ASEAN SOCIAL WORK JOURNAL

Volume 13 No. 2 December 2025

ISSN : 2089-1075
e-ISSN : 2963-2404

DOI : https://doi.org/10.58671/aswj.v13i2.115
www.aseansocialwork.com

Managing Community Home-Based Care Intervention for Children Living with HIV in Jakarta, Indonesia (2009-2024): Role of Social Workers

Gracia V.P.K. Simanullang*
University Center of Excellence – HIV AIDS Research Center Health Policy and Social Innovation
Faculty of Psychology
Atma Jaya Catholic University of Indonesia, Jakarta, Indonesia
*Correspondence: gracia.simanullang@atmajaya.ac.id

Evadana Rachmat
Lentera Anak Pelangi, Jakarta, Indonesia

Johanna Debora Imelda
Universitas Indonesia, Depok, West Java, Indonesia

Kartika Anggita
Lentera Anak Pelangi, Jakarta, Indonesia

Irwanto
University Center of Excellence – HIV/AIDS Research Center Health Policy and Social Innovation
Faculty of Psychology
Atma Jaya Catholic University of Indonesia, Jakarta, Indonesia
Lentera Anak Pelangi, Jakarta, Indonesia

Received: March 23, 2025 **Accepted:** December 02, 2025 **Published:** December 31, 2025

Abstract

Children and Adolescents living with HIV and AIDS (CALHIV) are one of the most vulnerable populations, especially those living in underserved and marginal communities. This article presents lessons learned and challenges of a Community Home-Based Care (CHBC) intervention by Lentera Anak Pelangi (LAP). This intervention program was initiated as an extension service during the university's research for a Harm Reduction Program to prevent HIV infection among injecting drug users (IDUs) managed by the HIV and AIDS Research Center, Atma Jaya Indonesian Catholic University (ARC-AJCUI). LAP was established to respond to community reports about children of IDUs who were neglected by community and families. Since 2009, AJCUI, assisted by government agencies, communities and professionals have supported the children of IDUs who were impacted (affected or infected) by HIV, by advocating their families and communities lacking the right information and education about HIV, and. providing access to resources to fulfill the children's basic needs and rights. Case file data accumulated over 15 years are presented to highlight LAP journeys as one of the very few HIV community organization providing home-based and multi-disciplinary intervention programs that fills the void in Indonesia's HIV services and make significant impacts to the lives of CALHIV in Indonesia.

Keywords: *Children and Adolescent Living with HIV and AIDS, community home-based care, social workers, ARV adherence, Viral Load suppression*

Introduction

This article is a review of *a Community Home-Based Care (CHBC) for* Children and Adolescent Living with HIV (CALHIV) in Jakarta, Indonesia. This program was an extension of an outreach program conducted by the HIV/AIDS Research Center at Atma Jaya Catholic University of Indonesia (ARC-

AJCUI). In 2002, ARC-AJCUI conducted a project to prevent HIV/AIDS infection among Injecting Drug Users (IDUs). In 2009, outreach workers reported a number of children were neglected by parents or extended families, and left behind in some hospitals throughout Jakarta. Further investigation found that a few of these children were born from mothers who were infected by their IDU sexual partners. In many (most or majority) cases, female sexual partners of IDUs were not aware or told of their partners' HIV status, until the IDUs were ill, hospitalized, or died. As a result of not knowing their HIV status (IDUs and their sexual partners), horizontal and vertical transmissions could not be prevented.

Based on this initial investigation, ARC senior staff formed a small team of outreach workers. Starting with one case manager and four outreach workers, Lentera Anak Pelangi embarked on a mission to support children living with HIV (CLHIV). Initial funds were obtained from the Indonesian National AIDS Commission (NAC-KPAN), set aside from the Indonesian Business Coalition funds for HIV prevention among Key Populations (transgenders, IDUs, men sex with men (MSM), sex workers, migrant workers, and others). The relatively small funds were used to establish an outreach center for CALHIV, which was called *Lentera Anak Pelangi* (LAP). Although funding was available only for the first year, the intervention and support program was able to create a model for impactful outreach, intervention and multi-disciplinary support for the most vulnerable and marginal CLHIVs and their families that can operate with limited budgets. Since 2010, LAP has raised awareness about the vulnerable populations of CLHIV among the communities, the private sector, individuals, and civil society organizations (CSOs). To date LAP has served over 250 CLHIV and their families, has intensively educated, has monitored their medication adherence, physical and mental wellbeing, as well as connecting them to the available care and support resources. In addition, LAP has created a tight-knit community through monthly support group activities for caregivers, caregivers with special needs CALHIV, children, adolescents. Each year, LAP strives to improve its services. Since 2024, LAP has provided online consultation for anyone in need. Because each child has different needs and challenges, LAP's motto is One Child One Life.

