

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





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# ABBREVIATIONS & ACRONYMS

<b>AIDS</b>	<b>Acquired Immuno Deficiency Syndrome</b>
<b>CABA</b>	<b>Children Affected by AIDS</b>
<b>CCC</b>	<b>Community Care Centre</b>
<b>CLHIV</b>	<b>Children Living with HIV/AIDS</b>
<b>CTP</b>	<b>Cash Transfer Program</b>
<b>FGD</b>	<b>Focus Group Discussion</b>
<b>HIV</b>	<b>Human Immunodeficiency Virus</b>
<b>KII</b>	<b>Key Informant Interview</b>
<b>NAP+N</b>	<b>National Association of People Living with HIV</b>
<b>NCASC</b>	<b>National Centre for AIDS and STI Control</b>

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*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*

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**66**

*Districts of Nepal are covered by the grant*

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**NPR. 1000**

*a month to CLHIV upto 18 years old*

# Executive Summary

## Background

The Save the Children Nepal program under the Global Fund HIV grant has implemented a Cash Transfer Program for children living with HIV (CLHIV) in Nepal since mid-April 2014. The Community Care Centre (CCC), managed by the National Association of People Living with HIV (NAP+N), implements the program in 66 districts of Nepal. The program provides 1000 Nepali rupees (approximately 10 USD) 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.

## 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 the Cash Transfer Program (CTP) among CLHIV.

## 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 **CLHIV** 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 for Children living with HIV. We have not used any acronym for children affected by AIDS and kept it as it is. Similarly, we have used the term **CABA** for both children living with and affected by AIDS.

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### INTERVIEW DETAILS

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**417**  
CLHIV

**388**  
Children Affected  
by AIDS

**10**  
Focus Group  
Discussions

**40**  
Key Informant  
Interviews

## Findings from CLHIV

### Socio-demographic Information

All documented CLHIV were benefited from the cash transfer program but, **0.7% (N=3) CLHIV** had discontinued CTP. The mean age of the children was 12 years, more than half (54%) of the children were male, and the majority were Hindus. Regarding parents' education, 35% of mothers and 14% of fathers of CABA were illiterate or never been to school.



#### THE CHILDREN

**12 years**

mean age of  
the children

**54%**

children  
were male

#### ILLITERATE PARENTS

**35%**

mothers  
of CABA

**14%**

fathers  
of CABA

### Health status and care-seeking behavior

64% of CABA had mothers as their primary caretakers. Similarly, 65% of 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%) of CABA had illnesses in the past year. A slightly higher proportion of CLHIV (36%) than children affected by AIDS (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 children affected by AIDS (56%) was the Government Hospital.

#### GOVERNMENT HOSPITAL AS PREFERENCE

**81%**

CLHIV

**56%**

Children Affected  
by AIDS

### 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.

#### STIGMA

**7%**

CLHIV faced  
stigma or  
discrimination

**5%**

Children affected  
by AIDS faced  
stigma or  
discrimination

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 were remotely located and faced difficulty accessing health services due to a lack of transportation.

### Educational Status



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

#### DISCRIMINATION IN SCHOOL

**47%**

CABA mentioned  
that their or their  
family members' HIV  
status was  
not disclosed

**49%**

mentioned they  
never faced any  
stigma 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 the CTP have aided the majority of CLHIV 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 status.

## 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.

## 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.

## 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.

## 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%).

### EMPLOYMENT SECTOR OF CAREGIVERS



### MONTHLY INCOME OF CAREGIVERS



## 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.

#### DISCRIMINATION IN SCHOOL



**82%**

Schooling



**58%**

Food



**51%**

Medical Treatment

#### Findings based on 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. With the adoption of a new constitution, a three-tier governance system, the change in federal structure added the need to coordinate with ward level 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.

##### 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.

##### 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.

## 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.

# 37.9M

*people lived with HIV  
by end of 2018 globally*

---

# 1.7M

*children aged below 15  
lived with HIV globally*

---

# 100,000

*is the estimation of AIDS-related deaths in 2018  
among children less than 15 years globally*

---



# 56%

*CABA had lost either one  
or both the parents*

---

*National Association of People Living with HIV  
(NAP+N) implements the cash transfer program to  
children living with HIV through community care  
center (CCC) in 66 districts of Nepal.*

---



# 1366



*children enrolled and benefitted  
from Cash Transfer Program*

## CHAPTER I

# Introduction

### 1.1 Background

HIV and AIDS have been a well-recognized pandemic throughout the world over the past two decades. Globally, an estimated 37.9(32.7–44.0) million people lived with HIV by the end of 2018. Among these, 1.7 million(1.3–2.2) are children aged below 15 (**UNAIDS, 2019**). HIV infection among adults has caused an immense impact on children<sup>1</sup>. Globally, around 160,000 children aged 0–14 years are newly infected with HIV in 2018, as per UNAIDS estimates. Although this is a significant decrease from 240,000 new infections in 2010, the target set for 2018 was fewer than 40,000 new infections. Children living with HIV are also left behind in HIV treatment scale-up and are not diagnosed and treated early enough. An estimated 940,000 children aged 0–14 years were accessing treatment in 2018, double the number on treatment in 2010 but far short of the target of 1.6 million set for 2018. Globally, only half of the infants exposed to HIV during pregnancy are tested before eight weeks of age. The estimation of AIDS-related deaths in 2018 among children less than 15 years is 100,000 (**UNAIDS, 2019**). The estimated number of People living with HIV (PLHIV) in 2020 was 29,587. Among them, 1171 (3.95%) are children aged 0–14 (**NCASC, 2020**).

In Nepal, a situation assessment of children affected by AIDS was conducted in five districts in 2009, showed more than half of the CABA (56%) had lost either one or both the parents. CABA were twice more likely to be paternally orphaned than maternally orphaned. Children infected with HIV were more likely to experience fear and isolation when left alone in the house<sup>2</sup>. A study (Shah, 2015) showed that stigma and discrimination mainly hinder the regular school attendance of children affected by AIDS, resulting in school dropouts, but no specific interventions address these problems.

Cash transfer programs can enhance child health and development. Studies highlight that cash transfers are an outstanding instrument of confronting poor households' vulnerability and advancing human capital investment<sup>3</sup>. Cash Transfer programs have emerged as a powerful instrument to improve child health<sup>4</sup>. Save the Children Nepal has been implementing a cash transfer program for children living with HIV.

The Save the Children Nepal program under the Global Fund HIV grant has been implemented as a Cash Transfer program for children living with HIV (CLHIV) in Nepal since mid-April 2014. The program implements through the Community Care Centre

1 Campbell et al., 2010; Surkan PJ et al., 2010  
2 HIV AIDS and STI Control Board, NCASC and Save the Children 2009  
3 de Walque et al., 2017; Rosati, 2016  
4 Bastagli et al., 2016; Leroy et al., 2009

(CCC) in 66 districts of Nepal. The program targets children living with HIV (CLHIV) until 18 by providing financial support to cover the costs associated with long-term illness due to HIV, including any required treatments or medications. Based on program data till April 2019, 1366 children ever enrolled and benefited from Cash Transfer Program. However, the 283 children who turned 18 years are no longer eligible for the program. Sixty-six children have also died since the implementation of the program.

There are ongoing challenges to implement long-term strategic support for those children and young key populations who reach the age of 18 and are no longer eligible for the cash transfer program. There is little understanding of the outcome and the transition when the children reach 18. This was the realization of the National HIV program and Youth LEAD in collaboration with its country partner, YKP Lead Nepal, and the National Association of People Living with HIV (NAP+N) to request some technical assistance to assess the needs of children living with/affected by HIV/AIDS receiving support under the current Global Fund HIV grant. YKP LEAD Nepal is assessing, evaluating, and documenting the long-term impact of the cash transfer program on the beneficiaries and sustaining themselves after the support ends. These studies are expected to provide critical insights to strengthen and improve the program's overall design, including improved transitional procedures.

Current issues and needs of CABA in Nepal are undocumented and unexplored as previous CABA assessment was conducted more than a decade earlier in 2009. So, a study that can provide recent evidence of status, prevalence and issues of CABA to inform further policies and programs for uplifting the situation of CABA is of paramount importance. The cash transfer program has been in implementation in Nepal since 2014. However, the actual impact it has been able to make in the lives of the targeted children is unknown. Hence, this study is vital to understand the significance of the cash transfer program, including current challenges and future implications.

## 1.2 Objectives of the study

### General Objectives:

The general objectives of the study were to:

Explore the overall situation of children living with and affected by HIV (CABA) in Nepal; and Evaluate the cash transfer program for children living with HIV.

### Specific Objectives:

The specific objectives of the study were to:

- Assess the extent of availability and accessibility to health care, education, economic and psychosocial support services provided for CABA;
- Identify the needs of children living with and affected by HIV;
- Assess the implementation of the cash transfer program to children infected by AIDS in terms of achievement, challenges, and lessons learned;
- Examine the situation of the CABA who have transitioned from the cash transfer program after the age of 18 and analyze their various aspects of living conditions, including education, socio-economic, treatment, personal growth, relationship;
- Identify opportunities for improving the cash transfer program to address the evolving need of the children living with HIV, their transition from childhood to youth; and
- Explore the opportunities to include children affected by AIDS in the program. The following methodology was applied in this study.



