



SOCIAL CONNECTEDNESS  
FELLOWSHIP PROGRAM

# **PSYCHOSOCIAL SUPPORT: FOR ADOLESCENTS VULNERABLE TO HIV**

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## Key Terms

**Healthcare Workforce:** All people who are engaged in actions whose primary intent is to enhance health, this includes physicians and nurses (WHO).

**Child and Youth Careworkers and Caregivers:** Trained careworkers, under the Isibindi Program, connect with children and youth in impoverished communities, building relationships with them through engaging in their daily life events.

**Safe Park:** Conceived under the idea that children have the right to play and dream even with the HIV/AIDS epidemic imposing adult responsibilities on them, Safe Parks provide children with the time and place to play within the protective circle of trained careworkers.

**Perinatally Infected:** A baby who becomes infected with HIV from their mother any time between the gestational period (22 to 28 weeks) to seven days after birth.

## **Abstract**

This study aims to identify the role of third-party psychosocial support in impacting the health — emotional, social, mental and psychical — of HIV-reactive adolescents (persons aged 12 to 18) in Johannesburg, South Africa. This is done by telling ‘health narratives,’ or stories of each individual's experience either providing (the careworkers) or receiving (the adolescents) psychosocial support. Based on findings and the use of secondary literature, policy recommendations and improvements are then suggested.

## **The Biomedical Approach for Health vs. Social Determinants of Health**

A much-debated question across multiple sectors, including medicine, epidemiology, environmental studies and sociology, is whether our biological predisposition is the only factor that affects our health. While previously relegated in favor of biological indicators, many scholars in these fields have now reached the consensus that our social determinants of health, in fact, play just as much, if not more, of a role in an individual's health.

The biomedical lens approaches health from genetic and biological factors, such as sex, age, and genetic makeup, as well as individual behaviors such as alcohol use, smoking, and non-adherence to treatment and medical care. This traditional viewpoint, with its narrow scope and definition of health, fails to account for the influence of wider social constructs, which are created by society based on perceptions of values, norms, ideas, and practices.

The social determinants of health refer to the circumstances in which people are born, grow up, live, and age, and the systems that are put in place to handle health, illness and wellbeing.<sup>1</sup> These non-medical factors that influence one's health are shaped by wider, intersecting structural forces and social structures. These factors can be categorized into three groups. Socio-economic determinants include age, gender, race/ethnicity, access to health services, educational attainment, and income. Community and societal expectations are characteristics such as poverty, residence (urban, rural, remote), inequality, tolerance of diversity, civic and political

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<sup>1</sup> "What Are Social Determinants of Health?" *WHO*. World Health Organization, n.d. Web.

involvement, social and community participation, and social support structures. Psychosocial factors, which this study will focus on, comprise of factors such as chronic stress, depression, coping, isolation, poor social networks, low-self-esteem, and insecurity.<sup>2</sup> The social determinants of health approach accounts for the limitations in the traditional health sciences approach. It avoids being reductionist by focusing on the wider social factors and is less judgmental, focusing on what *is* instead of what should be.

There is immense interaction between these factors; separating and categorizing them is virtually impossible. Understanding the correlated nature of these structural forces is important as they lead to social and environmental inequalities that contribute to health disparities. These disparities occur both within and across communities, whether they are geographically or socially defined. As a consequence of social inequalities, individuals and communities experience varying levels of access to resources that aid in mitigating the negative effects of unequal burdens.<sup>3</sup>

### **Is social and psychological support linked to healthcare?**

Social and psychological, or psychosocial, wellbeing is the “social and emotional wellbeing of an individual and the ability to fulfill their potential as a human being.”<sup>4</sup> Its importance in relation to healthcare is well documented, as is the paramount role that psychosocial support plays in impacting a person’s health. Such support can come from both the formal and informal sector — the former referring to the healthcare workforce and the latter including familial caregivers, volunteer caregivers, social workers, and the community as a whole.

### **Concept of Psychosocial Health and the Social Determinants of Health**

#### ***Social Support from Healthcare Workforce to Patients***

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<sup>2</sup> Ansari, Zahid, Norman J. Carson, Michael J. Ackland, Loretta Vaughan, and Adrian Serraglio. "A Public Health Model of the Social Determinants of Health." *Social and Preventive Medicine* 48.4 (2003): 242-51. Web.

<sup>3</sup> Schulz, Amy, and Mary E. Northridge. "Social Determinants of Health: Implications for Environmental Health Promotion." *Health Education & Behavior* 31.4 (2004): 455-71. Web.

<sup>4</sup> Republic of South Africa. Department of Health. Psychosocial Support (PSS) for Children and Adolescents Infected and Affected by HIV. By Republic of South Africa, President's Emergency Plan for AIDS Relief (PEPFAR), Center for Disease Control and Prevention, United States Agency for International Development (USAID), and South to South. N.p.: n.p., n.d. Print.

The psychosocial impact that the healthcare workforce can have on patients in their care is multifaceted and is comprised of elements of care. This relationship profoundly affects health outcomes.

### ***Healthcare Workforce as a Source of Motivation, Reassurance and Support***

For many, physicians and other members of the healthcare workforce represent a “formidable source of power and influence.”<sup>5</sup> As such, their behavior can reinforce patient’s self-confidence, motivate them, and sway their perceptions of their health to be positive, which then, indirectly, influences the patient’s health outcomes.<sup>6</sup> In one study, patients’ self-report of good or bad health was consistently correlated to the conversations they had with their physician as well as the behavior of their physician during the visit. Individuals with positive interactions reported fewer lost days of work, fewer health problems, and rated their health more favourably in subsequent visits than their counterparts whose physician exhibited negative body language, impatience, frustration, and anxiety.<sup>7</sup> The healthcare workforce can also positively influence patients’ health by incorporating factors such as a shared understanding, thereby strengthening a patient’s ability to manage their emotions, enhance their agency, and find common ground in terms of values.<sup>8</sup>

### ***Healthcare Workforce and Adherence to Treatment***

Social support from the healthcare workforce is shown to increase a patient’s adherence to the treatment regime. As is obvious, adherence improves disease status and physical wellbeing. Several studies that have analyzed the link between physician-patient relations and compliance with treatment plans focused specifically on HIV-reactive individuals who undertake strict treatment with, oftentimes, low success rates.<sup>9</sup> Patients who successfully managed treatment were more likely to perceive their nurses as supportive, easy to talk to, and felt integrated into these support systems. An indicator of non-compliance was social isolation.<sup>10</sup> Using seven

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<sup>5</sup> Kaplan, Sherrie H., Sheldon Greenfield, and John E. Ware. "Assessing the Effects of Physician-Patient Interactions on the Outcomes of Chronic Disease." *Medical Care* 27. Supplement (1989): n. pag. Web.

<sup>6</sup> Kaplan et al., 1989, p. 112

<sup>7</sup> Kaplan et al., 1989

<sup>8</sup> Street, Richard L., Gregory Makoul, Neeraj K. Arora, and Ronald M. Epstein. "How Does Communication Heal? Pathways Linking Clinician-patient Communication to Health Outcomes." *Patient Education and Counseling* 74.3 (2009): 295-301. Web.

<sup>9</sup> Fox, Matthew P., and Sydney Rosen. "Patient Retention in Antiretroviral Therapy Programs up to Three Years on Treatment in Sub-Saharan Africa, 2007-2009: Systematic Review." *Tropical Medicine & International Health* 15 (2010): 1-15. Web.

