection around the subject of my study. My original assumption was that living with HIV is a struggle, therefore my aims and my interview questions automatically evolved around that assumption. The somewhat careless use of the term “empowerment” in development literature was not questioned before leaving Sweden; therefore I was not critical towards the use of “empowerment” in the grey literature and wherever I read about it. Another problem with using the term “empowerment” is that the term is directly associated with something positive, a word so powerful that most people – including I – buy the whole concept and easily gets carried away thinking that “whoever is using the word ‘empowerment’ is doing something really good”, such as the BBAP. As a researcher working solely in one environment, it is fairly easy to be distracted and get carried away, starting to think along the same line

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<sup>9</sup> One 20-year old and one 29-year old

as the people at COE do. Thus, influenced by this I might have asked some questions during the interview that to an extent were biased. In the aftermath it was easier to take a few steps back and search for my own opinion and where it stands. During the whole experience of the field study it came apparent to me that this was a learning process, and that a research framework created miles away from the place of research may not always correspond with the reality on the ground.

### **5.3. Research methods**

The main methods used were interviews and observations. The study was based on key informant interviews, initially supposed to be carried out on an individual, face-to-face verbal interchange, but sometimes there were two interviewees at the same time. The main data was retrieved from key informants, all of them staff of the COE. The informants were social workers, doctors, volunteers and other people working closely with HIV-positive adolescents. The place of the interviews was at the COE. The interviews were of semi-structured nature according to an interview guide<sup>10</sup> that was created for this purpose, but not strictly relied on, as it was generally a guideline for the interview. The aim was to get genuine thoughts and answers, so there was a need to be flexible and put an emphasis on how the interviewee framed and understood issues and events (Bryman 2008:438).

To gain better understanding of the case, the primary data of the thesis will be complemented with secondary data to compare similarities and differences to get a more holistic view provided by similar cases.

### **5.4. Interviews**

Seven interviews with nine different people were conducted during the field study at COE. The interviewees were people from the human resource department at COE and were chosen because of their close work with the adolescents. Two one-year volunteers Emily and Vera, working for the BBAP were interviewed to see if their non-Batswana perspectives were similar to the permanent staff of the COE. The two heads of the BBAP Ntobeledzi “B2” Boitumelo and Dr Refilwe Sello were also interviewed to gain their perspectives of the work with adolescents from the ‘top’. The social worker working with the in-reach programme<sup>11</sup> at Baylor, Masego Pilane

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<sup>10</sup> Attached in Appendix 1

<sup>11</sup> A team that visits COE’s patients in their homes for evaluations and follow-ups

and the social worker Tapiwa Nkhwalume were interviewed because they have direct contact with the adolescents. The other people that were interviewed were Jerry, a nutritionist, Twelelo Masutlha that has been working with the Teen Club since the start and Matilda Engelton<sup>12</sup> who is working with the different Teen Clubs around the country with the help of NACA and the World Bank.

All interviews were conducted in English. In the cases translation was needed, it was provided by local volunteers and staff members of the COE. The interviews lasted between half an hour to one hour, depending on how many extra questions were asked in addition to the interview guide. The observations lasted from the shortest one, about half an hour, to the longest one, four hours. The recording of the interviews and observations were made with an audio recording device.

### **5.5. Observation**

Due to limitations on accessing HIV-positive adolescents the second method was observations. A “micro-ethnography” is described as an ethnographic study where the study is concentrated to a specific social setting to gain a deeper understanding of the work around management of HIV-positive adolescents, during a relatively short period of a few weeks to a few months, therefore not as extensive as a normal ethnography, thus most suitable for this study (Bryman 2008:403). The micro-ethnography was done at the different BBAPs at COE of an overt participation-observation nature in mostly closed settings, depending on the kind of activity observed. In some settings I was overt to the people that knew my real purpose, but covert to the rest as I was “disguised” as volunteer and therefore not seen as a researcher (Bryman 2008:404). The only time I needed to be disguised as a volunteer was during the Teen Club, thereby hopefully increasing the chance that the adolescents would act more natural if they knew they were not being the subject of a research. The role of the ethnographer can therefore change according to the circumstances (Bryman 2008:410). There was no problem of access, since a “gatekeeper” and a “sponsor” eased the access to the different branches of BBAP by providing information about my real purpose to those responsible for each branch.