## CHAPTER II

# Methodology

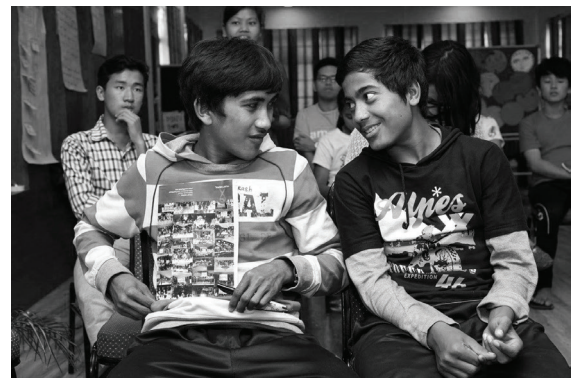
### 2.1 Research design

The study was carried out using a mixed-methods design using quantitative and qualitative data collection techniques. Mixed methods research is a methodology for conducting research that involves collecting, analyzing, and integrating quantitative and qualitative research. Its central premise is that using quantitative and qualitative approaches provides a better understanding of research problems than either approach alone. Typically for studies such as this situation assessment, the study team deemed a mixed-methods design would be suitable in order to provide a more complete and comprehensive understanding of the research problem. The study team also assessed that the quantitative findings would provide a documented statistics of the current situation and prevalence concerning CABA, while the qualitative findings would provide in-depth understanding of the factors and determinants to the current and previous situation. This method is suitable to explore the same phenomenon from a wide range of study participants. It allows to validate or triangulate the results obtained from other methods.

Among the different types of mixed-method design, this study used a concurrent triangulation mix method design. In this design, only one data collection phase is used, during which quantitative and qualitative data collection and analysis are conducted separately yet concurrently. The findings are integrated during the interpretation phase of the study. Usually, equal priority was given to both types of research.

### 2.2 Target group

The target groups included in this study are as follows:



- **Children Infected by AIDS:** A child less than 18 years and confirmed as having HIV infection. 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.
- **Children Affected by AIDS:** A child less than 18 years who was not infected with HIV, but having a family member with HIV infection in the same household.
- **Caregiver of children infected and affected by AIDS.**

- Key stakeholders of organizations implementing or providing support in the implementation of CTP.
- Children receiving support through CTP.
- Children who received support from the Cash transfer program in the past but are no longer eligible to be part of the program.

## 2.3 Study Area

This study was conducted in 20 districts (3 districts from each province except Karnali) namely. Only two districts in Karnali province have implemented CTP, so both districts of Karnali Province were selected for the study.

The following criteria were taken into consideration while selecting the districts:

- Number of CABA covered in CTP,
- Geographical diversity (all provinces)
- Ecological zones (Mountain, Hill, and Terai)

## 2.4 Tools for data collection

The data collection tools were developed in line with the study objectives as well as referring to the previously conducted situation assessment <sup>5</sup>**Focus Group Discussion (FGD)** guidelines and **Key Informant Interview (KII)** checklist were developed based on the **Development Assistance Committee (DAC)** criteria. All the tools were developed in English then translated into the Nepali language. A structured individual questionnaire was administered to CABA and their caregivers. A short structured individual questionnaire was administered to the caregivers/head of the households for soliciting information on socio-economic conditions.

FGDs with caregivers/parents, KIIs with stakeholders' techniques, and **In-depth Interviews (IDIs)** with children above 18 years were applied as qualitative methods. Tools were prepared based on objectives. Both quantitative and qualitative research tools were developed to address the context, relevance, effectiveness, changes/impact, sustainability, and lessons from CTP. Similarly, pre-testing among children was done before the training to the researchers to find out any gaps or inconsistencies in the tools and was revised based on findings from the pre-test.

## 2.5 Sample size and sampling procedure

Both quantitative and qualitative approaches were used to collect the data. According to data collected until April 2019, 1366 children have benefited from the cash transfer so far.

In this case, the following formula developed by **Sloven (1960)** is suitable to calculate the sample size.

$$n = \frac{N}{1 + Ne^2}$$

Where:

$n$  = Number of samples

$N$  = Total population

$e$  = Error margin / margin of error (5%)

By using this formula, the estimated minimum sample size for children infected by AIDS was **357**. Few children may refuse to participate, while few may have non-response to some questions. So, we added a 10% refusal rate and a 10% non-response rate. After adding both non-response and refusal rates, the total sample size was **393**.

Though CTP did not focus on children affected by AIDS, this study also covered the same number of children affected by AIDS to compare the finding between children infected and affected by AIDS. So, the total sample size will be **786**. However, we covered **805 CABA** children (417 infected children and 388 affected children) in this study.

A total of 10 FGDs with caregivers of CABA and 40 Key informants' interviews with different stakeholders (Program implementer to the beneficiary) were conducted. Furthermore, a total of 10 In-depth interviews (case study) were conducted with children who received support from the program in the past but are no longer eligible to be part of the program.

### INTERVIEWS

**10**

FGD

**40**

Key  
Informants

**10**

In-Depth  
Interviews



In summary, the study tools, sample size and participants included in the study are as follows:

Component	Study tools	Sample	Participants
Quantitative	Structured questionnaire	805	CABA
Quantitative	Structured questionnaire	741	Caregiver of CABA
Qualitative	FGDs	10	Caregiver of CABA
Qualitative	Key informant interview guideline	40	Govt stakeholders, program implementors, Beneficiary
Qualitative	In-depth interview guideline	10	Youth aged 18 and above who received support from the program in the past but no longer eligible to be part of the program

## 2.6 Data collection

Twenty-seven researchers (seven field supervisors and 20 field researchers) were involved in this study. For the quantitative component, 20 researchers were involved. A total of 20 trained enumerators who belonged to the PLHIV community were involved in data collection. Each team had three members (one supervisor and two enumerators), and one team covered one to two provinces. Seven supervisors also checked the quality of data collection and assisted enumerators. Furthermore, these supervisors were involved in conducting FGDs and KIIs with key stakeholders.



### INVOLVEMENT

**20**

Field  
Researchers

**7**

Field  
Supervisors

**20**

Trained PLHIV  
Enumerators

## 2.7 Recruitment and Training

Twenty-seven research assistants/enumerators (seven supervisors and 20 field researchers) were recruited for data/information collection. NAP+N helped in the process of selection of qualified researchers for the study. The core study team members and a National Centre provided a three-day residential training to the field researchers for AIDS and STD Control (NCASC) representative. During the training, the program objectives and purpose of the survey were explained, and the sampling methodologies were adopted to select respondents. Furthermore, the study team were oriented on ethical issues related to data collection and data security to all the researchers during the training sessions. Researchers followed research ethics throughout the study period.

## 2.8 Data management and analysis

Quantitative data was collected in tablets/mobiles using the Open Data Kit (ODK) platform. Numbers of quality check mechanisms such as range checks, logical checks, and skip instructions were developed, which helped detect the errors during the data collection. All collected data were kept secured in password-protected computers at the office.

The researchers analyzed both quantitative and qualitative data. For the quantitative data, descriptive statistics and bivariate analysis (chi-square test) were performed. Statistical Package for Social Sciences (SPSS) software version 26 was used to analyze the quantitative data. For the qualitative information, all the data collected from KIIs, FGDs and case studies were translated into English. Qualitative data were coded by the core team and analyzed thematically.

## 2.9 Quality Assurance & Quality Control

Core team members (Principal Investigator, Co-Principal Investigators) and field supervisors performed internal quality management of study conduct, eligibility assessment, quantitative and qualitative data collection, documentation, and completion.

The researchers implemented several quality check mechanisms during the study period. Quantitative data were collected on tablets/mobiles. Skip partners and several quality check mechanisms such as range checks and logical checks were developed to detect errors during the data collection.

The PI and Co-PIs took overall responsibility for the study. They supervised the data collection works—supervisors assigned to support the day-to-day tasks of the field research team. The field researchers/enumerators checked the completed questionnaire on the tablet after each

interview, and supervisors double-checked on the spot. The PI, Co-PIs, and supervisors provided onsite feedback.

## 2.10 Ethical considerations

This study was conducted in compliance with all relevant human rights and ethical standards. The researchers took ethical approval from the ethical review board of the Nepal Health Research Council (NHRC).

Researchers received a three-day training that included research ethics. An essential component of this training was the maintenance of confidentiality. Maintaining trust and confidentiality was critical to the success of this research study. All researchers were trained in the importance of maintaining confidentiality, as they handle sensitive information daily, and they have also signed an oath of confidentiality. In addition, they signed a code of conduct before visiting the field.

Documentation of informed consent or assent (for those under 16 years) was obtained individually from each study participant. Participants were encouraged to use initials or symbols to sign the form, rather than their name, to reduce the risk of identity via the consent forms.

All people who participated in the study as a target group consented. The consent form included a description of the study purpose, the participant's role in the research, procedures to be followed, benefits, risks, compensation, and confidentiality, expected duration of participation, right to refuse, the approximate number of study participants, and contact information if they have questions.

Children affected by AIDS are vulnerable populations. Socio-cultural barriers and self-stigma often keep this population from seeking health services through traditional venues because they fear outcomes such as poor treatment from providers or disclosure of their life/occupation choices or HIV status to family or community members.

Our quantitative and qualitative interviews were conducted as face-to-face interviews for structured and key informant interviews to reduce disclosure between participants and encourage trust to reduce the risk of social harm. Furthermore, all staff who had access to study participant information received training on procedures/ importance of maintaining confidentiality, including proper storage of all study documents and the importance of informing study staff if a breach of confidentiality occurs. All data shared with the government/stakeholders were aggregated and did not include any names or aliases for participants to reduce the risk of possible harm. The benefit of participating in this study is that the study's findings would help inform policymakers and stakeholders to develop policy and suitable programs for the children affected by AIDS at the national level.

## 2.11 Limitations

The recruited study participants may not represent the entire population of CABA at large since we recruited a limited number of participants covered in the CTP. In most of the information, we relied on self-report measures, which may not always be honest. Similarly, the emergence of the COVID-19 pandemic delayed the data collection process, which resulted in the extension of the whole study period.

## CHAPTER III

# Findings



### 3.1 Findings from Children

#### 3.1.1 General information

The study interviewed a total of 417 CLHIV and 388 Children affected by AIDS for the situation assessment. Out of all children, 76% resided in the municipality, whereas 24% resided in the rural municipality. In regards to CTP, all CLHIV surveyed were benefitted from CTP. Among them, 0.7% (N=3) of CLHIV had discontinued CTP. One child who was ever discontinued from CTP reported that the reason was each 'migration' and 'incomplete document'. The other child was not able to mention the reason for discontinuation.