<sup>10</sup> Besch, C. L. "Compliance in Clinical Trials." *AIDS* 9.1 (1995): 1-10. Web.

indicators of physician care — general communication, communication of HIV-specific information, participatory decision making, overall physician satisfaction, willingness to recommend physicians, physician trust and adherence dialogue — this study concluded that better physician-patient relationships and physician-patient communication resulted in better adherence to anti-retroviral therapies.<sup>11</sup>

***Social Support, Careworkers, and Social Workers***

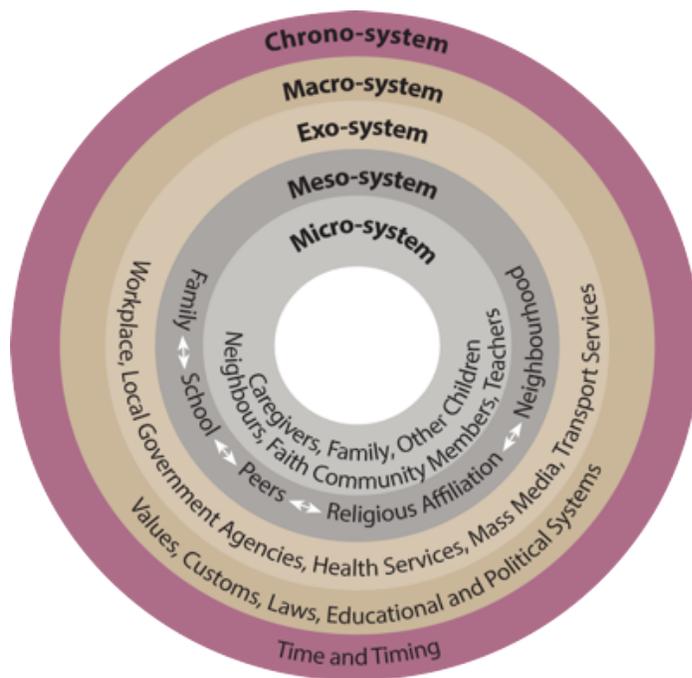


Figure 1. *The Ecological Systems Theory of Child Development*

While the physician-patient relationship has proven to be multi-dimensional and an important aspect of support, the question stands as to whether another party, not directly working in healthcare, can fill this role and ensure the same benefits for patients. The reality is that support from the healthcare workforce is often only present in areas with sufficient resources. In impoverished areas with overburdened clinics, and where HIV incidence tends to be highest, individuals rarely have a personal relationship with their healthcare workforce. Instead, their constant care comes from family, peers, and community members.

<sup>11</sup> Schneider, John, Sherrie H. Kaplan, Sheldon Greenfield, Wenjun Li, and Ira B. Wilson. "Better Physician-patient Relationships Are Associated with Higher Reported Adherence to Antiretroviral Therapy in Patients with HIV Infection." *Journal of General Internal Medicine* 19.11 (2004): 1096-103. Web.

Within the framework of psychosocial support, the individual, which in this case is a child, is always at the centre. Through familial relations and support, represented by the innermost circle, children gain access to the wider resources around them, including school, their community, and society. These relationships are interpersonal, moving from the inside out and continuously impacting one another. For example, by attending school a child is more likely to be exposed to members of their community, including their teachers, peers, and neighbors, than a child who does not attend school. In some cases, links between a child and their family are broken due to the child being abandoned, family members falling ill, they may be victims of conflict, violence, or sexual/emotional abuse, or their care may just be neglected. Regardless of the reason, when the child does not have support or care from their family, they lose the ability to attend school as well as interact with and become integrated in their community and society. This loss of access to other aspects of care has a profound negative impact on children. It impedes their psychosocial wellbeing and level of social connectedness, self-worth, sense of identity, and belonging. It also increases the likelihood of their basic needs being unmet, resulting in no positive child-caregiver interaction activities and making their exposure to stigma and bullying more likely.

An individual with a superior psychosocial state of living not only has their material needs met, such as food, shelter, and education, but they also have “emotionally responsive relationships.”<sup>12</sup> It has been theorized that by expanding the ‘family’ circle of care, emotionally responsive relationships between members of the community will be enhanced, facilitating a child’s full development and deepening their dependable bonds. Being met with success elsewhere in South Africa, The National Association of Child and Youth Careworkers (NACCW) developed the Isibindi Program. Developed as a response to the HIV/AIDS epidemic and the adult responsibilities it imposed on children, the program provides community-based care that trains careworkers to support children in poorly resourced communities. These careworkers meet the developmental needs of children by engaging and supporting them in their daily activities, and by assisting in caring for their wellbeing. The premise of the program is that it will prevent the young people in these communities, who have a higher probability of engaging in the risky behaviors outlined below, from doing so.

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<sup>12</sup> “*Psychosocial Support (PSS) for Children and Adolescents Infected and Affected by HIV.*”

### ***Social Support and Risk Behaviors***

It has been widely documented that care and social support are a buffer against risky behaviors, particularly among adolescents who are already navigating the difficult transition from childhood to adulthood. In literature, care has been defined as perceived social support, community empowerment, perceived social cohesion, and general social support from family and community.

### ***Social Support, Fighting, and Alcohol/Drug Use***

For both young men and women, the absence of social support was negatively correlated with fighting and alcohol/substance usage. A lack of parent and teacher interaction for girls and lack of empowerment for boys led to increased odds of fighting and alcohol and tobacco usage.<sup>13</sup> When care was specified as perceived parental support and perceived social cohesion, results were similar. For young girls, those who reported lower parental social support were more likely to engage in physical fighting, victimization, have suicidal ideation, use drugs, and engage in sexual intercourse. Male students who also felt they had low parental support were significantly more likely to report drug use and involvement in physical fighting than their counterparts who felt they had parental support.<sup>14</sup> Alcohol and drug use are linked to contracting, or being unable to properly manage, HIV/AIDS, for they act as social and structural drivers of the disease.<sup>15</sup>

### ***Social Support and Sexual Intercourse***

Low parental support is closely associated with higher levels of stress, depression, and anxiety. Young women who exhibited lower levels of social support and, consequentially, higher levels of depression had more sexual partners, were significantly less likely to report consistently using condoms, and had higher contraction rates of sexually transmitted infections (STIs).<sup>16</sup> It has also

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<sup>13</sup> Reininger, Belinda M., Adriana Perez, Maria I. Aguirre Flores, Zhongxue Chen, and Mohammad H. Rahbar. "Perceptions of Social Support, Empowerment and Youth Risk Behaviors." *The Journal of Primary Prevention* 33.1 (2012): 33-46. Web.

<sup>14</sup> Springer, Andrew, Guy Parcel, Elizabeth Baumler, and Michael Ross. "Supportive Social Relationships and Adolescent Health Risk Behavior among Secondary School Students in El Salvador." *Social Science & Medicine* 62.7 (2006): 1628-640. Web.

<sup>15</sup> South African National AIDS Council, and Republic of South Africa Department of Health. "Let Our Actions Count: South Africa's National Strategic Plan for HIV, TB, and STIs 2017-2022."

<sup>16</sup> Mazzaferro, Kathryn E., Pamela J. Murray, Roberta B. Ness, Debra C. Bass, Nadra Tyus, and Robert L. Cook. "Depression, Stress, and Social Support as Predictors of High-Risk Sexual Behaviors and STIs in Young Women." *Journal of Adolescent Health* 39.4 (2006): 601-03. Web.

been found that the absence of care for boys increases their odds of engaging in sexual activity.<sup>17</sup> Furthermore, several indicators of care — family connectedness, parent and adolescent communication, both in general and regarding sex, parental monitoring, and school connectedness — are found to have a protective association, or a positive effect, regarding adolescent sexual and reproductive health.<sup>18</sup>

It should be noted that support from peers is not a replacement for support from caregivers, and does not decrease risk behaviors among adolescents.<sup>19</sup> It is theorized this is due to the more stable nature of family relations versus friendships, and the effectiveness of these sources of support.<sup>20</sup>

## **About the Research**

### ***About Synergos***

Synergos Institute is a global non-profit organization that works alongside government, business, civil society, and local communities to find impactful and sustainable solutions to poverty. Synergos Institute South Africa is a leader in furthering social connectedness within and between communities in the region, supporting the psychosocial wellbeing of the young and old alike.

