

### **Overview of Generation Ubuntu**

Generation Ubuntu (GenU) is located in the township of Khayelitsha, one of the most impoverished areas of South Africa that has an HIV prevalence of 33% and is also home to one of the highest homicide rates in the world. GenU's mission is to improve the health and well-being of children and teenagers (ages 4-18 years) in South Africa who are living with HIV. We accomplish our mission through a comprehensive care model of Health & Nutrition, Psycho-Social Support, HIV & Life Skills Education, and Community Engagement.

Our integrated and holistic approach ensures that we address the whole person. Students attend (GenU's) afterschool program at our center in Khayelitsha, Monday through Friday, and consider it to be a home away from home. During afterschool programming, participants' bodies and minds are enriched as they are provided with nutritious meals and engage in fun, confidence-boosting activities and lessons led by enthusiastic facilitators.

We believe in fostering self-esteem and empowering children to be independent and capable. Once a student has successfully progressed through our program, they are equipped with the knowledge and confidence needed to care for him or herself and lead long, healthy, and productive lives.

#### **Demographic and Geographic Areas Served**

Generation Ubuntu serves children and teens living with HIV, ages 4-18 years, who are living in Khayelitsha, Cape Town, South Africa. Khayelitsha is a partially informal township located in the western portion of Cape Town with over 70% of the population living in informal shacks. The total population is estimated to be between 500,000 and 1,000,000 people; over 40% of Khayelitsha's population is under the age of 19 years.

Khayelitsha is one of the most impoverished areas of South Africa, where nearly half of all adults are currently unemployed. <sup>1</sup> Khayelitsha has an HIV prevalence of approximately 33% - one of the highest rates in the world - and is also one of the most violent neighborhoods globally.

<sup>&</sup>lt;sup>1</sup> World Health Organization (2003) <u>'Antiretroviral Therapy in Primary Health Care: Experience of the Khayelitsha Programme in South Africa'</u>



### **Organizational History**

Generation Ubuntu, NFP, was founded by Whitney Johnson in 2006.

Inspired by her experiences while studying abroad in Cape Town, South Africa and volunteering in an orphanage in the nearby township of Khayelitsha, Whitney was drawn to the cause of supporting children living with HIV. She noticed a gap in services and sustained assistance for children and teens infected. She wanted to ensure that these children received the care they needed to live long, healthy, and happy lives. Shortly after graduating from University, Whitney established Generation Ubuntu, a nonprofit organization with the mission of improving the health and well-being of children living with HIV in South Africa.

The organization began with a few children in the back of a crumbling church with weeds growing through the floorboards. Within two years, there were 30 children and additional volunteers. As the program continued to grow, Whitney successfully secured funding to establish a larger and more suitable center in Khayelitsha.

To date, the center has provided comprehensive care to over 200 children living with HIV and employs a multidisciplinary staff of 15. The GenU program strives to become a standard of care for every child living with HIV in under-resourced settings.

GenU provides Healthcare & Nutrition, Psychosocial Support, HIV & Life Skills Education, and Community Engagement to children and their families. Despite the overwhelming odds against them, every single child in Generation Ubuntu's program has not only survived, but thrived.

As CEO of Generation Ubuntu, Whitney continues to strive to engage young people and foster an empowered attitude towards HIV/AIDS around the world. Whitney was named a World Economic Forum Global Shaper in 2012 and a 2013 Young People in International Affairs Top 35 under 35 young foreigners making an impact in Africa.

### **Statement of the Problem that GenU Addresses**

According to UNAIDS, in 2014, a staggering 6.8 million South Africans were living with HIV,<sup>2</sup> more than any other country in the world. In South Africa, over 2.5 million children have been

<sup>&</sup>lt;sup>2</sup> UNAIDS (2012) ' Global Report: UNAIDS Report on the Global AIDS Epidemic 2012'



orphaned by AIDS and these vulnerable young people are at a particularly high risk of HIV transmission.<sup>3</sup>

In this poverty-stricken region, many children and teenagers living with HIV, a large majority of whom are orphans, struggle with accessing care and adhering to treatment regimes, live in poverty, with food insecurity and face neglect and stigma. UNICEF recently reported that AIDS was the leading cause of death in teens in Africa, with South Africa leading the way. AmfAR recently reported that HIV/AIDS is the leading cause of death for women in their reproductive years (ages 15-49) worldwide<sup>4</sup>. Pediatric HIV is considered a neglected disease and children and teens living with HIV have been largely overlooked. GenU focuses on children and teens living with HIV and thus fills a major gap within the healthcare and HIV/AIDS education system in South Africa.

