The Situation of Filipino Children Affected by HIV and AIDS:
A Preliminary Assessment
a deafening silence

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A Preliminary Assessment

by the
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The contents of this book reflect the views of the authors, and do not necessarily reflect the views of the United Nations Children’s Fund or any other United Nations Organization.

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Acronyms

AIDS  Acquired immunodeficiency syndrome
ARV  Anti-retroviral (drugs)
CRC  Convention on the Rights of the Child
DOH  Department of Health
HIV  Human immunodeficiency virus
NGO  Non-governmental organization
PNAC  Philippine National AIDS Council
PAFPI  Positive Action Foundation of the Philippines, Inc.
PLH  Person Living with HIV
PNAC  Philippine National AIDS Council
RA  Republic Act
RA  Research Assistant
RITM  Research Institute for Tropical Medicine
STI  Sexually transmitted infection
UNAIDS  United Nations Programme on HIV/AIDS
UNICEF  United Nations Children’s Fund
WHO  World Health Organization
If children are discriminated because AIDS has touched their lives, what can we expect when many more are infected?
In almost every country that has wrestled with the many headed monster that is AIDS a distressing scenario has played out in the months and years before the population was fully aware of the problem. The scenario starts with outright denial of the existence of the problem. It then changes into the idea that it is “other people” who have the problem and are bringing it into “our country.” Then, finally, it is begrudgingly acknowledged that AIDS has arrived but still it is seen as a problem affecting people who do “bad things,” usually adults. In almost every case, by the time it is acknowledged as a problem, it is far too late to avoid many deaths of adults, youth, children, babies, male and female alike.

For UNICEF, the time has come to take a stand for the children who suffer from this strange dance of denial that we seem to never tire of repeating. Children are today being affected by AIDS in the Philippines. Their numbers are still small – the ones we know of – but like children affected by AIDS everywhere they suffer a multiple burden of loss, stigma and discrimination. It is not too early to start thinking and acting for children affected and infected by AIDS in the Philippines. The issues that affect these children, when applied to a much larger number of children that will be affected by a wider AIDS epidemic portend a devastating problem for children.

UNICEF is working to mobilize the entire planet around the issue of children and AIDS with the Unite for Children, Unite Against AIDS campaign. Why? Only 3% of all the funding generated to fight AIDS goes to children. Only 5% of HIV positive children infected with HIV receive anti-retroviral medications. This, despite the fact that in 2004 510,000 children died of AIDS, and 640,000 children were infected with AIDS. We are saying to the world that children are largely missing from the global AIDS response. They are also largely missing from the Philippines AIDS response.

By shining a light on this problem now we stand a chance of avoiding the mistakes that so many have made before. By illuminating the world of these unique children whose lives have been touched by the worst public health threat in history, we might learn some valuable lessons about children and all people who may be stricken in the future. Stigma is one of the most fearsome heads of the AIDS hydra. Stigma mixed with denial combine to keep the society living in ignorance of AIDS. The discrimination faced by the children in “A Deafening Silence” is perhaps the worst foreshadowing of the future. If children are discriminated because AIDS has touched their lives what can we expect when many more are infected?

I trust that you will hold onto this study and learn the lessons that need urgently to be internalized in the Philippines. I hope that you will not forget that children too are falling to AIDS.

DR NICHOLAS K. ALIPUI
Representative, UNICEF-Philippines
It is imperative that a face be put to the cause of the Filipino child and HIV and AIDS, in the hope that it will help shape comprehensive interventions and encourage more stakeholders to become partners in creating a better life for these children.
Introduction

The Philippines has lived with HIV for the past 20 years since 1984 when the first case of HIV was reported in the country. In the two decades that have followed, the HIV and AIDS situation has been described as having "low prevalence and slow transmission" rate. Officially, a cumulative total of 2,354 HIV cases has been recorded (National HIV/AIDS Registry, September 2005), but the estimated number of people living with HIV in the Philippines is much higher, at around 9,000 (UNAIDS/WHO, 2004). The gap between the recorded and the estimated cases signals that for every known case, there are three to four individuals out there who are undocumented, most likely unaware of their own HIV status or the implications it could have on their and their families’ lives.

Today, the HIV epidemic in the Philippines is said to be "hidden and growing", where officially documented cases continue to rise steadily while the real situation remains concealed behind the known numbers. Yet, progress has been slow in meeting the needs and growing concerns of Filipinos living with HIV, while prevention efforts are faltering compared to the interest it garnered in the late 1990s.

In 1998, the Philippines enacted its AIDS Prevention and Control Act (Republic Act 8504)—often considered a model law in the region—which designated the Philippine National AIDS Council (PNAC) as the coordinating body for the national response to HIV and AIDS. Made up of 20 government organizations and six non-governmental organizations (NGOs), PNAC was expected to guide a comprehensive response, mobilizing national, regional and local government agencies and non-government players to take action in the face of HIV. However, because of the hidden nature of HIV in the Philippines, implementation of the law has remained limited until now. Ignorance about HIV remains widespread, while people living with HIV (PLH) struggle to gain access to treatment and care options.

Stigma and discrimination seriously impede the response to HIV and AIDS. They are fuelled by fear based on misconceptions, especially with regard to how it is transmitted (e.g., "You can get HIV through mosquitoes or deep
kissing”), and associations with marginalized groups (“AIDS only affects prostitutes”). Because HIV and AIDS are associated with immoral behaviour, such as sexual promiscuity and drug use, people living with HIV are quickly labelled as “innocent” or “guilty”, depending on how they are perceived to have been infected. In society’s eyes, those who are “innocent”—children, healthcare workers who are infected on duty, and faithful wives infected by roaming husbands—are considered worthy of sympathy and support, while the “guilty” deserve their fate.

The problem with this is that it perpetuates the climate of fear—fear of association with “guilty” people, rejection, or possibly becoming a target of sensationalist media, lead to fear of talking about HIV and AIDS or taking steps to protect oneself, fear of getting tested, and fear to disclose one’s status. It impedes prevention efforts and the reach of treatment and care services.

