Case Study 14

HIV PREVENTION AND TREATMENT FOR ADOLESCENTS

A SOCIAL STUDY OF AFRICAID WHIZZKIDS UNITED’S COMPREHENSIVE MODEL

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ABBREVIATIONS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
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<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>AZT</td>
<td>Zidovudine (an antiretroviral drug)</td>
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<tr>
<td>CD4</td>
<td>White blood cells that are part of the human immune system. HIV causes a reduction in these cells.</td>
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<tr>
<td>DOH</td>
<td>Department of Health</td>
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<td>GNP+</td>
<td>Global Network of People Living with HIV</td>
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<td>GRS</td>
<td>Grassroots Soccer</td>
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<td>HCT</td>
<td>HIV Counselling and Testing</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>MGL</td>
<td>Mixed Gender League</td>
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<tr>
<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
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<td>NAM</td>
<td>National AIDS Manual</td>
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<td>NGO</td>
<td>Non-governmental Organisation</td>
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<td>NPO</td>
<td>Non-profit Organisation</td>
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<td>OVC</td>
<td>Orphans and Vulnerable Children</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother-to-Child Transmission of HIV</td>
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<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<td>UNAIDS</td>
<td>Joint UN Programme on HIV and AIDS</td>
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<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<td>WKU</td>
<td>Africaid Whizzkids United</td>
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<tr>
<td>VMMC</td>
<td>Voluntary Male Medical Circumcision</td>
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SECTION 1

INTRODUCTION

This report describes the social aspects of the work of Africaid Whizzkids United (WKU) (hereafter, Africaid), an NGO providing comprehensive HIV prevention, treatment, care and support services to adolescents in the township of Edendale in KwaZulu-Natal, South Africa. The report’s emphasis on this group of Africaid’s clients was motivated by the relatively limited research available on this emerging population. Studying a very specific segment of Africaid’s clients also made sense given the limited duration of the research and format of this report.

A key feature of Africaid’s programs is that it uses football as a language and a medium to promote adolescents’ health through life skills training, peer education and a mixed-gender football league. It also provides youth-friendly, sexual and reproductive health and HIV and AIDS services. Africaid’s Whizzkids United Health Academy (hereafter, the Health Academy) is located next to Edendale Hospital in Pietermaritzburg, KwaZulu-Natal, South Africa. This innovative, new, youth-friendly health facility is a lynchpin for Africaid’s activities. In August 2011 health professionals based at the Health Academy first started providing antiretroviral drugs (ARVs) to adolescent clients. By the end of February 2013, it was managing 558 adolescents using ARVs (E-mail correspondence with Stefan Kunze, 15/03/2013).

“By the end of February 2013, it was managing 558 adolescents using ARVs”

I have based my report on interviews and informal conversations with Africaid staff, volunteers and clients attending the Health Academy. It also draws on material gathered from a focus group I held with adolescents living with HIV who are clients at the Health Academy. This research was conducted over three one-day visits to the Health Academy and two half-day visits to Africaid’s offices in Greyville, Durban from April to June 2012.

Africaid has an active monitoring and evaluation (M&E) program which is led by Rusha Govender and Dr Doug Wilson. The NGO has strong M&E systems which it uses to document the efficacy of, and changes to, their programs. It also produces detailed annual reports. These reports gave me an excellent understanding of the overall nature of Africaid’s work. To date, Africaid’s M&E reports have generally focused on the NGO’s HIV prevention programs aimed at all adolescents irrespective of their HIV status (WKU 2010b; WKU 2012b). In 2010 its M&E program engaged in quantitative research and found that there was a, “statistically significant improvement” in 19 out of 30 behavioural predictors measured (such as physical activity level, knowledge about HIV transmission and testing and self-efficacy to refuse unsafe sex) in participants in Africaid’s programs (WKU 2010b: 5). Africaid’s recent quantitative evaluation of
the implementation of its, “On the Ball” curriculum at primary schools in Northern eThekwini also found a statistically significant improvement in predictors of sexual risk behaviour such as HIV and AIDS related knowledge and attitudes, and self-efficacy in participants (WKU 2012b:10): this “On the Ball” curriculum for Life Skills training is described along with the Mixed Gender League (MGL) and the peer education program below (see pages 11—3).

In this report, I describe some of the geographical and socio-economic characteristics of Edendale, the community where Africaid conducts most of its work. I then move on to discuss the research methods I chose to use to compile this report and some of the ethical considerations which I had to bear in mind during the research and design phase of this project. The discussion of the research findings begins by describing the NGO’s origins as an HIV-prevention focused project founded by Marcus McGilvray, a British HIV-specialist nurse, and its development over time. This report also discusses how Africaid has developed the Health Academy as a pioneering, adolescent-friendly ARV clinic and details its particular strengths and challenges faced, especially in addressing HIV-stigma within extended families as a barrier to ARV adherence. Finally, it shares the perspectives of young people living with HIV who attend the Health Academy – due to ethical considerations these participants’ names and identities are not stated in this report. These interactions with the Health Academy’s young clients revealed that they truly value its provision of “youth friendly” services. I have included a literature review as an appendix at the end of this report. This may be of interest to specialists who wish to understand in more detail how I designed the study.

1.1 ABOUT EDENDALE: ITS SOCIAL, ECONOMIC AND GEOGRAPHICAL CHARACTERISTICS

Edendale is township adjacent to Pietermaritzburg, the capital of the province of KwaZulu-Natal, South Africa. It is situated in the municipality of Msunduzi. According to the 2011 census, the Msunduzi municipality has a population of 618 536 and covers an area of 634 square kilometres. The same census found that a high proportion of the population in Msunduzi municipality is adolescent (aged between 10—19 years old) with just over 1 in 4 residents falling into this bracket.¹ The township is densely populated and, like many communities in South Africa, it has a high unemployment rate.² Its inhabitants generally live in small two-roomed houses made of bricks and blocks or mud (wattle and daub).

Edendale was founded in the mid-nineteenth-century as a mission station. The area came to have a wealthy, educated African peasantry and it was also one of the first black freehold communities in South Africa (Gwala 1989; Epprecht 2010). The African community of Edendale was initially prosperous due to the increased agricultural production and livestock holdings which accompanied its founding and early settlement. The underdevelopment of Edendale began in the early twentieth-century when Pietermaritzburg’s city governors removed Africans to the fringes of the city. This segregation caused poverty, overcrowding, deteriorating housing, social breakdown and environmental collapse in African communities of Pietermaritzburg, including Edendale. Moreover, these trends

¹ The 2011 population census found that 26.6% of the population is under the age of 15. It also recorded that Msunduzi municipality had a total population of 618 536.
² The 2011 census also recorded that in Msunduzi municipality, the official unemployment rate among 15-65 year olds is 33% and there is a 43.1% youth unemployment rate (among 15-34 year olds).
Kwapata Senior Secondary School in Edendale, KwaZulu-Natal, one of the schools where Whizzkids hosts their programs. 

Photo © M Willman / Oxfam
continued and intensified during the apartheid era (Epprecht 2010). Throughout this period, municipal planners’ industrialisation policies also failed to create adequate employment. In the late 1980s and early 1990s, the area also experienced some of the worst political violence which was associated with South Africa’s transition to democracy (Gwala 1989; Epprecht 2010).

It is illuminating to think about the AIDS epidemic in Edendale (and South Africa, more broadly) from a historical perspective. While AIDS emerged in South Africa in 1982, it only began to expand rapidly during the 1990s, a period which unfortunately, coincided with the country’s transition to democracy. As Shula Marks has usefully observed, AIDS can be understood as, “an epidemic waiting to happen” in South Africa (2002: 17). Differently put: “a social template was established which suited ideally the propagation of...AIDS” (Marais 2005: 8). Edendale, like many African communities in South Africa, had several social factors which facilitated the rapid spread of HIV infection, not least, an impoverished populace which experienced extreme economic inequality, migration, rapid urbanisation, recent conflict and heightened gender inequality.

Today, Edendale has very high HIV prevalence and incidence (rate of new infections). A recent study found an HIV prevalence rate of 46.1% among sexually active women in Edendale between the ages of 18 and 35 who were not known to be HIV-positive or pregnant prior to the study (Nel et al. 2012). Africaid acknowledges the importance of tackling “social drivers” of HIV’s spread in order to hinder its further growth. Its 2012 annual report states that HIV and its drivers are the major challenges confronting Edendale’s youth today, and it lists them as follows:

- Gender inequality
- HIV-related stigma
- Poverty
- Youth vulnerability and despondency exacerbated by low self-confidence perpetuated by low levels of education
- High unemployment and a lack of opportunities for young people
- The lack of family and health-promoting social structures (WKU 2012a: 5).

A large number of adolescents are now living with HIV in Edendale because until quite recently, South Africa lacked effective prevention of mother-to-child transmission (PMTCT) programs using ARVs. There are several reasons why this was the case, including:

- The high prices of ARVs in South Africa, and globally, in the 1990s (when those who are now adolescents were born) (Mugyenyi 2008; Orbinski 2008; Waning et al 2009)
- A lack of political will was exhibited by previous government administrations to roll-out ARVs (Marais 2005; Nattrass 2007; Geffen 2010)
- Health system-related issues such as the underfunding of public sector health facilities and a shortage of health professionals in the country affected the general, overall quality of maternal and child health services provided to the poor in South Africa at the time when today’s adolescents were born (Gerein 2006; Schneider et al. 2006; Blaauw and Penn-Kekanna 2010; Ataguba and McIntyre 2012).

Although KwaZulu-Natal and South Africa’s PMTCT programs for pregnant women living with HIV have since undergone radical improvement, these occurred after the birth of today’s adolescents. Even when ARVs were introduced
for PMTCT in 2002, single-dose Nevirapine was the drug which was first rolled-out. This is much less effective in preventing infants from contracting HIV perinatally than two or three-drug ARV combinations. Two-drug combinations of Zidovudine (AZT) and Nevirapine were only introduced in public-sector health facilities in 2008. There is now a high coverage of PMTCT during pregnancy but concerns remain about the follow-up services provided to mothers and infants after birth [Grimwood et al. 2012]. In particular, fear of unintended disclosure can press mothers to engage in mixed feeding practices, as opposed to the breast-feeding exclusively on demand for the first six months, which is medically indicated, especially in resource-poor settings [Grimwood et al. 2012]. Moreover, mothers sometimes fail to seek HIV-related care for themselves and/or their babies in the post-birth period for similar reasons [Horwood et al. 2010]. Lastly, health professionals frequently fail to obtain CD4 results of pregnant (or recently pregnant) women who have tested HIV-positive or to start them on three-drug ARV therapy if it is required [Horwood et al. 2010]. These challenges indicate that babies will continue to be born with HIV or to acquire it in the post-birth period and that, as adolescents, these children will continue to need chronic ARV therapy for some time to come.

