**Submission to the High Commissioner's report on Human rights in the context of HIV and AIDS**

**Profile Submitting Organisations**

This paper is a joint submission of HIV and Human Rights civil society organisations in Indonesia as part of Advocacy Network for Public Services on Health. The Network is made up of Lembaga Bantuan Hukum Masyarakat (LBHM)**[[1]](#footnote-1)**, Lentera Anak Pelangi (LAP)**[[2]](#footnote-2)**, and YAPPIKA-ActionAid Indonesia (YAA Indonesia)[[3]](#footnote-3). This paper was developed based on the experience and evidence from the field work of LAP and the advocacy work towards the government of Indonesia.

1. **Gaps in the HIV/AIDS response at national and local levels**
2. Generally, in Indonesia, there are several issues faced by children living with HIV and their caretakers to maintain ARV treatment adherence and continuation, including accessibility and affordability of the treatment, stigma and discrimination related to HIV disclosure, the capacity of caretakers in administering daily medication, the nutritional status of the child, and the scarcity of child-friendly formulation of ARV.
3. Children aged 0-14 years old group is not included in the list of priority population in the draft of 2021-2025 National Strategic Plan on HIV and AIDS in Indonesia[[4]](#footnote-4) as well as in the two previous cycles (2015-2019 and 2010-2014). Additionally, the 2020-2024 National Action Plan on HIV, AIDS and STI does not include children living with HIV as part of their target populations. With this exclusion, children living with HIV continue to be left behind and opportunities to receive same level of recognition and support as other priority populations are very thin[[5]](#footnote-5).
4. Targets related to children living with HIV are primarily through elimination of vertical transmission from mother to child. This intervention focuses largely on the prevention aspect. And within the context of treatment and care, focus on ARV treatment and achieving viral load suppression only begins at the aged of 15. This means that there is a significant disproportion of care among children living with HIV aged 0-14.
5. It is estimated there are 12,691 children living with HIV in Indonesia, 3% of the total estimation of people living with HIV (Ministry of Health, 2021). The small number of estimates has become one of the biggest challenges in ensuring the availability of child-friendly ARV formulation[[6]](#footnote-6). This small number may also be considered of economic value and has little investment opportunity, particularly to pharmaceutical corporations in Indonesia to engage in competitive procurement of the much-needed formulation.
6. Availability of this children formulation is very limited in Indonesia. Its distribution is also very disproportionate across the country. The Ministry of Health, through its information system (SIHA) provides a regular report on ARV availability. However, child-friendly formulation remains unavailable in most of health service providers.
7. Civil Society Organisation (CSO) and the community with particular focus in providing care to children living with HIV is also very limited. The small number of estimates has also affected the level of funding from both international donors and domestic budget provided specifically to address the needs of children. The National AIDS Spending Assessment (NASA) report shows that there was only 0.16% of the total expenditure in 2018 was allocated for orphan and vulnerable children living with HIV. And none of this funding came from international donors.
8. The number of doctors with the right capacity to provide care to children living with HIV in Indonesia is also very inadequate. Most of children living with HIV can only access ARV in main hospitals since most of primary healthcare facilities do not have the human resource to provide the care. This also leads to increased burden at referral hospitals as well as from the patient’s point of view as often access to these main facilities can also become a major challenge.
9. **Policies, laws and programmes to meet targets on societal enablers and address gaps in the HIV/AIDS response**
10. The government of Indonesia through its Children Protection Law and National Health Law has a mandate to provide additional protection to children living with HIV. This protection includes ensuring equitable access to treatment and care that are provided with safety and security, quality, affordability and tailored to the needs of children. However, the lifesaving ARV for children is unavailable and inaccessible, and children must consume ARV for adults with adjusted dose for children. The inability to ensure child-friendly formulation may have been hindered by administrative requirements such as minimum amount requirement for purchase, and unregistered medications within the national e-catalog system. Additionally, there has been no efforts to initiate domestic production of this formulation.
11. The government of Indonesia has not provided competitive incentive for pharmaceutical corporations in Indonesia to develop and produce child-friendly ARV formulation due to the low market value compared to ARV for adults. However, this does not justify dispensing ARV for adults to children. The market of child-friendly ARV formulation cannot be seen only as a small fraction of the ARV market, but it must be as part of a mandatory comprehensive package, and it should be required by the government of Indonesia.
12. The Indonesia minimum standard of health service provides at least 3 standards that shall be enjoyed by children living with HIV, including the standard of amount and quality of medication, standard of amount and quality of human resources, and standard of service procedures. However, based on the documentation collected by LAP, in Jakarta, children living with HIV who are on ART receive a combination of medications that is not aligned with the standard guidelines for treatment for children living with HIV. There were at least 27 cases of ARV for adults dispensing to children.
13. The current national ARV guideline for children is also not up to date. The national guideline fails to comply with the 2016 Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection issued by the WHO.
14. Although an expert panel on HIV and AIDS exists in Indonesia, dialogues and decision-making process have not involved patients’ group, especially children living with HIV. The expert panel develops guidelines without involving people with lived experience, especially the experience and issues faced by children living with HIV and their caretakers in administering ARV on daily basis.