HIV-based discrimination has been documented in the Philippines. Some people living with HIV were denied medical care by healthcare workers. Some had their HIV-status revealed to their families or the whole hospital without their consent. There were cases where individuals were refused entry or asked to leave a public place, and many experienced isolation, ridicule, insults, harassment and even physical assault from family and community members (Pinoy Plus/APN+, 2003).

This climate of fear has been detrimental, not just to Filipinos living with HIV, but even more so for the most vulnerable members of their families: their children.

Around the world, HIV and AIDS are hitting the children and adolescents the hardest. Every 60 seconds, five children under the age of 15 are infected with HIV; one dies of AIDS; and four are orphaned, losing one or both parents to AIDS. More than half of the 14,000 people newly infected each day are young people, most of them girls. Yet, globally, less than 3 percent of all funding generated to fight AIDS, goes to children.
Let us listen to the voices of these 95 children, vulnerable, affected by HIV, yet not fully aware of the impact of HIV on their lives.
The Study


Goal

This research sought to improve the understanding of the situation of Filipino children affected by HIV, as a first step towards the creation of a comprehensive response for the protection of Filipino children, while particularly addressing the needs of children affected by HIV and AIDS. The findings are expected to:

1. Raise awareness on how children are affected by HIV and AIDS in the Philippines; and
2. Promote improved policies and legislation that provide supportive and enabling environment for families affected by HIV and AIDS.

At the very least, this rapid assessment is expected to contribute to the enrichment of the picture we have of the HIV epidemic in the country in general, and to the defining of immediate and long-term responses to children affected and infected by HIV and AIDS.

Objectives

This study was undertaken with the aim to assess how Filipino children are affected by HIV and AIDS, in terms of their rights to survival, development, and participation. Specific objectives for the rapid assessment were to:

1. Gather data on children infected or affected by HIV and AIDS in the Philippines;
2. Provide comprehensive, in-depth analysis of the situation of children affected by HIV and AIDS; and
3. Formulate recommendations, based on the findings.
Methodology

The research was undertaken based on the four Guiding Principles of the Convention on the Rights of the Child (see Box 2), as well as the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS (2004), which highlights the particular vulnerabilities that children face in light of HIV and AIDS. In particular, Lundman wanted to address the specific needs of children affected by HIV and AIDS in the Philippines, by allowing these children to participate meaningfully in the process, so that they can reflect and share their views on who they are, what they think, where they are, and how they are being treated.

“Children affected by HIV” were defined as children under the age of 18 who have close family members living with HIV; those who have lost close family members to HIV and AIDS; and those who are infected with HIV. Specifically:

1. A child, grandchild, sibling, niece or nephew of a person living with HIV.
2. A child with parents who are living with HIV and are vulnerable to HIV and AIDS’ effects on the family.
3. A child orphaned by parent(s) who died of HIV.
4. A child who was born with HIV, as transmitted by a mother-living with HIV.

Due to the sensibilities and the limited number of respondents, no differentiation was made between those “affected” and “infected” in this study. In some cases, children beyond 18 were considered as well. The only exclusion criterion was the denial of parental consent to participate in the study.

A core team of non-governmental organizations and HIV support groups, as well as stakeholders and key players, first met to define: 1) the parameters of the project, 2) the strategies and approaches that may be used for research; and 3) the expected output.

Since no statistics exist on children affected by HIV and AIDS in the Philippines, the only way to access the affected children was through the documented people living with HIV. Because of the sensitive nature of the information, seven

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1 Children featured in the case studies in this report were not necessarily participants in the interviews. Some of the data were added as new cases emerged after the interview phase was completed.
(7) people living with HIV were hired as research assistants (RAs). The research assistants, active members of the Positive Action Foundation of the Philippines (PAFPI) who provide counseling and other support to people living with HIV in their assigned areas around the Philippines. They had worked with Lundayan in a previous endeavour to track the number of children of people living with HIV and expressed interest in this study. The research assistants were involved in all subsequent phases of the study, from planning, identifying respondents, developing the questionnaires and gathering data, up to preparing the final report.

Together with the research assistants, the locations of potential respondents were identified and schedules for reaching them were finalized. A total of 22 out of 33 initially-identified areas were covered, and, from an initial listing of 190 children, a total of 95 children were reached.

The following processes were used to generate data:

1. **Meetings and sharing sessions with partner PLHs**, most of whom were parents themselves. Those who were also tapped as research assistants helped in planning and tracking down other people living with HIV making use of their existing networks through PAFPI. The research assistants encouraged the people living with HIV to have their children interviewed. Additional children were located with the assistance of the hospital-based HIV and AIDS Core Teams in Tacloban and Baybay in Leyte, and in Cebu City. The commitment, perseverance, and spirit of these persons living with HIV who also served as research assistants are imprinted in this rapid assessment.

2. **Structured interviews with children affected by HIV and AIDS**, as drafted and finalized with the help of the partner persons living with HIV. The parents' and children's rights to privacy were respected. Out of respect for the parents' right to decide whether to tell their children about their ailment, the interviews did not make specific reference to HIV and AIDS. Thus, the questionnaire was drawn up based on the areas addressed in the Convention of the Rights of the Child (CRC) with questions on the children's survival, development, protection, and participation rights, and was pre-tested on children affected by HIV and AIDS who were in the care of Lundayan. This ensured maximum data output without sacrificing the privacy of the parent living with HIV. Each child in turn, was protected by a consent form signed by his/her parents or guardian.

3. **Workshops with the children affected by HIV and AIDS**, for which 12 children were selected based on proximity, age, and gender. For two weekends, children went through capacity building and art workshops. The art workshops in particular allowed the children to express themselves through dance drama, movements, poems, collages, drawings, life graphs, and autobiographies. The questionnaire was translated into a creative methodology that brought to light children's stories and experiences without forcing the information out of them. These forms of self-expression also became a way of affirmation and recognition, as children shared their works with others.
The data gathered from the interviews and children’s workshop were collated and analyzed. The study also benefited from the inputs of the research assistants, based on their personal experiences, observations from the research phase, and previous knowledge regarding the children and families interviewed. Supplemental information was gathered from people living with HIV during the report writing phase.