Some of the Health Academy’s clients were, however, infected through either consensual sexual intercourse, or sexual abuse. Under South African law, the age of consent for individuals to lawfully engage in sexual acts is 16 years of age. Those over the age of 16 who engage in sex acts with persons under the age of 16 can be charged with statutory rape. It is also illegal for those between the ages of 12 and 16 to engage in sex acts with each other. Children under 12 years of age are deemed too young to consent to sex, and so any person who engages in sex acts with them is defined as committing rape or sexual assault. Any person with knowledge of such sexual offences is obliged to report them to the South African Police Services. In practice, adolescents between 12 and 15 who engage in consensual sex with each other are seldom prosecuted. Furthermore, in a country where there are high rates of pregnancy and HIV infection among adolescents, government policies and legislation (such as the Children’s Act of 2005) entitle them to access sexual and reproductive health services such as HIV testing, termination of pregnancy services and condom and contraceptive access, without the health care workers being legally required to tell their parents [Ramkissoon et al. 2010].

In South Africa, young women aged between 15—24 are substantially more likely to be infected with HIV compared to young men. One study revealed that 15.5% of women in this age bracket were living with HIV compared to 4.8% of their male age mates [Pettifor et al. 2005]. There are high rates of teenage pregnancy and HIV prevalence among older adolescents in South Africa, which indicates that young women are often unable to access contraception at public sector health facilities or to effectively negotiate consistent and correct condom usage [Pettifor et al. 2005]. These issues point towards importance of adolescent-friendly sexual and reproductive health and HIV and AIDS facilities such as the Health Academy.

Factors which can facilitate HIV transmission to, and among, young people include young women having older sexual partners, young men and women having a high number of sexual partners, inconsistent condom usage and presence of sexually transmitted infections (STIs). Young women in communities like Edendale frequently engage in unsafe sex for a variety of reasons, not least to access commodities such as food and cell-phone credit from older, wealthier sexual partners [Hunter 2002]. Sadly, it is also frequently the case that young women in South Africa are subjected to non-consensual or coerced sex, and the country has one of the highest reported rates of rape in the world [Jewkes and Abrahams 2009].

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3 This is under the Criminal Law (Sexual Offences and Related Matters) Amendment Act, 2007, which is commonly referred to as the Sexual Offences Act.
SECTION 2

RESEARCH

RESEARCH METHODS AND ETHICS

I conducted face-to-face interviews with three staff members and two of the Health Academy’s clients. In order to obtain a spread of views on Africaid’s work in Edendale, I interviewed the following staff members:

- Marcus McGilvray, Africaid’s Founder and Chief Executive Officer (CEO)
- Busi Madondo, the Head Nurse at the Health Academy
- Nelisiwe Phoswa, a Life Skills Trainer and HIV Testing Counsellor

I also had informal discussions with staff and volunteers at the organisation at its office in Durban and during the drives to Edendale from Durban when visiting the Health Academy. As of the end of March 2013, the organisation had 16 permanent staff in total, 2 of whom worked at its Durban office and 14 of whom were based at its Health Academy. Some of these employees technically worked for the Department of Health. Most of its volunteers are university educated foreigners between the ages of 20 and 30. During the period of the study they were largely visitors from North America or Northern Europe, who were often drawn to travel abroad in order to work for the project due to a love of football, an interest in development and a desire to travel to South Africa.

In this report, I have chosen to use these staff members’ and volunteers’ actual names because they are well-known in the community where they work and were happy to discuss their work with the organisation publicly. They were especially keen to do so in order to share critical elements of Africaid’s model of providing adolescent-friendly sexual and reproductive and HIV-related health services. Their willingness to publicly discuss the challenges and rewards of their work was also in line with the Africaid’s core-value of accountability to clients, colleagues, stakeholders and donors, which they believe can ensure the program’s ongoing improvement and success (WKU 2012a: 6).

The Health Academy largely sees clients between the ages of 10 and 20 years old. This means that, medically speaking, most of its clients are adolescents – a term Africaid prefers to use instead of the term “teenagers” when referring to the age category of their clients (E-mail correspondence with Stefan Kunze, 15/03/2013). From this report’s research and design phase, Oxfam, Africaid and I all agreed to retain the strictest of confidentiality in relation to the identities of the clients and staff.

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4 The standard medical definition of adolescents is that they are persons aged between 13 and 19 years of age [MedlinePlus 2010].
to the identities of the Health Academy’s clients, both because they were clients and owing to the fact that they remained legal minors. For these reasons, the clients’ real names and certain socially identifying features are withheld from this report, which makes use of pseudonyms.

Adolescence is a transitional phase between childhood and adulthood and within the literature on children and adolescents living with HIV there is some debate about which age ranges to include in these categories (Earls et al. 2008; Erdstorm and Khan 2009). Adolescents living with HIV are individuals whose sexuality is maturing and who have specific mental health and social needs. It is critical for them to feel empowered to discuss these needs freely with health service providers.

While the Health Academy’s clients are legal minors (defined as those under the age of 18 in terms of the Children’s Act of 2005) vulnerable to HIV-related stigma and discrimination from both their peers and members of the wider community, I felt it was important to listen to, and consider, their voices on their experiences of the youth-friendly services provided by Africaid. In this regard, the study is in line with international best practices. For instance, UNICEF has recommended that young people have a say in how programs which serve them are designed, implemented, monitored and evaluated (2011). Studies dealing with the mental health of adolescents living with HIV in sub-Saharan Africa also point to the need to move beyond perceiving of adolescents living with HIV as “passive recipients” of aid and instead move towards seeing them as change-agents who can alter their behaviour and those of their peers in community contexts (Earls et al. 2008: 303).

For all these reasons, I decided to interview two clients of the Health Academy, both of whom are living with HIV:
• A 16 year-old man.
• A 16 year-old woman.

Moreover, to gather a wider array of views from the Health Academy’s young HIV-positive clients, I also conducted a focus group where participants made collages and produced short plays which improvised around scenarios which have been presented in existing, relevant academic literature. These activities were used to spark discussion between the adolescents in an age-appropriate manner which would assist me in documenting the challenges they had experienced with maintaining ARV adherence and making healthy sexual behaviour choices.
An assistant life skills coordinator at Whizzkids facilitating a program that works to educate children around life skills using soccer and goal setting.

Photo © M Willman/Oxfam
EVOLUTION OF THE PROGRAM WITH A SPECIAL FOCUS ON THE HEALTH ACADEMY

Marcus McGilvray founded Africaid and has since been the driving force behind the organisation’s growth and development. In the late 1990s McGilvray was a British HIV-specialist nurse working at Mortimer Market Clinic and the University College Hospital’s Tropical and Infectious Disease ward in London, United Kingdom. At that time, he became aware of the large numbers of people who were living with HIV in Africa. So he decided to take a two-year sabbatical from his job in London to travel around Africa in order to use and share the skills he’d learnt in the United Kingdom on the African continent.

“Marcus McGilvray founded Africaid and has since been the driving force behind the organisation’s growth and development.”

A critical element of his earlier work in the UK (one which went on to shape his later work at Africaid) was that he was part of the team which started the first adolescent transitional clinic in the UK. In this period, McGilvray learnt the importance of providing combination ARV therapy and sexual and reproductive health services to young people in an adolescent-friendly environment: lessons he applied when he created the Health Academy in Edendale. The team that created that clinic had seen its necessity because they perceived that young people had needs which were not being met by existing paediatric and adult HIV clinics. His interest in HIV education for young people also began in this period: one where he was also part of a team which designed and delivered HIV education in schools.

McGilvray and Nicola Willis (a paediatric HIV specialist nurse) founded Africaid in 2002. They spent 2002—3 building a clinic where they provided HIV and AIDS and sexual and reproductive health services at a clinic in Tamale in Northern Ghana. Their work in Ghana foreshadowed Africaid’s later work in South Africa in many ways. In particular, it was in this period that McGilvray gained critical insights into how playing sports with teenage clients could combat HIV-related stigma and be used a forum to encourage them to come forward for HIV testing. During their time in Ghana McGilvray and Willis created a whole sports program to appeal to young people. There was a lot of land in front of the clinic
Students from Kwapata Senior Secondary School participate in Whizzkids education programs that teach life skills through sport.

Photo © M Willman/Oxfam
and so they put in a football pitch, a volleyball pitch, table tennis tables and a baseball pitch. They installed a TV and VCR inside the clinic which they used to show films. McGilvray told me that this approach: “just opened the doors to allow young people to be able to attend” (Interview 14/05/2012). Through these experiences he had seen the power of sport to facilitate youth access to health services and to communicate with young people about their sexual and reproductive health needs.

In 2003, McGilvray and Willis arrived in South Africa where they worked at Enhancing Care Initiative at the Nelson Mandela School of Medicine at the University of KwaZulu-Natal in Durban, South Africa. Together they designed a training manual for nurses which described how to administer ARVs to clients. At the time, many of the existing manuals to roll-out ARVs in resource-constrained settings were frequently perceived by nurses to be excessively complicated and difficult to read. The two British nurses visited hospitals and clinics in KwaZulu-Natal to ensure their manual would be based upon the actual needs of health facilities which were then scaling up provision of ARVs. McGilvray recalls that “the manual went viral” and there were 800 downloads of it from the website of NAM – where they published it -- within the first week (McGilvray and Willis 2004). NAM is a well-known British AIDS information-exchange charity.

In 2004 McGilvray went on to manage a project training counsellors and nurses from across KwaZulu-Natal in managing HIV clients, with a special focus on developing clients’ treatment-literacy in order to foster high rates of adherence to ARVs. During this period, McGilvray further developed his thinking on how sports could be used to teach life skills through his voluntary work with street children in Marianhill outside Durban. Initially he made the adolescents listen to a Life Skills lecture before they were allowed to play football, but he found that they often experienced difficulty in listening to his lectures. So, he had the idea of educating young people about sexual and reproductive health using football drills, which involved, “taking the game of football as an analogy for life” (Interview 14/05/2012).

Africaid became registered as a non-profit organisation (NPO) in South Africa in 2006. This was also a period when McGilvray documented and systematised his approach to using football to teach Life Skills to learners in schools using the WhizzKids United “On the Ball” curriculum. This Life Skills curriculum uses football as a “language” of instruction and it contains eight sections which use football drills and games to share HIV-related Life Skills and knowledge, including the importance of:

- Goal-setting and self-definition
- Anticipating obstacles and preparing for them
- Controlling sexual behaviour
- Staying away from dangerous situations in life
- Having trustworthy and trusted friends in life
- Career and life planning.