Methods

For this review, we utilized the LAP database and case file from 2009-2024 throughout the 15 years of the program. LAP is currently the only organization that can provide longitudinal case files and health data. LAP caseworkers work closely with caregivers and health care professionals in multiple public hospitals during the CALHIV routine medical examinations, lab work (CBC, Viral Load, CD4, chest x-ray), or when they are treated for opportunistic illnesses as well as hospitalization and health rehabilitation. In many cases, health professionals refer to newly diagnosed CALHIV, often with a VL of over 1 million, severely ill or malnourished. Data and information on nutrition and living conditions were obtained from periodical visits to the CALHIV homes. Beneficiaries were assisted in registering for national health cards to access health care, obtaining Anti-Retroviral Therapy (ART), managing opportunistic infections that occur when the immune systems are compromised (Opportunistic Infections - OI). Pareto of OI in CALHIV, especially in the case of late diagnosed CALHIV, include Tuberculosis (TB), prolonged diarrhea and wasting, febrile seizure, meningitis, and pneumonia. CALHIV is also prone to CMV, Hepatitis B and C, toxoplasmosis, candidiasis, dermatitis infections. OIs are a major cause of illness and death in people living with delayed, untreated or advanced HIV and are the key indicator of progression to AIDS.

Initially (2009-2011), LAP case workers identified the first 37 cases of CLHIV from healthcare facilities and communities. As a university-based intervention unit, LAP had no facilities for institutional care. Therefore, one of the biggest challenges early on was advocating families, communities and government for the rights of these children as defined in the United Nations Convention on the Rights of the Child (UNCRC), encompassing survival, development, protection, and participation. The poverty of the study population's primary and extended families was a contributing factor in their deteriorating and complex conditions. The families or caregivers did not have sufficient resources to meet daily needs, enroll them in school, obtain medical treatment and care. Over 76% of the CALHIV has lost one or both parents. The majority are cared for by a single parent or grandparent with compromised living and health conditions.

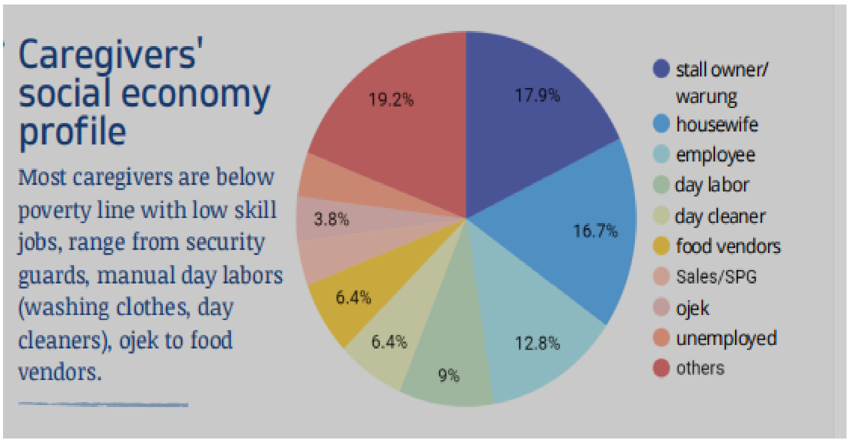

Figure 1. Caregivers socio-economic profile
Source: LAP Case Record (2024)

For LAP, the socio-economic profile of caregivers plays a critical role in shaping program feasibility and outcomes. Most caregivers live below the poverty line and earn unstable daily wages in low-skill, informal jobs such as manual labor, trash pickers, online transportation, or street vending. These conditions reflect a broader context of limited resources, where economic instability, long and uncertain working hours, and low educational attainment constrain caregivers' ability to consistently and adequately support CALHIV needs, making ART adherence, clinic attendance, and psychosocial wellbeing of CALHIV a tantalizing challenge. Recognizing these structural challenges, the intervention design integrates flexible and differentiated service delivery, simplified HIV care educational info sessions, and linkage to social protection schemes to adjust to the caregivers' realities of life. – LAP's empowerment of the caregiver as a key agent of support is essential for sustainable, community-based HIV interventions in resource-constrained urban settings.

Model Intervention

The literature review regarding childcare models in Thailand and countries in Africa, suggests that CHBC is the best approach in a setting with limited resources. A CHBC intervention model is a system where individuals receive provision of care, treatment, and other services including medical and social support for people living with HIV and AIDS, within their own homes, maintained by family members and/or community volunteers. This model is especially recommended for people with chronic and terminal diseases and for children (Phoro et al., 2005; van Graan et al., 2009; USAID Nepal, 2010). In CLHIV care, the primary caregivers are their biological parents or any member of extended families. However, this review warns that the CHBC approach should not be viewed as an attempt to shift the responsibility of the government to these children and families. The literature supports the concept that the government should recognize and acknowledge the volunteers render to the community (Qalinge, 2014). State actors may provide extra help through accessible programs such as social protection programs.