The observations made for this study were at Januarys Teen Club where the researcher was presented as a volunteer instead of a researcher, therefore covert to the

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<sup>12</sup> A brief description of the interviewees is attached in Appendix 2

adolescents observed, two observations at the Adolescent Forum where the researcher was participating as a researcher in the meeting but not interfering (therefore overt to the participants), at one of the Teen Mother Support Group where the role of the researcher was to be a volunteer (therefore covert as a researcher) and at one meeting of the Teen Leaders Meeting, where the role of the researcher was a visiting scholar/volunteer, also here covert to the participants of the real purpose of the researcher's participation.

### **5.6. Mode of analysis**

The main mode of data analysis was the narrative analysis. The interviews by the key informants were transcribed and then the transcriptions were reviewed. The information from the transcriptions was extracted with a thematic approach, meaning that data was taken from all parts of the body of the text and then arranged under suitable thematic headings (Holiday 2007:91).

## **6. Analysis**

The analysis below is divided into three sections: firstly, the main identified problems faced by HIV-positive adolescents today, according to the staff at COE. Secondly, how stigma might be contributing to these problems and thirdly, to what extent BBAP is treating these problems. Once again it is important to emphasise that the analysis is a mix of the perspective from the staff of the COE and my own observations.

### **6.1. Key problems faced by HIV-positive adolescents**

When asking the informants (the staff at COE) about their perception of the biggest challenges HIV-positive adolescents face today, the predominant answer was no doubt *medical adherence*. The COE mentioned in their annual report that as children are becoming teenagers, medical adherence tends to decrease (COE 2011:18). Different reasons for this is forgetting to take the pills, pill fatigue or simply that they don't want to take it. Other problems defined by the staff at COE are that everything HIV-positive adolescents do in life needs to be *constructed to a clinic*. Every six weeks they need to go for a medical check-up at the clinic and if the adolescents are thinking about starting a family, they need to get counselling about how to get pregnant without the risk of transferring the virus to both the partner and the baby. The HIV-positive adolescents have higher risks of *challenging home situations*. Some

of the patients have lost a parent to AIDS and the new caregivers (e.g. extended family) don't know how to handle the adolescent. HIV-positive adolescents are *missing school* because of illness and clinic visits, tend to *involve in risky behaviour*, which could ultimately lead to *teen pregnancies*. The last two problems are not solely related to HIV-positive adolescents, but the outcomes of these problems may have worse consequences. HIV-positive adolescents are also targets of *stigma* and because of this, *careful to disclose their status* to people because of fear of abandonment and spread of rumours. They have to *deal with psychosocial issues* such as accepting the fact that they are living with the virus, wondering why *they* got the virus and dealing with bitterness that might arise.

## **6.2. How stigma is contributing to the problems for HIV-positive adolescents**

A question that needs to be asked is: how did stigma become attached to HIV? When asked why stigma around HIV is prevalent, the answer was “because of misinformation” spread during a time when the knowledge around HIV/AIDS was limited. One of the heads of the BBAP, B2 explains:

“I would say what made people attach stigma to HIV was the very first way it was communicated to. We didn't just communicate HIV; that was the first mistake, we communicated AIDS, which is the end result of poor management of HIV. AIDS kills. AIDS is dangerous. AIDS is a monster. [...] It made people afraid, because we are all afraid to die. You don't want to die [...] so if I am going to tell you something exists that potentially can kill you if you come into contact with it, and it is very difficult to avoid, like HIV. [...] If some things are attached to something we can't resist, like intimacy in relationships, and being spread out as something that kills. [...] So what is driving stigma and making everybody afraid of coming close so somebody HIV positive is because they don't want to *die*.”

What B2 is saying is that HIV got the attention of being something that makes the most natural and normal situations in life – such as sexual relations – possibly dangerous and fatal. The mistake was also not to talk about HIV and AIDS separately. Emily, the BBAP volunteer explains: “*Frankly, most of the time it is adults trying to protect their family, not wanting it to spread. Thinking that you get it from kissing, holding hands, touching or whatever it is. There's still a lot of misinformation*”. Thus, Emily is saying that the rumours around how HIV spread were intentionally good, as parents were trying to protect the virus to spread to their families. This strategy however, contributes to the persistent stigma around HIV-positive people being

“naughty”, “irresponsible”, associated with “morally sanctionable behaviour”, perceived as “contagious and threatening the community” and “associated with an undesirable form of death” (Alonzo and Reynolds 1995:305).