GenU serves approximately 140 high-needs youth and their caregivers, in a country with one of the highest burdens of HIV and the largest number of children living with HIV in the world, the need for our program services is real and necessary. Further, many other children are in need of our services and would benefit from our expansion. On average, six children living with HIV are referred to our program in the township of Khayelitsha on a weekly basis. Without additional funding, we are unable to expand our program to provide these children with the health and psycho-social services these children desperately need.

As an organization based in one of South Africa's most impoverished regions, serving underprivileged youth, we feel that our work strongly aligns with the mission of The Coca Cola Company—to create goodwill and strengthen the communities served by The Coca Cola Company, and more specifically to support active healthy living, education, and youth development.

#### **The GenU Program**

We at GenU have learned that to treat a child living with HIV, we must treat the whole child in a holistic way. It is not enough to provide the necessary ARV medication, for example, without providing both a nutritious meal and adherence counseling and support. It is also not enough to provide necessities such as these without the love and psycho-social support crucial to any

<sup>&</sup>lt;sup>3</sup> Kuo, C. and Oparario, D. (2011) ' <u>Health of adults caring for orphaned children in an HIV-endemic community in South Africa</u>' AIDS Care 23(9):1128-1135

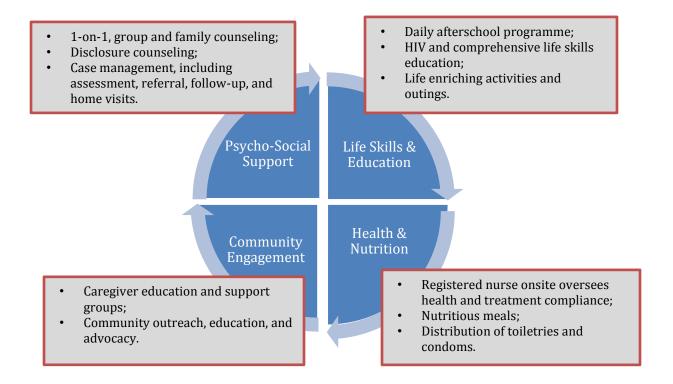
<sup>&</sup>lt;sup>4</sup> amfAR, The Foundation For AIDS Research (2016) Statistics: Women and HIV/AIDS



healthy child's development of self-esteem, resilience and self-efficacy. We have further learned that to foster healthy behavior and attitudes, education about both HIV and life is crucial. Long term change and growth can be realized and sustained when one is a member of a community and feels the warmth and sense of belonging that community brings.

This knowledge has led to the current GenU comprehensive care model. This care model is delivered to approximately 140 children between the ages of 4 and 18, all whom are living with HIV, by a multi-disciplinary team of 15 full-time staff, and rotating volunteers.

Below is an outline of the GenU Program:



More specifically, the GenU program is a comprehensive care model of four departments as follows: Health & Nutrition led by a Health Manager who is a Registered Nurse, Psycho-Social Support led by a Social Worker, HIV & Life Skills Education led by a masters trained Education Manager, and Community Engagement which is a cross cutting endeavor. Our program is delivered through an after school program, five days a week, all year including school holidays.



We have learned that our children succeed when they are provided the following GenU program services from our four departments:

#### I. Health & Nutrition Services

The Health & Nutrition Services Department at GenU provides the nutrition, health assessments, and health education that every child in the GenU program requires. As each of our children is living with HIV, it is essential that they are provided with these services.

Our Health Manager conducts total health assessments of every child, every month collecting and monitoring data such as BMI, skin and dental health and medication adherence. As she is onsite every day, she also has daily check-ins with individual or urgent/emerging cases. The Health Manager is in charge of relationship management with every clinic in Khayelitsha as well as with the Provincial and City Clinic managers. She visits every clinic, every week in order to receive referrals to GenU, follow up on any health issue noted in a child, and to gather any missing data to ensure total health of each child in our program. Finally, she is responsible for holding one on one and/or group health education sessions based on what she sees happening health-wise in a child, trends she sees in our children and/or what the national priorities are for that month. For example, she might give a group health talk on the importance of hygiene if she notes multiple outbreaks of scabies amongst the children.