### ***About Ikusasa Lethu***

Ikusasa Lethu was conceived in September of 2000 with the purpose of ensuring holistic development in the disadvantaged community of Freedom Park/Devland. It aims to combat the multi-dimensional and pervasive social challenges within the community, including poverty, unemployment, domestic violence, and chronic illnesses such as HIV/AIDS and tuberculosis. Ikusasa Lethu provides support for 650 vulnerable children through a variety of services, including with the Isibindi Program.

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<sup>17</sup> Reininger et al., 2012

<sup>18</sup> Markham, Christine M., Donna Lormand, Kari M. Gloppen, Melissa F. Peskin, Belinda Flores, Barbara Low, and Lawrence Duane House. "Connectedness as a Predictor of Sexual and Reproductive Health Outcomes for Youth." *Journal of Adolescent Health* 46.3 (2010): n. pag. Web.

<sup>19</sup> Reininger et al., 2012

<sup>20</sup> Greening, Leilani, and Laura Stoppelbein. "Religiosity, Attributional Style, and Social Support as Psychosocial Buffers for African American and White Adolescents? Perceived Risk for Suicide." *Suicide and Life-Threatening Behavior* 32.4 (2002): 404-17. Web.

### ***About Ekupholeni Mental Health and Trauma Center***

Ekupholeni is the only NGO in the informal settlement of the Katorus/Katlehong area of Johannesburg, which provides psychosocial counselling to victims of trauma. The organization address the needs of a community traumatized by political violence, poverty, unemployment, criminal and gender violence, substance abuse, family breakdown, school absenteeism, and gang activity. Ekupholeni specializes in providing support to HIV/AIDS-infected persons and those impacted by the epidemic.

### ***Importance of This Study***

The research undertaken in this report is important for a number of reasons. For one, previous studies that have assessed the role of psychosocial support and social connectedness in healthcare were not only almost entirely restricted to the adult population, but also to those who were chronically ill. Though research has proven the importance of psychosocial support, there are few qualitative studies that assess its significance to children and adolescents, and among those who are not chronically ill.

Furthermore, previous studies have used familial and peer support as indicators of social support and care. It is important to understand the effect that a non-family member or friend can have on a child's psychosocial wellbeing, and the extent in which this individual can supplement or fill in the role of a primary caregiver.

Finally, this paper aims to inform South Africa's policies related to HIV as outlined in the National Strategic Policy (NSP).<sup>21</sup> This refers to policies that address HIV-reactive and non-reactive adolescents.

### ***Current State of HIV/AIDS in South Africa Among Young People***

South Africa has one of the biggest and most high-profile HIV/AIDS epidemics worldwide. It has the highest number of people (7.1 million) living with the disease, the fourth highest adult prevalence rate, and the highest rate of new infections. Thus, the epidemic has become a priority

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<sup>21</sup> Other policies are beyond the scope of this paper and will not be analyzed.

issue for the government over the past decade.<sup>22</sup>

While the incidence of HIV has steadily been decreasing among several demographics, such as infants and men who have sex with men (MSM), it is worsening among adolescents. The rate of new infections for female adolescents, aged 15 to 24, is more than four times that of young men the same age. This demographic of young girls accounts for 25% of new infections in South Africa, with an estimated 1,983 new infections per week.<sup>23 24</sup>

Several government departments are responsible for developing and implementing policies related to HIV/AIDS in South Africa. The two primary ones are the Department of Health (DoH) and the Department of Social Development (DSD). The South African National Aids Council (SANAC), a voluntary association of institutions formed by South Africa's national cabinet, aims to enhance the response to HIV, TB and other STIs. Their quadrennial report, the National Strategic Policy (NSP) outlines the accomplishments and shortcomings from the previous four years' goals and identifies goals for the next four years. This study will focus on the policies put forward in the NSP.

### **Health Narratives**

The following narratives are products of interviews conducted with careworkers at Ikusasa Lethu Safe Park and Ekupholeni Mental Health and Trauma Center, and with the HIV-reactive adolescents they support. These accounts highlight the role that giving and receiving psychosocial support plays in each individual's life, within their unique situation and context.

### **The Careworkers — Tadiwa**

*"I took my own trauma and turned it into something that could help others."*

From great loss can come great growth and understanding. Those are words that resonate with

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<sup>22</sup> "The World Factbook: SOUTH AFRICA." *Central Intelligence Agency*, Central Intelligence Agency, Aug. 2017, [www.cia.gov/library/publications/the-world-factbook/geos/sf.html](http://www.cia.gov/library/publications/the-world-factbook/geos/sf.html).

<sup>23</sup> "HIV and AIDS in South Africa." AVERT, AVERTing HIV and AIDS, Aug. 2017, [www.avert.org/professionals/hiv-around-world/sub-saharan-africa/south-africa](http://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/south-africa).

<sup>24</sup> South African National AIDS Council, and Republic of South Africa Department of Health. "Let Our Actions Count: South Africa's National Strategic Plan for HIV, TB, and STIs 2017-2022."

Tadiwa, words that she chooses to live by. During the last years of apartheid, Katlehong, a black township, was the site of mass political violence between the African National Congress and the Inkatha Freedom Party. While the exact number of casualties as a result of the uprisings in the late 1980s and early 1990s is unknown, it is estimated to be in the tens of thousands. Among this unsettling statistic was Tadiwa's father.

[My father] was shot at home. We were all there in the house. It was on a Sunday afternoon when these attackers came and he was shot there. We just saw smoke in the house. Apparently it was the AK-47 bullet [that] went through the window, and after that, when we went outside, he was there lying there. So after that I started attending counseling sessions due to that.

It was the bereavement counseling Tadiwa received that allowed her to rebuild and realize there can still be life after a death. Most profound in her memory was a 'butterfly retreat' for bereaved teenagers she attended the same year her father was murdered, when she was in grade eight.

“[The counselors] worked with us and also we got through this butterfly story [about their metamorphosis]. It taught us a lot. Seeing that despite how painful the challenges that you went through, but there is still life out there. You still need to pursue your dreams.”

Counseling also helped Tadiwa cope with life without her father which, as she explained, was emotionally and financially strenuous.

[After he died] I had to go through thick and thin because we had to be left with my mother. She was unemployed, she was not well, but she had no choice. She had to go and look for domestic work, and I remember she only worked for one day a week and she used to get paid R500 [\$50 CAD] a month, and we were four at home. So we are still going to school so that money, you could see that it was little... After I completed High School I wanted to further my studies, but couldn't due to financial problems... I dropped out [of college] because of not having money to further my studies.

Despite the numerous tragedies Tadiwa has been faced with, she has chosen to channel it into something positive, turning it into her life's mission rather than be defeated. It was during these counseling sessions that she “developed a passion that I would also like to see myself working with people, getting them healed, recovering from their experiences. Yeah, so for me that's when I started to...fall in love with this kind of work.”

Becoming a careworker gave Tadiwa the opportunity to come out of her shell, a defence mechanism she developed after the loss of her father. Unlike before, she has become less shy and is now comfortable talking in groups of people, a skill necessary for careworkers who run several support groups a week. “I’m an introvert, but due to the work wherever I go I just find myself talking and talking, and afterwards, I [realize] I do not even know these people well!” Tadiwa’s work has greatly influenced her growth as a person, allowing her to become more “emotionally intelligent,” an adeptness she carries from her workplace to her home.

