

# A Situation Assessment of Children Infected and Affected by AIDS (CABA) in Nepal



## 1. Brief description

The Save the Children Nepal program under the Global Fund HIV grant has been implementing a Cash Transfer program for children living with HIV (CLHIV) in Nepal since mid-April 2014. The Community Care Centre (CCC), managed by National Association of People Living with HIV (NAP+N), implements the program in 66 districts of Nepal. The program provides 1000 Nepali rupees a month to CLHIV up to 18 years old.

Youth LEAD, in collaboration with its country partners, Young Key Populations (YKP) Lead Nepal, and (NAP+N) conducted a national study to assess the situation of CLHIV receiving cash support, including the children affected by AIDS who do not receive the cash support.

## 2. Objectives:

The main objectives of the study were to:

- Explore the overall situation of CLHIV and children affected by AIDS in Nepal; and
- Evaluate the relevance and effectiveness of cash transfer program (CTP) among CLHIV.

## 3. Methodology:

The study was carried out in 20 districts of Nepal using mixed methods (quantitative and qualitative techniques) research design. A total of 417 CLHIV and 388 children affected by AIDS were interviewed as part of the study. Likewise, 10 Focus Group Discussions (FGDs) with caregivers of CABA and 40 Key Informant Interviews (KIIs) with different stakeholders were conducted. Furthermore, 10 In-depth Interviews (IDIs) were also conducted among children (as case studies) who received support from the program. Throughout the study report, we have used the term **CLHIV** (Children living with HIV AIDS) for children infected by AIDS. Similarly, we have used the term **CABA** for both children infected by and affected by AIDS.

## 4. Key findings

### Findings from Children

Socio-demographic Information: All documented CLHIV benefitted from the cash transfer program, but 0.7% (N=3) of them discontinued the program. The mean age of the children was 12.2 years; more than half (54%) of the children were male. Regarding parents' education, 35% of mothers and 14% of fathers of CABA were illiterate or never been to school.

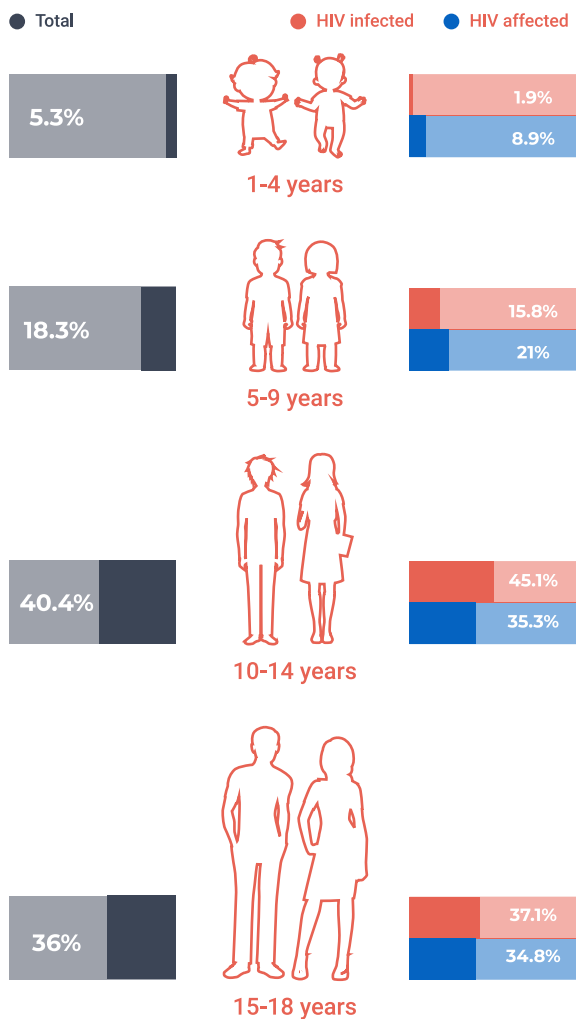


Figure 1: Age group of Children

### Health status and care-seeking behavior:

Sixty-four percent CABA had mothers as their primary caretakers. Similarly, 65% CABA were aware of the HIV status of the caretaker, and among them, the majority (89%) mentioned their caretakers were HIV positive. More than a third (34%) CABA had any illness in the past year. A slightly higher proportion of CLHIV (36%) than CABA (32%) had an illness in the past year. The most frequent type of illness was fever, cold/cough, and diarrhea. Among those who were ill, the majority (84%) had visited health facilities. Likewise, 29% of CABA usually visited health facilities once a month, followed by once in 3 months (17%). The most preferred health facility by CLHIV (81%) and CABA (56%) was Government Hospital.