The importance of adhering to their medication is crucial for HIV-positive people that want to have a chance at living a long and healthy life. Consistent medication is a necessary evil. Why then is medical adherence tending to decline at the adolescent stage? Adhering well to the medication requires adolescents to take their medication twice a day, at the same time every day. Taking medication is a sign for the observing “normal” person, that the person taking the medication is sick. This becomes a contradiction, as the adolescents do not take ART because they are sick, but rather to stay healthy. Tapiwa – a social worker at COE – explains how some adolescents feel in this situation:

“I [HIV-positive adolescents] don’t want to be taking medication anymore. I haven’t been sick at all ever since I took medication when I was still young. So I don’t see it would be any difference if I stopped taking this medication, so that I can be like any other normal adolescent who is not HIV-positive”.

According to Tapiwa, it is hard to motivate HIV-positive adolescents to take their medication, because if they already feel as healthy as a “normal” person does, why can’t they simply *be* a “normal” person and not associated with a sickness? This is related to Goffman’s theory about “stigma symbols”, where the medicine is the stigma symbol in this case. If the HIV-positive adolescents are not disclosed, it is hard for them to take their medication in some circumstances where the HIV-positive adolescents do not want to be associated with stigma symbols. Interestingly, poorer medical adherence during adolescence can be linked to Goffman’s (1971:46) theory about adolescents wanting to identify more to the “normal” than their own “stigmatised” identity. Taking medication is therefore something the adolescents would want to avoid. Not medically adhering well could then lead adolescents to fall ill and miss out on school.

Risky behaviour is another problem HIV-positive adolescents face. Stigma does not necessarily have to be the driver of risky behaviour of adolescents, but stigma could contribute to worsen the outcomes of risky behaviours. Similarly to “stigma symbols”, “stigmatised” people are expected not to be able to perform some certain activities “normal” people can, according to Goffman (1971:19). An example



of this scenario is related to HIV-positive people not being able to have unprotected sex, which Emily talks about: *“There is a pressure that I am reading about in questionnaires recently, about teen mothers not using protection during sex. If you insist on it, the partner – the man presumably – will think “you must be cheating on me” or “you’re hiding something, maybe you’re HIV-positive.”* Related to HIV-stigma, sexual intercourse without protection is a risky behaviour that “normal” people are perceived being able to do, but not the HIV-positive, which Emily described in the quote above. Demanding condom use in general has become a reason of suspecting that the partner is hiding something. This can lead to tragic consequences, such as further spread of the virus. Dr Refilwe, the other head of BBAP, talks about the risks of not being able to disclose:

“[Disclosure] is a bigger problem also when they [adolescents] are getting into sexual relationships, because if they’re having challenges with disclosing; that is when we have teenage pregnancies here. If they cannot disclose, they cannot insist on condom use with their partners; they get pregnant but they also might have infected another person. Living with knowing that you have intentionally infected another person cause you already knew you had HIV, might be hard for them”

As Dr Refilwe says, when coming to sexual encounters, non-disclosure can be a real disadvantage if the fear of being abandoned is greater than the fear of transmitting the virus to someone else. This kind of “risky behaviour” could lead to HIV-positive adolescents transmitting the virus to their partners or babies because they don’t want to be associated with the “stigmatised”.

This leads us to the next problem HIV-positive adolescents have to face: disclosure. When talking about disclosure, the thoughts of the informants are divided. Some claim that non-disclosure is something that protects the adolescent from being hurt, abandoned or stigmatised, while other informants stress the importance of disclosing to the closest people. Tapiwa elaborates about the dilemma HIV-positive adolescents face about disclosure:

“The rejection comes from all over, the community, the neighbourhood. So they [HIV-positive adolescents] think they are safe when they are the only ones who knows. They say it is enough if only one person knows. But what if something happens to that only person and then the rest of the people [family, relatives etc.] don’t know? They [HIV-positive adolescents] are struggling on their own, at the end of the day they are not managing.”