I apply creative thinking and knowledge in terms of how I respond to the situations that I cannot be emotional, or shout back at people, or take those grudges. But if someone has made a mistake, I can just sit down with the person, talk to him or her, without fighting.

In the years since she began at the Ekupholeni Center, Tadiwa has empowered numerous children, facilitating and encouraging their own personal metamorphosis in order for them to overcome their grief and/or become comfortable with their HIV status. One such child is Happiness, whose paternal aunt brought him to the Ekupholeni Center in 2005. After both his parents died of HIV/AIDS, his 14-year-old brother became the head of their household, responsible for then 8-year-old Happiness and their 4-year-old younger sister. Happiness’s poor health was hard to ignore. Tadiwa explained,

After losing both his parents to AIDS, he also came across with a bad incident. He was sodomized by his uncle and was also HIV-positive, although at the time they did not know about his status. So being sodomized, being HIV-positive, he had this problem of having warts in his anus. He would go to hospital in a year probably three times, four times, because every time after they have removed the warts, they will grow back again, and then they will remove them. They will grow back again... He would develop sores on his head. I remember that he used to have these sores that were not like controllable.

The cause of Happiness’s poor health was unknown until the Ekupholeni Center persuaded him to get tested for HIV. When the test came back reactive, his aunt immediately enrolled in disclosure workshops at the Center to learn how to tell Happiness about his status and support him in managing this disease. Gradually, Happiness “started to know the real cause of his health status” and began to attend individual counseling weekly as well as group counseling at the Center for persons with HIV. He started in the Bam Banani group for primary school children,

then proceeded onto the Kuruleka group for youth before going into the Kickstarter program, which provides matriculating students with life skills and career advice. Happiness completed High School last year and is currently enrolled at Monash University, one of the best universities in South Africa, and is studying psychology. “He makes me feel proud and reminds me that, you know, there is life [after tribulations].”

### **The Careworkers — William**

*“When you are a caregiver, you just have these experiences that make you grow as a person, and learn about the world, and see what the world is all about, and gaining new experiences in everything that you do.”*

Some people believe that they did not choose their career, their career chose them. William strongly believes this form of fate intervened in his own life. Compelled to become a careworker in 2010 due to the high incidence of youth unemployment and a lack of jobs available in Devland, the then-recent high school graduate heard about Ikusasa Lethu. “Back in those days, the only thing that was nearby [where someone could work] was this NGO. They gave you a little stipend so at least you could forge for yourself.” Soon, however, William found deeper meaning in the work he was doing.

I grew up in this community and there are many issues that face youth: unemployment, unstable homes without a mother and father, excessive discipline. Being a part of this NGO is when I recognized that the issues I thought [were] only with my generation are still being faced today [along with new challenges]... [and on top of that] there is no support in terms of family, in terms of community, they’ve been neglected. I have been driven to have this passion after seeing the challenges today and seeing that, okay, I can make a difference in this community.

William is now involved in several programs at Ikusasa Lethu, including the Determined, Resilient, Empowered, AIDS-free, Mentored and Safe (DREAMS) Initiative, which aims to reduce the HIV infection rate among adolescent girls and young women in ten sub-Saharan African countries, including South Africa. One of the children he provides direct support and care to, September, is an HIV-reactive adolescent involved in the program. William educates September and other girls in the program on social skills, life skills, career guidance, socialization, and he advises them on the challenges they may face at their age. Through providing them with this care and counsel, it is believed young girls who are HIV-negative will be

empowered and have the knowledge and skills necessary to avoid contracting HIV, while their counterparts who are reactive will be better equipped to thrive despite their status. This includes practical knowledge such as how to use a condom, why they are important to use, and what HIV is and how one can contract it. William provides an example of a scenario girls often ask him about:

Okay now [they come to me because] they are starting to have emotions for someone, or feelings for someone, [which] is not a wrong thing because you are at that age now, and you start developing those kinds of feelings. But now we teach the disadvantages of that; that you might lose your self-esteem while you put everything that you do towards that person. It's not about them, but it's about you, and how about you control [your feelings], and how you make [the relationship] work.

William describes September as “very intelligent, [...] someone who likes to be attached to someone. She's very emotional, she's very shy, she's a quiet person, that's September for you. She likes playing with other children, but not fully. She picks, so the circle of friends of September is very small. She picks who she plays with and that's her personality.”

William has recently seen September through a challenging period in her life, which many children across the country face. The majority of parents and guardians with perinatally infected children have a difficult time disclosing their child's HIV status to them — whether it be out of fear or guilt — as they grow up and are able to comprehend the repercussions of being HIV-reactive. Thus, it has become commonplace for parents to put their children on anti-retroviral drugs and either not tell them what it is for or say it is to treat another sickness, such as tuberculosis. September's mother, who recently passed on, failed to tell her daughter about her status, leaving the responsibility to September's grandfather and aunt. William explained,

[September finding out about her status is] recent, just now, but her family knew before, so the family did not disclose, they only gave her medicine. But now September went for an actual test because she is twelve<sup>25</sup>... hence, they told her she is reactive.

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<sup>25</sup> In South Africa, at the age of 12, a child is given the ability to provide informed consent for HIV testing, thus they do not need parental permission to undergo the test.

September struggled to accept this reality, one which has impacted her emotional health and social life. William shared a story of a recent event that took place, which exhibits the stigma and sometimes lack of confidentiality that surrounds HIV in certain areas.

Somehow September was playing with other children, but the child told her that she cannot play with her because she's HIV positive, and that impacted a lot on her family. So the family when they heard the story, they wanted to fight with the child, you see? So that's why it became a problem and saying, because now you cannot go and fight with children and say no, where did you get this information, why and this and this?

Upon hearing the news, William intervened.

I sat down with her and the aunt to talk to them about stigma, external and internal... That there are challenges that you need to be strong, that you need to stand against that stigma by realizing that if you listen to those things that goes out there, there's nothing positive that will come out of it. So you need to know that HIV is not a death sentence. HIV is not a bad thing... So it's something that the community sees it because they are uneducated. So they also need at least education, it's not because they are bad people. They may be not enlightened about HIV so that's when we sat down with the family, we discussed, okay, we talked about them. I made them understand about HIV and ever since then September has been... better.

William is passionate not only about helping the young person he cares for, but also about helping the family and community as a whole. As the Ecological Systems Theory (Figure 1) depicts, families are essential to children's development.

The children only spend two or three hours with the careworker, mainly their whole hours are spent with their families. So sometimes it's, as a careworker since you are well educated with HIV, and are trying to build the self-esteem of the child, and try to support the child directly, the more important part is the family. Because by supporting only the child it doesn't make the child strong. You have to empower the family... You build that relationship and support structure for the child in terms of treatment, their dreams, schoolwork, emotions, vision... but what will happen if you are no longer there? We are trying to empower the families. You're not trying to take the burden from the family and carry it. I think that is the most important thing when it comes to a child because HIV is something that can... close a lot of doors in your life in terms of growth, opportunities, [and] living your life.

Empowering young people and families to support and uplift one another has had an impact on

William's personal life and affected the way he engages with his own family as he brings these transferable and soft skills home. His communication skills and ability to build meaningful relationships have greatly improved. Being a careworker "changes everything about you: your communication, how you listen to people, how you behave within society." He has also become more empathetic, taking into consideration his feelings as well as the feelings of those with whom he interacts. This is especially the case with his own children, an ability he feels has made him a better father.