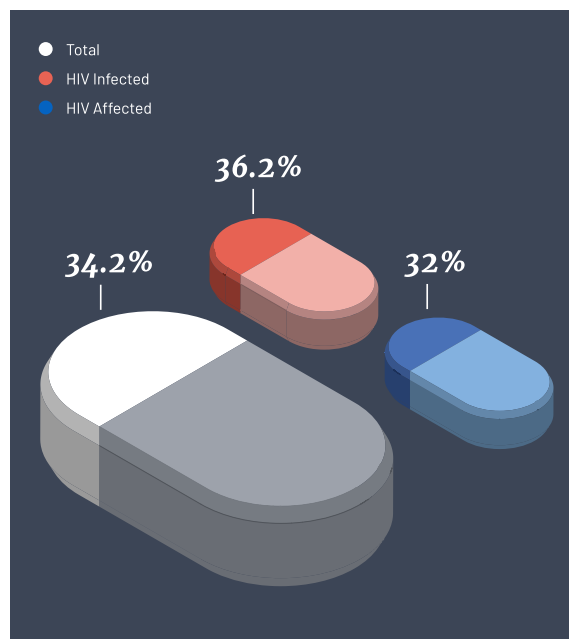
### Satisfaction with health services:

A significant proportion (68%) of CABA mentioned they were satisfied with the health services received, while 18% were very satisfied and 5% were dissatisfied with the health services. Although 9 out of 10 CABA never faced any stigma or discrimination by doctors or staff at the hospital, 7% of CLHIV and 5% of children affected by AIDS sometimes faced

stigma or discrimination. The finding is similar to the Nepal Stigma index 2011, which found that seven percent of the PLHIV were denied health services, including dental care, because of their HIV condition.

Qualitative findings showed that although there has been progress in health service-seeking behavior, CLHIV still face stigma and discrimination, and instances of lack of privacy for counseling and treatment. Similarly, some of them were remotely located and were facing difficulty in accessing the health services due to lack of transportation.

Figure 2: Had an illness in the past year



“Health service centers are not so CABA friendly. My daughter had a bad experience of getting abused by nurses.”

-FGD participant

### Educational status:

An overwhelming majority (96%) of children aged six years or above were enrolled in school. A slightly higher proportion of CLHIV (98%) were enrolled in a school than Children affected by AIDS (94%). Almost all (98%) children were currently going to school. Seventy four percent children had been studying basic level education while 10% had SLC and above education. Similarly, with regards to the discrimination in school, 47% CABA mentioned that their or their family members' HIV status was not disclosed, and 49% mentioned they never