Limitations

The study has the following limitations:

Sample size is small. The number of children-respondents and the amount of data that could be gathered from them given the controlled circumstances do not allow the findings to be generalized to all children affected by HIV and AIDS. Nor is it intended to provide a comprehensive view of all children affected by HIV and AIDS in the Philippines.

Some reasons behind the small sample size are:

- **Difficulty reaching people living with HIV**: The lack of updated and accurate information on people living with HIV in the Philippines is one of this project’s major limitations, as it was necessary to first reach the parents living with HIV before the children could be reached. Some families had transferred away from the addresses on record or the records only indicated their municipality. If a PLH died, tracking the children was not always possible as they often moved from one relative to the other.

- **Unwillingness of parents to consent to children participating**: Many parents living with HIV were unwilling to have their children interviewed because they were afraid that it may expose themselves and their children to discrimination. Matters were further complicated by the fact that few of the parents had disclosed their status to their children.

- **Time and logistical constraints**: While the time frame of the research was extended from the original 3 months to 6 months, due to the realization that reaching the PLH and their children was more difficult than anticipated, time was still an issue. Given the wide range of locations that the RAs were required to cover, coordinating schedules with the children in school was also a challenge.

Questions had to be limited in scope because many of the children are unaware of HIV and AIDS. Most of the parents living with HIV had not told their children about the presence of HIV and AIDS in their lives. Thus, a majority of children did not know about their parents’ health condition, and could not be asked questions directly related to HIV and AIDS. The questionnaires and workshops were limited to issues about the children’s lives in general, zeroing in on their rights under the Convention on the Rights of the Child. There was no mention of HIV and AIDS in these processes; at most, what was obtained was data on what they thought of their health and well-
being. Even when there were issues or follow-up questions that RAs and workshop facilitators would have wanted to delve into with the children, the agreement with the parents not to talk about HIV was respected.

Some of the children were also too shy to talk about themselves and their families, and particularly for the workshops, some of them didn't feel like sharing their work with the other children-participants. Many of the parents living with HIV were also wary of talking about their older children, most of who seem to have left home, are missing, or have established their own separate lives. This made it difficult to paint a more accurate picture of the children's families.

While the study is not a large-scale situation analysis, the findings provide a snapshot of how children in the Philippines are currently being affected by HIV and AIDS. This is the story of what maybe come of Filipino children and HIV, particularly the challenges that arise when parents living with HIV remain silent, unable to discuss their condition with their own children.
In this study, all three children living with HIV do not know that they are infected with HIV.
The Findings

General Situation

The study reached a total of 95 children between the ages of 0-20, most of who were in the 6-11 year-old range. Overall, 52 (55%) were boys and 43 (45%) were girls. (See Figure 1.)

The geographic spread of these children’s locations indicates a presence in most areas nationwide. (See Figure 3.)

Three children were found to be infected with HIV; all three maternal orphans, living with their fathers. Of the three boys, two were sibling. All three were between 6 to 8 years old.

Forty children were orphans, having lost one or both parents, and they were almost evenly distributed between boys and girls. (See Figure 2.) There were more single orphans (those who had lost one parent; 32% of total) than double orphans (those who had lost both parents; 13%).

With regard to living arrangements, 56 of the respondents lived with at least one parent. Some of the children with living parents were being cared for by relatives. None of the children whose parents have died of HIV and AIDS live in an institution. (See Figure 4.)
Figure 3: Areas covered by the study
All children were from low-income families, and lived in the poorer neighbourhoods of different areas of the country. Many have limited access to basic services like education, community support, and health benefits. But these children carry a bigger burden than other children from the neighbourhood, as they suffer from the absence of parents as a result of HIV and AIDS, without understanding why.

![Table: Living arrangements by parental status of respondents](image)

**The Silence: Stigma and Discrimination**

The history of the HIV epidemic has been marked by denial and silence in many parts of the world. However, thanks to the global efforts of strong leaders and advocates from different levels of society—whether they were heads of state or groups of people living with HIV—voices have started to be heard.

Not in the Philippines—and particularly not for Filipino children. The lack of prevention and treatment services and options available to Filipinos, particularly for those living with HIV, 21 years after the first documented HIV case in the country is indicative of this silence. Many of the PLHs in the Philippines perpetuate this silence themselves, as they fear to be “found out” and become victims of discrimination or subjects of sensationalism.

Many mothers have not been tested for HIV, despite having husbands who are HIV-positive, out of denial or fear, as well as from simply being ill-informed about HIV and AIDS. Of course there are those who just cannot pay for the HIV test. As a result, the majority of children of parents living with HIV do not even know that HIV is in their lives.

In this study, all three children living with HIV do not know that they are infected with HIV.

Even children learn to perpetuate the silence. It was observed during the workshop that the few older children who knew of their parents’ HIV-status were wary of sharing too much information. Parents were quiet out of fear that others might find out. For these children, as with their parents, silence was the defence against discrimination.

The actual numbers are difficult to ascertain, but as HIV spreads in the country, the number of children affected by the disease will continue to increase. The silence is deadly for them.
Figure 5: Problem among children and families affected by HIV / AIDS

For every individual living with HIV, there are family members, particularly the children, who are also affected. HIV infection in an adult can lead to economic and psychological distress for a child, depriving them of their rights to health, education, shelter, for example. The child is made increasingly vulnerable to discrimination and exploitative circumstances, such as child labor, sexual exploitation, and life on the street. These, in turn, place the child at greater vulnerability to HIV infection herself or himself.

Economics: In Poverty

The children’s economic status was generally dependent on the financial state of their families as dictated by their parents’ sources of income and employment. Out of 95 respondents, 48% had working parents and 39% had unemployed parents. The remaining 13% had lost their parents to AIDS and were fully dependent on other caregivers.