In the quote above, Tapiwa says that rejection has become related to disclosure. Because of fear of the consequences, HIV-positive adolescents are careful to disclose their status to people, even to their closest. HIV is a stigma that is relatively easy to hide for temporary contacts and strangers: HIV-positive adolescents can choose the ones they can trust enough to disclose to. By controlling who knows and who does not know about their status, they can predict some situations where they are likely to be mixed with both these “groups”. HIV-positive adolescents can then choose to avoid these situations, having to constrain their lives to a “half world” (Goffman 1971:21). Consequently, this leads the adolescents to having to live in a “double world” where some people know about their status and some don’t. Living in a “double world” is however not risk-free, as the people who knows the HIV-positive person’s status can threaten to reveal it (Goffman 1971:85). Disclosure among the closest is generally encouraged, but sometimes it is hard to decide whom to disclose to or not, as Tapiwa says:

“It is important for them to disclose, but I am not going to advice an adolescent to say: ‘if you know you are changing five boyfriends in three months, you have to make sure to disclose to each and every boyfriend’. But you have to know what is right for you and you have to know what to do right. If every one of them [boyfriends] is saying ‘I don’t want to use condom’ [...] you have to have a stand and say ‘if we are not using a condom, we are not going to do it’”.

Tapiwa shows a hesitation towards disclosure in some circumstances, such as HIV-positive adolescents who frequently change partners. She emphasises the importance for HIV-positive adolescents to know what is right for *them* and first-handily think about what they can gain from disclosure. In terms of being able to disclose – or in other ways handle problems that might arise around living with HIV – HIV-positive adolescents *are* being “empowered” at BBAP.

### **6.3. “Empowering” HIV-positive adolescents at Botswana Baylor Adolescent Programme**

The COE is empowering their adolescents at the grassroots level, based on “agency” and the importance of self-esteem, i.e. focusing on empowerment from “power from within” (Mayoux 2003:16). The staff at the COE is what Goffman calls the “wise”, i.e. people that are in any way working with or helping the “stigmatised” (1971:37). As a part of the “empowerment” strategy the BBAP helps to (quoted by B2): “*create an environment or conditions or assisting place the disadvantaged part can open*

*their eyes and see things that are around them that they are aware of, that they can act upon to promote their own lives*”, meaning that the BBAP is providing the adolescents a “stigma free” environment to give them a feeling that they can live in their “normal” world (ironically, because of their well known work at the COE, the COE has itself become a “stigma symbol”), a world where “normal” people know about the HIV-positive adolescents’ statuses without attaching a stigma to them.

Much of the empowerment discourse at COE is striving for the teens to be able to “make their own choices” and being able to do this freely. To make the adolescents aware they are full of potential to make their own choices and to control their own lives, BBAP gives them *psychosocial support* by giving the teens a feeling they are not alone, improving their self-esteem and trying to make the teens understand they are in power of their own lives. However, the BBAP is not solely focusing on emphasising the rights of the HIV-positive adolescents, but also trying to make them aware of their *responsibilities* as well. Being HIV-positive, despite all its implications, comes with particular responsibilities. As mentioned earlier in the paper, adolescents in general tend to involve in risky behaviour, and the outcomes of these could be more severe in the case of HIV-positive adolescent because they might be putting other people at risk. That is why the BBAP also works with promoting “behaviour change” with the adolescents, or like one of my informants Matilda says: *“Making them aware, because the most important thing is to make them aware that they are part of the prevention and initiatives, they are the prevention themselves”*. Because the adolescents themselves can hold the key to minimise HIV-infections, “agency” is in this change applicable to “empower” HIV-positive adolescents to change their behaviours. However, she further elaborates that to be able to alter behaviour, mind-sets must be changed, and this does not only apply for the “disempowered”. Matilda says that to be able to change mind-sets: *“We [the BBAP] are changing the culture that has been in these teens ever since they were born. We are also fighting the societal norm that they have grown up to see and that is being accepted”*. Here we see the need for challenging the “structure” in order to achieve a society where people have equal power to make decisions, not having to be restrained by stigma.

The strive for “power from within” with the “agency” approach has proven its successes among HIV-positive adolescents. My informants mention improvements such as the teens are being more open, more confident, adhering better to their

medication and starting to have a positive outlook on the future. Inside the walls of the COE and during the activities of BBAP, from the observations and interviews conducted there I can agree that the teens have found a place where they belong, where the teens still can be happy knowing everybody knows about their status. It is a place that arguably is free of HIV stigmatisation, where HIV-positive adolescents are “empowered” to socialise with other HIV-positive adolescents and HIV-negative people together in an open environment where there is no discrimination.