Since its inception, LAP has been committed to providing professionally managed community-based services. Data management is continually improved and expanded through accountable case work and case filing. Program development was planned based on data to ensure the programs are relevant to the needs and trends. LAP case workers performed case analysis and casework practice to find solutions through interdisciplinary teamwork so that LAP can provide direct impacts and benefits for CALHIV within the limited financial constraint optimally. In developing our CHBC program, our outreach case workers were assigned to support and educate families and local communities in taking responsibility for CALHIV care at home. Due to a lack of HIV, extended families tended to fear infection and refused to care for the children at home. As a result, there were a number of cases of neglected CALHIV. There were cases of children who lived with the extended family, but were isolated from other family members. Being cared for by their own family or extended families is the only and best option for the survivors of CLHIVs.

The key to success of the LAP intervention model was the development of a positive relationship and communications among the case worker, caregivers, communities, healthcare workers, and partner network (government and non-government organizations). Through continuous HIV education and advocacy to the families, communities and public audience, LAP beneficiaries' families and a number of their communities become aware that CALHIV is not something to be feared.

Due to limited funding, LAP was only able to serve around 80-100 CALHIV each year. During the COVID-19 pandemic, with mobility restrictions, LAP extended its outreach program through online platforms and provided more than 40 online consultations to families/caregivers caring for CLHIV throughout Indonesia, in addition to the existing beneficiaries. The hybrid in person and online consultations enabled LAP to expand its services and share the 15 years of expertise to many more families caring for CLHIV in Indonesia. The hybrid model also allowed LAP to serve many more beneficiaries with less cost. To make the hybrid model effective in managing and supporting CALHIV and families, LAP conducted differentiated service delivery by categorizing the beneficiaries into intensive (those with VL more than 40, or with poor health, malnourished, and those who need additional psychosocial support) and non-intensive (stable VL and health, have better family support and care). Among them are 47 children and adolescents with disabilities (including cognitive and intellectual, neurologic, and neuro-skeletal disabilities).

During the Covid-19 pandemic, 2020-2022, LAP case workers observed that adolescents have a higher risk of Loss to Follow Up (LTFU). Therefore, in August 2022, LAP initiated a Peer Support Group and Youth Program to mitigate the risk. As of August 2024, LAP has served 252 CLHIV and their caregivers, including 44 online beneficiaries. The number of beneficiaries and the LAP community continue to grow.

Results and Discussion

Growing up not knowing HIV status: Challenges

Since HIV/AIDS is a chronic infection, CLHIV experience changes according to the physical, mental, social, and emotional development of the child. In early 2009, all LAP beneficiaries were 0-12 years old. A 2022 profile of LAP beneficiaries (see below) shows the shift of beneficiaries age as our beneficiaries have reached the age of adolescence, in addition to new adolescent's beneficiaries of whom the majority were LTFUs.

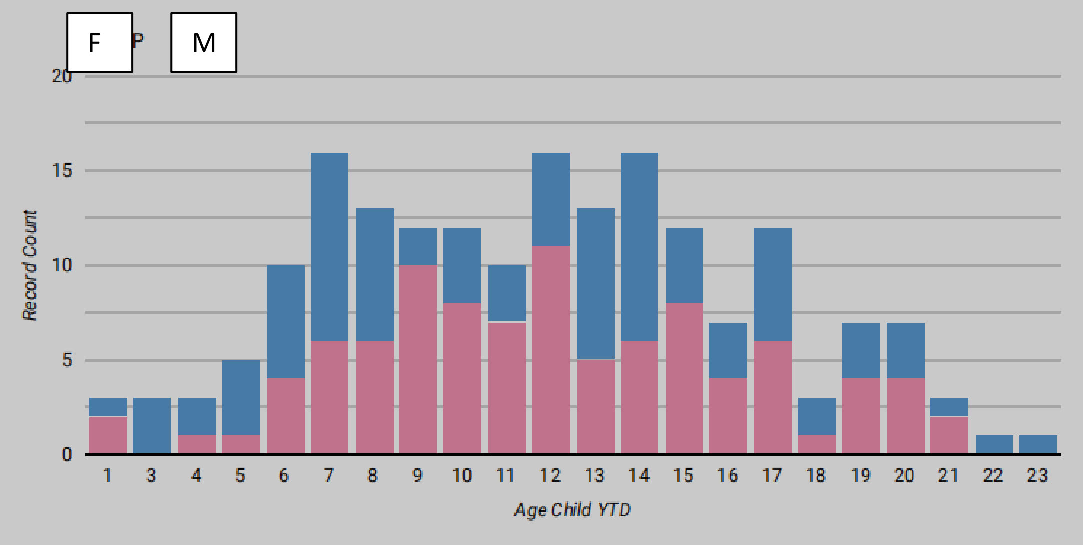

Figure 2. CALHIV profiles in LAP (2022)
Source: LAP Case Record 2022 (count 185)

The growing maturity of children raised several programmatic challenges. The first was to maintain children taking ARVs consistently to achieve an adherence level (95% or higher) for the ARV to effectively suppress the VL to be undetected (VL of 0-40). After so many years of consuming ARVs (The majority had to take adult medications as pediatric ARV in Indonesia is not widely available) and dealing with the ARV's side effects, many of the children were struggling to maintain high adherence level, a few refused to take medications by hiding or throwing away the medications without the knowledge of the caregivers.