### **The Adolescents — Rethabile**

*"My careworker helped me to realize that some of the things in my relationship with my boyfriend that I thought were normal, that felt normal, were not."*

Rethabile, or Thabi, is one of the lucky few in her community. Unlike many of her peers in Devland, she is rhapsodized when she speaks about her family. The 16-year-old is quick to attribute her happiness and content life to her single mother, who she describes as her "mother, [her] father, [her] everything" and biggest support system. Alongside her mother is her 21-year-old sister, who takes on some of the family's responsibilities. Thabi explained that she is "not struggling, [she's] happy" due to the overwhelming support she has in her life. In addition to the strong female figures in her home, Thabi gets care and support from careworkers at Ikusasa Lethu.

Mama Elizabeth, as Thabi endearingly refers to her careworker, not only is always available to talk, but she also "plays games with us where, at the end of them, it teaches us a lesson." This form of support is different than what her mother, sister and friends provide her with.

Sometimes you need to have someone by your side because you have a problem. There are those times when you can't talk to your mom about some private stuff... and you can't even tell your friend. I's 16, my friend is also 16. We don't have a lot of experience in or about life. You need someone older and they can't be in your family [because you need them to be impartial]. So having Mama Elizabeth by my side is helpful because I can come to her about anything. I want to speak to her because she is free.

Throughout southern Africa, there is a power dynamic between youths and their elders. Careworkers bridge this dynamic by being someone who is older and wiser, yet acts in the same

capacity as a peer. Mama Elizabeth has greatly influenced Thabi's aspirations and goals for the future; "she makes sure that I can reach them." After expressing her wish to become a writer, her careworker provided her with books and writing materials. "After I wrote something for Ikusasa Lethu, [...] they started [encouraging] me and giving me advice. This led Thabi to discover another passion: archaeology. She has planned her high school courses to suit her interests and future aspirations.

The support systems she has at Ikusasa Lethu have also made her aware that she will face obstacles that may make reaching her high aspirations more difficult, if not impossible. Particularly, they made her aware of the unhealthy power dynamics young girls are susceptible to and the risk of gender-based violence. Thabi talked about having experienced such challenges before having a careworker.

I had to talk to them about my boyfriend... speaking up and telling them this is what [couples do together]. They gave me advice, that I shouldn't do certain things with a guy because we will have xyz consequences... The big thing was unprotected sex, drinking alcohol, going to parties [and those kinds of things]. They told us that boys have a lot of influence on us and know how to make girls say yes to certain stuff. They know how to take advantage of us. I became more aware [about my relationship] and realized some things I thought were normal are not. I ended up breaking up [with my boyfriend] because I realized boys are big trouble, and I need to be single in order for me to reach my goals.

While Thabi is fortunate to have multiple forms of psychosocial support, she is very aware that many people do not have such support to act as a barrier to stigma. "Many times, this stigma comes from people within an HIV-reactive person's [micro-system]. You know in some families, they do not accept your HIV status." She began to recount people she knew and experiences she has had in school.

[Someone] in the clinic, [they're] not going to school. Then in school [the teacher asks], 'How many times have you been absent? [I can see you've been absent all these days] and she wants to know why. You tell her she should talk to your mum because you went to the clinic... So she wants to know why you are going to the clinic and people in the class can hear it.

Thabi also described how, oftentimes family members themselves may expose a person's status

to the community to seek revenge after an argument. “It’s bad because [once someone is exposed], they can become ostracized by their community, which makes their health worse.”

Thabi’s close micro-system, consisting of her mother, sister, careworker, and supportive and HIV-reactive friends are the reason she is “happy while [HIV-reactive adolescents without support] are sad.” Due to this support, she said, “I know how to handle many different situations, since I get advice from different people and have people I can also talk to.”

### **The Adolescents — Dumisani**

*“Support is important because if you get support from someone else, it really makes you believe in yourself.”*

At the young age of 17, Dumisani had a realization regarding the way he was living his life and became resolute that he would make better decisions. For the past year, this has been his guiding principle.

I was like a kid who grew up going to parties and things like that. Always chasing around chicks, but then I started seeing that this is not the real reason why I’m living this life. I had to stop doing those bad behavior things.

His adverse decisions had harsh consequences, the most impactful of which was his consistent inability to pass his classes. After failing several years of school and needing to repeat grades multiple times, Dumisani was expelled. “[After failing] I felt like I am a failure, and then I started thinking maybe [I was failing] because I am HIV positive?”

Failing school “really affected” Dumisani to the point where he decided to re-evaluate the relationships and friendships in his life. Like Thabi, he finds great value in surrounding oneself with individuals who are older and more experienced. “So I don’t only chill with people who are on my same level of age. I only speak with people that are older than me because they’ve gone through things that I haven’t been through before. I haven’t experienced much about life, but then learning from other peoples’ experiences really tells me, I shouldn’t go that far, I should choose this way and this path.” The careworkers — including Tadiwa who facilitates the support group for HIV-positive adolescents — also act as a voice of reason and provide advice.

No like only me and my mother, we are HIV positive, but then we cannot talk [about] everything together, so like coming to the Center...yeah. I get to [feel] more free... I get more free spirited to talk about anything else with anyone who is here because we understand one another.

Prior to attending the group, Dumisani describes how he felt isolated and alone in his journey learning how to manage his disease.

I used to think maybe I am the only one who was HIV positive. I didn't have people who were like me at that time. Even though it's not written [on me that] I'm HIV positive, but I can feel at that time, I thought like I was the only person who is HIV positive. I didn't really have much understanding about life and being HIV positive and stuff like that.

Dumisani feels this is no longer the case, and that while he is still learning, he has a better grasp on life and his actions. This is in part due to his mother, who always encourages him to focus on school and "stay on the right path," as well as his spiritual leader who has taught him how to live a great life through conversations with God. The care he receives at the Ekupholeni Center acts as an extra facet of support in his life.

Well, I must say they're trying to show us...you cannot be left out just because you are HIV positive, and I really felt like I was left out. And then being here really shows how much they support me as being HIV positive. Because support to me really is important. Getting support in everything that you do is really important. Like they understand who you really are. Being [out of my usual environment] where I can share my experiences and how I feel, it's really important.

He credits these multiple levels of support for the sense of self-worth and confidence he has, particularly when he was undergoing his transition from risky behaviors to making better decisions. "Support is important because if you get support from someone else, it really makes you believe in yourself."

As he pursues careers in modeling and nursing, he believes his status has influenced his goals. Had he not been HIV-reactive, he believes he would not have discovered his passion for nursing and helping others cope with illnesses.

Now, Dumisani has a positive outlook on life and sees the lessons in his mistakes rather than allowing them to overpower him.

Life has problems and when you face them you sometimes feel so sad about this is happening, and then as time goes on you realize there is no reason why you should be sad, that things are happening to your life.

### **The Adolescents — Naledi**

*“I used to always be alone, frustrated in a room alone and not getting comfort, isolating myself from other children and asking, ‘why me?’”*

She was angry, she was frustrated and she was confused. “I used to ask my mother, ‘why were you not protecting me?’” Naledi went on a long journey, from bitterness to accepting that she was born perinatally infected with HIV. “I was blaming my mother. ‘Mama, why?’ It is your problem that I have this disease. If it wasn’t for you, I wouldn’t have HIV.”

The support groups and ‘mothers’ at Ikusasa Lethu saw Naledi through her journey. “Now I am feeling okay because I have accepted that I’m HIV-reactive. The support I get [at Ikusasa Lethu] has encouraged me and made me realize that [having HIV] is not the end of the world for me. They teach me how to live, what to eat, to continue drinking my pills every day, and then I’ll be like anyone else who is living in this world. Because when I walk in the streets, it will not be written that someone is HIV positive.”