The question is then, why can't this be applicable outside the walls of the COE? The results show an interesting value of “safety” for these adolescents. Inside the walls of the COE the adolescents are encouraged to not be afraid to be open about their disease (and its implications), whereas outside the walls they are *not* encouraged to the same extent to do this. This is a case where “agency” is prioritised over challenging the norms by changing the “structure” in society. The majority of my respondents said that the teens are “safe” in society because they are, as Goffman refers to it: “discreditable” (1971:50). No one can tell by their looks or behaviour that they are positive; they can't be *distinguished* from any other teens and that is why they are protected. Their underlying assumption is that if the HIV-positive kids can stay as closely to the norms and the “normal” as possible by following the expectations from the society, *that* is when they can live a safe life outside the “safety zone” of the COE. Living a life being one of the “normal” is, according to the staff at COE, the wish of many of the HIV-positive adolescents. This can be related to what Goffman argues, that adolescence is the stage where many of the “stigmatised” experience an identity shift from their “own” stigmatised group to the “normal” (Goffman 1971:42).

Nevertheless, to be one of the “normal” sometimes has its implications caused by the “structure”. As the teens are approaching adulthood they are most likely about to seek jobs in the near future and almost 13% of the children aged 13-17 needs to work while attending school at the same time (Lottering 2010:37). When asking the respondents if the teens could be honest about their status in a job-seeking situation or at the work place, the answers were somewhat pessimistic. As one of the heads of the BBAP, B2 says:

“There are still people out there who believe that if you are HIV-positive they won't hire you and will go to an extent of finding something that they can make as an excuse of not according

you the opportunity, but not believe that he [the applicant] didn't qualify. So I think young people will be disadvantaged if their status is known. It will be a disadvantage, but not in all cases.”

In the quote above, B2 explains that some people still can avoid employing a HIV-positive person, but use another excuse to not employ them. B2 says that in this case, disclosure might be a disadvantage for the adolescents.

To be able to take a job, the applicant should not have to tell anybody about their status, unless they choose to do so. Why then not hide the fact that you are HIV-positive, if it means less trouble to get employed? Masego, a social worker from the in-reach programme, explains:

“It is going to be hard for them [adolescents] because they are not tested before they are given a job; your status is private to you. But once you are employed and every month you have to go to see your doctor, every month you have to go get medication. Then probably they will make their own connections that this person is out of work maybe two times a month; that means that somehow they are losing”.

What Masego implies is that HIV-positive can be undesirable as employees because they need to visit a clinic regularly, thereby contributing to companies losing money. Is it in this case not a question about stigma, but a pure economic question? Is it a question of companies not affording *any* of their staff to get sick leave twice a month, or just the HIV-positive people? Despite successful resource management (mostly from minerals), development in Botswana has led to few jobs. The success in governing the economy has not led to a broad-based and diversified growth as there was no serious attempt to diversify the economy into manufacturing, therefore not creating more jobs (UNRISD 2010:51). Botswana's formal health protection including state, social and mutual health insurance schemes is 100% universally covered (UNRISD 2010:172), but then it seems like the health systems can't help companies employing HIV-positive people. Nonetheless, in this case, any kind of exclusion of HIV-positive people in the work force is further contributing to the stigmatisation of HIV-positives as people undesirable as employees.

Are then HIV-positive adolescents able to achieve “power from within” solely by the “agency” approach? The adolescents can be “empowered” in the way that they can feel more confident living with their status without telling anybody about it, but

as in this case, there is actually not much adolescents can do to influence their position as the “structure” is still dominating the stereotypes. This is another example that communication between the HIV-positive and the society is lacking. To change the “structure” it needs to be a call for supporting organisations that are able to challenge injustice and stigma. Hence the “power with” approach would be more suitable. Masego ends the previous statement with *“That is why I am saying the employers need to be sensitised and maybe taught about the kind of generation that we are moving into”*. With this Masego is saying what is highly related to the interplay with *both* the “structure” and “agency” in order to achieve “empowerment” (Mayoux 2003:16).