The second challenge was in the case of vertically transmitted CLHIVs. Most of them did not know of their HIV status at an early age. WHO recommends school-age children (6-10 years old) to be partially disclosed about their illnesses. Partial disclosure involves informing children that they have an illness that requires them to take daily medications without naming HIV as the illness. At age 10 and above, WHO recommends children to be fully disclosed, which includes explaining the illness in detail and naming HIV as the illness. However, LAP observed that most children or even a few adolescents' maturity was not yet at the point where they were ready to receive full disclosure. In addition, the caregivers were very hesitant to disclose due to fear of the consequences: stigma, discrimination, reactions of children to the caregivers, or ability of children to keep it as confidential information to their friends or teachers, and many other concerning reasons.

Thirdly, a number of adolescents and young adults who were unaware of their HIV status or not well informed of the transmission risk, started to explore and engage in a myriad of risky behaviors, from having intimate-sexual relationships, including engaging in commercial (online) sex, gang fights, to using controlled substances.

As LAP supports more adolescents and a number of young adults, it became apparent that a comprehensive disclosure program was an urgent matter. Disclosure is a process in which an individual is fully informed about the HIV status and its risk. Disclosure is not a one-time event; it is a continuous effort that has to be conducted in multiple phases spanning over months to over a year to mitigate the negative psychosocial impact of this life changing event. It starts with the preparation and readiness assessment of the caregiver and CALHIV and coordination with the health professional. To date Indonesia does not have a standard process on disclosure, and more importantly does not have adequate resources for post disclosure support and monitoring. Since early 2024, LAP with the assistance of AJCUI and health professionals (doctors, psychologist, psychiatrist with experience in the pediatric and adolescent HIV care) conducted research with multiple sources (Thailand, US, Africa) to create a comprehensive disclosure training manuals with the objective to be utilized as the national standard.

Fourthly, adolescents transitioning to young adult (18 and above) need to be productive and earn a living. There is a need to prepare them to enter the workforce. This is a tremendous challenge because a number of children and adolescents quit formal education as early as elementary school due to the families' low education background, financial or health and mental conditions. LAP sees the need for life skills education and career development. However, LAP cannot do this alone.

Children's health status prior to LAP intervention

Indonesia has one of the lowest achievements in meeting the triple 95 global HIV target. As of December 2024, based on the Health Ministry annual report, Indonesia's achievements were 60-67-56. (342.977 of HIV cases are known, 231.247 received ART, 128.367 of those who received ARTand have successfully suppressed the VL to undetected). Voluntary Self Testing is low due to high stigma and discrimination; Prevention Mother to Child program (PMTCT) in Indonesia was only made available in 2016 and the implementation of PMTCT is sporadic due to geography and funding challenges. Adding to the challenges, Early Infant Diagnosis is not conducted consistently. Thus, the HIV transmission of non-key populations in Indonesia goes undetected and growing.

Delayed HIV Diagnoses

Most LAP's beneficiaries did not know that they had HIV until they became symptomatic with various OIs. Some were severely ill that caused permanent health problems and disabilities. Because of the persistent illnesses due to compromised immune systems, these children were then tested for HIV.

Based on LAP Case Records from 2009-2024, 193 CALHIV already have symptomatic opportunistic infections; 164 children were recently diagnosed before becoming LAP beneficiaries. Per disease category based on the Center for Disease Control (CDC – USA) Childhood HIV-Related Disease Categorization, 88 CALHIV already progressed to AIDS prior to joining LAP. TB topped the list (29.3%), followed by chronic and persistent diarrhea (18.1%), and febrile seizures (12.1%).

Delayed HIV diagnoses and ART treatment, as well as the poor health conditions of CLHIV becomes the first line of care for LAP case workers. LAP works with caregivers and health professionals to immediately access the child to testing and ART program, which is available for free at government healthcare facilities. LAP with the assistance of multiple sponsors, prioritize these children for nutrition and medical support in order to sustain and improve their health. In a number of cases, HIV diagnoses were too late: a number of children passed away even with the support and monitoring from LAP.

The lack of medical intervention prior to becoming a beneficiary of LAP is a big programmatic challenge for LAP. All children have had access to ARV (combination of tenofovir, lamivudine, and efavirenz). Prior to joining LAP, beneficiaries were not receiving ARV, which is standard treatment for people diagnosed with HIV. (ARV treatment, antiretroviral therapy, refers to the use of medications to treat HIV infection. These drugs, known as antiretrovirals (ARVs), work by suppressing the replication of the virus in the body. While ARV treatment cannot cure HIV, it can significantly slow down the progression of the disease, improve immune function, and reduce the risk of HIV transmission.

