

# Challenges in home-based care and support for children (0-12 years old) in Jakarta, Indonesia

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## **ABSTRACT:**

### **Background**

HIV and AIDS epidemic in Indonesia is considered isolated in communities of most at risk or key populations. In the past five years, the course of infection change from primarily driven by Injecting Drug Users to recently heterosexual (over 53%) couples. Consequently, vertical mother to child transmission is increasing significantly. At present is it estimated that 7,546 children are living with HIV – over 1,000 of the lived in the Jakarta Greater Areas. Lentera Anak Pelangi (LAP), a community service division of the Atma Jaya Catholic University Center for HIV and AIDS Research has been providing home-based care services for children living with HIV and AIDS in Jakarta. Currently 51 children are accessing our services.

### **Intervention services**

LAP currently provides nutritional intervention, general health monitoring, medical check-up, psychosocial counseling and program. All services are free of charge. Three case managers and three trained volunteers from the beneficiaries provide weekly visitation and consultation. Our case managers also assist children and families to access ARV, ambulatory care, and various tests.

### **Challenges**

Many of them (70%) are orphans and live with grand parents or other caregivers. It is very common for them to experience TB, other acute respiratory infection, malnutrition, skin rash, and digestive problems. Since most of our children came from poor families, some do not receive proper childcare and monitoring. All of them are on ARV. Because lack of monitoring, over 30% of them are on the second line ARV. Case managers reported difficulties in managing ARV adherence partly mothers or caregivers have not been open about the HIV status of their children. Disclosure becomes a dilemma in our service. Other challenges include eating habit of children, stigma and discrimination at school age, sustaining livelihood and health of parents, and dealing with trauma and grief when children or parents die.

### **Success story**

Since 2009 we were able to reduce morbidity and mortality among our children from 6% to under 2%. We were able to improve nutritional status of over 85% of our children. Four medical doctors and one dentist have volunteered regularly in our monthly medical care. Three children have graduated elementary school and ready for new challenges and intervention. Cooperation and coordination with hospitals, other NGOs with specific services, and with the government are running very well.



### **Future Direction**

We should encourage disclosure and relevant supporting services. We have to find ways to sustain support for children who are older than 12 years old. We are planning to engage in training of family members and volunteers in task and skill shifting program.

**Key words:** children living with HIV, home-based care, ARV adherence, disclosure, task and skill shifting.