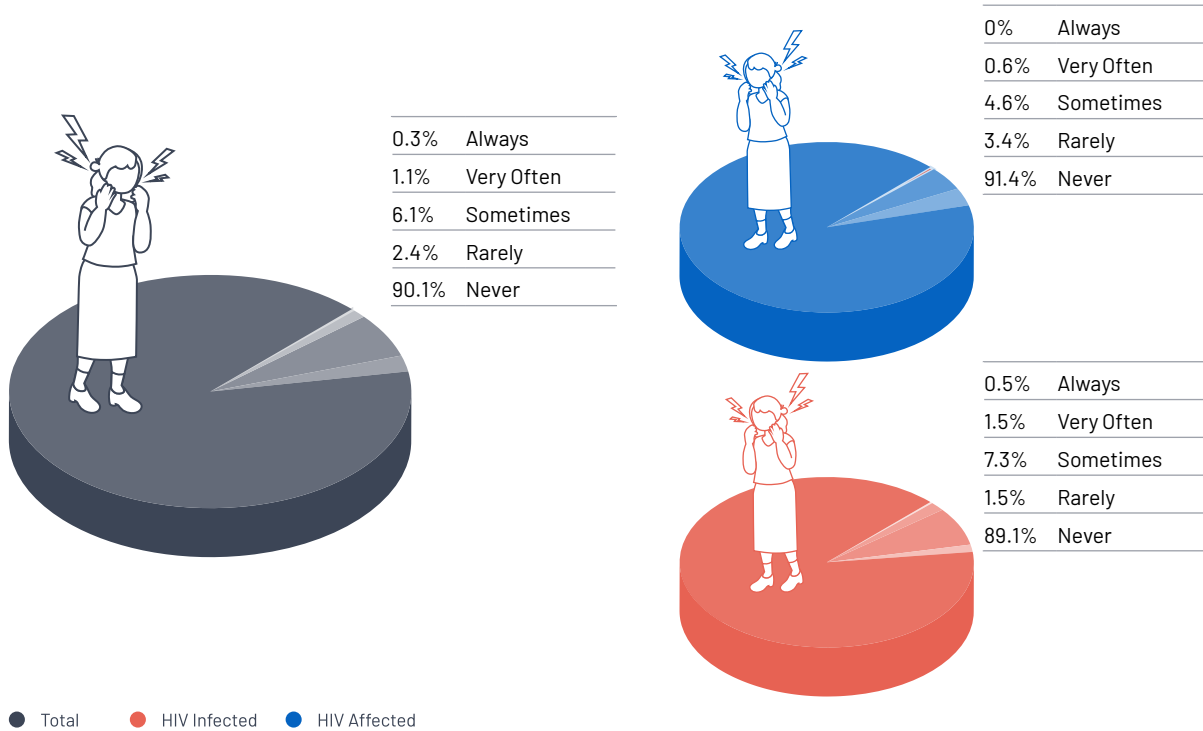


Figure 3 : Faced any stigma or discrimination by doctors or staff at the health facilities.

faced any stigma or discrimination by friends at school. Similarly, qualitative findings showed that educational attainment status among CABA has improved over the years, as observed by people in the community. The 1000 rupees received from CTP have aided majority of CABA to stay in school, by helping to pay their fees, buy stationery, uniforms, or lunch.

**Nutritional status:**

Although 76% of children had three or more meals last month, the remaining 24% had less than three meals. An overwhelming majority (%) of CABA mainly consumed home-cooked food in the previous six months. Similarly, 69% of children consumed protein-rich foods less than three times a week. Likewise, 28% stated that they had some changes in consumption patterns during the past 12 months. It is of note that 45% of CABA had some problem with managing food.

**Psychosocial issues:**

Regarding the fear experienced by CABA, 10% (12% CLHIV and 8% Children affected by AIDS) were fearful of being gossiped about. Similarly, 8% and 3% of children were afraid about being verbally insulted and being physically harassed, respectively.

Besides, it was found that 13% of CABA experienced feeling ashamed, in which the proportion was higher among CLHIV (17%) than Children affected by AIDS (8%). Likewise, 11% of CABA (14% infected and 11% affected) experienced low self-esteem/self-worth. Similarly, 1.5% of CABA also experienced the feeling of committing suicide.

The findings from qualitative interviews also support quantitative results as they showed that CABA face various psychosocial problems. In some cases, CABA have shown behavioral issues knowing about their HIV status when they reach the age of maturity. They become very distressed and aggressive towards their parents. The HIV infection has also affected CABA emotionally as they seem to have low self-esteem and fear that others might not accept them, knowing about their HIV condition.



“ I know one girl who came to know about her status quite late. She has turned very aggressive towards her parents, showing violent behaviors. Her parents are afraid to even be in front of her now.”  
**-FGD participant**

### Experience of exclusion from social gatherings or activities:

Majority (93%) of CABA did not experience exclusion from social gatherings or activities in the last 12 months. However, still, 7% of children experienced exclusion from social gatherings/activities.