The curriculum has the goal of cultivating qualities in its young participants such as self-efficacy, a love of learning, support and promotion of gender equality and an appreciation for the positive dimensions of an active lifestyle (WKU 2013).

While Edendale has been the pilot site for all Africaid’s projects since 2005, its model of using football to communicate Life Skills has attracted a great deal of attention internationally, and has been implemented in several different countries, including: Ghana [2007]; Uganda [2008]; with aboriginal children in Australia [2009] and in the United Kingdom [2010].
Another important innovation was Africaid’s Mixed Gender League, which ran from October 2010 to March 2011. Each team was gender mixed and consisted of four boys and four girls and each league contained eight teams from primary schools close to the Health Academy. Every team got to play a match once a week on the tarmac outside the Health Academy. The MGL’s goal was to advance gender equality through sport and emphasize the fact that the facility was a youth-friendly place for the league’s participants to access sexual health and HIV services. 62 of the 64 players in the MGL underwent HIV Counselling and Testing (HCT) and 49 of the 64 players received an Orphans and Vulnerable Children (OVC) assessment, 31 of whom qualified and received social support services from the Department of Social Development [WKU 2011: 15].

In Africaid’s early years, it trained peer educators in schools in this “On the Ball” Life Skills curriculum. The thinking was that these peer educators would reinforce the messages contained in the Life Skills curriculum and also serve as a first point of help for youth in trouble and refer them to the appropriate places. These peer educators were specially trained and supported by the Life Skills trainers. Africaid partnered with the organisation GOLD in Edendale. GOLD is another NGO which has specialised in peer education. As a part of this partnership, GOLD’s peer education programme was linked to Africaid’s Life Skills programme. The NGO hopes that in future, the Health Academy’s clients will grow into leadership and trainer positions, a process which may develop alongside the greater provision of youth-led services.

In 2010, South Africa hosted the FIFA World Cup™ – the first time the contest had been held on the continent of Africa. To mark this historic contest, FIFA financed the building of 20 Football for Hope Centres across Africa with the goal of advancing education, public health and social development in disadvantaged communities through football-based programs. In this important year in the history of South African football, Mr. Wilfred Lemke, the UN Special Adviser to the Secretary-General on Sport for Development and Peace, provided a critical endorsement for Africaid’s WhizzKids United approach.

The NGO’s WhizzKids United program has since been widely implemented across the province of KwaZulu-Natal in the communities of Edendale, Umlazi, Tongaat-Verulam-Osindisweni and Jozini. It has also been implemented at schools and a youth correctional facility in the North West province and in rural communities in the Western Cape.

Africaid and the KwaZulu-Natal Department of Health jointly opened the WhizzKids United Health Academy on 1 June 2010 on the grounds of Edendale Hospital [WKU 2010a]. McGilvray’s thinking in establishing the Health Academy was clearly shaped by his time working with adolescents living with, and affected by, HIV in Ghana and the United Kingdom. These earlier experiences made McGilvray see the importance of making the facility adolescent-only, with staff that were welcoming to young people. He also saw that its psychosocial support groups needed to arrange social activities that young people would find enjoyable, that food and beverages had to be readily available and that it had to have a television and a football pitch on site [Interview 14/05/2012].

While Africaid financed the building of the Health Academy, it is owned by the Department of Health and it is on their land. This arrangement is built upon McGilvray’s history of warm relations with the KwaZulu-Natal Department of Health (DOH) which were fostered during his time assisting it with developing its ARV training programs in 2004 – a job he considers among his greatest achievements as he was part of a team which arranged for 70 000 clients in KwaZulu-
Natal to be placed on ARVs (Interview 14/05/2012). He found that when he developed a business plan to build an adolescent-friendly HIV health facility on the grounds of Edendale Hospital, officials at the KwaZulu-Natal DOH were receptive to his idea. According to Africaid’s CEO, the KwaZulu-Natal DOH has always part-staffed the Health Academy and in early 2012, most of its staff were still government employees (Interview 14/05/2012).

From its outset, the Health Academy provided a very diverse array of services, including:

- Tuberculosis screening
- Family planning
- Pregnancy testing
- Management and treatment of Sexually Transmitted Infections (STIs)
- 3 month sexual health risk assessments
- Testing of vital signs
- Nutritional analysis and support
- Psychosocial services such as: support groups, couples counselling, peer counselling and rape and trauma counselling.
- A 3 session adherence training course
- Homework clubs
- Life skills training
- Peer education
- Voluntary Male Medical Circumcision (VMMC)
- HIV Counselling and Testing (HCT)
- Psychosocial support for children heavily affected and/or orphaned by AIDS, including home visits (WKU 2010a).

Approximately 2,000 clients visited the Health Academy in 2012 and staff there provided 12,000 services to them (Correspondence with Stefan Kunze 15/03/2013). The Health Academy started treating its first adolescent clients with ARVs in August 2011, when Dr. Nonhlanhla Madlala, an HIV specialist clinician joined its team (WKU 2012a). By the end of February 2013, staff at the Health Academy were managing the treatment of 558 clients with ARVs, which points to the unmet need for which the facility has catered (E-mail correspondence with Stefan Kunze, 15/03/2013).

“Approximately 2,000 clients visited the Health Academy in 2012 and staff there provided 12,000 services to them (Correspondence with Stefan Kunze 15/03/2013).”

In 2012 the NGO’s board and management decided to make Edendale the focus for all its operations in South Africa so that it could evolve its model of community-based, youth-friendly health promotion and care services (WKU 2012a). It is useful to view this decision in the context of the great investment of resources the NGO has made in building infrastructure, facilities and developing its staff in Edendale: trends which have become intensified with the plans to build the Football for Hope Centre next to the Health Academy.
TACKLING THE CHALLENGES OF STIGMA AND ANTIRETROVIRAL (ARV) INITIATION AND ADHERENCE

HIV-related stigma (hereafter, stigma) emerged as a critical barrier to ARV initiation and adherence in my interviews and conversations with Africaid staff at the Health Academy. The Health Academy has purposefully designed its services to be provided in a way that reduces and overcomes such stigma, but there are still some outstanding challenges in addressing it, which the staff acknowledged and mentioned that they are trying to overcome. In particular, staff and clients described HIV-related stigma as particularly difficult to overcome within families whose members are mobile and where disclosure had not occurred between parents, guardians and extended family members and clients.

“In particular, staff and clients described HIV-related stigma as particularly difficult to overcome within families whose members are mobile and where disclosure had not occurred between parents, guardians and extended family members and clients.”

Stigma is a critical factor which adversely affects the health of adolescents living with HIV in two ways:

- It discourages young people from getting tested for HIV, owing to fear of being discriminated against because of their medical condition by peers, relatives and neighbours.
- It hinders disclosure of HIV status by parents and guardians to young people and young people from disclosing their illness to older relatives with whom they are staying or whom they are visiting for short periods of time, such as school holidays. This, in turn, can lead to less-than-ideal ARV-adherence because it can make adolescents feel the need to hide the fact that they are taking the drugs.
4.1 AFRICAID’S WORK REDUCING THE STIGMA AROUND HIV TESTING AMONG ADOLESCENTS

One critical issue that Africaid has tried to address is adolescents’ general reluctance to attend public-sector clinics for sexual and reproductive health services, including HIV Counselling and Testing (HCT). In order to reduce illness and deaths among adolescents living with HIV it is critical to increase rates of HCT: this is because, on a basic level, an infected individual cannot be treated with ARVs without first being diagnosed as living with the disease. In many parts of South Africa, young people experience public-sector clinics as intimidating facilities where staff are frequently rude and express judgmental views about the fact that they are sexually active, when they try to seek sexual and reproductive health care services [Jewkes et al. 1998; Campbell 2003]. There have also been several instances where HIV-positive clients have experienced nurses as being insensitive in discussing their diagnosis publicly and loudly in the clinic (O’Reilly and Washington 2012).

Young people’s negative perceptions of most other public-sector health facilities also emerged in interviews with Africaid staff. For instance, Nelisiwe Phoswa, a Life Skills trainer and counsellor at the Health Academy shared in an interview that clients at the Health Academy report feeling scared of asking nurses for contraceptives at other public-sector health facilities. This is apparently because they are often told that: “they are having sex at an early age so they don’t want to give them pills to prevent [pregnancy]” (Interview 02/05/12). By contrast with the perceived prevailing norms at health facilities of nurses treating their young clients in a “top-down” manner, the nurses at the Health Academy wear the NGO’s branded t-shirts instead of conventional uniforms. The thinking behind this is that seeing as young people are often scared of nurses at regular state clinics, the Health Academy’s nurses wearing of Africaid’s branded t-shirts supports the message that they are warm and welcoming to their adolescent clients (Interview with Nelisiwe Phoswa 02/05/12; Interview with Busi Madondo 02/05/12). During visits to the Health Academy, clients’ interactions with nurses appeared to be friendly: the extent to which this can be attributed to the t-shirts is difficult to ascertain, but overall, the young people who participated in the study reported finding the facility a welcoming space.

“... the Health Academy’s nurses wearing of Africaid’s branded t-shirts supports the message that they are warm and welcoming to their adolescent clients...”

In many public-sector clinics it is also often the case that young people, including Health Academy clients fear bumping into their mothers or neighbours, which accentuates the fear of HIV-disclosure in the event of a positive diagnosis following HCT. The Health Academy aims to address this fear by being an adolescent-only clinic. When clients express concerns about their confidentiality being respected at the Health Academy, Phoswa reassures her clients that: “this is an adolescent clinic. You can’t even find your mother or your neighbours there if you come for family planning” (Interview 02/05/12). She often adds that: “even something that you share in a room [with a counsellor], it’s confidential, it cannot go out until you...a client tells somebody else, but us, we are trained to be confidential” (Interview 02/05/12).
“When clients express concerns about their confidentiality being respected at the Health Academy, Phoswa reassures her clients that: “this is an adolescent clinic. You can’t even find your mother or your neighbours there if you come for family planning”

Instead of viewing young people whose sexuality is emerging and who are sexually active as a nuisance, the Health Academy does active outreach in the community of Edendale to encourage them to come forward for sexual health services, as well as HCT. These outreach activities consist of Life Skills educators using football analogies to explain why HIV testing is important. There is a part of the Life Skills “On the Ball” training which Phoswa and other Life Skills trainers provide in schools where they talk about, “finding your opposition and knowing your opponent [HIV]” (Interview 02/05/12). Condom-less sex and not getting tested for HIV are likened to not having a goal-keeper and, thereby, allowing the virus to “win”, because “if there’s no goal-keeper, it’s easy for the ball to get through” (Interview 02/05/12).