Most of the children’s working parents were engaged in low-income contractual jobs. Fathers were employed as carpenters, tricycle drivers, construction workers, and seamen; mothers were vendors, food servers, seamstresses, and employees in barangay offices. There were parents who were volunteers in health offices and HIV and AIDS support networks, and those who had their own small home-based businesses such as sari-sari stores. Some of the mothers had been engaged in sex work before becoming infected, and even returned to it for a lack of alternatives.

According to the children themselves, these jobs were insufficient to provide for their family’s needs. Of the children surveyed, 68% said that their parents’ income could not provide for proper food, health, and education, while 9% explained that their parents’ income was only enough for food. Only 23% said that their family income was sufficient for their basic needs of food, education, and health services. (See Figure 6.)

Parents living with HIV also have no access to alternative skill-building venues that may allow them to obtain better paying jobs. For a significant number of PLHs, their HIV-positive status has kept them from pursuing jobs for which
they were trained or used to be employed in, mainly for the reasons of poor health. Those who require hospital care are further rendered incapable of earning for their family’s basic needs.

Relatives who have turned into caregivers for these children also come from the low-income bracket of society, which makes having children affected by HIV and AIDS in their lives a challenge. Grandparents have limited lifespans and diminishing capacities, and some of them have been forced to be part of the informal workforce to fend for their grandchildren. Aunts and uncles, meanwhile, have their own families to take care of, and little food or finances may be spared for an additional child affected by HIV and AIDS. These caregiver-aunts/uncles are forced to find ways to augment their income in order to provide for the additional member of their family. Most of the time, caregivers are unable to take on more than one child, which means separating siblings from each other—traumatic for children, particularly so for those who have lost their parent. There is little support set in place for these relatives-turned-caregivers.

Some of the caregivers indicated that their new wards had older siblings who have stopped going to school and are part of the informal workforce—doing odd jobs and living off the streets. The RAs also knew that some of the children were working themselves, but no child admitted to it.

Health and Nutrition: Not Quite Enough

The health of a child was measured by this project based on two things: 1) the child's access to medical and health services, and 2) the number of meals a child has in a day. For both these surveys, a majority asserted that they were healthy.

Eighty-four (84) percent of the children claimed that they were healthy, of which 65% said they are brought to the doctor when they got sick. (See Figure 7.) However, almost one fourth of the children who said they were healthy indicated that, if they got sick, they are not seen by a doctor. Thirty-two percent claimed that they go for regular medical check-ups, and 67% also asserted that they have had complete immunization and vitamin supplementation. For many of these children, treatment of ailments consisted of over-the-counter drugs or available medicines at the health centre.
All three HIV-positive children were sickly and needed periodical medical care. As no paediatric formulations of antiretroviral (ARV) drugs were available in the Philippines, two of the children were sharing ARVs with their mother and continued when she died. The medications were adult formulations, and despite attempts to measure out amounts for a smaller body, were still too strong, resulting in strong side effects, such as blisters on the tongue and rashes. In addition, their nutritional intake was restricted, as the blisters prevented the children from eating solid foods.

Updated information and services are not always available for pregnant women. One young pregnant mother was conflicted about whether or not to continue with her ARV therapy, as she was concerned of the effect of ARVs on herself as well as her unborn child.

With regard to food, 80% of the children said that they had three meals a day. 10% reported having only 2 meals a day, while another 10% indicated they had 1-2 meals, sometimes because they needed the money for transportation expenses to get to school. (See Figure 8) Piped water was being used as drinking water by 46% of the children, while 14% said they obtained water from a deep well; 22% claimed they drank bottled mineral water. The rest did not respond.

Despite a majority who spoke of being healthy and well-nourished, there were children with observable nutritional and medical needs. Many children showed signs of malnutrition and stunting. One young boy had an overdue tube inserted in his arm, but his parents did not have the money to bring him back to the doctor to have it removed. Another girl had suspected sexually transmitted infection (STI), but again, the parents did not have the money to take her to the doctor. Some children were known by the RAS to be often sick. None have been brought in for HIV testing.

**Shelter: Clean and Tidy, but “Tight”**

A majority of the children at the workshop claimed that they live in well-built houses with clean and tidy surroundings.

The interview results show that 80% of the children say they have private toilets in their homes, 8% admit to accessing public sanitation facilities and 12% did not respond.
Again, the majority of the children interviewed failed to account for various aspects of their homes. Most of their houses are two-room facilities, which mean a living area and one bedroom for everyone in the house. Many of the children also live with extended family members, such as grandparents and uncles.

Education: Access to Learning and HIV and AIDS Information

As with the other aspects of these children’s lives, a majority of school-aged children said they are going to school. Ten percent of the children were not yet of school-age. The bulk of those who are in-school are at the elementary level. A minority go to preschool while only a few are in college. (See Figure 11.)

Access to schooling, however, is precarious for some, due to primarily to financial constraints. Many of the children are highly active in school, participating in school-related activities such as sports, dance and music clubs, but still fear the possibility of losing their scholarships and educational assistance from private organizations.

The school performance of children is also affected by this financial instability. Some of the children forego meals in order to spend for transportation to go to school. A significant number of children are also sickly, which forces them to be absent from class and miss lessons and requirements.

Fifteen (15) percent of the affected children of school-age who were out of school may continue to be so for irresolvable reasons. Almost half of them are sickly or are physically unable to meet the requirements of daily schooling. Others have parents who are ailing, forcing the children to take care of their younger siblings or of their sick parents living with HIV.

None of the three HIV-positive children have ever been to school, although they are of school-going age. Their father tried to place them in school, but the children refused to be left at the school out of fear that they would be bullied for their rashes and blisters, the side effects of the ARVs.
So far, there is no data on the receptivity of schools to HIV and AIDS concerns, and the general silence about these children affected by HIV and AIDS makes it virtually impossible to generate such information while respecting the children's right to privacy.

Since the children themselves did not know that they were being affected by the disease, direct questions about HIV and AIDS and their schools could not be asked. However, it is unlikely that any school activities would prepare them for the realities of HIV and AIDS in their lives.

Psychosocial Issues: Who is supporting who?