#### ASSESSMENTS

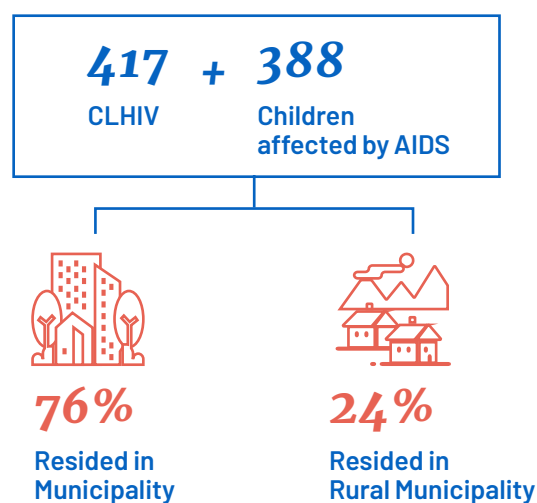


Table 1: General information of children

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
PLACE OF RESIDENCE						
Municipality	75.3	314	77.6	301	76.4	615
Rural Municipality	24.7	103	22.4	87	23.6	190
CASH transfer program						
Benefitted	100.0	417				
Not benefitted						
EVER DISCONTINUED FROM THE CASH TRANSFER PROGRAM						
Yes	.7	3				
No	99.3	414				
TOTAL	100.0	417				
REASON FOR DISCONTINUING						
Migration	33.3	1				
Incomplete documents	33.3	1				
Do not know	33.3	1				
TOTAL	100.0	3				

### 3.2 Demographic characteristics of children

Regarding the demographic characteristics, the mean age of the children was 12.2 years (SD=4), and many children were aged 10-14 years (40%), followed by 15-18 years (36%).

More than half (54%) of the children were male. Thirty-two percent were Hill Brahmin/Chhetri, Hill Dalit (25%). A high majority of children (89%) were Hindus.

#### DEMOGRAPHY KEY NUMBERS

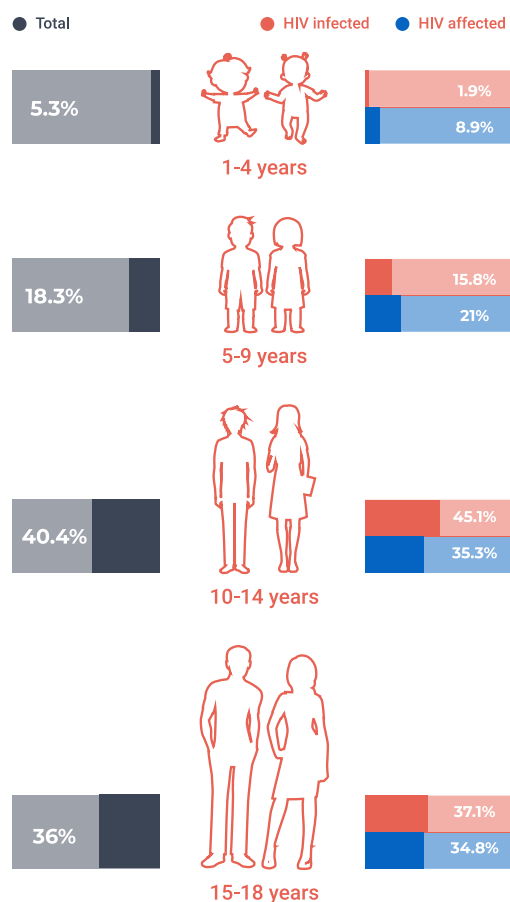
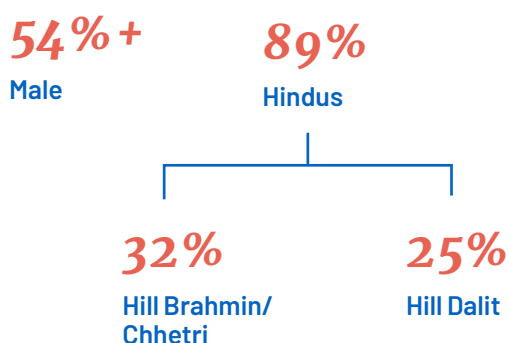


Figure 1: Age group of Children

Table 2: Demographic characteristics of children

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
COMPLETED AGE						
1-4 years	1.9	8	8.9	35	5.3	43
5-9 years	15.8	66	21	81	18.3	147
10-14 years	45.1	188	35.3	137	40.4	325
15-18 years	37.1	155	34.8	135	36	290
Mean Age	12.7		11.6		12.2	
SEX OF THE CHILD						
Male	53.2	222	55.2	214	54.2	436
Female	46.8	195	44.8	174	45.8	369
Ethnicity						
Hill Brahmin/Chhetri	30.9	129	33.5	130	32.2	259
Hill Adivasi/Janajati	20.6	86	19.8	77	20.2	163
Hill Dalit	25.4	106	25.3	98	25.3	204
Terai Brahmin/Chhetri	5.3	22	2.8	11	4.1	33
Terai Adivasi/Janajati	10.3	43	11.9	46	11.1	89
Terai Dalit	4.1	17	2.3	9	3.2	26
Muslim	3.1	13	3.4	13	3.2	26
Others	.2	1	1.1	4	.6	5
RELIGION						
Hindu	90.6	378	88.1	342	89.4	720
Buddhist	1.7	7	3.9	15	2.7	22
Christian	3.8	16	4.4	17	4.1	33
Muslim	3.1	13	3.1	12	3.1	25
No religion	.5	2	.5	2	.5	4
Others	.2	1			.1	1
TOTAL	100.0	417	100.0	388	100.0	805



### 3.3 Demographic and socio-economic characteristics of family

#### 3.3.1 Demographic characteristics

Regarding the family characteristics, 27% and 25% had four and six or more members in their family, respectively. Similarly, 66% had either one or two siblings, followed by three siblings (19%). Overall, 74 percent of CLHIV and 96 percent of Children affected by AIDS lived with their mothers.



Table 3: Characteristics of Family

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
FAMILY SIZE						
One	1.7	7			.9	7
Two	7.7	32	8.5	33	8.1	65
Three	20.9	87	22.2	86	21.5	173
Four	27.8	116	26.3	102	27.1	218
Five	14.9	62	20.9	81	17.8	143
Six or more	27.1	113	22.2	86	24.7	199
NUMBER OF SIBLINGS						
One	32.3	112	38.4	122	35.2	234
Two	32.9	114	28.3	90	30.7	204
Three	17.9	62	19.5	62	18.6	124
Four	8.6	30	7.9	25	8.3	55
Five	3.5	12	5.3	17	4.4	29
Six or more	4.9	17	.6	2	2.9	19
FAMILY MEMBERS+						
Father	46.8	195	69.1	268	57.5	463
Mother	73.6	307	96.1	373	84.5	680
Sister	56.4	235	55.9	217	56.1	452
Brother	55.9	233	57.2	222	56.5	455
Grandfather	11.3	47	10.1	39	10.7	86
Grandmother	22.1	92	16.8	65	19.5	157
Alone	.2	1	.3	1	.2	2
Others	18.2	76	7.7	30	13.2	106
TOTAL	100.0	417	100.0	388	100.0	805

+Multiple responses

### 3.3.2 Parental education status

The educational status of parents of CABA was also examined in the study. 35% of mothers and 14% fathers of CABA were illiterate or never been to school. Similarly, 23% and 16% of mothers completed primary education and non-formal education, respectively. Likewise, 26% of fathers had also completed a basic level of education.

Table 4: Parental education status

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
EDUCATION LEVEL OF MOTHER						
Never been to school/Illiterate	32.6	136	38.4	149	35.4	285
Basic(1-8 grades)	19.9	83	27.1	105	23.4	188
Secondary(9-10)	4.3	18	8.5	33	6.3	51
Higher secondary	2.4	10	3.4	13	2.9	23
Non-formal	14.4	60	16.8	65	15.5	125
Do not know	2.9	12	3.6	14	3.2	26
Not applicable (Mother not alive or not in contact)	23.5	98	2.3	9	13.3	107
EDUCATION LEVEL OF FATHER						
Never been to school/Illiterate	11.0	46	16.8	65	13.8	111
Basic(1-8 grades)	23.7	99	28.2	109	25.9	208
Secondary(9-10)	5.3	22	10.3	40	7.7	62
Higher secondary	1.7	7	2.8	11	2.2	18
Non-formal	8.4	35	11.9	46	10.1	81
Do not know	5.0	21	5.4	21	5.2	42
Not applicable (Father not alive or not in contact)	44.8	187	24.5	95	35.1	282
TOTAL	100.0	417	100.0	387	100.0	804

### 3.4 HIV Status of children and their primary caregiver

An overwhelming majority (95%) of CABA ever had their HIV tested. Sixty-four percentage of CABA had mothers as their primary caretakers, followed by fathers(21%). The proportion of children having mother caretakers was higher among Children affected by AIDS than infected ones. Similarly, 14% of CLHIV reported that their primary caretaker was officials (staff or volunteers) from child care organizations. Likewise, 5% of CLHIV were taken care of by their grandmothers.

Similarly, 65% of CABA were aware of the HIV status of caretakers, and among them, the majority(89%) mentioned their caretakers were HIV positive. Similarly, among the children whose primary caretakers were not parents, 44% of children knew the HIV status of their parents, and among them, nearly half(49%) mentioned both father and mother were HIV positive.