De-stigmatisation of HCT is also enabled by the Health Academy because there are many extra-curricular activities taking place there. A young person at the facility could be there to watch music videos on the television, see a physiotherapist for a football injury, to get tested for HIV, or to use the onsite, free internet café. The fact that there is a football pitch outside the front of the facility where teams made up of both young men and women play in a “mixed gender league” is also designed to make the place into a “cool hang-out” for adolescents.

Phoswa shared with me that it is rare, in her experience, for adolescents to decide to be tested for HIV before having sex. This is despite the reality that adolescents living with the virus could have contracted HIV while their mothers were pregnant, or through having been mixed-fed in the weeks and months after their births. So, one way Phoswa encourages young people not to feel scared of the shame of an HIV-positive diagnosis is to talk to them about the fact that “they could have been born with it” (Interview 02/05/12).

Busi Madondo, also known as Mam’Busi, is a professional nurse trained in primary health care, who has also done courses on HIV and ARVs left Africaid in 2012. During her time at the NGO she also helped to run the Health Academy and was its most senior nurse. One of the first things Madondo shared with me in an interview is that since the facility was founded it was decided that it should not be called a clinic “because we decided to rub away the stigma” (Interview 02/05/12). In Madondo’s recollection, the decision to call it a ‘Health Academy’ revolved around the fact that their clients were young people and also because they saw their work as based upon educating their clients about HIV prevention and successful ARV adherence.

Before working at the Health Academy, Madondo worked at another public sector clinic as a health practitioner and found that many of her colleagues adopted an approach more in line with that Phoswa reported hearing about from clients. She has observed that there is often a tendency in such settings for nurses to judge young clients, if they mention that they are engaging in sexual activity. This is mainly because of their young age and especially applies to young women seeking family planning. By contrast, Madondo shared that: “here, at WhizzKids United [the Health Academy], we don’t judge them, we offer them the things they want without being judgmental” (Interview 02/05/12).
“Madondo shared that: “here, at WhizzKids United [the Health Academy], we don’t judge them, we offer them the things they want without being judgmental”

Another issue which young people apparently experience at other public-sector health facilities is that if they come to the clinic in the morning, during school hours they are often asked why they are not in school. Instead, Madondo mentioned that Africaid has a policy of being non-judgmental in their provision of services. This policy is mindful of the reality that it’s highly likely that “we’re going to lose them, if we say they must come at a particular time. If they come in the morning we attend to them and give them the slip to produce at school.” Instead of telling the young people to return to school, they attend to them, “as soon as they come”, also trying to “make sure they don’t spend more than two hours at the clinic” (Interview 02/05/12). The Health Academy is also rendered more accessible to clients by being open on one or two Saturdays every month. As more resources become available in the short-term, it is hoped that additional staff may be hired or provided by the Department of Health who could enable the facility be open every Saturday (E-mail correspondence with Stefan Kunze (15/03/2013).

One potential solution to missed classroom time in schools (due to adolescents having to travel to the Health Academy) would be for sexual and reproductive health services to be provided on-site at schools in the area. This is an idea which Africaid explored at one point and decided not to implement for reasons McGilvray outlined to me. The fear was that if HCT were provided in a gazebo or a room within the school and an adolescent took an hour to emerge, it would be obvious to other learners that s/he had been diagnosed with the disease. By contrast if a learner was “in and out in ten minutes” then it would be obvious they were “fine” and all the learners in the queue would be “looking to see how long each person is in” (14/05/12).

Instead, what McGilvray said would be more useful would be for the Health Academy to have a minibus to transport young people between the facility and schools so transport time could be cut. Ideally, if funding could be found he would like for every young person in the area to be able to access the Health Academy’s services once every three months. This idea also arose in an informal conversation with Stefan Kunze, Africaid’s Communications Manager, as one way that the NGO could reach more young people with its various services, including HCT.

The “re-branding” of the facility as a “Health Academy” extends to the way the staff and volunteers refer to the young people they serve. Instead of calling them “patients”, I noticed during my visits there that it is customary for staff and volunteers at the Health Academy to refer to the young people they serve as “clients”. Kunze confirmed that Africaid prefers to use the term “clients” to “patients” to describe visitors to the Health Academy as it provides educational, counselling and recreational facilities in addition to health services (E-mail correspondence 15/03/2013). The use of the term “client” implies that the young person making use of the facility is more akin to a consumer with rights to receive quality goods and services there. It also implies that the clinical team at the Health Academy wishes to instil a culture of professionalism and putting the interests of the young people they see first.
“The use of the term “client” implies that the young person making use of the facility is more akin to a consumer with rights to receive quality goods and services there. It also implies that the clinical team at the Health Academy wishes to instil a culture of professionalism”

Sometimes, the staff [understandably] slip back into describing clients as patients, perhaps because this is more customary in such settings. But there are real and consistent efforts to create the best possible relations between the adolescents who attend the facility and its staff and volunteers. For instance, when describing the confidentiality policy which applies to counselling provided at the facility, Phoswa shared that, “even something that you share in a room, it’s confidential, you cannot go out until you, as a patient, not a patient, a client tells somebody else, but us, we are trained to be confidential” [Italics are my emphasis, Interview 02/05/12].

4.2 COUNSELLING TO FOSTER DISCLOSURE WITHIN HOUSEHOLDS AND ARV ADHERENCE

According to McGilvray, the Health Academy initially started out taking adolescent clients who had been attending the family clinic which is next door to it on the grounds of Edendale Hospital. The emphasis was on treating adolescents with very low levels of adherence, those “whose CD4 was showing very, very little sign of improvement at all” and whose viral load was “still high” [Interview 14/05/12]. When I interviewed McGilvray eight months into the Health Academy dispensing ARVs, he stated that: “I would say that we have seen a huge improvement in the biological markers in terms of CD4 increase and viral load going down in about 90% of the youth we’ve worked in” [Interview 14/05/12]. In describing the things which made the Health Academy attractive to adolescents, including those seeing a doctor or a counsellor about their ARV therapy, he listed the same ones which encouraged them to come forward for testing: welcoming staff, the other “clients” there are also adolescents and there is a TV. Africaid also makes food and beverages available to children who have been orphaned and heavily affected by AIDS who are part of its feeding scheme, to Mixed Gender League (MGL) participants and where possible, to HIV-positive youth waiting to see health professionals at the Health Academy.

“I would say that we have seen a huge improvement in the biological markers in terms of CD4 increase and viral load going down in about 90% of the youth we’ve worked in”

ARV adherence is critical to ensure durable viral suppression of HIV, to reduce the emergence of drug-resistant strains of the virus, to minimise deaths among clients and enhance their quality of life (NIH 2012). The amount of non-adherence which is acceptable to still meet these goals depends upon which ARVs a patient is taking (Bangsberg 2006). That being said, it is commonly accepted in HIV medicine that for the therapy to have a high chance of success, it is desirable for a patient to take 95% of their doses at the correct time, every day, as prescribed [Paterson et al.
This leaves little room for patient-error in terms of missed doses. The Health Academy emphasizes to clients the importance of trying to take each and every single dose correctly, as prescribed.

Counselling sits at the centre of the facility’s success in fostering ARV adherence. As McGilvray explained it to me, the counsellors at the Health Academy: “spend a lot of time with them [the clients], talking through not just their ARVs but you know, how is HIV fitting in with the rest of their lives? How are they coping?” (Interview 14/05/12) Given the reality that there are often long queues at public facilities, health providers frequently feel pressured to deal with clients’ problems as quickly as possible (Maharaj and Cleland 2005). This can sometimes result in clients feeling that they have had inadequate time to ask questions or discuss problems they might be experiencing which could hinder their ability to knowledgably adhere to their treatment. Lay counsellors who are empathetic and good communicators can answer many questions clients might have in relation to their sexual and reproductive health which are more social/cultural in nature. They can, thereby, reduce pressure on health professionals to address these types of issues in a more comprehensive manner (Maharaj and Cleland 2005).

There is a sizeable body of psychological research, internationally, which points to the importance of psychological well-being as a factor which influences whether adolescents can take their ARVs correctly and on time, every day (Brown et al. 2000; Earls et al. 2008). The provision of counselling designed for adolescents and social work with their families is also especially critical given that many adolescents living with HIV have also lost one or both parents to AIDS-related illnesses. Studies show that children (including adolescents) orphaned by AIDS are more likely to perceive of themselves as not having close friends, having difficulty concentrating and to suffer from nightmares (Cluver and Gardner 2006).

Young people’s home environments are a critical determinant of their mental health and ability to adhere to their ARV medicines. The international literature shows that it is important for children living with HIV to know that they are living with the disease because it can reduce their sense of shame and strengthen the emotional trust and closeness within a family (Brown et al. 2000; Earls et al. 2008). In interactions with Health Academy staff and clients, a theme which consistently emerged was that parents/guardians’ non-disclosure of an HIV diagnosis to adolescents is widespread and something the facility’s counsellors and nurses try to address through various means. Clients’ perceptions of this issue are discussed in more detail in section 5 below.

“In interactions with Health Academy staff and clients, a theme which consistently emerged was that parents/guardians’ non-disclosure of an HIV diagnosis to adolescents is widespread”

In her interview with me, Madondo described the “challenge” that in the case of: “most of the children who were born with HIV, their parents don’t tell them that they are taking treatment or ARVs” (Interview 02/05/12). In some cases parents or guardians have been known to tell adolescents born with HIV that they are taking treatment for tuberculosis (TB). As TB drugs are usually only taken for 5 or 6 months, they can start to question why they are still taking drugs if they “only” have TB. This outlook can result in adolescents starting to neglect taking their ARV treatment, or lead to them defaulting on the drugs (stopping taking them all together). They can also end
A professional nurse at the Health Academy consults with a patient.

Photo © M. Willman/Oxfam
up missing medical appointments. In these instances, the staff at the Health Academy will try to tell their clients that they are HIV-positive and to also inform them that their ARV treatment is for life.

"Madondo described the "challenge" that in the case of: "most of the children who were born with HIV, their parents don’t tell them that they are taking treatment or ARVs”

According to Madondo, this is especially important, given the reality that when young people are not told the facts about HIV and ARVs because “they are growing up, they mix with friends and get mixed opinions about taking the treatment” (Interview 02/05/12). This can make clients “confused” because sometimes they also hear myths about living with HIV and ARVs from their peers (Interview 02/05/12).

She added that it is also part of the Health Academy staff’s strategy in such instances to “involve the parents” or guardians (Interview 02/05/12). Their ultimate goal is to encourage parents, or guardians, to tell their children they are living with HIV and have to take ARVs for life. They try to urge their HIV-positive clients to “live positively” with their status and strive to achieve their goals, mentioning that if they choose to have children in future, they can be born HIV-free (Interview 02/05/12).