Low Adherence leading to death

As it is a tremendous challenge to require a child to take regimented daily medications which some of the meds are not in the child-friendly form (adult tablets which are too big for children to swallow,, bitter taste, and difficult to cut due to the consistency of some of the tablets as well as reduced effectiveness when cut) 60% of children did not have good adherence to ART, or completely abandoned ART, which cause drug resistance and ineffectiveness in suppressing the VL and opportunistic infections leading to high morbidity and deaths. From 2009-2024, LAP has lost 37 beneficiaries, with mortality percentages per year fluctuating between 0 and 6.90.

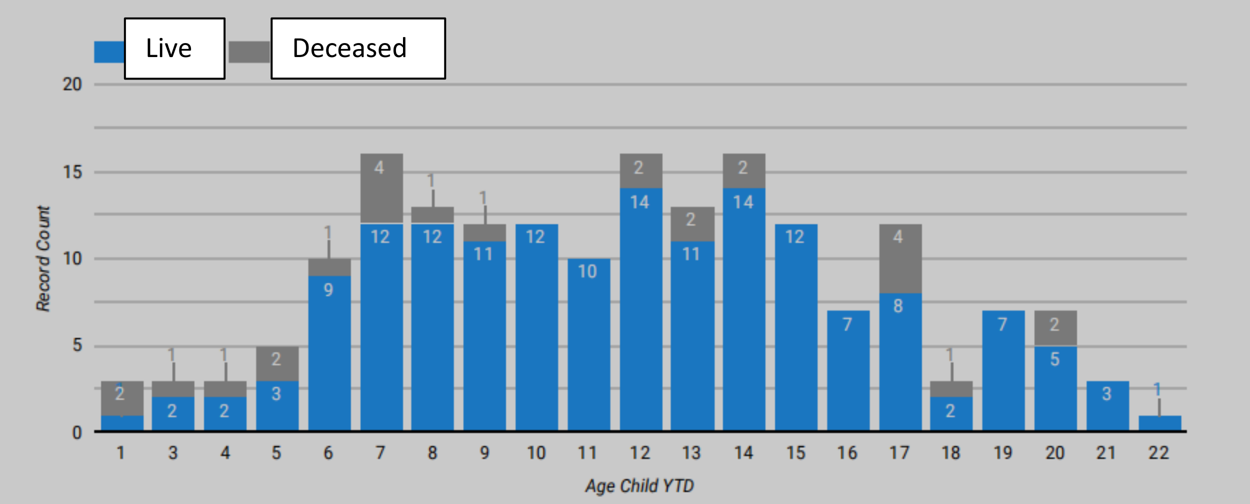

Figure 3. LAP's beneficiaries: CALHIV who are alive and CALHIV who have died based on age
Source: LAP Case Record 2022 (Record count: 183)

Improving psychosocial and mental health support

From published evidence, we have learned that children and adolescents with HIV may live longer when supported by family, community or peer in school, and religious institutions (van Graan, 2009; Khosa, et al, 2014; Busza, et al., 2014; Mushamiri, et al., 2021). Since its inception, LAP invested its resources in advocacy to reduce exclusion and discrimination, which greatly impacts the mental, emotional, and physical well-being of its beneficiaries and their families. The disclosure program was a planned and systemized activity to help children understand their HIV infection status. The initial program was assisted by doctors or health workers, which involved parental psychoeducation. Once the child was notified, further information can come from parents, or volunteers, or available health workers. Disclosure is not completed in just one meeting, but in stages. Each stage (initially called partial disclosure, then full-disclosure, and post-disclosure) includes aspects of mental health (shock and grief) and psychosocial support (negative emotion to parents or caregivers or to oneself).In 2023 and 2024 LAP initiated small studies assessing the mental and emotional status of teenagers both those who had participated in the full disclosure program (n = 42) and those who have not undergone disclosure (n = 34). The studies measured various mental health issues.

Generalized Anxiety

Symptoms of generalized anxiety are a daily condition that is felt in the form of unstable emotions, and occasional fear, confusion about plans or goals for daily activities, and reduced interest in socializing with peers. This condition is measured using 7 statements that ask teenagers to report how many days in the last two weeks they felt anxious. Each statement has four answer choices ranging from never (0), a few days (1), almost every day (2), to every day (3). Scores are assessed in the form of a scale to state that: 0-4 minimal anxiety, 5-9 mild anxiety, 10-14 moderate anxiety, 15-21 severe anxiety (Spitzer et al., 2006).

Table 1. Anxiety Symptoms by Severity Category and Disclosure Status (N=76)

Category	Total Frequency (%)	Full Disclosure Frequency (%)	Non-Disclosure Frequency (%)
Severe (15-21)	5 (6.58)	5 (11.9)	-
Moderate (10-14)	11 (14.47)	9 (21.43)	2 (5.88)
Mild (5-9)	18 (23.68)	10 (23.81)	8 (23.53)
Minimal (0-4)	42 (55.26)	18 (42.86)	24 (70.59)
Total	76 (100)	42 (100)	34 (100)

Source: LAP Case Record 2024

Table 1 above shows that around 21% of the total participants reported having moderate to severe anxiety symptoms with 7% of participants reporting experiencing severe anxiety symptoms. Children and adolescents who had complete knowledge of their HIV status were more likely to report symptoms of generalized anxiety than those who had not been informed of their HIV status. Only about 5% of participants who had not been informed about their HIV status reported moderate anxiety symptoms, while 95% of them reported symptoms of mild to moderate anxiety.