Table 5: HIV test of children and their primary caregiver

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
EVER TESTED HIV						
Yes	96.6	403	92.5	359	94.7	762
No	0	0	7.0	27	3.4	27
Do not know	3.4	14	.5	2	2.0	16
TOTAL	100	417	100	388	100.1	805
HIV STATUS						
Infected (HIV +ve)	97.5	393			51.6	393
Not infected (HIV -ve)			95.8	344	45.1	344
Do not know	2.5	10	3.9	14	3.1	24
I don't want to answer			.3	1	.1	1
PRIMARY CARETAKER						
Father	15.6	65	27.6	107	21.4	172
Mother	59.0	246	70.1	272	64.3	518
Grandmother	5.3	22	.8	3	3.1	25
Grandfather	1.7	7	0	0	.9	7
Siblings	3.6	15	.8	3	2.2	18
Self	.7	3	.5	2	.6	5
Others (organization people)	14.1	59	.3	1	7.5	60
AWARE ABOUT HIV TEST OF CARETAKER						
Yes	65.5	273	64.2	249	64.8	522
No	14.6	61	23.7	92	19.0	153
Do not know	19.9	83	12.1	47	16.1	130
HIV status of caretaker						
Infected (HIV +ve)	87.9	240	90.8	226	89.3	466
Not infected (HIV -ve)	10.6	29	8.8	22	9.8	51
Do not know	1.5	4	.4	1	1.0	5
INCASE CARETAKER IS NOT PARENTS, HIV STATUS OF PARENTS						
Yes	44.4	185	42.8	166	43.6	351
No	22.3	93	31.7	123	26.8	216
Do not know	31.7	132	23.2	90	27.6	222
I don't want to answer	1.7	7	2.3	9	2.0	16
PARENTS HAVE DONE HIV TEST						
Father	12.4	23	16.3	27	14.2	50
Mother	29.2	54	30.7	51	29.9	105
Both	58.4	108	53.0	88	55.8	196
HIV STATUS OF PARENTS						
Father is HIV +ve	10.3	19	24.1	40	16.8	59
Mother is HIV +ve	31.9	59	32.5	54	32.2	113
Both are HIV +ve	54.1	100	42.8	71	48.7	171
Both are HIV -ve	3.8	7	.6	1	2.3	8
TOTAL	100.0	185	100.0	166	100.0	351



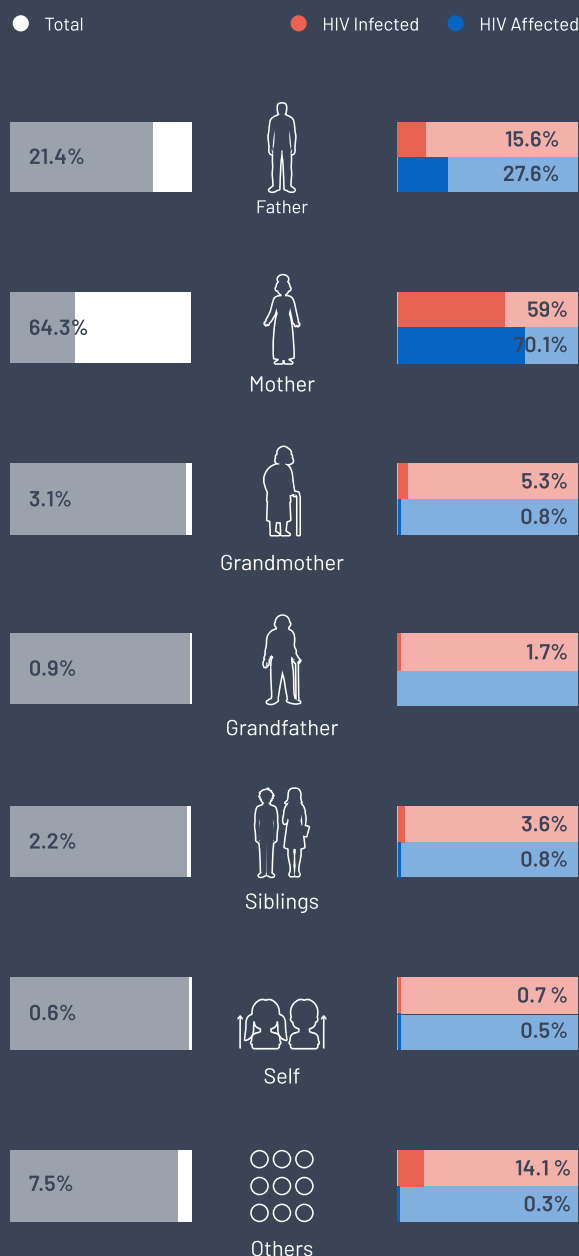


Figure 2: Primary caretaker

The sickness and healthcare-seeking behavior of CABA was also examined in the study. It was found that 34% of CABA had one or the other illness in the past year.

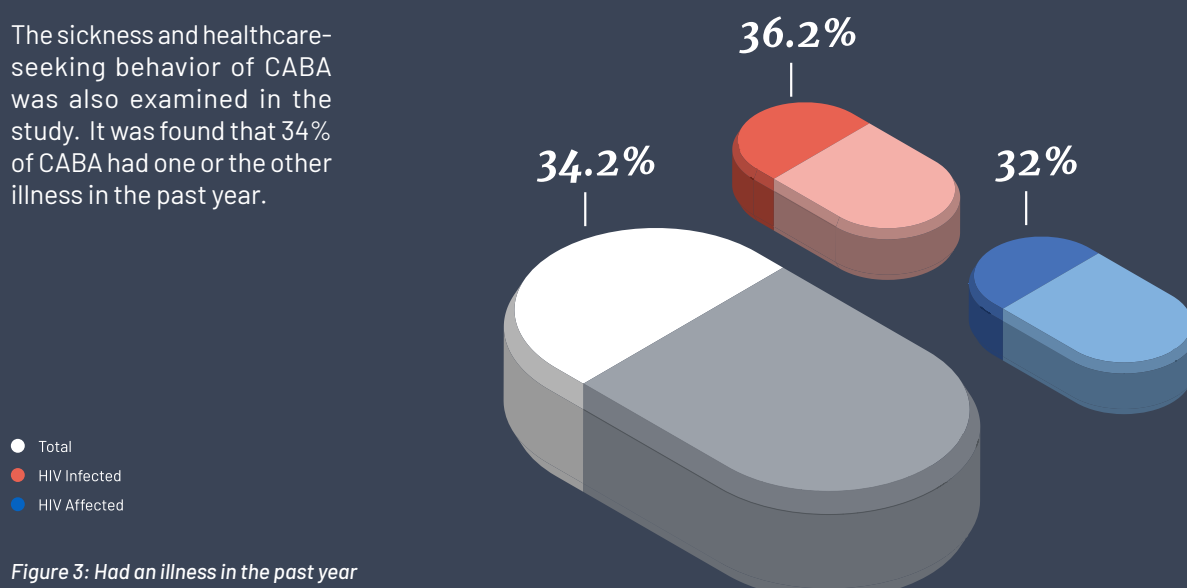


Figure 3: Had an illness in the past year

### 3.5 Availability and Accessibility of Health services

#### 3.5.1 Sickness and care-seeking behavior

The sickness and healthcare-seeking behavior of CABA was also examined in the study. It was found that 34% of CABA had one or the other illness in the past year. Although statistically not that significant (Chi square=1.6 and p=0.204), a slightly higher proportion of CLHIV (36%) had an illness than Children affected by AIDS (32%) in the past year.

Province-wide analysis shows that a higher percentage of CLHIV in Karnali province (51%) followed by Province 2 had an illness (44%) in the past year. A similar trend was observed among children affected by AIDS (Karnali=42% and Province 2=41%). On the other hand, Bagmati province had the lowest percentage of children of ever having an illness (CLHIV=21% and HIV affected=24%). (Annex table P1)

Among those who had an illness in the past year, the most frequent type of illness was fever (62%), followed by cold/cough (57%) and diarrhea (18%). Among those who were ill, the majority (84%) had visited health facilities. Those who did not visit health facilities were further asked about the reasons for not visiting in which the majority of them (91%) mentioned that they did not visit because it was just a minor illness, and 9% also said it was because services related to COVID was not available.

KII participants mentioned that free CHBC and ART services helped to improve health services seeking behavior among CLHIV and their caregivers. Besides, due to the distribution of medicines through CHBC mobilizers, the overall health status of CLHIV has improved.

In the districts where the National Health Insurance scheme has been implemented, most CABA and their family have already been enrolled in the program while some are yet to be enrolled. However, those who lack documents might have been left out from this welfare scheme, too, as well as from CTP.