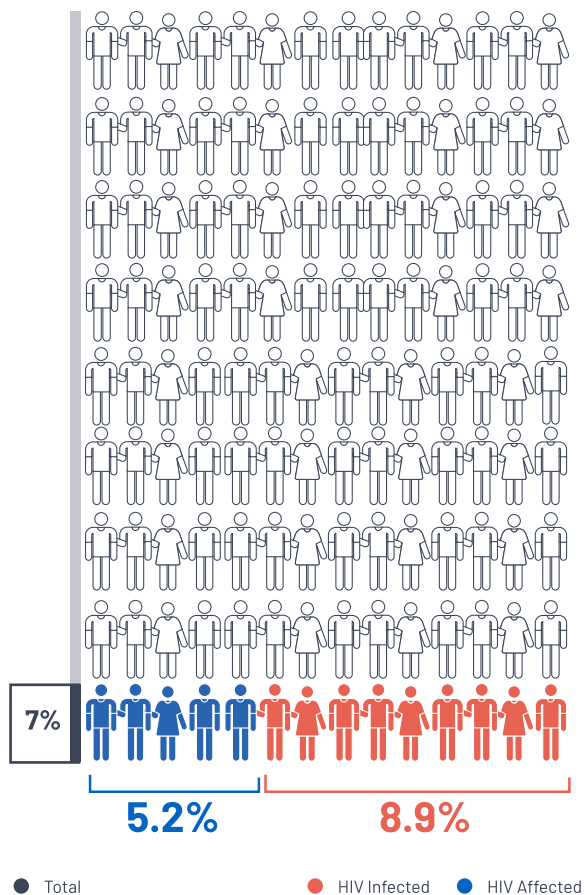


Figure 4: Excluded from social gatherings or activities in the last 12 months.

### Experience of stigma or discrimination in family and community:

Overall, 6% experienced discrimination or stigma from neighbors, 5% from friends and family members, and 3% from anyone.

Many parents hide their child's status until they reach an appropriate age when they can understand about the infection and the disease. They fear that the child might not be able to handle it properly.

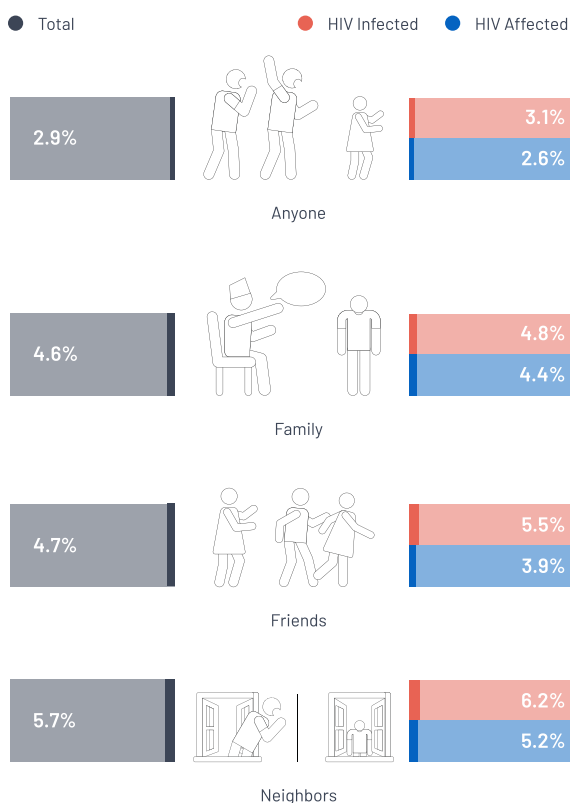


Figure 5: Experience of stigma or discrimination

● Total ● HIV Infected ● HIV Affected

### Knowledge and access to HIV AIDS-related information and services:

Sixty-six percent CABA had heard about HIV, but half of the children affected by AIDS have not heard about HIV. The majority (82%) of children were aware of how people can get services related to HIV.