Mental health assessments suggest that having been informed about their HIV status may increase the risk of experiencing higher symptoms of depression and anxiety among CALHIV. Their perception of the disease has the potential to be a strong significant factor in the mental health of CALHIV and it is therefore important to design interventions that can reduce negative perceptions about HIV and empower them with accurate knowledge and understanding of HIV, including care, treatment and prevention, which can play an important role in helping them overcome their disease, maintain their health, and better adhere to their treatment (Simanullang, G.V., 2024). Routine mental health screening is highly recommended (UNAIDS, 2023) and psychological and social support should be included in HIV programs for CALHIV.

Symptoms of Depression

Daily anxiety may lead to a condition of feeling loss and helplessness. If help is not accessible to children, the feelings may grow in intensity and frequency until children may isolate and harm themselves. Participants were asked how often they experienced each of 9 depressive symptoms per day during the past two weeks. Each statement allows one of three possible answers ranging from never (0), several days (1), almost every day (2), and every day (3).

Table 2. Depression Symptoms by Severity Category and Disclosure Status (N=76)

Category	Total Frequency (%)	Full Disclosure Frequency (%)	Non-Disclosure Frequency (%)
Severe (20-27)	1 (1.32)	1 (2.38)	-
Moderately Severe (15-19)	4 (5.26)	4 (9.52)	-
Moderate (10-14)	21 (27.63)	13 (30.95)	8 (23.53)
Mild (5-9)	26 (34.21)	15 (35.71)	11 (32.35)
None (0-4)	24 (31.58)	9 (21.43)	15 (44.12)
Total	76 (100)	42 (100)	34 (100)

Source: LAP Case Record 2024

The table above shows the frequency and percentage of depressive symptoms by severity category among 76 adolescent participants. Around 34.21% of the total participants reported moderate to severe depressive symptoms. Children and adolescents who had fully disclosed their HIV status reported a higher frequency of depressive symptoms than those who had not disclosed their HIV status; 42.85% reported moderate to severe depressive symptoms.

Conclusion and Suggestions

Conclusion

Children and Adolescents living with HIV need to develop motivation, resilience and self-care skills. Every day they try to find that living is worth preserving while consuming meds with side effects, often without information, and facing negative responses from their own families and communities. In LAP, establishing trust between social workers, children, and parents has sparked love, hope, respect, and passion for everyone involved in this project.

Lesson-learned

1. Home-based care for children with HIV provides ample opportunities to mobilize social capital at the grass-root level, thus mitigating the effect of limited public resources.
2. Training staff to respect a child's feelings and to acknowledge their needs is an essential element in forming a relationship. In this program, the assessment of a child's needs guides the case manager's interventions to find solutions to our populations' psychosocial problems.
3. Although working with parents and caregivers on support and finances is always a challenging situation, outreach and social work practice in advocating for services through a network usually resolved the problem.
4. Addressing mental health and social issues is a basic part of social work with this population. especially when our beneficiaries are no longer children. Psychosocial assessment has to be standardized and used to support our daily programming. Addressing mental health and social issues is a fundamental aspect of social work with this population, especially when our beneficiaries are no longer children. Psychosocial assessment must be standardized and consistently integrated into daily programming to ensure comprehensive support. Standardization involves the use of validated tools and frameworks to assess key indicators such as symptoms of depression, anxiety, and early warning signs of risky behaviors (e.g., substance use, self-harm). It also includes evaluating the presence and quality of social and community support, as well as identifying opportunities for advocacy and empowerment. By systematically incorporating these dimensions, social workers or practitioners can better tailor interventions to meet the evolving needs of adolescents and young adults.

Future Challenges and Directions for Social Work Education

Indonesia is still struggling with an HIV and AIDS epidemic. More women and children will continue to be infected, and their problems and needs will become very complicated. These are a number of future challenges:

1. Since the closing of the HIV/AIDS National Commission in 2017, the national coordinating mechanism for HIV and AIDS is not yet in place, TB and Malaria have been added to their already complex missions. At the same time international funding will slowly diminish as Indonesia moves into being identified as a middle-class country.
2. The failure to stop new HIV transmission of non-key populations means that women and children, living among the general population, is considered not urgent.
3. The CHBC intervention is the recommended model in resource limited settings (USAID Nepal, 2010; Osafo et al., 2017; Mushramiri, 2021; Tomlinson; 2024). To be effective the model should be managed by social workers who are prepared to work within an interdisciplinary framework. Social workers also need knowledge and skills in dealing with major factors that maintain chronic and extreme poverty such as structural injustice fueled by stigma and discrimination, and the consequences of climate change on poverty and emerging pandemics.
4. Social workers need to be resilient, characterized by those who are not easily give up and committed his/her work despite hard and challenging situations, including team members and the most vulnerable population in this program – CALHIV. In order to be resilient, she/he requires advanced knowledge, model, and skills to promote health and support CALHIV and their families despite the challenging environment (Laro, 2023).
5. Within the micro-skill domain, social workers are challenged to network with various institutions and professions, to design and provide psychosocial and mental health prevention, and to advocate for meeting basic needs and protection of CALHIV and their caregivers.
6. Since the world has become digitally saturated, social work education should re-evaluate their curriculum and facilities to ensure that social workers in training are trained for the future.