Prior to accepting her status, Naledi isolated herself due to shame and self-stigma. This is a common theme among persons living with HIV; in the previous SANAC report 43% of reactive persons experienced internal stigma. “I was isolating myself from other kids, I didn’t want to play with them. I would stay in my room and ask myself, ‘Why me? Why not others?’ I was frustrated in a room, alone, and with no one to comfort me.” Naledi’s inability to accept her status made her feel as though others, even if they were unaware that she is reactive, would shun and reject her. This fear of the stigma she could potentially face, and eventually began to face, was also related to the fact that every week, on Thursdays, she would have to go to the clinic.

My mum used to go alone to fetch my tablets because I was [facing] stigma and afraid of what people would say if each and every Thursday of the month I have to

be absent from school, but then I would come on Friday. I started to experience stigma and did not want to go get my pills or take them because people started to ask if I was taking chronic medication [and would make fun of me].

Naledi describes her careworker, Sister Connie, as being “like my mother, because she is the one who has always been on my side and is playing a role in my life.” She was the one who was able to give Naledi the confidence to ignore her peers’ inquiries and continue taking her medicine.

I told Sister Connie that, what my peers were saying, and then she said, I should not worry and they will never know my status [unless I disclose to them] so I should not be bothered by what they are saying. They were probably just playing... so now when they [inquire about my absences], I join them and [sarcastically] say ‘ja, I am taking chronic medicine’ so they stop teasing me.

Naledi also began to slowly bring herself out of isolation as she met friends at Ikusasa Lethu. “[Before Ikusasa Lethu], I didn’t have friends to talk to or to play with [because I had isolated myself.] I came here and I started to make friends, to know people, and talk with them about life, play, have jokes like everyone else.”

In addition to her mental, emotional, and social well-being improving since coming to Ikusasa Lethu, Naledi has encountered significant changes in her physical health. She described herself as being exceptionally thin during her period of isolation. Her weight was conjointly attributed to the disease and her diet, driving her further into isolation as she feared people in the community would deduce that she was HIV-reactive, as thinness is a revealing side effect of HIV. Her careworker informed her of the major role that diet plays when one is on anti-retrovirals, and the immense impact it can have on her physical health.

I used to always eat [unhealthy foods], [but then I learned] in this disease you have to eat fruit and vegetables... and you have to have a balanced diet. Sometimes [at Ikusasa Lethu] they provide breakfast, and sometimes at home we don’t have breakfast [so] I come here and they provide breakfast for us.

As she began to interact with other adolescents and changed her diet, Naledi saw her body change. “Now I play, and when I play, I gain weight and people have even started to notice.” Like Thabi, she appreciates the care she receives from her careworker and the organization.

I'm comforted here; I feel like I'm home when I'm at Ikusasa Lethu. Being here is a privilege because you have a compassionate careworker and people who think of others and who know how to make others feel good. I think being here has changed how I live and my health because I am no longer having [negative] thoughts [about being HIV-reactive] or isolating myself. I'm free now.

### **Policy Recommendations**

In the most recent National Strategic Plan on HIV, TB and STI's (NSP), several key challenges were identified that had prevented the previous years' goals from being met. Some key obstacles that relate to HIV among adolescents, their careworkers, and the themes they highlighted during their interviews are:

- “Addressing gender inequality and gender based violence and sexual violence”
- “Tackling alcohol and substance abuse and lack of harm reduction services, especially among youth...”
- “Tailoring combination prevention strategies for different populations, especially those with higher risk behaviors... that increase their vulnerability”
- “Reducing externalized and internalized stigma for HIV...”
- “Ensuring that key and vulnerable populations, including young women and girls, children... receive acceptable and accessible services”
- “Enabling intersectoral planning and integrated services delivery, especially at community level”

The following policy recommendations seek to mitigate these challenges, and help meet the NSP's 2017-2022 targets.

#### ***1. Expanding the Isibindi Program to build social connectedness and avoid risky behaviors that can lead to infection***

While several demographics have decreasing HIV infection rates, the rate for adolescents, especially young women and girls, is on the rise. This is attributed to many factors, which several caregivers identified, mainly a lack of comprehensive sex education and transactional/intergenerational relationships between young women and older men. Speaking on

the former, one of the careworkers at Ekupholeni noted how many young people do not understand the fundamentals of condom usage, as “girls ask the man to wear a condom once, maybe twice, [and then] after that she trusts him and he doesn’t use a condom. So the condom failed for our system.” Another careworker described the culture of dating amongst young people and the influence of poverty and a lack of opportunities in driving transmission.

The environment where they live in is over-crowded and there’s nobody who is checking who is who, you know, because everyone thinks, today what am I going to eat? What is going to happen? So they are only concerned about themselves. So once a girl [turns] 15 or 16, [society] tells her to get a boyfriend and because she wants to have style [and he can provide her nice things], she says ‘okay if I need’, let me get a boyfriend who can provide for me. So this is also a cause [of infection rates continually increasing].

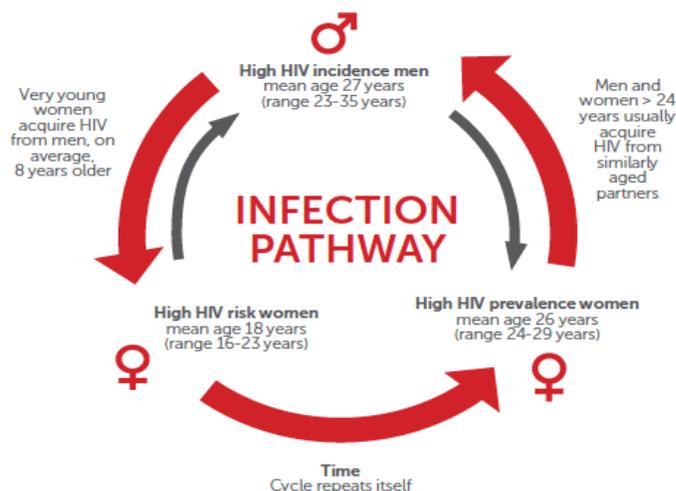


Figure 2. Cyclical Diagram from the NSP highlighting the transmission of HIV and STIs

This belief has been corroborated by research.<sup>26</sup> As Figure 2 displays, young women acquire HIV from men on average eight years older than they are. Men and women over age 24 usually acquire HIV from similarly aged partners.<sup>27</sup> Thabi is a prime example of what many girls in these communities face. Though her relationship was not transactional, it had several unhealthy aspects. As adolescents grow up, their perceptions of what a relationship is, and how it should be, is framed by those around them; however, many of these relationships involve forms of coercion, manipulation, transactional sex, gender-based violence, and an overall unhealthy dynamic.

<sup>26</sup> Bangol, B, and E Chamo. “Intergenerational Relationships in Mozambique.” Sexual Health Exchange, 2004.

<sup>27</sup> South African National AIDS Council, and Republic of South Africa Department of Health. “Let Our Actions Count: South Africa’s National Strategic Plan for HIV, TB, and STIs 2017-2022.”

These factors are highly correlated with HIV contraction. Studies have found that women with a violent or controlling male partner are at increased risk of infection, as their male partners are more likely to have HIV and impose risky sexual practices on their partner.<sup>28</sup> Some women in intergenerational relationships have little-or-no decision-making power, and their relationships are “characterized by coercion and manipulation,” which makes negotiating safe-sex practices difficult.<sup>29</sup>

### ***1a. What about the boys? Male Empowerment***

In the same sense that the culture of dating for young women has contributed to their increased infection rates, interviews highlighted that the culture and belief of what a ‘masculine man’ should be, as well as the emphasis on women, has also contributed to infection rates.