An HIV-positive diagnosis can make an adolescent enter into an emotional state of denial, foster feelings of anger and it can be hard for them to accept their situation. In cases where they experience particularly difficult mental health consequences of being diagnosed with such a serious, chronic, stigmatised illness they are referred to a psychologist who can help them to adjust to their new reality. In 2012, staff at the Health Academy referred 68 of their clients to a psychologist (Africaid 2012).

Health Academy staff identified 1,800 adolescents in the Edendale area who have been orphaned by AIDS, who have visited the facility during 2012 (E-mail correspondence with Stefan Kunze, 15/03/2013). The sheer scale of the challenge presented by the high number of children orphaned by AIDS in Edendale was also underscored for me during one of my trips to the community. On that day in late June 2012, I joined Africaid volunteers and Life Skills educators at a football tournament they were hosting with learners aged between 12 and 13 at a local primary school. As I watched the games from the side-lines I started conversing with the school’s principal: what emerged from our discussion was that the school has roughly 50 learners who are children orphaned by AIDS.

The Health Academy’s work on this issue appears to compliment and shade into social work targeting children orphaned by AIDS in the area. Some of the adolescents identified to have been orphaned by AIDS are referred to social workers based at the Department of Social Development, if it is felt that this is necessary (Africaid 2012:17). Informal conversations with counsellors indicated that on occasion they will visit the homes of clients orphaned by AIDS and/or who live in households which appear to be experiencing extreme socio-economic distress on account of being heavily affected by AIDS. On days when I visited the Health Academy, the kitchen was always a hive of activity with
staff preparing food for adolescents orphaned by AIDS. I noted that on one of these days, donated essential toiletries (new soap bars, toothbrushes, toothpaste and deodorant sticks) had been carefully packaged in colourful paper bags for circulation to these clients.

Phoswa shared with me that adolescents orphaned by AIDS face particular challenges in adhering to ARVs. For instance, she recounted that sometimes they would be living with an aunt who gives them ARVs “and they don’t know what those pills are for” (Interview 02/05/12). When she asks the adolescent client, “What are those pills for?” they will often say, “It’s for the heart” or, “it’s for a headache” (Interview 02/05/12). In these instances, as a counsellor she will tell the client that they are HIV-positive and taking ARVs. She expressed the view that in these situations the guardians should disclose to adolescent that they are living with HIV. In her opinion, in these situations, the real issue is “not that they [the guardians] are ignorant, it’s that they are scared to discuss it with the kid” (Interview 02/05/12).

She also shared some methods she uses to discuss the issue with adolescents in this situation. One approach she told me that she had found to be fruitful was to talk to them about the importance of “knowing your opponent”: that for people living with HIV, it is important to be aware of what HIV does to the body and that their bodies can get sick very easily if there isn’t the defence of ARVs to preserve health. Another productive approach is to ask the client who at home has HIV and this can be a “signal” to them that they were born with HIV (Interview 02/05/12). This approach rests on giving them the information “so that each can come to their own conclusion that their mother was HIV-positive” (Interview 02/05/12). It also helps them to see that the reason why it has not been openly discussed at home, was that their care-givers did not want the adolescents’ peers to know about their HIV diagnosis. In her experience, those who have participated in the Life Skills training conducted in schools are more receptive towards them on these issues compared to others.

Adolescents living with HIV tend to ask Health Academy counsellors for “the facts” (Interview 02/05/12). Failure to provide them in a candid way can foster feelings of distrust in their clients. Phoswa, therefore, holds it as imperative to: “give them the facts and be honest with them and tell them everything we know” (Interview 02/05/12). She also shared that it is part of Africaid’s ethos that: “If we aren’t sure about something they ask us, it’s our duty to go and research it and give the correct information to them [the clients]” (Interview 02/05/12).

This dedication to giving clients correct information and allowing them plenty of time to ask questions was very much in evidence on each of the site visits undertaken to produce this report. On at least one occasion (20/06/2012), I was at the Health Academy until 6pm and saw the last clients leaving around that time, indicating that staff there take their duties very seriously indeed.

Madondo added that clients who have defaulted on their treatment are “started fresh with 3 adherence classes”. These consist of health education as to how to successfully take ARV treatment and to come to appointments on due dates. Africaid also has support groups for adolescents living with HIV, which it runs jointly with Sinomlando Centre, an NGO based at the School of Religion, Theology and Classics at the University of KwaZulu-Natal in Pietermaritzburg. In 2012, it had 20 ARV clients attending its support groups (Africaid 2012).
SECTION 5

VIEWS

AFRICAID’S HEALTH ACADEMY: ADOLESCENT CLIENTS’ VIEWS

It is increasingly recognized by international NGOs and the UN that young people living with HIV have a positive role to play in preventing HIV transmission. As the Global Network of People Living with HIV (GNP+) has usefully pointed out, narrow understandings of “positive prevention” can be experienced as stigmatizing and disempowering to those living with the disease (2011). Rather than stigmatizing young people living with HIV as people presenting a “disease-threat” to others, it is widely recognized in international policy-making arena that it is more productive to consider the ways in which existing legal, social and cultural environments can be altered to prevent transmission of the virus. It is also increasingly viewed to be critical for health professionals to avoid the potential temptations to become paternalistic, or patronizing, in dealing with young people living with HIV. Instead, international guidelines urge service providers to create multiple opportunities for them to comment on the health services provided to them.

GNP+ has also added that it is critical to provide HIV prevention services to people living with HIV as part of a continuum of care (2011). This is all the more imperative given that ARV therapy has been shown to reduce HIV transmission by 96% in couples where only one person is living with HIV (Cohen et al. 2011).

In this section of the report, I present perspectives of HIV-positive teenage Health Academy clients based upon one-on-one interviews with two of them and a focus group with seven of the adolescents. In all cases I obtained full, informed consent from research participants. In my interactions with Health Academy clients living with HIV, I was especially keen to ask, in a preliminary way, whether they felt its programs had impacted on their self-efficacy – that is, upon their sense of their ability to shape their own lives, homes, communities, and schools in ways which would make them healthier.5

5 The literature on self-efficacy is discussed in greater detail in the literature review section of this report.
5.1 PERSPECTIVES OF TWO HEALTH ACADEMY CLIENTS

Gugu Mofokeng, the Health Academy’s Program Manager, helped me to identify two HIV-positive Health Academy clients who would be willing to participate in in-depth interviews with me, on an anonymous basis, as a part of the research to produce this report. The two interviewees were both sixteen years of age. Following questioning, both said that they had yet to become sexually active. One was a female, whom I shall call “Nandi” and the other was a male whom I shall call “Sipho”.6 A brief narrative account of some of the most important elements of the interviews is included in text boxes below.

SIPHO

SIPHO’S EXPERIENCES AT THE HEALTH ACADEMY

Sipho is sixteen years old. He lives in a house in Edendale with his foster mother, who is his main care-giver as Sipho was abandoned as a baby. No-one in his household is employed.

His foster mom told him that he was living with HIV in 2005, when he was nine years old.

An avid football player, he has been very involved in the MGL and told me that, “we [the young people at the Health Academy] like it and enjoy playing together”. He also shared that while he felt uncomfortable talking about HIV at school, where he could not recall having attended classes on the issue, he has enjoyed interacting with the Life Skills trainers at the Health Academy. He mentioned to me that he sensed that his feelings of confidence in talking about living with HIV at home had increased as a result of participating in the MGL.

As an athlete, he said he had found that he could relate to the ideas Africaid’s Life Skills trainers have shared with him. He told me that he cared a lot about his team winning and had started thinking about his own life goals and how he could be strategic in not allowing HIV to be a barrier to accomplishing them.

Sipho mentioned that he had a girlfriend at the time of the interview but that they were not yet having sex. In his experience, answering the sexual health risk assessments which all clients are encouraged to undergo was not

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6 Not their real names.
especially hard as he felt that he had learnt a lot from the counsellors and Life Skills trainers at the Health Academy in relation to how to avoid risky behaviour. When he was at the Health Academy he felt comfortable when discussing his concerns in terms of avoiding risky sex and adhering to his ARVs. He also appreciated the support group and told me that he valued: “being able to have someone to talk to one-on-one and being able to make friends and get close with other young people who visit the Health Academy and the staff there”.

“When he was at the Health Academy he felt comfortable when discussing his concerns in terms of avoiding risky sex and adhering to his ARVs.”

He said that he thought that having actively participated in Africaid’s programs would make him more comfortable in discussing using condoms when he decided to have sex in future.

The keen football player emphasized that he felt he could play a positive role in combating HIV and strongly believed in the idea of all young people (including himself and others living with HIV) having safer sex. His strong intentions to have safer sex when he became sexually active became especially clear to me when he added: “I feel it is important because while doctors are busy trying to combat HIV, we should not be busy spreading it”.

In relation to ARV adherence, he told me that he had recently felt very anxious about the sticking to the doctor’s requirement that he take his medication at exactly the same time every day. He sometimes found that he ended up taking them 5 or 10 minutes late and had thought that this was the same as totally missing a dose. When he discussed this concern with the counsellors at the Health Academy they urged him to keep working on taking his medication at the same time every day. They added that if he was late in taking a dose he ought to take it as close as possible to the exact, prescribed time. This has made him a lot more confident in adhering to ARVs on a daily basis.

Sipho said that sometimes he finds it hard when he thinks about his parents and the fact that they abandoned him as a baby. He wondered why they did so. Since he had talked with the counsellors at the Health Academy he had come to think about himself less and less as a person who was abandoned as a child. My over-riding sense leaving our interview was that he was a young man who had felt rejected by his biological family and suffered great hardship but who had come to feel a striking sense of belonging and acceptance at the Health Academy.

Mofokeng assisted me with isiZulu-English translation during my interview with Sipho. This made sense because she is his counsellor anyway and had helped me arrange it. International literature indicates that Sipho’s feelings of anxiety are very common among adolescents living with HIV. It also points to the fact that the psychological well-being of a person living with HIV shapes their ability to adhere to ARVs. Sipho’s perception that talking about his feelings of sadness and anxiety helps him feel better indicates the crucial importance of counselling of the type provided at the Health Academy – something which can also help improve ARV adherence and, in a wider sense, the medical management of HIV.
Nandi’s experiences at the Health Academy

Nandi is a 16 year old young woman. She lives in a formal house in Edendale with her mother – her main caregiver. Her mother is self-employed. Two months before our interview, Nandi had learnt that she was living with HIV after receiving counselling at the Health Academy.

Africaid first came to her attention when she was 11 years old and still in primary school, when its Life Skills trainers came and educated her and her classmates about HIV using football. Later, she told me that she went on to become a peer educator with the NGO.

She told me that she was not yet sexually active.