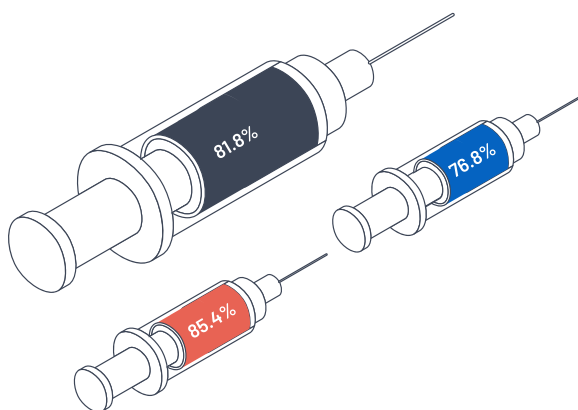
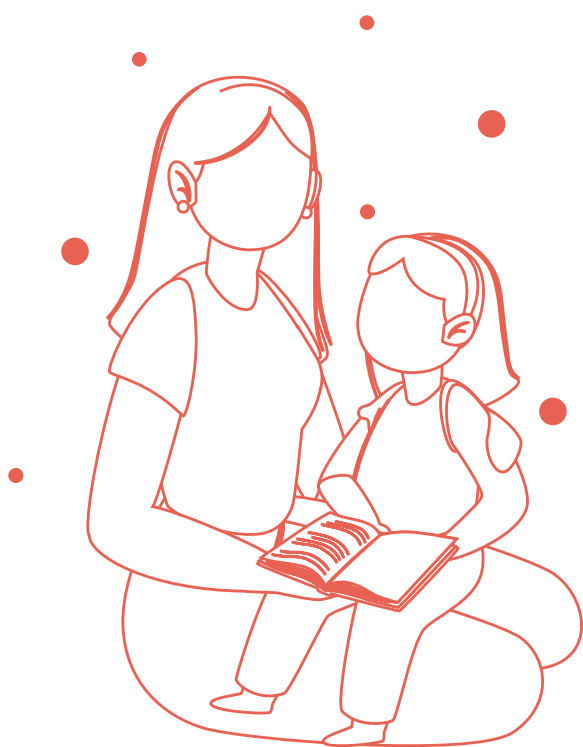


Figure 6: Awareness about health facilities providing HIV services

## Findings from Caregivers



### **Socio-demographic and economic characteristics:**

Sixty-one percent caretakers were mothers, followed by fathers (27%). More than a third (35%) of caregivers were involved in agriculture, followed by daily wages (23%) and private service (12%). Similarly, 35% caregivers had monthly income below 5000 rupees, followed by 5,000-10,000 (32%) rupees. Concerning education, more than a third (36%) of caregivers were illiterate, followed by basic level education (32%). Only six percent of caregivers had higher secondary level education. More than half (56%) of the children had both biological parents alive, but 8% had none of their parents alive, and the proportion was higher among CLHIV (12%) than Children affected by AIDS (8%).

### **Other Major Findings:**

Sixty-three percent caregivers of CLHIV reported that they disclosed HIV status to the child. Similarly, nearly half (47%) of caregivers stated that their child had received any counseling care or support from anyone in the past 12 months. Similarly, 70% of caregivers had received any counseling or support from anyone in the past 12 months. Likewise, 31% of caregivers mentioned that older or adult siblings of children would be the child's caretaker if the primary caretaker won't be able to due to health problems. An overwhelming majority (97%) of the caregivers mentioned they worry about the

responsibilities as a guardian for the child. In this regard, caregivers mostly worry about money to send children to school/daycare (88%), money for food (59%), clothes (47%), and caring for a sick child (54%).

The most common areas to spend the money obtained from CTP were school (82%), food (58%), and the medical treatment (51%). Only 7% caregivers mentioned that they had enough money to cover the child's medical expenses related to HIV.

## **DAC FINDINGS:**

The OECD DAC Network on Development Evaluation has defined six evaluation criteria: relevance, coherence, effectiveness, efficiency, impact, and sustainability. The below findings are based on the DAC criteria.

### **Context:**

The CTP was rolled out in Nepal before promulgation of the new Constitution of Nepal, 2015 and before the local level elections of 2017. The change in federal structure after the adoption of a new constitution added the need to coordinate with local level government to implement CTP. The frequent turnover of government officials at the local level has made it difficult for the CABA CTP implementers to select appropriate representatives.

### **Relevance:**

CTP has been relevant to a large extent as this is the only financial support program, in the form of social protection for CLHIV. Some of the local governments are also providing small amounts for supporting the infected children. However, these programs appear to be uneven and do not provide uniform educational or nutritional support to the children throughout the year.