For many of the children, the future is something to fear, even when they do not have a clear sense of HIV and AIDS in their lives. The children fear having their core family break up and being separated from their siblings, as much as they fear a guardian's or caregiver's inability to provide for their needs. Without realizing that HIV and AIDS had everything to do with the changes in their lives, the children are forced to face many life-shattering changes, from caring for an ailing parent, to losing a parent, to being transferred to another family. The fact is, these children's worst fears are made more possible by the silent presence of HIV and AIDS in their lives.
For many of these parents, not disclosing their HIV-positive status is a way of protecting their children from the stigma and discrimination that they themselves have had to face. By not speaking to their children of their health condition, the parents hope to at least let the children live normal lives to the extent possible.

But this is a double-edged sword. The children are, in fact, already suffering in various ways because of the presence of HIV and AIDS in their lives. Because they are not told of their parent's condition, the difficulties and losses that HIV and AIDS bring are beyond their comprehension. Impoverished as they already are, the burden these children carry become heavier as they witness their parents' suffering and are forced to "grow up" faster, taking on more adult roles.

During the workshops, children also did not admit to working to earn money, perhaps it was their way to protect their parents from being viewed as incapable of providing for their own children.

The children were already taking on the emotional burden of a caregiver, as a result of their parents' illness.

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**Case Study 2**

**Jonjon: A Change in Life**

Eleven-year-old Jonjon grew up in the province, cared for by his foster parents. They were not his real parents, but they were the only ones he knew. Jonjon's life was one of happiness and love because of the way the two had cared for him. He even admits to having abused the love sometimes, playing video games and going out with friends instead of helping with household chores or studying his lessons for school.

In October 2003, Jonjon was told by his foster mother about his real parents in Manila. That same year, he met his parents, as well as his younger brother. He was told that he also had a sister in Manila. Jonjon was given the choice to move to Manila with his family. Jonjon said yes.

When Jonjon arrived at his parents' home in Manila, he was surprised to see nurses and doctors there. He soon realized that they were in a house cum hospital, and Mama told him that this is Bahay Lingap. It wasn't explained to Jonjon why it was that doctors and nurses had to come visit his Mama Anchi all the time. But he found many children like him in Bahay Lingap, who also lived in their parent's rooms.

One day, Mama sat Jonjon and his siblings down, and told them that she was HIV-positive. Knowing of Mama's condition saddened Jonjon, but not knowing what HIV is all about and what it does to his mother's body continues to confuse him. He can't understand why his mother has mood swings, making his visits to her in Bahay Lingap difficult.

Staying with his father and brother at home, Jonjon also doesn't understand why they cannot be together as a family, and why his Mama has to constantly go to Bahay Lingap. She had to stay there especially long when his new baby brother was born.

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1 Bahay Lingap is a government facility attached to San Lazaro Hospital, where PLH and their families can stay together while accessing the medical services of the hospital.
Jonjon is now living at 17-B, without truly understanding why. And yet, he says, he is fine. He enjoys the school he goes to, as his teachers are kind. He wants to finish his studies and do work that will benefit the poor, and maybe even become president of the country. He enjoys the big spaces of 17-B and has found friends and classmates in the community. Jonjon says he is grateful to Jesus and his families for always looking out for his needs.

It had already been difficult for Jonjon to deal with the change from the quiet life in the province to bustling Manila. He is removed from what is happening to his Mama, because he doesn’t understand HIV. And while he enjoys 17-B, it is painful for him to see his family apart all the time. It is beyond this eleven year old boy’s ability to comprehend.

*All names have been changed in this story*

Emotionally, parents and caregivers are ill-equipped to handle the trauma and stress that these children are going through. And children end up feeling that they are a burden to both their parents and their caregivers, without truly understanding why.

Because of this silence, and because the children could not be asked directly about HIV and AIDS in their lives, the workshops provided a venue for 12 child-participants, out of the total 95 respondents, to speak out about what is important to them, giving a glimpse into their psychosocial state. For these children, life is not about having HIV and AIDS — it is about family and the freedom to be children.

Children mention the importance of being loved by their parents, being allowed to play freely, and being able to continue with their education; they also speak of being able to eat well, and of living happily and freely.

This same workshop also revealed the children’s concept of their rights, particularly when asked what things disregard their right to live. The children spoke of abuses in general, but also mentioned various things in particular as a form of abuse: when children are forced to do heavy work, they are made to take drugs, when they are orphaned, when they are beaten up, when they are told to leave their homes. For many, abuse may be about being deprived of something as basic as quality time with their parents, or of something as important as education and the right to play.

For the children, their sources of emotional support are first and foremost their families — parents, siblings and other relatives. For those who have availed of them, PLH support groups and other NGOs provide counselling and other services. In particular, the support and facilitation of PLH groups have played a key role in allowing parents to share their HIV status with their children, cushioning the impact and helping them with the coping and grieving processes. To break the silence, what is most important is that there is emotional support so that parents living with HIV and their children are not afraid of being alone.

7 “17-B” is a home-setting facility set up by Lunduyan for children affected by HIV and AIDS, where they can participate in interventions involving the whole family to facilitate the healing and recovery process.
Case Study 3

Mel: On His Own

The province of Bulacan in the Philippines was home to Mel for 19 years, where he lived with his Nanay (mother) and other relatives. His father abandoned him when he was a baby, and now lives in the United States. Mel didn’t meet his father until he was 17.

It was when Mel was 18 when his mother died of a stroke, leaving Mel on his own. He stopped going to school, and started working as a tour guide while waiting for his father to petition him to live in the US. It was during this time that Mel started going out with Janice, and they often went out at night with his group of friends, drinking and dining.

The drinking in his adult life was an extension of the kind of life he lived as a high school student, when Nanay was still alive. Mel had a barkada (his group of buddies) who would do marijuana and shabu after drinking sessions and in between chess and basketball games.

When Nanay died, Mel called it quits, after three years of being a habitual shabu user. He continued to be the party boy though, and clearly remembers a party he went to in 2004 – a reunion of different groups of gays, women, straight guys, and bisexuals. Food, wine, and drugs were shared, and Mel woke up with only his underwear on.