At school she recalled having learnt about HIV in life orientation classes, but said: “When we are sitting in school listening to our teachers we get bored”. By contrast with the “theory, theory, theory” presented in these lessons, Nandi preferred the way in which Africaid had used “the game to show how HIV works in life in a way which is more practical.”

Nandi shared that participating in Africaid’s programs had made her more confident in talking about HIV and AIDS at school and, as a peer educator she felt that she was talking about: “something I’m experienced in discussing and which I am more knowledgeable about”. This confidence had made her want to “pour the knowledge out to other young people”.

Her experiences in the Mixed Gender League (MGL) were more varied than Sipho’s. She loved the fact that for once I was not treated like “She’s soft, she’s a girl”. Instead, both the boys and girls on the team had had to learn to interact with each other as a team – something which took a lot of work as sometimes the boys on the team would refuse to give girls possession of the ball. On some of these occasions, she recalled the Life Skills trainers having intervened and told the boys that they needed to pass the ball an equal number of times to boys and girls. She has also found that girls can get injured easily, as boys often play “carelessly”. Notwithstanding these challenging experiences, she mentioned that she thought that participating in the MGL had made her more confident in talking to boys and she finds that now, “I can say when I don’t like something”.

As a participant in MGL she had learnt a critical lesson about the roles people living with HIV can play in reducing of transmission of the virus and in protecting themselves from re-infection. One day one of the Life Skills trainers working with the MGL had organised an ice-breaker on HIV transmission where all the team-mates wrote down their names on pieces of paper and passed them on “which showed how easily one can become infected and re-infected”. Nandi elaborated on what she took away from the exercise: “Like it’s best not to re-infect yourself [allow yourself to become re-infected] because if you are re-infected you can get a different type of HIV, which is harder to control”.


When a counsellor at the Health Academy revealed her HIV diagnosis to her she recalled that: “I felt like I was dying at the same time. I felt very angry and upset”. She found it helpful to talk about her feelings about her diagnosis with the counsellors at the Health Academy in order “to relieve them” and she had found that when something is bothering her “it helps to lay it out” with a counsellor.

In her view, the Health Academy is vastly superior to other health facilities: the fact that it is not called an “HIV clinic” made her feel “less stigma” spending time there. At other health facilities, she said: “the counsellor is as old as your mother and you feel threatened”. Young people could play at the Health Academy, which made her feel “more comfortable” there. She said she liked doing homework on the Health Academy’s veranda and found the receptionist friendly and welcoming and because most of the Health Academy’s staff were young too, “they bear with you, it’s all about how they talk and smile”.

Her experiences at the Health Academy had been overwhelmingly positive and she found it, “very useful and helpful for us young people – we really love it”. Her main suggestion was that they make it bigger – something that, as we have seen, Africaid plans to do with the building of the FIFA™ Football for Hope centre. She also expressed a wish that it also had a netball ground.

5.2 A FOCUS GROUP DISCUSSION WITH SOME OF THE CLIENTS

As part of the research, I held a focus group which made use of age-specific structured play with members of an HIV support group for adolescents living with the disease who attend the Health Academy. In designing the research for this report, I chose this research method in order to access multiple clients’ perspectives on their experiences at the Health Academy.7 To draw forth discussion between participants on their perceptions of the Health Academy, I designed two interactive, creative activities: a poster making based discussion session and a drama-based role-playing session, which presented common HIV prevention related scenarios which have emerged from existing, relevant literature. I was assisted by Sibonelo Ngubane of Sinomlando Centre in running the focus group. Ngubane also aided me with isiZulu-English translation between myself and focus group members and helped me to facilitate for the session. Ngubane facilitates for the support group on a regular basis.

Seven support group members participated in the focus group – three girls and four boys. All were between the ages of 14 and 16. At the beginning of the focus group session, I explained to participants that their real names and socio-cultural features which might personally identify them as individuals who are Health Academy clients living with HIV

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7 For a useful discussion of focus group research as a method for social research in adolescents see: Wood Charlesworth and Rodwell [1997]; Bloor et al. [2001].
would be excluded from both my notes and audio-recordings of the event and this final report. To ensure anonymity in relation to recordings of the research activity, participants were encouraged to adopt pseudonyms which consisted of the names of their favourite sports stars and celebrities who work in the entertainment industry.

Focus group participants were broken up into three small groups and worked together on producing a poster using paint, felt-tip pens, glitter and cut outs from magazines. Two of these posters are reproduced and discussed below.

![Figure 1](image1.jpg)

**Figure 1:**
Figure 1 shows participants’ perceptions of whether they felt more confident in discussing HIV at home or at school after participating in Africaid’s programs.

This image (figure 1) depicts focus group participants’ perceptions of whether they felt more confident in discussing HIV at home or at school after participating in Africaid’s programs. It is important to note, that this sentiment was far from universal among the participants. While Nandi (the young woman whom I individually interviewed) felt more confident talking about HIV at school and at home after participating in the Mixed Gender League and Life Skills training, one young man shared that: “I don’t like talking about HIV at school. I’m worried people might find out that I am living with the disease.” He also added that he still felt totally uncomfortable talking about the issue anywhere other than the Health Academy, even though he lived with the disease. The football element of the program was represented by participants in the top left-hand corner of the poster (figure 1). While they were asked to comment on whether they felt that the Life Skills and Mixed Gender League programs had discouraged them from engaging in unprotected sex, drugs and alcohol, the poster only directly shows drugs and alcohol, which may have reflected clients discomfort in discussing sexual matters with a relatively unknown adult (myself).
The Health Academy clients who co-produced this poster (figure 2) were asked to describe challenges they experience in taking ARVs at the right time every day at home and at school. It emerged that the adolescents perceive of their obligations in terms of household chores as making it hard for them to remember to take their medicines regularly – this is reflected in their inclusion of the phrase “busy trying to cook” (in green lettering on the right hand side) and having chores to do (purple lettering on left hand side) on the poster. It emerged from the discussion of the poster that juggling chores and taking ARVs was especially hard when staying with relatives. Prayer times in homes could also clash with the times when ARVs had to be taken – this is shown in the green lettering at the top centre of the poster. Non-disclosure to friends also meant that if the times ARVs had to be taken conflicted with times when the clients were playing with them, they found it hard to take their ARVs because of the questions it would invite. Further probing of the meaning of the references to cinema (blue lettering at the bottom of the poster) and movies revealed that although the young people who made the poster engaged in a variety of hobbies and social activities with friends, they had chosen it as a kind of short-hand to describe their after-hours socialising and were using this to refer to their fear of their friends learning about their diagnosis. Issues of HIV-related stigma in schools emerged later in the focus group.

Support group members were then broken up into two small groups each of which dealt with a different scenario, based upon relevant evidence in relation to HIV prevention which has been presented in ethnographic and public health literature. In the first scenario, an older man (28 years old) driving an expensive car and wearing a wedding ring propositioned a younger woman (16 years old) who was a Health Academy client offering her gifts (a fast-food meal and to purchase her a new cell phone). Participants were asked to describe what the young woman would have learnt at the Health Academy about engaging in relationships where one’s partner has other sexual partners. They confirmed that it was discouraged by Health Academy staff and that the young woman would have felt more confident

**FIGURE 2:**
Figure 2 shows some of the challenges the Health Academy clients who co-produced this poster experience in taking ARVs at the right time every day at home and at school.
in rejecting his advances or asking him to use a condom following conversations with Health Academy staff. All the participants claimed not to be sexually active yet so it is difficult to know whether these assertions were merely hypothetical, or based upon personal experience, or observation of peers’ sexual decision-making.

Some critical details about adolescents’ experiences of barriers to ARV adherence emerged from the second small group’s role-playing and the whole focus group’s discussion of it. The second small-group enacted a scenario whereby a young man (aged 15) living with HIV was struggling to take his ARVs on time, every day. He discussed his problems with taking his ARVs regularly with a counsellor at the Health Academy and he shared with her that his mother had been very ill and often forgot to remind him to take his medicines on time because she was sleeping more frequently and often in pain. His mother’s ill-health made him angry and scared about living with HIV. In the scenario he didn’t want to take his ARVs because of wanting to forget his HIV status.

One thing which emerged very strongly from the group’s discussion of the second enacted fictional scenario was that the young people frequently stay with relatives during school holidays and also throughout the year. In many cases their parents or guardians with whom they normally stayed had not discussed the fact that their teenage children were HIV-positive with the adult relatives with whom they were staying for short periods because of their sense of shame at the implication which would be revealed that their parents are/were also living with the disease (as discussed, the majority of the Health Academy’s clients were perinatally infected, while their mothers were expecting them or shortly after they were born). When Ngubane and I introduced the topic of potential solutions to this problem, one strategy the young people mentioned was that they sometimes go into the bushes or hide away from their relatives’ houses in order to take their ARVs out of sight. This points to the fact that organisations such as Africaid may still have a great deal of work to do in collaborating with clients to de-stigmatize their diagnosis within their own extended families in order to foster greater ARV adherence.

“Organisations such as Africaid may still have a great deal of work to do in collaborating with clients to de-stigmatize their diagnosis within their own extended families in order to foster greater ARV adherence.”
A professional nurse at the Health Academy is taking the blood pressure of a member of the community.

Photo © M Willman/Oxfam
Africaid offers an innovative model for how to provide comprehensive HIV prevention, treatment, care and support services to adolescents living with HIV in a high-prevalence, resource-constrained setting. Its Health Academy is central to its activities and it succeeds in attracting young people to use sexual and reproductive health services and in improving their ARV adherence in ways which should be replicated at other health facilities.

The organisation has a dynamic CEO, who drew on his specialist knowledge and many years of experience working on similar programs in the United Kingdom, Ghana and South Africa when he designed the Health Academy. Its exemplary relationship with the Department of Health is also built upon his years of notable service for the KwaZulu-Natal provincial government.

The Health Academy has experienced particular success in bolstering its clients’ ARV adherence – something critical to both the medical management of HIV and to reducing transmission of the virus. Accurate and empathetic counselling of clients appears to be a vital element of Africaid’s work encouraging ARV adherence and ongoing health of clients. In contrast to other health facilities, the Health Academy provides a welcoming environment to young people through its recreational facilities and activities, its staff’s youth-friendly attitudes and the organisation’s overall ethos of service to adolescents living in the area.