### **Effectiveness:**

The CTP has contributed to improving the living standard of CABA by the regular provision of funds. It has helped improve the nutritional and educational status of the children as families spend most of that amount on buying food or educational materials for children. Many, especially those who live distant from the service centers, also use it to cover travel expenses to receive ART services. CTP has particularly effectively reached the economically marginalized groups who have benefitted the most from the program. Moreover, CTP has successfully linked cash support with other treatment and care programs that jointly have enhanced CABA health and living status.



“ Although the children receive 1000 rupees, it is not enough for them. Yet getting 1000 rupees is better than getting nothing.”

- KII Respondent

“ Many 18+ youth drop out of education after they stop getting cash transfer. Many start working as a daily wage earner along with their parents.”

- KII respondent

#### Impact and Changes:

Improved health seeking behavior was observed among the people due to CTP. Along with other ART and counseling services, the program has encouraged CLHIV and their parents to take their medicines regularly. By boosting morale and upgrading their living standard to some extent, CTP has changed their perception and increased acceptance among them of their HIV status. It has indirectly helped make them realize that they can live a normal life if they consume medicines regularly.

#### Sustainability:

Due to the absence of government-funded social protection programs for CABA, the program’s implementation through non-governmental organizations had made caregivers and stakeholders skeptical about the long-term continuity and sustainability of CTP. They fear that such support will be stopped after the termination of the project.

#### 5. Recommendations:

##### Increase in CTP allowance:

The amount provided by CTP should be increased, observing the increased healthcare-seeking behavior, inflation in the economy, and more number of needs of CABA. Inclusion of children affected by AIDS in the program would also be beneficial as they are also being deprived of the basic standard of living.

##### Needs Assessment prior to capacity development of CTP graduates:

A Needs Assessment should be conducted to identify the priority of skill development training to the CTP graduates. Based on the assessment, a comprehensive skills development transition package (with job opportunities) should be designed and implemented for CABA to become self-reliant.

**Ownership of local government for sustainability:**

For the project's sustainability, central, provincial, and local government officials should take ownership of the project and provide services and facilities to CABA in collaboration with other stakeholders. However, it is essential to consider that even if the local government takes ownership of the project, confidentiality issues might arise. At the central level, involvement of key officials from the Ministry of Women, Children and Senior Citizens will be more favorable for the sustainability of the project.

**Creation of safe and non-discriminatory environment in educational institutions and local communities:**

Educational institutions and local communities should create a safe and non-discriminatory environment for CABA, or for any other child for that matter.

**Creation of child-friendly spaces:**

Health facilities should be child-friendly where CABA or PLHIV are not discriminated against and treated with respect as any other service seeker. Given the sensitivity concerning CABA and PLHIV (or any children/adolescents for that matter), appropriate measures need to be taken to ensure privacy and confidentiality while receiving health services.

**Behavior change communication through awareness campaigns:**

Mass awareness campaigns should be conducted for both CLHIV and the general community, alongside scaling up counseling programs for CABA in order to address their mental health issues.

## 6. Conclusion:

The assessment showed that the overall situation of CABA in Nepal is gradually improving compared to past years as a result of many interventions focused on CABA. Specifically, such as CTP has proven to have contributed in improving the living standard of CABA to some extent. It has also helped improve the nutritional and educational status of the children as families spend most of the amount on buying food or educational materials for children. Findings also reveal better healthcare-seeking behavior among CABA as most of them visited health facilities in case of any illness, and more than a fourth usually visited health facilities once a month. The educational status of CABA was satisfactory too, as an overwhelming majority of children aged six years or above were enrolled in school, and among them, almost all were currently going to school. Regarding the nutritional status of CABA, above three-fourth of children had three or more meals in the last one month, but remaining about a fourth child had less than three meals. Despite improvement in certain areas, the assessment showed that CABA is still deprived of psychosocial well-being as many expressed fear and anxiety on different issues and had experienced many unpleasant feelings such as feeling ashamed and low self-esteem.

Hence, despite improving the situation of CABA and the notable effectiveness of CTP to upgrade their living status, several aspects should be pondered upon to uplift their quality of life further such as improving their nutritional status and psychosocial wellbeing.

### Suggested Citation:

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