15. Programmes for children living with HIV has been very limited to only nutritional support for parents/caretakers in form of formula milk. This support is provided through Social Welfare Institutions, district Health Office, and the local AIDS Commission. A family support programme focusing on caring for children living with HIV is also part of the intervention, but most of the time, this support is only provided to organisations that are registered as Social Welfare Institution within the Ministry of Social Affairs. Additionally, funding has always been limited and therefore, it has not been able to provide equal coverage to those with the most needs.
16. There has been no policy that is specific in addressing the needs and issues of children living with HIV, such as education, social and others. Policy that is relevance to children living with HIV is only a small part of the elimination of vertical transmission programme.
17. Existing programmes for children living with HIV include nutritional support, psychosocial support, and institutions providing shelter and care for children living with HIV that are implemented by non-government or civil society organisations. Despite the limited support and funding, these programmes remain available, although at low scale.
18. Community support to children living with HIV has also been very low due to the lack of knowledge on issues related to children living with HIV. In this context, the society is often the main actor of stigma and discrimination that are experienced by children living with HIV and their caretakers.
19. **Concrete action being taken to implement such laws, policies and programmes and relevant challenges**
20. Although key policy and legal framework is in place, such as the Children Protection Law, the National Health Law, and the National Education Law, implementation of these laws is still a major gap, particularly in protecting the rights of children living with HIV to gain equitable access to treatment and care. This can be clearly seen by the arguments of the government where structural and policy framework has always been the barrier in ensuring the availability of child-friendly formulation, such as the minimum requirement of purchase, high purchase price, lack of interest among the local vendors and distributors, and complex multisectoral coordination.
21. Efforts by CSOs in Indonesia to advocate for the availability of child-friendly ARV formulation have been done directly to the Ministry of Health by addressing barriers and issues (such as ARV stock-out, incompliance of the guidelines of treatment for children living with HIV, tablet crushing and grinding, lack of sufficient information upon dispensing medication), regular dialogues have been conducted involving multi stakeholders to identify solutions, and a formal report to Ombudsman of Indonesia has been filed on the allegation of maladministration of ARV by the Ministry of Health towards children living with HIV.
22. Additionally, several CSOs has also put the pressure on UNAIDS Indonesia and other international development agencies to become more proactive in facilitating discussions and dialogues with stakeholders (Ministry of Health, the expert panel on HIV, pharmaceutical corporations) to identify solution in fulfilling the rights of children living with HIV.
23. **Recommendations**
24. To include children living with HIV aged 0-14 as priority/key population within the National Strategic Plan on HIV and AIDS, globally or nationally, or to redefine priority/key population to include children living with HIV in order to receive the level of attention from Member States and the international community.
25. To meaningfully involve children living with HIV and their caretakers in developing policy that is responsive to the needs and rights of children living with HIV, putting behind the economic or market value of ensuring the availability of child-friendly ARV formulation.
26. To call the government of Indonesia, other Member States, and the international community, including international donors, to commit to providing the same level of support and attention towards children living with HIV, regardless of their number, to leave no one behind and to truly achieve the end of AIDS as a public health threat by 2030.
1. **Community Legal Aid Institute (LBHM)** is a human rights organisation based in Jakarta that provides free legal aid services for marginalized communities, including people in the death row, people who use drugs, LGBTI people, people living with HIV, and people with psychosocial disabilities. LBHM website: <https://lbhmasyarakat.org/> [↑](#footnote-ref-1)
2. **Lentera Anak Pelangi (LAP)** is a caring program for children living with HIV in Jakarta. Our vision is to be the leading multi-disciplinary provider that improves the quality of life for children with HIV. Our missions are to reduce the morbidity and mortality of HIV children by improving their health and nutrition, to improve the psycho-social well-being of the children and caregivers, to keep children from being neglected or maltreated, and to develop an acceptable intervention model while setting the standard of care for HIV children nationwide. LAP website: <https://www.lenteraanakpelangi.org/> [↑](#footnote-ref-2)
3. **The Peoples Participation Initiative and Partnerships Strengthening Foundation (YAPPIKA - a member of ActionAid International (hereinafter referred to as YAPPIKA-ActionAid Indonesia or YAA Indonesia))** is a non-profit organisation that has been standing and working together with some communities in Indonesia since 1991 to encourage government policies to improve public services in between the fields of education and health and advocate for a better enabling environment for civil society. YAA Indonesia Website: <http://yappika-actionaid.or.id/> [↑](#footnote-ref-3)
4. The National Strategic Plan on HIV and AIDS (2021-2025) is an effort of the government of Indonesia to identify strategic actions within the scope of the National Health System that can be implemented to achieve the Medium-term National Development Plan (2022-2024). The Strategic Plan is also an advocacy tool that can be used to identify and determine the different roles and involvement, including actions that can be contributed by health actors and non-health actors such as civil society, in the HIV response in Indonesia. [↑](#footnote-ref-4)
5. Priority or key populations are the primary targets of policy and programming of the HIV response in Indonesia, due to their large proportion of estimates and for the achievement of the global targets and commitments such as the 95-95-95. Indonesia defines priority or key populations as 1) men who have sex with other men, 2) person who inject drugs, 3) transgender people, 4) direct and indirect sex workers, and 5) population in Tanah Papua [↑](#footnote-ref-5)
6. Child-friendly ARV formulation is one of the recommendations to increase treatment adherence among children. This formulation can significantly reduce the bitter taste, combine ARV regiments into fixed dose, simplify administration to once a day, and to change from tablet form into fine powder that is easier to be mixed with drink or meal. [↑](#footnote-ref-6)