We think [young men and boys] need to be tough. But they are also fragile in their own way, but nobody listens to men. Yes, even if there is a bereavement or someone has passed on, maybe in an accident, first thing, paramedics go to women, not men or...so that needs to be changed that maybe we need more organizations that specifically work with young males. They need their voices heard from a young age... because right now they do not have that self-esteem. Most of them have low self-esteem and have a sense of worthlessness. Male unemployment is so much higher... They are frustrated with the system [because] when they finish matric they don't get learnership [sic]. Their result doesn't meet the equivalent of university criteria so they are stuck.

While transforming the notions and ideas of love, relationships, and self-worth among young people is a challenging and long-term task, theories of social connectedness provide insight into how these risky behaviors among adolescents can be decreased.

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<sup>28</sup> Dunkle, Kristin L, et al. “Gender-Based Violence, Relationship Power, and Risk of HIV Infection in Women Attending Antenatal Clinics in South Africa.” *The Lancet*, vol. 363, no. 9419, 2004, pp. 1415–1421., doi:10.1016/s0140-6736(04)16098-4.

<sup>29</sup> Nkosana, Josephine, and Doreen Rosenthal. “The Dynamics of Intergenerational Sexual Relationships: the Experience of Schoolgirls in Botswana.” *Sexual Health*, vol. 4, no. 3, 2007, p. 181., doi:10.1071/sh06070.

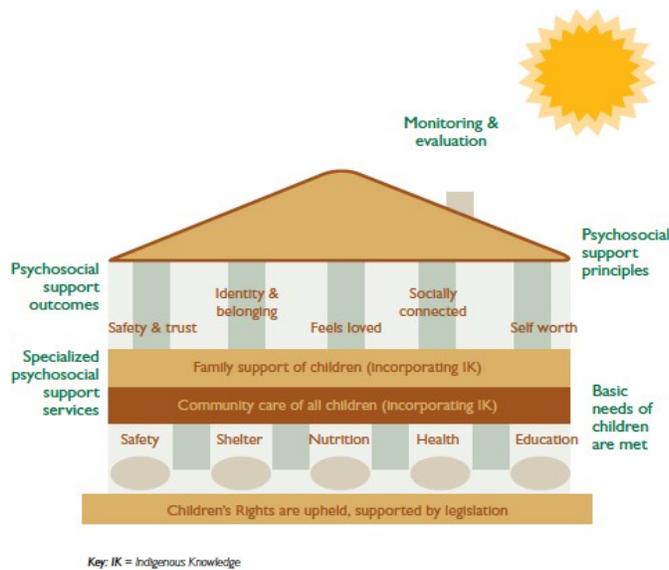


Figure 3. “*Psychosocial Support (PSS) for Children and Adolescents Infected and Affected by HIV.*”

The house in Figure 3 represents the several levels of support adolescents can access. The foundation represents their basic needs, such as shelter and education. The majority of children across South Africa receive this support, largely due to the Child Support Grant and other bursaries provided by the government. The second level of the house represents psychosocial support (PSS). These indicators can be further broken down into emotional or intrapersonal wellbeing, social or interpersonal wellbeing, and skills and knowledge or competencies. The intrapersonal domain is concerned with an “individual’s capacity to live a full and creative life and the flexibility to deal with life’s inevitable challenges.”<sup>30</sup> The ability to do so depends on self-awareness, self-worth, control over one’s behavior, and having hope for the future. Interpersonal wellbeing relates to how one interacts with those around them, as well as the extent and quality of these interactions and relationships.

The theory behind these domains of PSS is that when an adolescent has strong interpersonal relationships, it will positively influence their intrapersonal wellbeing. In other words, if an adolescent knows someone cares about them and that they matter to someone, they will have strong self-worth, a sense of pride, and self-respect. These characteristics are directly related to decision-making. For example, if a young woman has the opportunity to engage in a transactional relationship with an older man, instead of accepting the offer she may think, “I will

<sup>30</sup> *Psychosocial Support (PSS) for Children and Adolescents Infected and Affected by HIV.*

not engage in this relationship because something may happen to me, and I have too much self-love for that to occur.” Careworkers are essential in building these characteristics and inner resiliency as they encourage meaningful relationships and act as a person who cares about the wellbeing of the young person. Thabi had the same relationship with Mama Elizabeth, the individual who helped her realize she was too important to be manipulated or mistreated by her boyfriend.

Instilling feelings of self-worth and confidence in young people is directly linked with the expansion of the Isibindi careworker program under the National Association of Child and Youth Careworkers. Each child in every community should have the right to access the forms of PSS represented by the second level of the house in Figure 3. When this occurs, risky behaviors decrease as knowledge that one matters increases. For girls, this has the potential to decrease intergenerational relationships, and for boys, it can communicate the notion of men as protectors and supporters of women from a young age. For both genders, it instills self-worth and self-esteem. Thus, by having careworkers who can facilitate a reduction in risky behavior, it is believed that infection rates will decrease.

These recommendations are directly related to meeting several of the 2017-2022 goals outlined in the NSP. The first of which is Objective 1, to “accelerate prevention to reduce new HIV and TB infections and STIs,” which specifically mentions reducing new infections among adolescent girls and young women from 2000 per week to less than 800. One way in which they plan on achieving this is by providing “sensitive and age-appropriate sexual and reproductive health services and comprehensive sexual education.” As all of the adolescents mentioned, they value their careworker as a more knowledgeable peer whom they can “feel free” around when discussing any matter, including sexual health. Thus, careworkers offer informed, non-judgmental advice that can act as a deterrent to new infections.

Objective 4 also calls for “addressing the social and structural drivers of HIV, TB and STIs.” They plan to accomplish this by reducing risky behaviors through programs that build resilience of individuals, parents and families; extending support for learners; strengthening the capacity of families and communities; ensuring infected persons have access to eligible social grants; and

increasing the availability of economic opportunities. As Sam explains, careworkers do not focus solely on the child but also their families. Their responsibilities also include helping families access and budget their income and various grants. At Ekupholeni, their Kickstarter program provides life and job advice that has assisted several HIV-reactive children, such as Happiness, in pursuing their education and careers. As such, careworkers' responsibility includes all of the aforementioned tasks, further demonstrating the essential role they play in reducing new infections and supporting those who are already infected.

## ***2. Involve several stakeholders and grassroots initiatives in policy creation and implementation***

Several careworkers voiced their frustration with government bodies, especially the Department of Social Development (DSD) and Department of Health (DoH), which are primarily responsible for policies surrounding HIV. Careworkers felt the DSD and DoH do not do enough work at the grassroots level, rendering careworkers "voiceless" in terms of the policies they are expected to implement.

Even the DSD is not sure about the policies. They don't come to grassroots level to ask people, they decide. Maybe they interview, they do sampling for 10 or 15 people, it's not enough. Because the people that they need to be reaching, in rural areas or urban areas or disadvantaged areas, they don't really go there. Then even with us, we are voiceless. But if they can take themselves and go to grassroots level...HIV could be less.

Another careworker shared similar sentiments, saying:

The confusion is not entirely that there is not enough funding. But it is also the government, they are not doing enough. The government, what they do is, they decide the programs and they bring it down. They never at that point have said to NGOs, 'What is it that you want from us, what you want to do?'... It should also go up and come down... because for now really every program that is coming, we just hear there's a new program, deal with it. From [the] NGO level, now you have to make it fit for the people [we serve in the community] and trying to make it work. They're not dealing with... the people we are dealing with.