#### ILLNESS STATISTICS



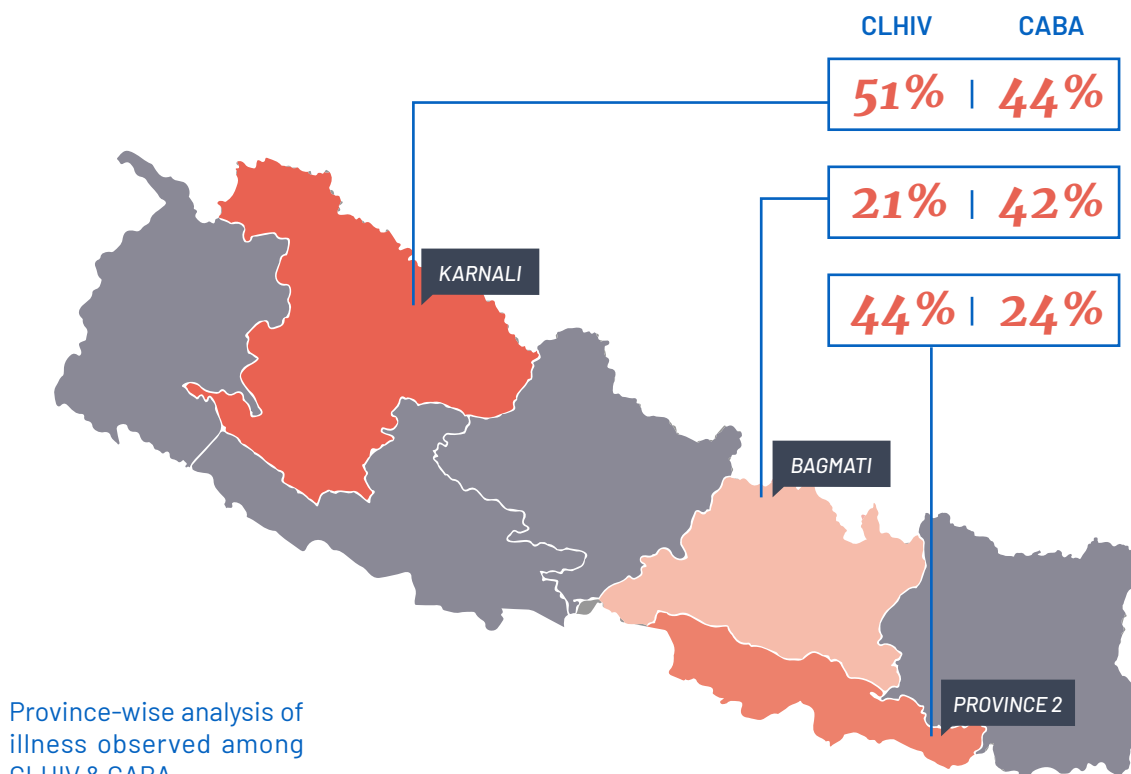
**62%**  
Fever



**57%**  
Cold/ Cough



**84%**  
Diarrhoea



Province-wise analysis of illness observed among CLHIV & CABA

Table 6: Sickness and care-seeking behavior

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
EVER HAD AN ILLNESS IN THE PAST YEAR**						
Yes	36.2	151	32.0	124	34.2	275
No	63.8	266	68.0	264	65.8	530
Types of illness +						
Fever	57.6	87	66.1	82	61.5	169
Cold/cough	55.6	84	58.1	72	56.7	156
Diarrhea	21.9	33	13.7	17	18.2	50
Chest pain	8.6	13	4.8	6	6.9	19
Loss of appetite	8.6	13	7.3	9	8.0	22
Others specify	21.2	32	16.1	20	18.9	52
VISITED HEALTH FACILITIES						
Yes	86.8	131	79.8	99	83.6	230
No	13.2	20	20.2	25	16.4	45
REASON FOR NOT VISITING ++						
Minor illness (cold/cough)	95.0	19	88.0	22	91.1	41
Did not have money			4.0	1	2.2	1
Services related to COVID-19 not available	10.0	2	8.0	2	8.9	4
Lack of transport facilities due to COVID			8.0	2	4.4	2
TOTAL	100.0	20	100.0	25	100.0	45

+Multiple responses

++ Chi-square value=1.61, p=0.204

### 3.5.2 Information about health facility where respondents usually visit for the services

It was found that 29% of CABA visited health facilities once a month, followed by once in 3 months (17%) and once every two months (10%). A higher proportion of CLHIV (41%) visited health facilities monthly than Children affected by AIDS (16%). The most preferred health facility by CLHIV (81%) and Children affected by AIDS (56%) was Government

Hospital. Nearly half (49%) CABA mentioned that it took one hour or more to reach the health facility, followed by 30-59 minutes (26%). Likewise, 68% of CABA visited the nearest health facility, while 32% visited the nearest health facility. Among them who did not visit the nearest health facility were asked about its reasons, and many of them mentioned the unavailability of required service (56%) and expensive service (21%).

Table 7: Information about health facility where respondents usually visit for the services

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
FREQUENCY OF VISITING THE HEALTH FACILITY						
Weekly	1.0	4	1.8	7	1.4	11
Monthly	40.5	169	16.0	62	28.7	231
Once every two months	10.3	43	9.3	36	9.8	79
Once every three months	24.0	100	10.3	40	17.4	140
I don't remember	8.4	35	18.8	73	13.4	108
Never	.5	2	3.9	15	2.1	17
Never felt ill	4.6	19	12.6	49	8.4	68
Others	10.8	45	27.3	106	18.8	151
HEALTH FACILITY PREFERRED						
Health Post	7.1	28	13.3	43	9.9	71
PHCs	1.3	5	.9	3	1.1	8
Government Hospital	81.1	321	55.6	180	69.6	501
Private Hospital	3.0	12	9.0	29	5.7	41
Private Clinic	6.3	25	19.4	63	12.2	88
HIV Testing Centers	.8	3			.4	3
Others	.5	2	1.9	6	1.1	8
TIME TO REACH THE HEALTH FACILITY						
Less than 15 minutes	5.8	23	16.7	54	10.7	77
15-29 minutes	12.1	48	17.3	56	14.4	104
30-59 minutes	23.0	91	29.3	95	25.8	186
One hour and more	59.1	234	36.7	119	49.0	353
VISITING NEAREST HEALTH FACILITY						
Yes	59.6	236	77.2	250	67.5	486
No	38.9	154	22.5	73	31.5	227
Do not know	1.5	6	.3	1	1.0	7
REASON FOR AVOIDING NEAREST HEALTH FACILITY						
Fear of being identified	4.4	7	2.7	2	3.8	9
Due to felt stigma	1.9	3			1.3	3
Staff is unfriendly	2.5	4	4.1	3	3.0	7
Service is expensive	15.6	25	33.8	25	21.4	50
Required service is unavailable	59.4	95	50.0	37	56.4	132
Low quality of service	10.6	17	5.4	4	9.0	21
Others	5.6	9	4.1	3	5.1	12
TOTAL	100.0	160	100.0	74	100.0	234

According to the qualitative findings, those who live in remote areas or at a distance from the health facilities are deprived of health and counseling services. For them, bearing the cost of travel is burdensome, because of which some of them even discontinue the medication.

### 3.5.3 Satisfaction with health services

Regarding the satisfaction with health services, 68% of CABA mentioned they were satisfied, and 18% were 'very satisfied' with the health services, while 5% were dissatisfied with the health services. Although it should be noted here that no health care services in hospitals or other health facilities were known of which particularly provided CLHIV centered services, or even CABA for that matter. Besides, the privacy and confidentiality of HIV-infected patients in few places is also a serious concern.

“ Once when I went to get medicines in a hospital, a nurse called out loud in front of all the people asking the HIV positive ones to come with her.”

- FGD participant



Table 8: Satisfaction with health services

Satisfaction with health services	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Very dissatisfied	.4	1			.2	1
Dissatisfied	9.3	22	1.6	4	5.3	26
Neither satisfied nor Dissatisfied	8.1	19	9.6	24	8.8	43
Satisfied	62.7	148	72.0	180	67.5	328
Very satisfied	19.5	46	16.8	42	18.1	88
<b>TOTAL</b>	<b>100.0</b>	<b>236</b>	<b>100.0</b>	<b>250</b>	<b>100.0</b>	<b>486</b>

### 3.5.4 Faced any stigma or discrimination by doctors or staffs at the hospital

Notably, 90% of CABA reported of never facing any stigma or discrimination by doctors or staff at the hospital. On the other hand, 7% of CLHIV and 5% of children affected by AIDS sometimes faced stigma or discrimination by the doctors or staff at the hospital (Figure 5 and Annex table 1). The finding is almost similar to the Nepal Stigma Index 2011, which found that seven percent of the PLHIV had been denied health services, including dental care, because of their HIV status.

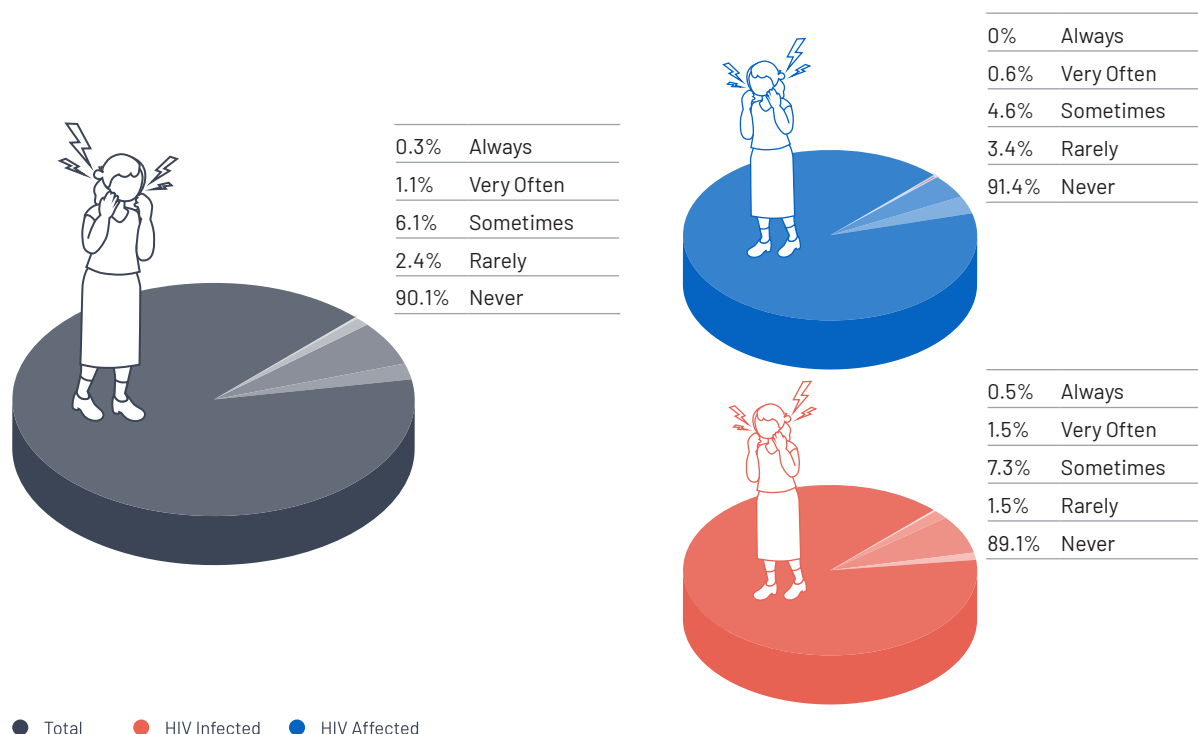
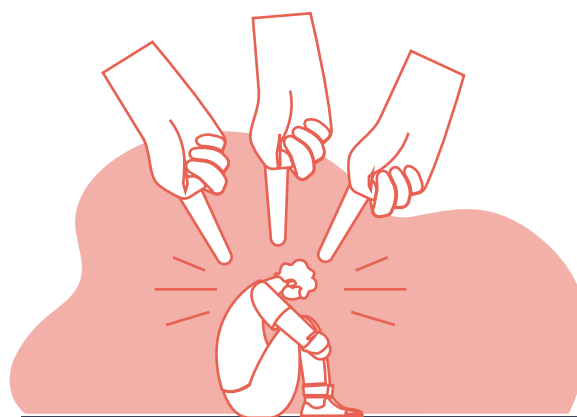


Figure 4 : Faced any stigma or discrimination by doctors or staff at the health facilities.