That same year, Mel was confined for three months in a hospital. With no money to pay for his release, Mel jumped from the hospital’s third floor and onto the concrete roof of the house next door. The hospital guard saw him, but Mel was fast enough to get on the street and to hop onto public transportation.

Mel returned to Bulacan, this time to live with his maternal stepbrother, Kuya Pat. But he continued to be sick, and two months after, he was brought to the hospital with the financial support of a paternal stepbrother.

This was when Mel was diagnosed as HIV-positive, and his world came crashing down around him. He did not know what to do. He felt hopeless and useless. Janice, his girlfriend through all this, feared infection and was anxious about having herself tested. None of his friends knew that he has HIV because Mel didn’t tell them.

Mel continued to live with his Kuya Pat after the diagnosis, but before the month was over, NGO workers came to speak with him about his condition. They found Mel weakened by HIV, and decided to bring him to the Research Institute for Tropical Medicine (RITM) for confinement and examination. While in the hospital, Mel felt depressed and used to just gaze for long periods at a photo of his mother. Mel’s father never visited him, which made him sad.

After RITM, Mel found himself in 17-B.

Now, life is totally different for Mel. His day consists of sleeping, TV viewing, and taking his life-saving medicines. He has cleaned up his lifestyle: no cigarettes, no drugs. A sister in the States has promised to continue funding his medical needs, even though his father still does not visit or call.

Mel considers the staff of 17-B as his family now. He is amazed at how much they have done and are willing to do for him. He has found purpose in being able to play with the younger children at 17-B, and even helping them with their studies. Mel has learned to accept his condition, and is strongly motivated to fight and survive HIV.

*All names have been changed in this story.
Protection Issues: Quięt Vulnerabilities

The general silence that pervaded the whole research process made it difficult to get data on how exactly HIV and AIDS had changed these children’s lives, including the children’s own reluctance to reveal too much information about themselves.

None of the children admitted to seeking employment themselves, even if most of the research assistants knew that they actually did. It is not improbable, considering that there is only so much that sick or absent parents can earn. For many of these orphaned children, employment is a necessity if they want to keep going to school or to simply have extra money to augment what their caregivers can give them.

Given these children’s ages, it is likely that they get odd jobs in the neighbourhood or live off of the streets. That children mentioned “doing heavy work” and “being forced to sell drugs” in the workshops as forms of abuse. This shows that they are aware of what other children are doing, if they are not doing it themselves. Child labour itself can often be hazardous. It also makes these children vulnerable to abuses by older children and organized groups that operate on the streets. Some older siblings of those interviewed had moved away from their homes. The question is: what kind of living can these children eke out on their own?

HIV-induced disruptions in family life and the same factors that drive children to work also expose them to sexual exploitation and all the ensuing hazards to their health. With sickly parents, children lose an important layer of protection. This is even worse for children who have lost one or both parents and are cared for by others. It also exposes them to sexual abuse in the home. One young girl was suspected of being molested by her grandfather’s sexually active live-in partner, but has yet to be brought to a doctor; the parents claim they do not know where to bring her. Services for child victims of sexual abuse and sexual exploitation are limited in the country, and the loss of a parent makes it more difficult for a child to find a place where they can feel safe and seek help.

In the end, the silence with which these children live is not only silence about HIV and AIDS, but about many aspects of their lives, including child labour and possibly sexual abuse and sexual exploitation. HIV-affected children face the same challenges and hardships as other children from economically underprivileged backgrounds. But their burden of silence is heavier, as they too often do not have the tools to understand HIV and AIDS and its impact on their families, living in the shadow of their own and their parents’ fear of discrimination.
Case Study 4

Nina: Growing up Alone

Nina was born and grew up in the country where her father was working as a technician. Her mother had quit her job as a healthcare worker when she got married, but had earned enough to buy a house and a car in the Philippines with her savings.

I was around four years old when my mother was first hospitalized. When I turned seven, life for me and my parents became a ‘roller-coaster ride’ that never went up!

That was when my mother became sicker than before. She stayed very long in the hospital. When she finally got out, she had to move into a house near the hospital. I had to change school to be able to be with her. When Mama lost so much weight, her friends stopped visiting us.

My parents and I returned to the Philippines when I was 10 years old. Mama had not gotten any better but was happier to be here. Her relatives are easy to reach and the health services were better. We had not yet settled down in the house my mother bought outside Metro Manila when my father was hired in the country we just left.

I was very sad because I needed Papa near me. I was afraid I would not be able to take care of Mama very well. I felt too young to be able to do so. Nonetheless, he had to go. Mama needed all the money to get well. I wanted her to be okay as soon as possible.

But that was the last time Mama saw Papa.

The first few months since Papa left, Mama found the energy to attend to my needs. She was even able to get into a small business where she got the extra money to send to my aunts and uncles in the province. I, too, adjusted to my new home, school, friends and the separation from Papa.

This did not last long though. Mama became increasingly cranky and hot headed. She seemed to be always angry at me. Nothing I did was right for her. She was blaming me for all the not-so-good things happening to her and Papa. I could not understand why I felt so guilty and sad. Maybe she was right. Because of me, for my needs and my future, Papa had to continue working away from us.

Much later, I found out that Papa has stopped sending money. Mama also learned that my father was having an affair with another woman.

It must have been very tough for Mama. We were all financially dependent on her—my aunts, uncles and I. I could not imagine how she managed to also buy her medicines on top of it all. Later, I was told she borrowed money from my grandmother and some other relatives in order to pay for her medications. She was also assisted by some organizations. But in the end, we were forced to sell our house and move to the province.

I remember, one time when she came from that hospital, she brought many small papers with the words HIV and AIDS. I asked her what these were and she said, “Some day, you will understand.”

In the province, we lived in a small apartment near my school and my relatives. Mother often had to go to Manila often for treatment, for more than a week at a time, because they couldn't help her in
the province. I couldn’t go with her because I had school, and besides, someone had to look after the house.

That is why I had to amuse myself whenever I was alone in the house. I often wore my superhero costumes and stood on my bed. I pretended I had enemies, the bad people who entered our house to steal. These bad people would never succeed in getting any of our things.