Most important in evaluating the Health Academy’s work are the perspectives of the young clients themselves on the facility. They clearly value its counselling services, and the fact that only other young people attend the facility and its recreational programs and facilities. The Health Academy is a place where many young people living with HIV feel a sense of belonging and acceptance. Sadly, some clients expressed the view that this was not always the case in other settings: while some felt more comfortable talking about HIV at school after participating in the Health Academy’s programs, others still felt totally uncomfortable when the topic came up with friends. The research also revealed that a lack of disclosure within extended families is a common barrier to adherence, especially when young people are staying with them during school holidays. This suggests that an outstanding challenge for the Health Academy’s counsellors is to work to de-stigmatize HIV and foster disclosure within young people’s extended families.
A life skills coordinator and assistant leading a class during one of WKU’s class programs. Photo © M Willman/Oxfam
I would like to propose the following research be conducted in future:

- **A greater volume of interviews with adolescent clients of the Health Academy, which is more reflective of the full spectrum of their age-range and HIV statuses and where those who are sexually active are also interviewed.**
- **Home-visits to canvass the views of parents and guardians on the facility and the services it provides.**
- **Interviews and focus groups with staff who work at units/centres at Edendale Hospital and the community of Edendale with whom Africaid regularly engages in close collaboration: for instance, Sinomlando Centre, the Thuthuzela Centre, the adult ARV clinic and the Obstetrics and Gynaecology department at Edendale Hospital.**

Africaid’s ARV provision to adolescents will probably continue to be necessary for at least the next decade, given the reality that improvements to PMTCT programs occurred relatively recently and that they are still not optimally provided in such a way as to entirely eliminate perinatally acquired paediatric AIDS. Its Life Skills and peer education programs’ use of soccer as a medium will remain relevant for the foreseeable future and its teachings are clearly very memorable and relevant for young people.

In South Africa, where Life Skills programs in schools are frequently lacking in comprehensiveness, or presented in a way which young people do not find compelling, Africaid’s HIV prevention programs are especially critical. Moreover, young people living with HIV can frequently “fall through the cracks” in the system at adult-focused clinics: their health and social needs are different from those of adults so it is especially important to provide ARVs and sexual and reproductive health services to them in an institution tailor-made for them. At a time when South Africa is fundamentally re-designing its health system by means of the introduction of a National Health Insurance scheme, it is especially important that the government and other stakeholders study service-focused, effective and efficient health facilities such as Africaid’s Health Academy.
7.1. INTRODUCTION

Research for the case study was preceded by a review of relevant literature. Literature was chosen and analysed for this review to illuminate the truly exemplary and innovative aspects of Africaid WhizzKids United’s HIV prevention programs, which are tailored to suit the needs of all adolescents, including those living with HIV, who are generally on combination antiretroviral therapy (ARVs). The literature review also shed light on international thinking in relation to principles which should guide HIV prevention interventions and social research involving adolescents living with, and affected by, HIV.

It found only one unpublished evaluation of an HIV-prevention-relevant social (psychological) intervention for adolescents living with HIV. The review did, however, uncover pertinent literature in the following five areas:

- Conceptual and ethical challenges related to conducting social research on adolescents living with HIV
- Intergenerational vulnerability to HIV infection and sexual risk behaviours among adolescents affected by HIV
- HIV-related stigma and its adverse impact on the psychological well-being of orphans and vulnerable children, with critical implications in terms of whether or not they exhibit health-seeking behaviour
- Assessments of interventions for adolescents living with HIV in Brazil and South Africa
- The international consensus on principles which should guide HIV prevention for adolescents living with HIV

A very basic complexity of conducting social research on adolescents living with HIV, which emerges from the literature, is that there is some confusion, both domestically and internationally, over the correct definition of adolescents with important implications for HIV and AIDS programs. Researchers examining the experiences of, and services for, adolescents living with HIV (a marginalised social group) also have to grapple with critical ethical and methodological choices in designing and conceptualising studies, if they wish to ensure that their research does not contribute to their further disempowerment.

Adolescence is generally defined in paediatric (medical) literature as the transitional stage of sexual and reproductive development which occurs in persons between the phases of puberty and legal adulthood: and it is used to refer to people who are between 13—19 years of age (MedlinePlus 2010). However, as Jerker Edstorm and Nichola Khan have
pointed out, the data published by the Joint United Nations Program on HIV/AIDS (UNAIDS) data on HIV-positive children only includes those under the age of 15: this is in contrast to the international definition provided in the Convention on the Rights of the Child, which designates all those under 18 years of age as children (2009). As they have gone on to argue, this has meant that global figures on HIV in children between 15 and 18 years of age have often been subsumed under the adult category. The legally problematic nature of UNAIDS’s definition of children with AIDS as being under 15 has also been highlighted by other scholars (Earls et al. 2008).

Part of the confusion, doubtless, stems from adolescence being a transient phase between two major life stages – childhood and adulthood. There are substantial social debates – both in South Africa, and internationally, about whether or not it is best to recognise adolescents as maturing individuals who require sexual and reproductive health services.

In South Africa, there are high rates of unwanted teenage pregnancy and HIV prevalence among older adolescents, which points to an unmet need for contraception and dual protection – that is, protection against both pregnancy and sexually transmitted infections, including HIV (Pettifor et al. 2005). Despite the fact that its constitution forbids discrimination on the grounds of gender and sexual orientation, South Africa remains a country where many hold conservative views on issues of sexuality, especially adolescent sexuality: for instance, some have opposed abstinence plus HIV prevention education (which both encourages delayed sexual debut and provides accurate information on condom-usage) in schools (Buchel 2009).

Many adults in South Africa use judgmental language in relation to youth sexuality and are unwilling to acknowledge adolescents’ emerging sexual desire, particularly when it is manifest among girls (Campbell et al. 2005). This was not always the case, as historians have pointed to the fact that in South Africa’s past there were relatively high degrees of frank sexual education by and for adolescents (Delius and Glaser 2002). Instead, it was the introduction of Christianity, colonialism, migrant labour and urbanisation which fundamentally altered how adolescents were educated and prepared for sexual debut (Delius and Glaser 2002). Deborah Posel has highlighted that in contrast to the myriad of apartheid-era regulations and prohibitions on sexual representation and practices, in post-apartheid South Africa there has been an “explosion of sexual imagery, display and debate” and a concurrent ferocious set of social debates about whether it is better to be silent or to discuss sex. These are social conversations that have been fore-grounded by the country’s generalised HIV and AIDS epidemics (2005, p.129).

For these reasons, internationally, many programs for “orphans and vulnerable children” (OVC) or “children affected by AIDS” (CABA) have focused on ameliorating their poverty and avoided addressing participating adolescents’ emerging sexuality because it has frequently proved controversial among local communities and donors (Erdstrom and Khan 2009).

There is also some debate as to the merit of using the term orphans and vulnerable children (OVC). Critiques of the use of these terms have been fourfold. Firstly, some have viewed the term “OVC” as potentially stigmatizing (Earls et al. 2008). Secondly, the focus on vulnerability can convey the idea that children and adolescents are “passive and lacking in agency” (Erdstrom and Khan 2009, p.45). Thirdly, there is residual confusion in medical, public health and development circles about which group of children the term can be applied to as for many years it was only used internationally, in relation to those who had lost a mother or both parents, but not a father alone (Earls et al. 2008).
Lastly, the concept of vulnerable children could be used to describe most children in areas with generalised epidemics – such as most poor communities in South Africa (Earls et al. 2008). For several of these reasons Felton Earls and his colleagues have argued that the term “OVC” has “outlived its utility” and that “children requiring medical and social attention should be characterized precisely in terms of their needs” (2008, p.305).

It can, therefore, be said that those researching adolescents in terms of the ways in which they are affected by AIDS-related social crises and are sexually active and at risk of HIV and AIDS, Sexually Transmitted Infections and unplanned pregnancies face significant representational challenges (Erdstrom and Khan 2009). At a bare minimum, researchers examining this topic should not contribute further to the sidelining of adolescents living with HIV by overlooking the implications of their sexual maturation or silencing them – even if this is motivated by a desire to protect their best interests.

In this vein, UNICEF has recommended that there is a need for adults running HIV and AIDS programs (including researchers) to treat young people (including adolescents) living with HIV “as the young people they are: with real lives, real challenges and aspirations for the future” (UNICEF 2011, p.27). A related imperative is to ensure the meaningful involvement of young people living with HIV in policy and program design, implementation and monitoring and evaluation (UNICEF 2011). Differently put (as described in more detail below) existing studies point to the fact that positive benefits can flow from moving beyond viewing adolescents as “passive recipients” and towards “activating youth in a community context on changing personal behaviour” (Earls et al 2008, p.303).

UNICEF’s recommendation that youth living with HIV should have a say in policy and program design is far from universally accepted: most adolescents in South Africa are under 18 and so lack political power, as exercised through the right to vote or run for office. Moreover, many older adults in the country struggle to see all young people (including adolescents) as a constituency deserving of a policy voice, or as anything other than “mad, bad or deviant” (Campbell et al. 2005).

7.2 INTERGENERATIONAL VULNERABILITY TO HIV INFECTION AND CHILDREN AFFECTED BY HIV AND AIDS

A substantial number of adolescents living with HIV have also lost one or more parent to AIDS-related illnesses; therefore, studies dealing with orphans’ risk of contracting HIV are also pertinent to some adolescents living with the virus. Erdstrom and Khan have argued that we know relatively little about whether children who have been affected by AIDS grow up with “compromised sexual well-being” and engage more frequently in risk behaviours (2009, p.42). It is useful to distinguish between the cross-generational perinatal transmission of the virus itself and intergenerational (largely socially) produced vulnerabilities in children of people living with HIV.

Tonya Thurman and her colleagues analysed data from a survey of 1,694 Black South African adolescents aged 14—18, 31% of whom were orphaned by AIDS (2006). The study found that both male and female adolescents orphaned by AIDS were significantly more likely (49% versus 39%) to have engaged in sex compared to non-orphans. Moreover, a significantly greater proportion of adolescents orphaned by AIDS reported a younger age of sexual debut compared to non-orphans (23% said they had had sex by the age of 13 compared to 15% of non-orphans). The adolescents
orphaned by AIDS more commonly reported that they had engaged in survival or transactional sex (8% versus 3% of non-orphans). A critical gender difference was that only about one-half of all girls who participated in their study described their sexual debut as willing, suggesting that a number may have experienced sexual abuse or exploitation. It also found no difference in condom use between orphans and non-orphans, suggesting common sexual risk behaviours between both groups. Recommendations which emerged from the study included the creation of programs which blended comprehensive care, social assistance and reproductive health and HIV prevention.

Lucie Cluver and Frances Gardner’s study involved interviews with sixty children who were orphaned by AIDS in townships and informal settlements surrounding Cape Town and compared them to thirty non-orphans from the same neighbourhoods, ethnicity, age and gender. They found that children orphaned by AIDS were more likely to perceive themselves as not having any good friends, to experience extreme difficulty in concentrating and to suffer from nightmares (2006). This finding chimes with psychiatric literature from the United States which has shown that adolescents living with HIV (many of whom have also been orphaned by AIDS) experience greater subjective distress than their uninfected peers and that some of them have reported engaging in risky sexual behaviour and been found to have conduct or hyper-activity disorders (Brown and Lourie 2000).