Province-wise comparison shows that 11 percent of CLHIV reported that they had faced stigma very often CLHIV from Gandaki province. Similarly, about 20% of CLHIV who reside in Karnali and 15% CLHIV who lives in Province 2 had faced stigma sometimes (Annex table P2).

Data from FGDs and KIs reveal that discrimination still persists as faced by many CABA and caregivers in hospitals.



“ In hospitals, they attend the HIV patients only when staffs of the organization are present. If the staff from the organization is not there, the hospital staff do not attend or admit them, saying that your people are not here. They even hesitate to touch their wound. They wear 2-3 gloves when treating them.”

- KI respondent

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

-FGD participant

### 3.5.5 Awareness among CABA regarding amount required to access health services

It was found that 64% of CABA were aware of each month's amount required for accessing health services. Among them, 34% and 29% said they needed 500-999 rupees and less than 500 rupees respectively.

Table 9: Awareness among CABA regarding amount required to access health services

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
AWARE OF THE AMOUNT REQUIRED EACH MONTH FOR ACCESSING HEALTH SERVICES						
Yes	64.9	257	63.6	206	64.3	463
No	35.1	139	36.4	118	35.7	257
TOTAL	100.0	396	100.0	324	100.0	720
THE AMOUNT REQUIRED EACH MONTH FOR ACCESSING HEALTH SERVICES.						
Less than 500	31.9	82	24.8	51	28.7	133
500-999	34.2	88	34.0	70	34.1	158
1000-1999	19.5	50	26.2	54	22.5	104
2000 and more	14.4	37	15.0	31	14.7	68
TOTAL	100.0	257	100.0	206	100.0	463

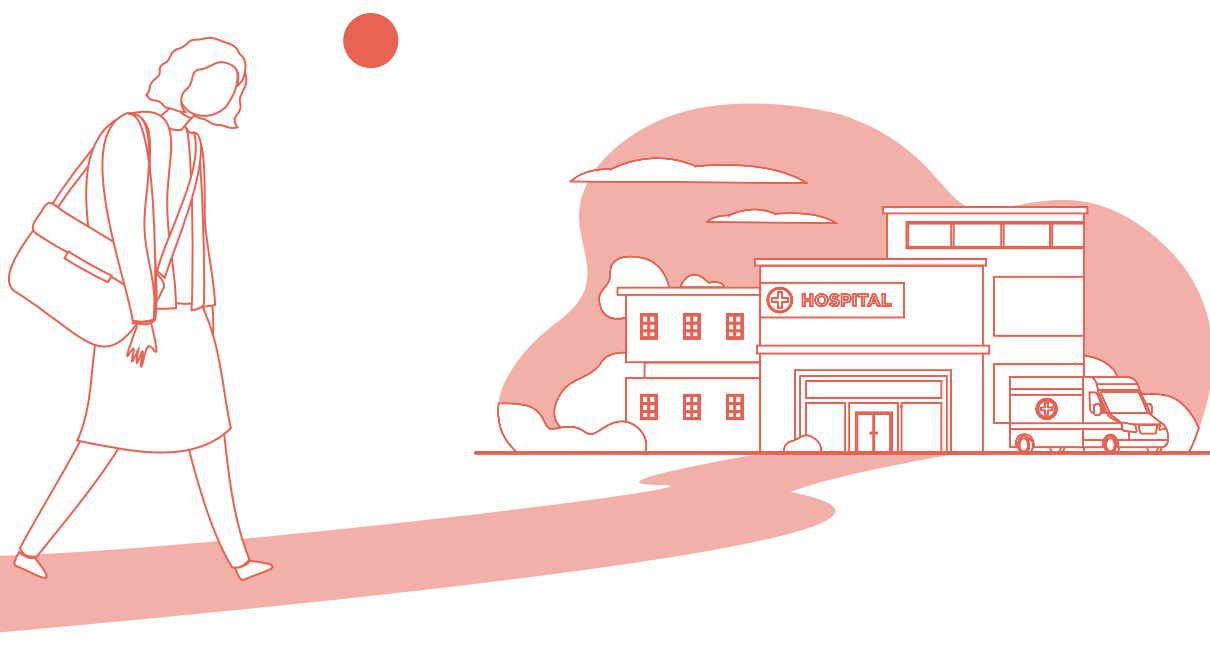
However, those who live in remote areas, or distant from the health facilities, are deprived of health and counseling services. For them, bearing the cost of travel is burdensome, because of which some of them even discontinue the medication.

“ People living with HIV, living in remote areas, are forced to walk an entire day to reach hospitals for ART as they have no money for transportation.”

- KII respondent

“ I visit ART center in hospital once every month. On each visit, I spend about 100-200 rupees. It is easy if my father has money, but sometimes, it is difficult to manage. At such time, my friends drop me to the hospital.”

- CTP Graduate



### 3.6 Education status (6 years and above children)

Educational attainment status among CABA has improved over the years, as observed by people in the community. Some CABA go to private schools, while most others go to government schools. The 1000 rupees from CTP have aided many of them to stay in school by helping to pay their fees, buy stationery, uniforms, or lunch. While schools do not provide scholarships to CABA based on their needs, they sometimes receive books, notebooks, and other stationeries through various organizations and local municipalities.

According to the survey data, 96 percent of children aged six and above were enrolled in school. A slightly higher proportion of CLHIV (97.5%) was enrolled in a school than Children affected by AIDS (94.4%). The difference is statistically significant ( $p < 0.05$ ). Among those who did not enroll in school, almost a third reported major reason to be financial crisis (62%), followed by having to earn on their own (10%) and no desire to study (10%). Province-wise comparison shows that all CLHIV from Lumbini, Karnali, and Sudurpaschchim provinces while only 91% CLHIV in Gandaki and 93% CLHIV in province 2 had ever enrolled in school (Annex table P3).

Qualitative results corroborate this finding showing that school dropouts among older CABA are an apparent issue. There might be several reasons for this. Parents of CLHIV have revealed that their children, when they know about their HIV status, show little interest in education because they feel that they will not get a decent job or pursue a career they want to engage in even when they study. Some drop out of school to earn a living and support their family.

Drop out is even more common among adolescents who are 18 years and above. Earlier, they were at least able to pay their fee through CTP, but when they reach 18, they don't even receive that amount, pushing them to leave their education and engage in work.

“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

Among those who were ever enrolled were further asked whether they are continuing the study. Almost all (98%) children were currently going to school. Seventy-four percent of children had been studying basic level education while 10% had SLC and above education. Similarly, with regards to the discrimination in school, 47% of CABA mentioned that their or their family members' HIV status was not disclosed, and 49% noted they never faced any stigma or discrimination by friends at school. Two percent of children reported that they sometimes faced stigma or discrimination, while one percent said they often faced stigma or discrimination by friends at school. Similarly, almost two percent of children reported that they faced stigma or discrimination by teachers at school (very often 0.3%, sometimes 1.3%, and rarely 0.3%). Likewise, 25% of children who dropped out from school reported discrimination by friends (17%) and teachers (8%).

KII and FGD respondents have mentioned that awareness programs in schools have helped reduce stigma in schools, but CABA still choose to hide their HIV status from their teachers and friends, distressing over being discriminated against at school. School-going adolescents in most communities learn about HIV through their textbooks. However, one can assume that the knowledge about HIV alone is not enough and that lack of comprehensive sexuality education for adolescents might have encouraged early and unprotected sexual intercourse among adolescents in some communities.

#### DROPOUT CABAS

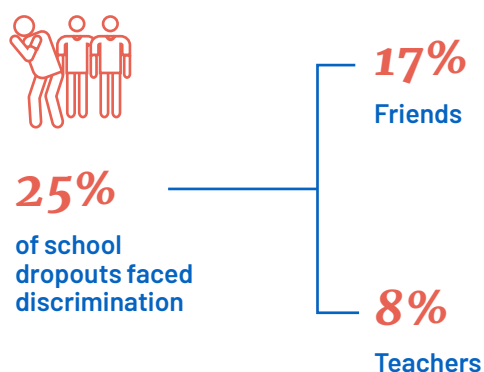




Table 10: Education status of CABA (six years and above)

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
ENROLL TO SCHOOL*						
Yes	97.5	383	94.4	321	96.0	704
No	2.5	10	5.6	19	4.0	29
TOTAL	100.0	393	100.0	340	100.0	733
REASON FOR NOT ENROLLING TO SCHOOL						
Financial crisis	60.0	6	63.2	12	62.1	18
I didn't want to study	10.0	1	10.5	2	10.3	3
I have responsibilities at home	10.0	1	5.3	1	6.9	2
I have to earn by myself	10.0	1	10.5	2	10.3	3
I got married	10.0	1	5.3	1	6.9	2
I don't want to answer			5.3	1	3.4	1
TOTAL	100.0	10	100.0	19	100.0	29
CURRENTLY GOING TO SCHOOL						
Yes	97.9	375	98.8	317	98.3	692
No	2.1	8	1.2	4	1.7	12
TOTAL	100.0	383	100.0	321	100.0	704
CURRENTLY STUDYING GRADE						
Basic(1-8)	73.8	276	75.0	237	74.3	513
Secondary(9-10)	17.9	67	12.7	40	15.5	107
SLC and above	8.3	33	12.3	40	10.1	72
TOTAL	100.0	375	100.0	317	100.0	692
REASON FOR NOT CURRENTLY GOING TO SCHOOL+						
Discrimination by friends	12.5	1	25.0	1	16.7	2
Discrimination by teachers			25.0	1	8.3	1
Financial crisis	25.0	2	25.0	1	25.0	3
I didn't want to study	50.0	4			33.3	4
I have responsibilities at home	25.0	2	25.0	1	25.0	3
Do not know			25.0	1	8.3	1
Other Reason	12.5	1			8.3	1
Grade at dropping school						
Basic(1-8)	100.0	8	50.0	2	83.3	10
Secondary(9-10)			50.0	2	16.7	2
TOTAL	100.0	8	100.0	4	100.0	12
FACED STIGMA OR DISCRIMINATION BY FRIENDS AT SCHOOL						
Very Often	1.3	5	.6	2	1.0	7
Sometimes	2.9	11	1.6	5	2.3	16
Rarely	1.6	6	.3	1	1.0	7
Never	30.0	115	71.0	228	48.7	343
HIV status not disclosed	64.2	246	26.5	85	47.0	331
TOTAL	100.0	383	100.0	321	100.0	704