Each child is provided with a nutritious meal, cooked fresh at the center every day. GenU serves over 31,000 home cooked meals a year. We employ rotating mothers (of our children) to come in and cook for the children. This helps make our children's caregivers more economically viable as well as gives them skills to potentially work outside of GenU.

GenU recognizes the importance of skin and dental health for children living on ARVs and responds to that by distributing quarterly hygiene packages consisting of everything the children need to maintain oral and overall hygiene. We distribute over 600 hygiene packages a year, the contents of which always contain items such as toothpaste, toothbrush, soap, deodorant, feminine product,s and at certain times throughout the year, will also contain facecloths and towels.

### II. <u>Psycho-Social Support Services</u>

The Social Development Department is headed by a licensed Social Worker who oversees two Social Auxiliary Workers. This department understands the importance of supporting and developing in our children an emotional resiliency towards HIV. We work to instill in our children a sense of hope, self-esteem, and self-efficacy.



The department has divided the children amongst themselves to ensure that each child is closely followed and emotional well-being is attended to prior to an issue occurring. Each child in the program has an individual treatment plan that charts their expected social development while with GenU; this is written and monitored by the Social Development Team.

This team conducts home visits of every child before they begin at GenU and then as needed throughout the child's time with GenU. This helps ensure that GenU has the whole picture of a child – do they have sanitation, water, food security and/or other people living with them? This information is imperative in ensuring the safety of and the overall social development of the child.

The Social Development department provides both the children and their caregivers with individual and group counseling as needed, including trauma counseling. HIV disclosure support is provided to both the children and their caregivers as well since one of the criteria for being part of GenU's program is that the child has been partially or fully disclosed to depending on their age.

Finally, this department provides referrals and follow up to appropriate national departments such as Home Affairs and Social Development for birth certificates, identity cards and/or social welfare and child grants.

#### III. HIV & Life Skills Education Services

We are constantly looking to our children to determine how best to provide the holistic care that they need. One crucial component of our programming is delivering HIV & Life Skills Education that aims to empower them with the knowledge and confidence needed to care for themselves and live long, healthy lives.

Our HIV & Life Skills Education department is directed by an Education Manager and facilitated by four Youth Facilitators. Our children are divided into four classrooms, based on age; each classroom is led by one facilitator who executes on our first-class curriculum. The children benefit from structured physical activities and games led by facilitators to foster overall health, motivational speakers who are related to the module being taught in the curriculum in order to reinforce the message, job skills preparation through our Senior's Program, and outings that pertain to the curriculum, enrich the child's understanding of their community and culture and allow them to live some of their dreams.

GenU's HIV & Life Skills Education addresses the following challenges commonly faced by our children:



- 1. Lack of emotional resilience towards HIV:
- 2. Lack of awareness, information, and understanding about their HIV status and appropriate healthcare;
- 3. Struggles with self-esteem and self-efficacy;
- 4. Vulnerability to high-risk behaviors such as substance abuse, unhealthy relationships and criminal activity;
- 5. Few opportunities to express themselves emotionally and creatively;
- 6. Limited communication and leadership skills.

The HIV & Life Skills Education is guided by a detailed curriculum that gives facilitators 22 modules to be covered in their classes throughout the year. These modules are critical to developing confidence in our children and teens as it allows them a safe environment to discuss myths, stigma and other daily challenges they encounter living with HIV in South Africa. Topics covered include, but are not limited to:

- 1. Body, Hygiene and Nutrition
- 2. HIV Basics
- 3. Feelings and Emotions
- 4. Friendships and Peer Pressure
- 5. Problem Solving and Decision Making
- 6. School, Learning and Leadership
- 7. Money and Finances
- 8. Violence, Crime and Gangs
- 9. Child Rights and Self Protection

The curriculum we teach our children is ever-evolving. We at GenU have learned that as our children grow, and as the knowledge of how to respond to HIV changes, their needs evolve and it is important in our holistic work that we continue to evolve with them. Many people in these children's lives have "written them off" and assume they won't succeed. As our children live and enter their teen years, we see them struggle with this reality; our program is designed to address this and to nurture their resilience, self-confidence and leadership potential.