I remember one time when Mama was packing her things for Manila, she suddenly paused and gave a big sigh. She said, “Nina, please bear with me. I just need to get well.” I pretended not to hear her and continued with my drawing. After a while, I thought I should not add onto my mother’s worries. So I said instead, “I will be okay here, Mama. I am not a cry-baby and I am not afraid of ghosts!”

It was not what I really wanted to say. I wanted to say I did not want her to leave me. And that I was scared for her.

That night, like any other nights, I wished the treatment of Mama in Manila would end soon. I prayed so hard that she would get well soon so that she could come home and be with me right now. I wished that whatever was making Mama very sick would disappear, so that I would not be afraid anymore. I wished for all these to happen so that I would never be afraid to be alone.

Mama finally told me what was ailing her all these years. She also informed her sisters and brother. There was not much time left for us.

In desperation, with the help of some of Mama’s friends, I tried to go to the Philippine Embassy to help locate my father. I knew then that Mama would go. I made many trips to the Embassy, and every time I went, I felt my love for my father disappear. I told myself, I do not love my father anymore because he left Mama and me.

Wherever my mother went to the hospital in Manila and I didn’t have class, I could be at my mother’s bedside. During those times, she would be as cranky as could be. She would often tell me or her friends that “I should not have been born” or it was my fault my father left her. It hurt when she said this but I could not hold this against her. I knew she was going through awful times. She was in and out of this hospital, up to the last.

During the latter part of Mama’s treatment, many of her friends came by to find out or discuss how my life would be when Mama passed away. I would always say, “I hope Papa comes home to take me.” I really didn’t want to be cared for by my aunts or uncles. They seemed to not like me from the start. Otherwise, I preferred to live alone. I would like to continue studying. Someday, I might just be a very good artist.

After her mother’s death, Nina was first taken into her uncle’s care. He had drinking problems and was living in a troubled family life. She managed to continue her studies until NGOs finally succeeded in contacting her father, who returned to the Philippines. He was then with another woman who was expecting his child.

Nina now lives with her father and his new partner, and her newborn half-sibling. She works as the baby’s “yaya” (nanny).

*All names have been altered in this story.*
Conclusion and Recommendations

This study is but a first step towards the Philippines' contribution in achieving the global goal of reaching children affected and infected by HIV.

The silence echoes. Researchers had to fill in several gaps. There was general lack of information. There was general wariness of having names, faces and voices. These all point to one thing: the need for all stakeholders in the Philippines to take action to break the silence enveloping HIV and AIDS.

The study endeavoured to let children speak about their experiences in relation to HIV and AIDS, only to find that a majority of the 95 children-respondents had no idea it was even in their lives. Yet they were suffering its consequences—missing their parents, missing their childhood by having to grow up faster and take on more adult roles, missing out on health, on medicines, on education and on protection, and missing out on options for the present and the future. The lack of knowledge about what is going on in their parents' lives confuses the children about the kind of family life they have. Because they are not told that their parents are sick, they do not know why they are being brought to caregivers' houses, or why they are always in a hospital. The amount of money spent on medicines does not make sense to them; the lack of money for their educational needs is beyond their comprehension.

There is dilemma. The parents would rather keep silent about the disease, so as to keep their children from suffering through the stigma and discrimination. Yet, these children are and will continue to be affected by HIV and AIDS wherever they go or whatever they do, as proven by the life stories here. The lack of information about the disease, the state of confusion in which they find themselves and the loss of a strong family base cause suffering for the child. All of those are emphasized in this research, which admittedly, speaks of a very small number of respondents. What could be the implications if the complete picture of the real, nationwide scale of this problem is determined?

The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS outlines five strategic areas for action. These areas point to the need for stronger more capable families as well as supportive communities. It also emphasizes the importance of government leadership and non-government support for access to basic services, as well as addressing the particular needs of the vulnerable children. Actions that
focus on these areas allow for a holistic and comprehensive response, in which national and local stakeholders should take part.

Based on the findings, the following are areas of action that may be taken towards the long-term goal of protecting Filipino children affected by HIV and AIDS:

1. **Conduct a thorough situation analysis on children affected by HIV and AIDS.**
   The current study is only a snapshot of a small group of HIV-affected children in the Philippines. Just as there are people living with HIV out there who are not documented, there are many more children who are affected by HIV and AIDS. Efforts are being made to verify the low prevalence rate in the Philippines, and one possibility is to tie that to a system to track the affected children, along with a thorough analysis of their situation and identification of those rights that are not being fulfilled.

   The situation analysis is crucial as a first step to break the silence by raising awareness of the plight of children and to inform the development of appropriate interventions that serve the fulfillment of the children’s rights.

2. **Undertake continuous awareness-raising to fight stigma and to promote a compassionate and understanding society.**
   One reason behind the stigma and discrimination is ignorance and misconceptions about HIV and AIDS. Therefore, it is necessary to disseminate the facts about HIV and AIDS so that it becomes common knowledge. These should include clear messages about basic HIV and AIDS facts, providing simple but specific information on how HIV can and cannot be transmitted, so as to diminish baseless fears about interacting with people living with HIV.

   Messages must challenge the tendency to think of HIV as something that affects only "others" who are deviant or immoral, and not those of "us" who are normal, moral and upright. Messages must also encourage greater compassion and understanding that HIV can come into our lives in many ways, and that the stigma and discrimination can actually be just as harmful to people affected by HIV and AIDS as the physical manifestations of the illness. Education on what it is like to be living with HIV should also be incorporated into prevention efforts.

   The Global Campaign for Children and HIV and AIDS and related campaigns are ways to spark a new level of interest and awareness, but equally—if not more—important is the sustained availability of the same information and
messages through venues such as schools and healthcare facilities, so that anyone accessing the facilities will automatically and repeatedly be exposed to the relevant information.