Cluver and Don Operario conducted a comprehensive review of published and unpublished literature on the “intergenerational impacts of HIV” (2008 p.2). They found that there was evidence suggesting that children orphaned by AIDS and in AIDS-affected families experienced more psychological stress and educational shortfalls. Most importantly, for this case-study, they also found some “initial” evidence that children orphaned by AIDS might be at a heightened risk for HIV infection compared to non-orphans (2008 p.2).

So, what has been shown to counteract such intergenerational vulnerability to HIV infection among HIV-negative children from AIDS-affected families? All interventions to reduce HIV transmission, including those targeting adolescents, occur in particular social contexts, which can often facilitate their success or failure (Campbell 2003, Campbell et al. 2005). A consensus has emerged in psychological literature that self-efficacy is an important psychosocial quality to try to foster to prevent transmission among all adolescents in HIV-affected communities. Self-efficacy is a term that refers to a young person’s sense of their own capacity to influence their social environment, such as their home, school or neighbourhood through reading, communication and playing sports (Earls et al. 2008).

At least one South African study suggests that such self-efficacy can best emerge in more cohesive communities. Kelly Hallman showed that girls who lived in communities where they had trusted friends and adults, and who participated in local social groups were much less likely to have ever had sex in general and also, non-consensual sex (2008). The same study also found that girls who belonged to athletic groups were more likely to have used a condom in their last sexual encounter.

Grassroots soccer (GRS) is an approach initially tried in Zimbabwe, which is similar in certain key respects to that of Africaid WhizzKids United, and one which has also been brought to Musina in the Limpopo province of South Africa. It offers one potentially promising community-based approach designed to appeal to young people (Earls et al 2008). GRS merges HIV prevention and football training. In 2010 an evaluation was conducted of the GRS program in
A former professional footballer and trained life skills developer is working with the students on the field during a sports clinic.

Photo © M.Willman/Oxfam
Musina which deployed mixed methods which included a quantitative analysis of questionnaires which were self-administered by participants before and after the intervention and qualitative interviews (Luppe 2010). It found modest increases in participants’ HIV-prevention-related knowledge, attitudes and self-efficacy following the intervention (Luppe 2010).

In 2011, the findings of a pertinent groundbreaking, multinational, randomized clinical trial were published: there was a 96% reduction in HIV transmission between sero-discordant couples, that is, in relationships where only one partner was living with the virus, when that person initiated combination ARV therapy early (before it was therapeutically necessary for that patient) (Cohen et al. 2011). Since the announcement of the findings of this study, early starts and adherence to HIV treatment have become critical to reducing new infections. This study has also and brought into sharper focus the HIV-prevention-relevance of studies dealing with psychological and social aspects of successful ARV therapy.

In the case of adolescents living with HIV, the literature from the United States (US) suggests that the environment in their family home is a crucial determinant of: their mental health; whether they have been told that they are living with HIV in an age-appropriate manner; and, their ability to adhere to their drug regimens (Brown et al., 2000, Earls et al. 2008). Case reports from the US also suggest that when children living with HIV know that they are living with the disease they feel less of a sense of shame and that it can strengthen the emotional intimacy within an HIV-affected family (Brown et al., 2000). For these reasons, the medical and psychological literature on adolescents living with HIV converges around the importance of family-centred and multidisciplinary approaches to care provision (Brown et al., 2000, Earls et al. 2008).

7.3 ASSESSMENTS OF INTERVENTIONS FOR YOUNG PEOPLE LIVING WITH HIV IN BRAZIL AND SOUTHERN AFRICA

Adolescents living with HIV have age-specific needs in terms of social and health services. Like others their age, they are changing physically, cognitively, emotionally, socially and behaviourally but in contrast to most other adolescents they are also living with a serious, chronic illness which can be sexually transmitted to others. As Cluver and Operario have acknowledged, in general, the empirical literature on children living with HIV who survive into adolescence remains very limited, especially in relation to Sub-Saharan Africa (2008). This is because, until recently, ARVs were seldom provided to children living with HIV in this region so a substantial cohort of perinatally infected adolescents living with HIV is only emerging now. There are several understudied issues which affect this group in an African context such as: whether or not they experience specific challenges in preventing transmission of the virus, and issues surrounding their access and adherence to combination ARV therapy.

Some studies have been conducted assessing mental health interventions for adolescents living with HIV in the United States and Europe. Given the circumscribed nature of the literature on the phenomenon in South Africa, they can offer some possible leads on challenges and successful approaches involving perinatally infected adolescents living with HIV, in HIV prevention in South Africa. A review of studies and reports on the psychiatric care and development of
adolescents living with HIV in the United States suggested that interventions to address their needs ought to factor in their cognitive developmental stage and exploratory learning behaviour, and be built around appropriate goals such as increasing their empathy and desire for responsible sexual behaviour (Brown et al. 2000).

A Brazilian study utilized the qualitative research method of twenty one months of ethnographic fieldwork to study the life trajectories of children and adolescents living with HIV or orphaned by AIDS. It may hold important lessons for interventions in the South African context: both South Africa and Brazil are highly unequal, middle-income, developing countries where there are high levels of violence. This study found that while the introduction of combination ARV therapy improved HIV-positive adolescents’ quality of life and survival, and reduced the stigma they experienced overall, it presented new challenges (Abadia-Barrero et al. 2006). In particular, the healthy-looking adolescents went from being viewed as ill and “innocently infected” victims to being feared as potential “victimizers” as a consequence of their burgeoning sexuality (Abadia-Barrero et al. 2006).

In the course of producing this case study, only one unpublished evaluation of an intervention specifically for HIV positive adolescents was identified. Shlaine L’Etang implemented a cognitive-behavioural counselling model for adolescents living with HIV in Lusikisiki (a rural setting) in the Eastern Cape to produce her doctoral dissertation (2009). Her assessment of the intervention indicated that “exposure to the counselling model was associated with a significant reduction in the level of somatic symptoms, anxiety and insomnia, [and] social and severe dysfunction” compared to a control group who attended weekly support group meetings facilitated by counsellors (2009:184). This study may be of relevance to HIV prevention because, as discussed above, international literature indicates that psychological well-being is an important factor in adolescents’ adherence to antiretrovirals, which as we have seen, can cut transmission of the virus. It also, doubtless, influences adolescents’ perceptions of their self-efficacy – that is their perceptions of their ability to influence their own lives and social environments in health-promoting ways.

### 7.4 The International Consensus on the Principles Which Should Guide the Role of Adolescents Living with HIV in HIV Prevention Programs

Since 2009, the Global Network of People Living with HIV (GNP+) has asserted that there is a need to move beyond narrow notions of “positive prevention” which focuses on the role of people living with HIV in preventing the transmission of HIV. GNP+ has instead called for “Positive Health, Dignity and Prevention”, an approach which focuses on creating an enabling socio-cultural and legal environment to reduce the likelihood of new HIV infections (2011). It has also situated HIV prevention alongside a continuum of health and social programs and services for people living with HIV. This approach also highlights the roles that people living with HIV are playing and have played as leaders in addressing socio-cultural and legal barriers to better health and dignity for people living with, and affected by, HIV (2011).
In 2010, the UN held a global consultation in Kampala, Uganda, which produced a consensus statement on what types of social and health support and services should be provided to adolescents living with HIV. The meeting’s key recommendations included that there should be:

• Active efforts to identify undiagnosed perinatally and horizontally (sexually) infected adolescents, including provider-initiated counselling and testing, out-reach and community-based HIV counselling and testing and prevention of mother-to-child-transmission as entry points
• A continuity of quality, multidisciplinary and multi-sectoral youth-friendly care and support for adolescents living with HIV: a critical part of this should be referral and partnership between health professionals, counsellors, caregivers and young people living with HIV between across different sites such as health facilities, communities, schools and the home.
• “Non-stigmatizing, quality, comprehensive sexuality education implemented at scale and evaluated” (UNICEF et al. 2010: 2).

Owing to their young age, it is tempting to view abstinence-only education as the best HIV-prevention strategy to present to young adolescents (10—14). Yet, as UNICEF has pointed out, abstinence “plus” programs (which offer abstinence, condoms and safer sex strategies as options to prevent HIV transmission) have been found to be more effective in lessening risk behaviours in studies in North America (2011). Age-appropriate sexuality education can raise young adolescents’ knowledge about HIV prevention and also lead to less sexual risk-taking (UNICEF 2011). Among older adolescents (15—19) life skills and sexuality education are an internationally recognised as important prevention tools (UNICEF 2011).

More recently, this has been echoed in UNICEF’s writings on the topic. The UN agency has stated that the role of adolescents living with HIV in preventing further transmission of the virus should be addressed as part of a “broad vision of their physical and mental health” which would encompass advancing their human rights, addressing gender inequality and ensuring adequate access to sexual and reproductive health services (UNICEF 2011, p.27).

### 7.5 Conclusion

The literature review conducted to produce the case study revealed only one unpublished evaluation of an HIV-prevention-relevant social intervention – a psychological programme for adolescents living with HIV in South Africa. This is because paediatric ARV therapy has only been rolled out relatively recently in the country (since 2004) which means that a sizeable cohort of adolescents living with HIV is only emerging now. Existing literature was identified and analysed to provide guidance for the case study’s design in terms of internationally-accepted norms for social research in this marginalised population and to tease out exactly what was truly innovative in Africaid WhizzKids United’s model. Identified and analysed literature can be classified in terms of five areas: conceptual and ethical challenges of research on this topic; existing evidence and conceptualisation of intergenerational vulnerability; assessments of social and health interventions for this population; and, the international consensus on principles which should govern their involvement in HIV prevention.
Students from Kwapata Secondary School participate in Whizzkids sports clinics and education programs, that teach life skills through football.

Photo © M. Willman / Oxfam
INTERVIEWS WITH KEY INFORMANTS

Interview with Busi Madondo on 2 May 2012 at the WKU Health Academy in Edendale.
Interview with Marcus McGilvray on 14 May 2012 at WKU’s Offices in Greyville, Durban.
Interview with Nelisiwe Phoswa on 2 May 2012 at the WKU Health Academy in Edendale.
Interview with male client of Health Academy on 20 June 2012 the WKU Health Academy in Edendale.
Interview with female client of the Health Academy on 20 June 2012 the WKU Health Academy in Edendale.
Focus group with 7 Health Academy clients, 28 June 2012 at the WKU Health Academy in Edendale.

BOOKS, ARTICLES AND RESEARCH REPORTS


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