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
FACED STIGMA OR DISCRIMINATION BY TEACHERS AT SCHOOL						
Very Often	.3	1	.3	1	.3	2
Sometimes	1.3	5	1.2	4	1.3	9
Rarely	.3	1	.3	1	.3	2
Never	46.2	177	75.1	241	59.4	418
HIV status not disclosed	52.0	199	23.1	74	38.8	273
TOTAL	100.0	383	100.0	321	100.0	704

+Multiple responses, Note: \* Chi-square value=4.44, p=0.035

### 3.7 Nutritional status

The nutritional status of CABA was also examined in the study. Seventy-six percent children had three or more meals in the last month, while 24% had less than three meals. It is encouraging that an overwhelming majority (98%) of CABA mainly consumed home-cooked food in the last six months, and the food was cooked mainly by the mother (73%). Similarly, 69% of children consumed protein-rich foods less than three times a week, and more than a fourth (27%) consumed more than three times a week. Likewise, 28% stated that they had some changes in consumption patterns during the past 12 months.

Furthermore, 75% of CABA mentioned that they consumed fruits less than three times a week, and 7% said they never consumed fruits. Similarly, 61% of CABA consumed vegetables more than three times a week, and 18% consumed them daily. It is of note that nearly half (45%) CABA had some problem with managing food.



#### MEALS

**76%** Had 3 or more meals

**24%** Had less than 3 meals

**69%** children consumed protein-rich foods less than three times a week

**27%** children consumed protein-rich foods more than three times a week

**75%** CABA consumed fruits less than three times a week

**7%** CABA never consumed fruits

**61%** CABA consumed vegetables more than three times a week

**18%** CABA consumed vegetables daily

Table 11: Dietary status of CABA

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
THE DAILY EATING PATTERN OF LAST ONE MONTH						
Less than 3 meals	26.6	111	21.6	84	24.2	195
More than or equal to 3 meals	73.4	306	78.4	304	75.8	610
THE PRIMARY SOURCE OF COOKED FOOD IN THE LAST SIX MONTHS						
Purchased from outside	1.0	4	1.8	7	1.4	11
Home-cooked	98.8	412	97.9	380	98.4	792
Other	.2	1	.3	1	.2	2
Person preparing food at home						
Father	2.4	10	1.5	6	2.0	16
Mother	62.6	261	84.3	327	73.0	588
Siblings	6.0	25	3.9	15	5.0	40
Self	7.0	29	5.4	21	6.2	50
Others	22.1	92	4.9	19	13.8	111
FREQUENCY OF CONSUMING PROTEIN-RICH FOOD						
Daily	2.2	9	.3	1	1.2	10
More than three times a week	23.5	98	31.2	121	27.2	219
Less than three times a week	71.5	298	67.0	260	69.3	558
Never	2.9	12	1.5	6	2.2	18
HAD ANY CHANGES IN CONSUMPTION PATTERN DURING THE PAST 12 MONTHS						
Yes	29.5	123	25.5	99	27.6	222
No	70.5	294	74.5	289	72.4	583
FREQUENCY OF CONSUMING FRUITS						
Daily	1.2	5	.3	1	.7	6
More than three times a week	12.0	50	22.9	89	17.3	139
Less than three times a week	81.1	338	69.1	268	75.3	606
Never	5.8	24	7.7	30	6.7	54
FREQUENCY OF CONSUMING VEGETABLES						
Daily	20.1	84	15.2	59	17.8	143
More than three times a week	57.1	238	66.0	256	61.4	494
Less than three times a week	19.4	81	16.5	64	18.0	145
Never	3.4	14	2.3	9	2.9	23
HAVE ANY PROBLEM MANAGING FOOD						
Yes	42.0	175	48.7	189	45.2	364
No	58.0	242	51.3	199	54.8	441
TOTAL	100.0	417	100.0	388	100.0	805

### 3.8 Psychosocial issues

The findings from qualitative interviews showed that CABA face various psychosocial problems. Stigmatization of HIV due to lack of awareness among people, the poor economic condition of CABA, and other factors have negatively impacted the psychosocial well-being of both infected and affected children. Children infected with HIV sometimes get counseling services through CHBC, CCC, and health facilities, but there are no counseling services available for affected children. In some cases, CABA have shown behavioral problems in knowing about their HIV status when they reach the age of maturity. They become very distressed and aggressive towards their parents.

“ 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

However, it has also been observed that if proper counseling is provided to CABA from an early age, they will cope with the situation better.

“ When I came to know about my status, I dealt with it very calmly. I did not have fear or anything. It is not that I came to know about it at once. When I was a small child, I didn't understand what HIV is. But as I grew up and learned in school and from others, I started understanding about it, and I didn't take it as a big deal. The organization also used to give me counseling after I started taking medicine.”

- CTP graduate

HIV has also affected the relationships of CABA. They have low self-esteem and fear that others might not accept them because of their status.

“ Sometimes, I feel bad that I will not be able to build a romantic relationship because of my HIV status. I am afraid to express my feelings.”

- CTP Graduate

“ I don't have a boyfriend. I never had one. Because of my HIV status also, I am afraid to be in a relationship. If they will know, I fear that everyone in the village might know about my status.”

- CTP graduate





### 3.8.1 Fear about certain things in last 12 months

The study also assessed CABA feelings, whether they felt fearful about certain things in the last 12 months. In this regard, 10% (12% CLHIV and 8% of children affected by AIDS) children were fearful of being gossiped about. Similarly, 8% and 3% of children were fearful about being verbally insulted and being physically harassed, respectively. Likewise, 4% of CABA were fearful of being physically assaulted (Figure 6 and annex table 2).

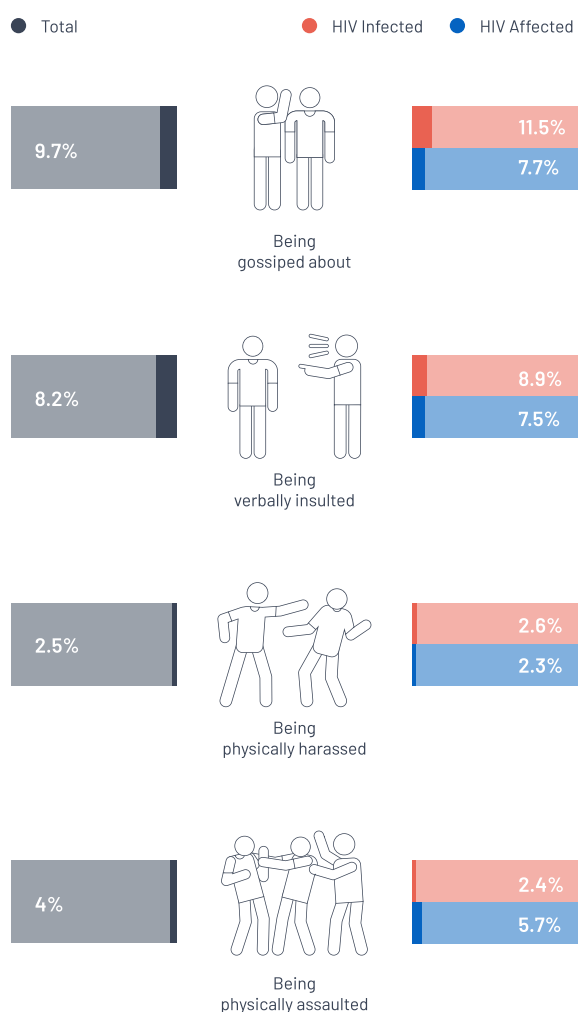


Figure 5 : Fear about certain things in last 12 months

### 3.8.2 Unpleasant feelings experienced

The study also investigated whether CABA experienced any unpleasant feelings in the last 12 months. 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%) children. Similarly, 4% of children experienced feeling guilty, 9% experienced feeling lonely, and 15% experienced feeling angry at themselves. Similarly, 22% of children experienced feeling angry at others. 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 (Figure 7 and annex table 3).

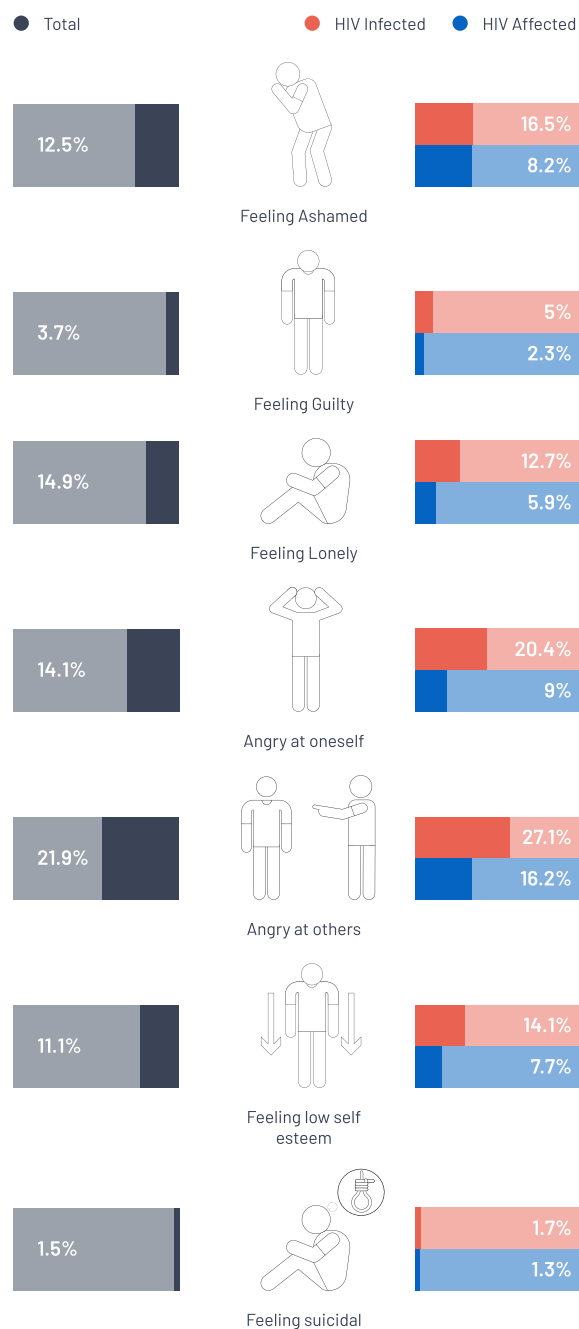


Figure 6 : Experienced feelings by CABA in the last 12 months.