3. **Improve access to and quality of services for prevention, treatment and care.**

Information and education are important, but these not enough to ensure a better life for children affected by HIV and AIDS. Services and access to commodities, both for HIV prevention and living with HIV, must be strengthened. Services should include counselling for prevention; before and after testing for HIV, sexually transmitted infection (STI) and HIV; and treatment for HIV, STIs and opportunistic infections. Medicines for opportunistic infections and STIs must be accessed. Anti-retrovirals (ARVs) and condoms must also be secured. For affected children, they need better access to primary healthcare, which could mean helping families to access insurance schemes or subsidies. Psychosocial support networks are also most crucial for people living with HIV and their families.

Improving the services requires appropriate capacity building of the relevant service providers and strengthening of the systems. It also means finding creative ways to integrate HIV-related services into existing services and programmes, such as the formal and non-formal education systems (e.g., facilitating the development of children’s psychosocial competencies/life skills), teen centres, parenting skills classes, antenatal care and STI clinics.

4. **Strengthen coordination among all parties.**

Disseminating information and improving services call for the involvement of a wide range of actors. For this reason, coordination is crucial to ensure a holistic response to HIV and AIDS, as well as to maximize available resources. In some cases, national and local governments need to clarify and agree upon their respective responsibilities (e.g., surveillance is a national responsibility, but who provides for HIV testing?), in accordance with the Local Government Code (RA 7160) and towards the fulfillment of the AIDS Law (RA 8504) and other relevant laws for children, such as the Special Protection of Children Against Child Abuse (RA 7610).

Especially at the local level, local government unit (LGU) leadership is key to moving the response forward. Local government units can take on the agenda of protecting children and their families from HIV, with special sensitivity to the impact on children.

Throughout, the meaningful participation of the children and families, who are affected by the local government unit decisions and interventions and who are most vulnerable to their effects, is a key principle to help ensure that the solutions are effective and sustainable.
The first challenge is breaking the silence — the silence that is violating the children’s rights to health, education, information, and to a family — and overcoming the stigma of HIV and AIDS.
Challenges and Opportunities

Challenges
The Philippines faces challenges in addressing the situation of children affected by HIV and AIDS. Considering the climate of fear surrounding HIV and AIDS, many people living with AIDS remain silent. Lessening the impact of HIV and AIDS on Filipino children is an issue. Silence after all, is what has allowed for this disease to become a global pandemic.

Sustaining the interest
The first challenge, then, is in breaking the silence—the silence that is violating the children's rights to health, education, information, and to a family—and overcoming the stigma of HIV and AIDS.

Ironically, the countries' apparent low-prevalence of HIV and AIDS poses a challenge in terms of garnering enough attention of the leaders and the people on the issue. Even the known numbers of adults living with HIV is relatively small, and services for them are limited. How can services for adults living with HIV be provided while keeping in mind the special needs of their children?

Prevention is the key in a low-prevalence setting. How can the interest be raised and sustained? There are indeed so many more pressing needs that require attention, and yet, now is the best time to act. Preventing a large-scale epidemic is much more cost-effective than shouldering heavy medical costs and lost productivity should HIV spread more in the Philippines.

Reaching the children
Another major challenge that this study highlights is in actually finding those who are affected or infected in the first place, and in reaching them with the appropriate services. As evidenced here, in this climate of silence, people living with HIV are unlikely to disclose their status to anyone, especially to their children, preventing them from accessing the services and support that they could avail of.
Opportunities
At the same time, there are also many opportunities to be maximized. The seemingly low prevalence means that there is a chance for the Philippines to avert new infections, and prevent the unnecessary suffering of many families and children.

Networks and advocates
There are vocal PLH support groups who were tapped for this study and who are now open and excited in taking action to protect their children. These PLH are powerful allies in reaching those affected by HIV and AIDS. The Philippines also has the advantage of many dedicated individuals in the government system, civil society and among health workers, as well as vocal and active NGOs who are already working with many vulnerable groups.

Access to treatments
At the national level, there is a sense of hope for improved access to treatment. In 2005, the national government is embarking on ARV procurement for 20 million pesos, long-awaited by many PLH. A portion of the ARVs will be paediatric formulations to cover 10 children.

Laws and policies
A national review of the 1998 AIDS Law (RA8504) is being undertaken during 2005, with the possibility of making it "louder" on children. Already, the 4th AIDS Medium Term Plan focuses on children as a specific vulnerable group, and spells out actions to ensure that they are included in the national HIV response.

At the local level, a number of LGUs have already supportive local chief executives and active local AIDS councils, or local councils for the protection of children that are taking on, or preparing to take on, the issue of children and HIV and AIDS. Although the challenge of securing local commitment and funds in a sustainable manner continues to be a challenge and many local councils are still struggling to become functional, the emergence of structures and political will in certain locations are certainly positive developments.

Valuing family
And finally, one should not underestimate the strength of the Filipino values placed on the family and the children. It is these values that can be the driving force in the efforts to break the silence on HIV and AIDS in the Philippines.

Unite for Children. Unite against AIDS.
Bibliography

Documents


Websites

About Lunduyan

Lunduyan para sa Pagpapalaganap, Pagtataguyod at Pagtatanggol ng Karapatan ng Pamatao Foundation, Inc., (Lunduyan) is an NGO whose vision and mission is centered on the rights of the child. It conducts activities with children from underprivileged communities, primarily in Quezon City, with the aim of empowering them to fully realize their rights as enshrined in the CRC.

As an NGO representative in the Philippine National AIDS Council and member of the Council for the Protection of Children, Lunduyan is a vocal advocate for the advancement of children's rights, and works to ensure that children are at the centre of HIV and AIDS agenda of the Philippine government.

Its research projects include collaboration with the AIDS Society of the Philippines on an intervention study, "Understanding the Psycho-Social Needs of Children," as well as the development with NORFIL Philippines of a Training for Alternative Parental Care Providers (foster parents in institutions and the communities). It works in partnership with Department of Education and various NGOs, such as ERDA, to assist children with their educational needs and requirements, and with the Positive Action Foundation of the Philippines, Inc. (PAFPI), a support group of people living with HIV, to provide livelihood projects to help children's families to cope with financial burdens of HIV and AIDS.