Botswana is an example of what Goffman explained about familiarity. Even though HIV is prevalent in the Botswana society, there is still a feeling of contempt towards the disease and people living with it (Goffman 1971:61), because of the construction of the societal norms. Consequently, familiarity with a stigma does not necessarily mean the stigma gets more accepted or more used to (ibid.). All my informants agreed on the fact that there is still stigma around HIV-positive people in the society, making life harder for people living with HIV. Even though they admit this – and the fact that “stigma and discrimination” is one of the main problems around the high HIV-prevalence – there are still no guidelines in the BBAP directly targeting elimination of stigma, at least not through challenging the “structure”. BBAP is part of COE, an institution that has a lot of influence in government policies and for shaping guidelines for working with HIV-positive adolescents. Thus, the COE could easily use their position to try to challenge the “structures” in society. Although it seems to be the government that initiates “anti-stigma” campaigns, as Masego told me:

“The government has tried different ways of trying to maybe reduce the stigma and discrimination. They once designed t-shirts that said, “I’m HIV-positive” just for people to know that anybody can be HIV positive. Here, in our clinic we had a sponsor walk last year, a fun walk, fun run actually. I did not attend but I thought it was one of the inventions that could help in people knowing that there are kids out there who are HIV positive and they have to be treated like any other kid.”

The “fun run” mentioned in the quote by Masego is an example of BBAP moving into challenging the “structure” as well as they are “empowering” the HIV-positive

adolescents through “agency”.

Overall, the staff is happy with what they are doing for the HIV-positive adolescents at the COE. Nevertheless, the informants are getting more aware that what they are doing at COE is only “empowering” the adolescents to a certain extent. HIV needs to be communicated beyond the COE; therefore a more extensive approach towards creating opportunities and choices for HIV-positive adolescents is needed, as Matilda says in the quote below:

“[...]I still think this needs to be done outside Baylor in terms of receiving these adolescents, because they [HIV-positive adolescents] are ready, they want to go public, they want to be normal. But I feel the community is not yet ready because the community itself has not yet accepted that themselves [...]. You still find people, adults who are HIV-positives struggling to fit in the community because of their HIV status. IF the community, IF the society can deal with that issue on its own, then they can be ready to receive these teenagers. But until then I think we still need to do more on the outside. What we are doing here is enough, we know what we are doing and we help these teenagers, we understand. But the information in the community is very limited. So we really need to do more in the community site to involve them.”

Matilda realises that the “agency” approach is not enough, if we want a real change in the “structure” to more easily accept HIV-positive people in society. Are we about to see a change in society? Can the prevailing stigma be challenged by promoting participation with the “disempowered” and the ones with the power to deny the “disempowered” their choices in life?

## **7. Concluding Discussion**

During my field study I experienced the issues and problems some of the HIV-positive adolescents face in Gaborone, Botswana through the eyes of the staff of COE. One fourth of the Batswana people carry the disease, which means even more people are indirectly affected. Even though the disease is highly affecting the nation, stigmatisation forces the young HIV-positive population to live with the disease in silence, being afraid that disclosing their status to people might harm them and minimise their chances of getting employment, finding good relationships and living a life not having to be afraid of discrimination. The work of the BBAP tries to “empower” this particular age group “from within” to be more confident with an

“agency” approach by improving their self-esteem, by vocational training and also by emphasising that *they are not alone*, that there are others just like them in society, that living with HIV is not an obstacle in life. As the process of “empowerment” translates into being able to make more choices, it seems to function within the context of the COE; the adolescents get a chance to choose whoever they want to talk to about issues surrounding living with HIV and all its implications. This “stigma free” environment is needed, because unfortunately as many of these adolescents choose not to disclose their status to anybody but maybe one or two close people, the HIV-positive adolescents are not taking the discussion to the society in general. Even though the society encourage people to take the discussion of the widely spread disease, stigmatisation seems to be too powerful for HIV-positive adolescents visiting the COE (as the rest of the HIV-positive population) to collectively act against these oppressive social relations. Hence, stigma seems to be creating a vicious circle perpetuating the continuous spread of HIV, denying people making choices in life. Solidarity within the HIV-positive population is increasing; but related literature suggests that solidarity also needs to expand beyond the people directly affected by the disease to the whole society to be able to challenge the underlying assumptions that are causing problems for HIV-positive adolescents.