The inclusion and consultation of grassroots initiatives when designing and implementing

policies have proven to be crucial. The 2001 Commitment on HIV/AIDS agreed by United Nations member states explicitly called for the involvement of civil society in implementing and evaluating HIV programs. “Civil society organizations have played a significant role in the direct provision of HIV-related services due to their presence in or connections with affected communities... As public health hospitals became overburdened with AIDS patients in highly affected areas, for example, civil society have assumed responsibilities for health care provision; in many places, they were the pioneers of counselling and of home-based care for the sick.”<sup>31</sup> Decades of caring for the community has helped careworkers develop extensive knowledge. Thus, their voice is crucial in efforts to decrease HIV incidence. As the careworkers deal with these adolescents on a daily basis, they understand their specific needs and the strategies that could target the young people and prove effective and sustainable. Not including them fails to tap into the invaluable resource they represent and oftentimes leads to ‘technocratic’ policies that do not assist those who need the assistance the most.

While the objectives in the NSP advise that HIV-reactive and grassroots individuals from the community be more included, additional steps can be taken to make these policies more effective. For example, Objective 3.1.1 states, “All national and provincial AIDS Councils will include at least one representative from a key and vulnerable population.” While this goal is a start to further inclusion, more than one individual should be included for optimal effectiveness. Vulnerable and key populations include sex workers, transgender persons, men who have sex with men, drug users who inject, adolescent girls and young women, migrants and undocumented workers, orphaned and vulnerable children, people living in informal settlements, and many more. These individuals have diverse backgrounds, and to only incorporate one of their voices into AIDS Councils would be majorly unrepresentative. Instead, Councils should include individuals from various vulnerable populations, or conduct qualitative studies on the ground that would allow for their opinions and thoughts to be heard.

Lastly, Objective 6 aims to “promote leadership and shared accountability for a sustainable response to HIV, TB and STIs.” This relates to the collaboration of persons from several sectors

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<sup>31</sup> Peersman, Greet, et al. “Increasing Civil Society Participation in the National HIV Response: The Role of UNGASS Reporting.” *JAIDS Journal of Acquired Immune Deficiency Syndromes*, vol. 52, 2009, doi:10.1097/qai.0b013e3181baee06.

and with different expertise. Careworkers can be instrumental in this faction. This would be especially valuable given that the NSP highlights civil society sectors that should be involved. Careworkers work across these sectors, including with children, disability, health professionals at the clinic, and youth. Having members of the Council or the SANAC secretariat visit some of these NGOs and organizations for an adequate period of time, possibly 5 to 10 days, to talk to the careworkers and experience their day-to-day activities alongside them, can inform policy. This measure can also prevent careworkers and other individuals who work on the ground from feeling like policies “fall from the sky.”

### **Conclusion**

While it is undeniable that South Africa has come a long way in its efforts to combat HIV, and has made strides in thwarting the damage it causes, the country still has a long way to go. This is especially true in relation to its adolescent population. The young people interviewed in this study shared the intimate ways in which careworkers in their community have positively impacted their lives, while the careworkers also expressed the changes they have noticed in themselves and their community. Incorporating careworkers and theories of social connectedness into the National Strategic Policies for 2017- 2022 may help the South African government achieve its objectives, a feat that was not entirely possible during the 2012- 2016 period. Furthermore, social connectedness has the dual ability to decrease new infections by decreasing risk behaviors, and empower those already infected to accept their status and manage the disease while living a fulfilling life.

## Works Cited

Ansari, Zahid, Norman J. Carson, Michael J. Ackland, Loretta Vaughan, and Adrian Serraglio. "A Public Health Model of the Social Determinants of Health." *Social and Preventive Medicine* 48.4 (2003): 242-51. Web.

Bangol, B, and E Chamo. "Intergenerational Relationships in Mozambique." *Sexual Health Exchange*, 2004.

Besch, C. L. "Compliance in Clinical Trials." *AIDS* 9.1 (1995): 1-10. Web.

Dunkle, Kristin L, et al. "Gender-Based Violence, Relationship Power, and Risk of HIV Infection in Women Attending Antenatal Clinics in South Africa." *The Lancet*, vol. 363, no. 9419, 2004, pp. 1415–1421., doi:10.1016/s0140-6736(04)16098-4.

Fox, Matthew P., and Sydney Rosen. "Patient Retention in Antiretroviral Therapy Programs up to Three Years on Treatment in Sub-Saharan Africa, 2007-2009: Systematic Review." *Tropical Medicine & International Health* 15 (2010): 1-15. Web.

Greening, Leilani, and Laura Stoppelbein. "Religiosity, Attributional Style, and Social Support as Psychosocial Buffers for African American and White Adolescents? Perceived Risk for Suicide." *Suicide and Life-Threatening Behavior* 32.4 (2002): 404-17. Web.

Kaplan, Sherrie H., Sheldon Greenfield, and John E. Ware. "Assessing the Effects of Physician-Patient Interactions on the Outcomes of Chronic Disease." *Medical Care* 27. Supplement (1989): n. pag. Web.

Markham, Christine M., Donna Lormand, Kari M. Gloppen, Melissa F. Peskin, Belinda Flores, Barbara Low, and Lawrence Duane House. "Connectedness as a Predictor of Sexual and Reproductive Health Outcomes for Youth." *Journal of Adolescent Health* 46.3 (2010):

Mazzaferro, Kathryn E., Pamela J. Murray, Roberta B. Ness, Debra C. Bass, Nadra Tyus, and Robert L. Cook. "Depression, Stress, and Social Support as Predictors of High-Risk Sexual Behaviors and STIs in Young Women." *Journal of Adolescent Health* 39.4 (2006): 601-03. Web.

Peersman, Greet, Laura Ferguson, Mary Ann Torres, Sally Smith, and Sofia Gruskin. "Increasing Civil Society Participation in the National HIV Response: The Role of UNGASS Reporting." *JAIDS Journal of Acquired Immune Deficiency Syndromes*, vol. 52, 2009, doi:10.1097/qai.0b013e3181baee06.

Reininger, Belinda M., Adriana Perez, Maria I. Aguirre Flores, Zhongxue Chen, and Mohammad H. Rahbar. "Perceptions of Social Support, Empowerment and Youth Risk Behaviors." *The Journal of Primary Prevention* 33.1 (2012): 33-46. Web.

Republic of South Africa. Department of Health. *Psychosocial Support (PSS) for Children and Adolescents Infected and Affected by HIV*. By Republic of South Africa, President's Emergency Plan for AIDS Relief (PEPFAR), Center for Disease Control and Prevention, United States Agency for International Development (USAID), and South to South. N.p.: n.p., n.d. Print.

Schneider, John, Sherrie H. Kaplan, Sheldon Greenfield, Wenjun Li, and Ira B. Wilson. "Better Physician-patient Relationships Are Associated with Higher Reported Adherence to Antiretroviral Therapy in Patients with HIV Infection." *Journal of General Internal Medicine* 19.11 (2004): 1096-103. Web.

Schulz, Amy, and Mary E. Northridge. "Social Determinants of Health: Implications for Environmental Health Promotion." *Health Education & Behavior* 31.4 (2004): 455-71. Web.

South African National AIDS Council, and Republic of South Africa Department of Health. "Let Our Actions Count: South Africa's National Strategic Plan for HIV, TB, and STIs 2017-2022."

Springer, Andrew, Guy Parcel, Elizabeth Baumler, and Michael Ross. "Supportive Social Relationships and Adolescent Health Risk Behavior among Secondary School Students in El Salvador." *Social Science & Medicine* 62.7 (2006): 1628-640. Web.

Street, Richard L., Gregory Makoul, Neeraj K. Arora, and Ronald M. Epstein. "How Does Communication Heal? Pathways Linking Clinician-patient Communication to Health Outcomes." *Patient Education and Counseling* 74.3 (2009): 295-301. Web.

"The World Factbook: SOUTH AFRICA." *Central Intelligence Agency*, Central Intelligence Agency, 30 Aug. 2017, [www.cia.gov/library/publications/the-world-factbook/geos/sf.html](http://www.cia.gov/library/publications/the-world-factbook/geos/sf.html).