To train social workers to obtain such capacities, the curriculum of professional social workers should ensure the following requirements:

1. Every graduate of a social work education should learn key macro and micro skills and knowledge. They should be versed in rights-based policy and effective communication at macro and micro settings.
2. Improve the hours and quality of problem-based learning by cutting unnecessary contents which are not relevant to the future challenges of the profession. For instance, overly theoretical or outdated courses, redundant historical overviews or abstract philosophical debates, can be reduced in favor of applied learning modules that might include case simulations on gender-based violence response, digital outreach for marginalized youth, or cross-sector collaboration in disaster response scenarios.

3. Improve the hours and quality of curriculum on Case Management and Data and Knowledge management to support evidence-based intervention practices.
4. Highlight teamwork and project-oriented learning, especially through multidisciplinary internships in relevant institutions and communities.
5. Expose and create opportunities to learn about digitally enhanced social work practice and intervention.
6. Students who choose to develop his/her career in the social work profession should have clear personal values and ethics adopted by the professional organization.

Acknowledgement

The authors would like to acknowledge the contribution of all the participants - the children and their families who contributed and shared their time and personal life experience to this program, each of the Lentera Anak Pelangi staff from 2009-2024 who has provided invaluable support and knowledge into this program, and all LAP's partners and donors, who has made everything possible to run the program.

Author/Authors Brief Bio

Gracia V.P.K. Simanullang

Director, University Center of Excellence – HIV AIDS Research Center Health Policy and Social Innovation, Atma Jaya Catholic University of Indonesia, Jakarta, Indonesia. Lecturer, Faculty of Psychology, Atma Jaya Catholic University of Indonesia, Jakarta, Indonesia. MSc in Health Psychology (The University of Sydney, Sydney, Australia); Ph.D in Public Health (University of Illinois Chicago, Chicago, USA). Research Interests: Children, Adolescents, Women, HIV, Health, Mental Health, and Psychosocial Interventions among marginalized populations.

Evadana Rachmat

Director, Lentera Anak Pelangi, Jakarta, Indonesia. MBA (Haas School of Business at UC. Berkeley, California, USA) and BSc in Industrial Engineering (Northwestern University, Illinois,USA).

Johanna Debora Imelda

Associate Professor, Department of Social Welfare, Faculty of Social and Political Sciences, Universitas Indonesia. MA in Population and Development Studies (the Institute of Social Studies, The Hague, The Netherlands); MA in Medical Anthropology (Universiteit van Amsterdam, The Netherlands); Ph.D (the Faculty of Social and Behaviour, Universiteit van Amsterdam, The Netherlands). Concerns: Children, Women, and Health. Recent publications: Book Chapter: Tacit Power: A Case of HIV- Positive Housewives in Indonesia. (The SAGE Handbook of Global Sexualities, 2020); The Dynamics of Power Relations and Injunctive Norms on Child Participation in Development Planning (Jurnal Ilmu Sosial dan Ilmu Politik Q3 SJR 2021=0,17, 2023); Book Chapter: Economic Imperatives and Implementation Biases Inhibit the COVID-19 Response (seajunction, 2023).

Kartika Anggita Tanuwijaya

Psychosocial Advisor, Lentera Anak Pelangi, Jakarta, Indonesia. Board member, PETKI (Association of Indonesian Christian Blind). M.InterDevPractice in International Development Practice (Monash University, Australia). Research interests: disability & social inclusion, marginalized population, children, and development. Recent publication: 2024. Finding alternative community-based learning delivery for parenting skills during Covid-19 for mother with children aged 0-3 years old. (Front. Educ. 9:1386679. DOI: 10.3389/feduc.2024.1386679).

Irwanto

Full-time Professor, Lecturer, Faculty of Psychology, Atma Jaya Catholic University of Indonesia, Jakarta, Indonesia. Founder and Advisor, Lentera Anak Pelangi, Jakarta, Indonesia. Senior Advisor, University Center of Excellence – HIV AIDS Research Center Health Policy and Social Innovation, Atma Jaya Catholic University of Indonesia, Jakarta, Indonesia. Adjunct Lecturer, Faculty of Politics and Social Sciences, University of Indonesia, Depok, Indonesia. Post-doctoral Fellow, Department of Community Health, University of Illinois, Chicago, USA. MSc. and PhD. In Child Development and Family Studies, Purdue University, Indiana, USA. Expertise: children, youth, and young adult with drugs and HIV, disability, stigma and discrimination, leprosy Initiatives, violence against children, and the rights of children and member of social minority groups. Recent publication: Incorporating acute HIV infection screening, same-day diagnosis and antiretroviral treatment into routine services for key populations at sexual health clinics in Indonesia: a baseline analysis of the INTERACT prospective study (Journal of the International Aids Society, 2025).