As argued earlier by Mayoux (2003:16), to be able to reach a society where all individuals are equally capable of making choices (and not denied these because of a prevailing stigma), it is important to challenge the attitudes and behaviour of the “structure” *as well as* the “agency” among the disempowered. A possible future scenario could be displayed when the current HIV-positive adolescents grow into the next generation where *they* could become the ones shaping the norms and beliefs in the “structure”. Will we see a decline in stigma, or will HIV-positive people still be living a life having to adjust to stigma? Time will tell if HIV-related stigma is only a question of getting adjusted to the fact that it is a chronic disease that some people happened to be born with. While we are waiting, we have to do what we can to change the society into treating HIV-positive people as they are – “normal” people living with a chronic disease that actually can be managed.



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# Appendix 1

## Interview Guide for people working at Baylor (COE)

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*This is a basic outline on interview guide. This guide is not final and can (should) be adjusted to the person I am interviewing. For the Teen Leaders (if I am able to interview them) the focus will be more on empowerment.*

What is the main purpose of Baylor's Adolescent Programme?

What is your role in the work of empowering HIV-positive adolescents?

Describe how an ordinary day looks for you

What is empowerment to you?

Why do you think there is a need to empower adolescents?

What is the biggest problem these adolescents have to face?

- What do you believe?
- How do we address these issues?

The teens seem happy and satisfied when they are participating in the Teen Club, but how do you think these young people are perceived in the society, outside this safe zone?

What do you think are the prejudices around HIV infected adolescents? Would they, for example, be denied a job in favour of someone that is HIV negative?

What differences can you see with the adolescents since they started to join COEs' Adolescent Programme?

What is the best way to stop stigma and prejudices around HIV/AIDS?

How is the contact with these adolescents outside COE? Do you do any follow ups and psychological support? What happens next?

### Implementation outside COE

How is COE affecting the government the other way, do you have an impact on policies of HIV-positive adolescents and how they should be treated?

Can you see the adolescent programs like the Teen club being implemented at a national policy level?

## **Appendix 2**

A brief description of the key informants interviewed for this thesis.

### **1. Emily Kossow**

Emily is a one-year volunteer at COE from the United States who started in July 2011. Her work involves helping to plan the events of the Teen Club, the Teen Mother Support group, the tutoring programme and the Teen Leaders training programme. Her role is also administrative, and she is helping the COE writing reports and project proposals as well.

### **2. Vera Drüphake**

Vera is the other overseas one-year volunteer from Germany. She started her work at COE in September 2011 and has about the same position as Emily, except for report writing.

### **3. Ntobeledzi “B2” Boitumelo**

B2 is one of the two managers of the BBAP. Apart from being head of the programme, he is also helping with logistics arrangements, management, empowerment as well as supervision. He also describes himself as an older brother to anyone adolescent who wants to talk to him. B2 started working at COE June 2009.

### **4. Dr Refilwe Sello**

A doctor, or adolescent focused health care provider, at COE and the other one of the two managers of the BBAP. Her role as the manager of the BBAP is to provide leadership, coordinate different activities and make sure they are adolescent friendly. Her work includes about three days a week of seeing patients and the other two days are for administrative work e.g. filing, writing journals. She has been working at COE since 2007.

### **5. Masego Pilane**

Masego is a social worker from the in-reach programme that mainly do home visits to patients if they seem to have challenges or psychosocial problems, like poor

adherence. She is also involved in the Teen Mothers Support Group and has been working at COE since December 2010.

#### **6. Matilda Engelton**

Matilda is working at COE through a NACA project called “O’icheke”, a campaign trying to encourage people to test themselves for HIV and also encourage behavioural change among HIV-positives. She is not only working at the COE placed in Gaborone, but is also stationed at some of the satellite Teen Clubs around the country. She has been working at COE since March 2010.

#### **7. Tapiwa Nkhwalume**

Tapiwa is a social worker at COE who mainly counsels adolescents. If an adolescent is having psychosocial troubles or troubles of adherence, they can be referred to Tapiwa. She has been working at COE since February 2010.

#### **8. Jerry**

Jerry is a nutritionist at COE whose job is to inform adolescents about nutrition, he participated in the end of the interview with Tapiwa.

#### **9. Twelelo Masutlha**

Twelelo has been working at COE five years. His work includes being a full-time volunteer at the Teen Club, where he has been working mostly during his time at COE. He is also helping with consultation at the clinic, as well as being a nurse prescriber.