#### **IV.** Community Engagement Services

At GenU, we have learned that as social beings, and in the spirit of "Ubuntu," our children and teens need community to feel fulfilled, be supported and inspired. We also know that long term change and growth are most likely to be realized and sustained when one is a member of a community and feels the warmth and sense of belonging that only community provides. The best way to birth the first HIV-free generation is to not only educate and build resilience in



children living with HIV, but to do the same in the community in order to rid it of stigma and allow HIV to be a routine, chronic affliction.

For this, there are many meaningful ways GenU engages with the community. GenU's Social Development team facilitates monthly caregiver workshops where the caregivers of our children come to our center and are given a safe platform to ask questions, receive education and provide feedback about the GenU program and the community. GenU children speak at and/or perform at large World AIDS Day campaigns, for example, were they advocate for stigma reduction. Annually, GenU hosts a Family Day where hundreds of community members including our children and their families have access to free health screenings including HIV testing and counselling. Our children hold annual community service events where they distribute thousands of condoms in the community and hold community awareness campaigns. Our relationship with our community of Khayelitsha is established and solid. Our staff, children and their families are all from this community and our center is based in the heart of Khayelitsha; our children are empowered by being a member of the GenU community.

### **The GenU Outcome**

Generation Ubuntu improves the health and well-being of our children and teenagers, all of whom are living with HIV. Most of our children come to us uncertain of their illness and their future, food insecure and not in control of their virus. We provide them a safe place to be children and teens living with HIV while providing them with the life skills to understand HIV, fill their food insecurity, become in control of their virus and thrive in their community and beyond.

To date, over 200 children have benefited from GenU, and we receive on average 6 additional referrals of children who desperately need our services every week. 100% of children, who have regularly attended the program, have both survived and thrived in their communities. We serve over 31,000 nutritious meals annually and conduct nearly 2,000 medical exams.

GenU tracks and monitors the services we provide through weekly and monthly data collection on our GenU specific data tools. All of our data is entered into our database which is in the exclusive control of one staff member. We track multiple health and nutrition indicators such as body mass index (BMI) as well as ARV-related indicators such as adherence levels and type of ARV. We also track the number of meals we serve, children's attendance to our program and numerous qualitative indicators of psycho-social well-being. Our commitment to our children is



to stick with them for the long term, and to make sure that each and every one of them is given the tools and support they need to excel, thrive, and shine in their community and beyond.

The stories of the children themselves are the most gratifying measurement data we could ever have. Take, for example, the story of Philiswa. When Philiswa came to Generation Ubuntu, she was malnourished, underweight, and unaware that she was infected with both HIV and tuberculosis. Both of her parents had died of AIDS-related illnesses and she was being abused and neglected by her caretakers. At age 10, she weighed only 35 pounds and tests revealed that her immunity was severely compromised, registering only 0.4% of that of a normal child. Her health was dire. Philiswa was shy, incapable of making eye contact, and would not interact with GenU's staff or her peers. After six months in GenU's program, Philiswa transformed into a bright, energetic, and healthy girl. Philiswa gained 42 pounds, was successfully complying with her medication regimen, and had raised her immune cells significantly. She became outgoing, and spent hours playing with center staff and new friends. Today, Philiswa aspires to be a social worker so that she can help other children to live fulfilling, happy lives.

#### In Closing: Healthy Kids and Bright Future of South Africa with GenU

Generation Ubuntu was created with the belief that the children of South Africa didn't have to succumb to a virus that is 100% manageable with the right medication, nutrition, education, support, and love. We still believe this—and know this—to be true; as we see children flourish and thrive at our center every day. We see that when kids are healthy, there is a bright future for South Africa. We ask that you join in this holistic work and this unwavering confidence that our children and the children of South Africa deserve and are capable of having bright futures and to realize their potential. Please join us in the spirit of 'ubuntu.' As the great Nelson Mandela, one of the worlds' most esteemed teachers, and the pride of South Africa, so eloquently stated:

In Africa there is a concept known as 'ubuntu' - the profound sense that we are human only through the humanity of others; that if we are to accomplish anything in this world it will in equal measure be due to the work and achievement of others.

-Nelson Mandela