References

Busza, J. Besana, G.V.R., Mapunda, P., Oliveras, E. (2014). Meeting the needs of adolescents living with HIV through home absed care: Lessons learned from Tanzania. Children and Youth Services Review, Vol. 45(October): p137-142. H

Ferrand RA, Simms V, Dauya E, Bandason T, Mchugh G, Mujuru H, Chonzi P, Busza J, Kranzer K, Munyati S, Weiss HA, Hayes RJ. The effect of community-based support for caregivers on the risk of virological failure in children and adolescents with HIV in Harare, Zimbabwe (ZENITH): an open-label, randomised controlled trial. Lancet Child Adolesc Health. 2017 Nov;1(3):175-183. doi: 10.1016/S2352-4642(17)30051-2. PMID: 29104904; PMCID: PMC5656092.

Khosa, J.Z,& Gutura, P. (2014).The roles of social workers and community volunteers in providing services to foster care children living with HIV in South Africa: A scoping review. Social Work & SociSaol cSicaileWncoerskR&eviSeowci2a4l (S2c)i,en6c-e3s2R. hevttipews://1d8o(i1.o)rpgp/1.105.1-39021/swssr.v24i2.2014

Laro, A. L. (2023). Resilient Social Work Practice: From the Experiences of Filipino Social Workers. ASEAN Social Work Journal, Vol 11:2. https://10.58671/aswj.v11i2.56

Mushamiri I, Belai W, Sacks E, Genberg B, Gupta S, Perry HB. Evidence on the effectiveness of community-based primary health care in improving HIV/AIDS outcomes for mothers and children in low- and middle-income countries: Findings from a systematic review. J Glob Health 2021;11:11001.

Osafo,J., Knizek, B.L., Mugisha, J., & Kinyanda, E. (2017). The experiences of caregivers of children living with HIV and AIDS in Uganda: A qualitative study. Globalization and Health, Vol 13:72. DOI10.186/s12992-017=0294-9.

Phoro, S.N. & Tolfree, D. Family and Community-Based Care for Children Affected by HIV/AIDS: Strengthening the Front Line Response. IIn J. Wlliamson (2005). A Generation at Risk: The Global Impact of HIV/AIDS on Orphans and Vulnerable Children. Chapter 1. London: Cambridge University Press.

Qalinge, L. (2014). Community home-based care programme: a marginalised key community resource. Social Work/Maatskaplike Werk, 47(1). https://doi.org/10.15270/47-1-142

Rochat TJ, Mitchell J, Stein A, Mkwanazi NB and Bland RM (2016) The Amagugu Intervention: A Conceptual Framework for Increasing HIV Disclosure and Parent-Led Communication about Health among HIV-Infected Parents with HIV-Uninfected Primary School-Aged Children. Front. Public Health 4:183. doi: 10.3389/fpubh.2016.00183.

Richter, L. M., Sherr, L., Adato, M., Belsey, M., Chandan, U., Desmond, C., … Wakhweya, A. (2009). Strengthening families to support children affected by HIV and AIDS. AIDS Care, 21(sup1), 3–12. https://doi.org/10.1080/09540120902923121

Simanullang, G.V. 2024. Emotional and Behavioral Health among Adolescents Living with HIV in Seven Cities in Indonesia. Ph.D. Dissertation. Department of Health Policy and Administration, University of Illinois Chicago.

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). Generalized Anxiety Disorder 7 (GAD-7) [Database record]. APA PsycTests.https://doi.org/10.1037/t02591-000 https://www.phqscreeners.com/select-screener

Tomlinson, M., Karlow, M., Stewart, J., & Makheta, M., Sekotio, T., Mohale, S. et al. (2024). A community-based child health and parenting intervention to improve child HIV testing, health, and development in rural Lesotho (Early Morning Star): a cluster-randomised, controlled trial. The Lancet HIV. Vol. 11(1): p42-51.

UNAIDS (2023). Home and Community base care.

UNAIDS (2024). Data 2024.

USAID Nepal, FHI Nepal, AFSA (2010) Community and Home-based care for Adolescent and children Living with HIV: Standard Operating Procedure Manual.

van Graan, A, van der Walt, E., & Watson, M. (2009). Community-based care of children with HIV in Potchefstroom, South Africa. (2009). https://doi.org/10.2989/16085900709490426

USAID Nepal (2010). Community and Homebased care for Adults anf children living with HIV: Standard Operating Procedure Manual.

Wu L, Li X. Community-based HIV/AIDS interventions to promote psychosocial well-being among people living with HIV/AIDS: a literature review. Health Psychol Behav Med. 2013 Jan 1;1(1):31-46. doi: 10.1080/21642850.2013.822798. Epub 2013 Aug 6. PMID: 25264499; PMCID: PMC4164241.