### 3.8.3 Experience of exclusion from social gathering or activities

The majority (93%) of CABA did not exclude social gatherings or activities in the last 12 months. However, still, it is discouraging that 7% of children experienced exclusion from social gatherings/activities. It was found that a significantly higher ( $p < 0.05$ ) proportion of CLHIV (9%) than Children affected by AIDS (5%) experienced exclusion from social gatherings/activities (Figure 8 and annex table 4).

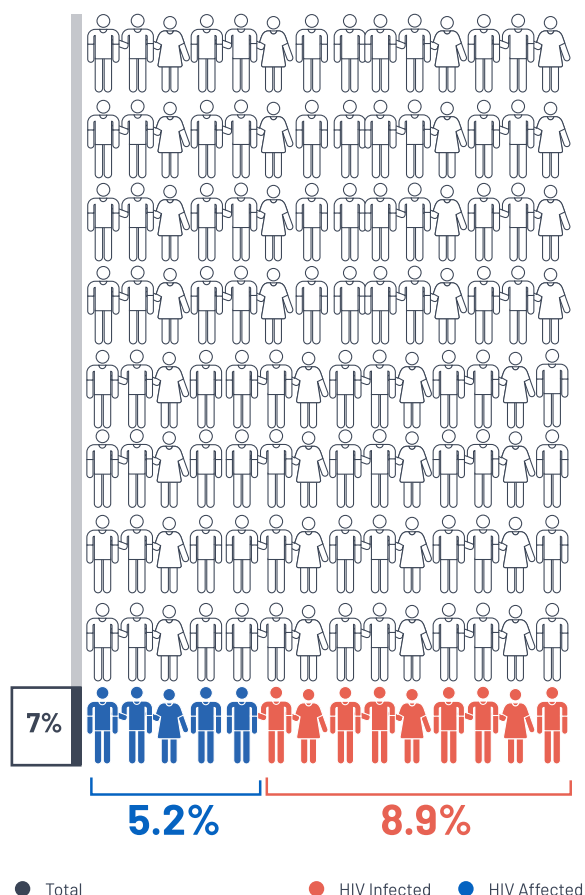


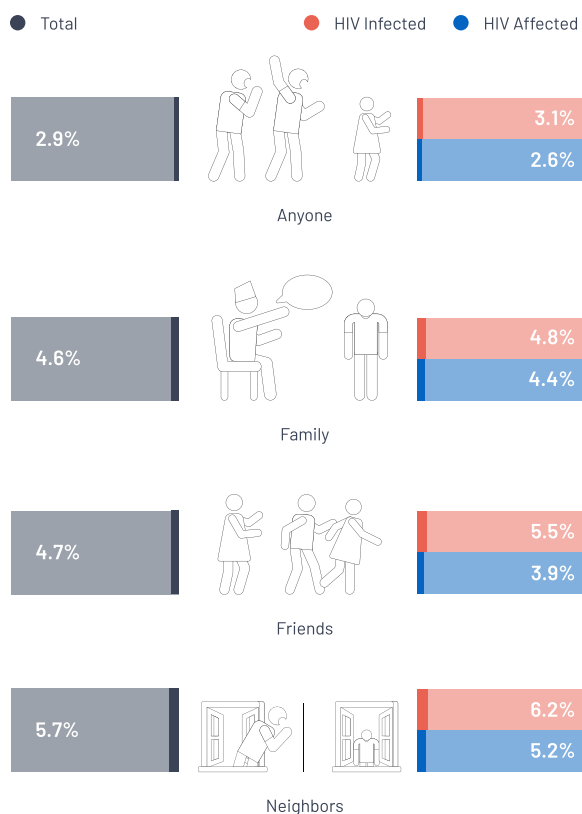
Figure 7: Excluded from social gatherings or activities in the last 12 months.

A higher percentage of CLHIV in Bagmati province (13%) followed by Lumbini (9%) and Sudurpashchim (9%) had excluded from social gatherings/activity. Similarly, 10% of HIV-affected children who reside in Bagmati province reported that they had been excluded from a social gathering (Annex table P4).

### 3.8.4 Experience of stigma or discrimination

Regarding the experience of stigma or discrimination by CABA, 6% experienced discrimination or stigma from neighbors, 5% from friends and family members, and 3% from anyone (Figure 9 and annex table 5).

Figure 8: Experience of stigma or discrimination



According to the qualitative findings, most people living with HIV/ AIDS do not disclose their condition to others because of the stigma and discrimination they fear they will face in society. Those who reported that they had not felt any discrimination also said they had not disclosed their status to others. Among those who have disclosed, some have faced discrimination in schools by friends and teachers, family, and other places that have directly affected their mental well-being. The discrimination is even more layered when it involves people from poor economic backgrounds, lower castes, women, and sexual minorities. This has created difficulties for CLHIV to accept their condition.

“ In a school in Dhanusha, students and teachers were not coming to the class as they came to know that one of the students was infected.”

- KII Respondent.

“ A daughter of HIV positive woman was about to get married, but the marriage was cancelled because the groom’s family came to know about HIV status of the girl’s mother.”

- FGD Participant

### 3.8.5 Ever experienced any type of mistreatment

It was also investigated whether CABA experienced mistreatment, and multiple responses were obtained on it. In this regard, 8% experienced emotional mistreatment, and 2% experienced physical mistreatment. Similarly, one percent reported that they experienced sexual violence (Figure 10 and annex table 6).

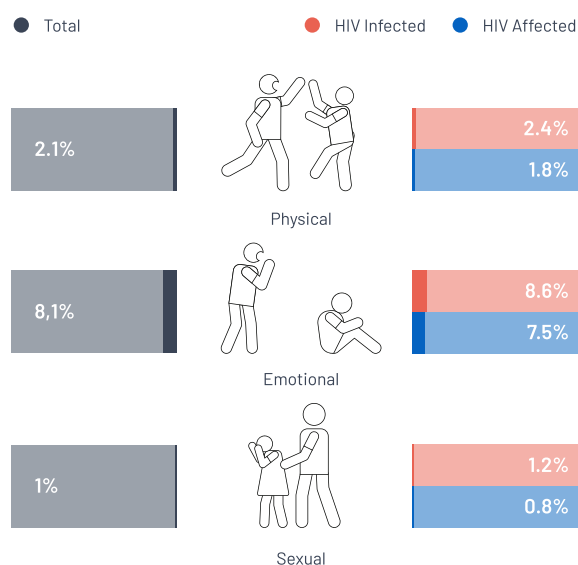


Figure 9: Ever experienced any type of mistreatment.

Province-wise analysis shows that 9 percent CLHIV of Lumbini province, followed by 3 percent in Bagmati province, had experienced physical

violence. Almost 15 percent of CLHIV in Karnali and Sudurpaschim provinces faced emotional violence, while 7 percent of CLHIV in Lumbini province reported they experience sexual violence (Annex table P5).

Qualitative findings show that there had been instances when PLHIV faced mistreatment from people and sometimes from their family members.

“ My husband refused to take medicine when he was undergoing medical treatment.. Then he was sent to Kathmandu. He was sent back home as he was depressed. Family members hesitated to touch us. They used to slide the plate while giving us food, and eventually, we were thrown out of the house. I was pregnant, so we came to Kathmandu for delivery. After birth, my baby was given to a friend as we could not raise the child. My husband died after some time. My daughter also committed suicide at the age of 18.”

- FGD participant

### 3.8.6 Ever faced fear when left alone

Twenty-one percent respondents mentioned that they faced fear when left alone. A statistically significantly higher ( $p < 0.001$ ) proportion of CLHIV (25%) experienced fear than Children affected by AIDS (18%)(Table 12). Province-wise analysis shows that 44 percent of CLHIV in Province 2 followed by 33 percent in Lumbini province, and 28 percent in Sudurpaschim provinces mentioned that they faced fear when left alone. Similarly, 23 percent of CLHIV in province 1, 17 percent in Gandaki province, and 15 percent in Bagmati province felt fear when they were left alone. Furthermore, more than a third of children affected by AIDS of Province (34%) followed by 19 percent in Lumbini province, had faced fear when left alone (Annex table P6).

Table 12 Ever faced fear when left alone

Ever faced fear when left alone***	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Yes	24.7	103	17.5	68	21.2	171
No	48.7	203	42.5	165	45.7	368
Never stayed alone	26.6	111	39.9	155	33.0	266
<b>TOTAL</b>	<b>100.0</b>	<b>417</b>	<b>100.0</b>	<b>388</b>	<b>100.0</b>	<b>805</b>

Note: \*\*\* Chi-square value=17.34, p=0.000

### 3.9 Care or support

Nearly half (48%) CABA received any counseling care or support from anyone in the past 12 months. A significantly higher proportion ( $p<0.001$ ) of CLHIV (68%) received counseling or support than Children affected by AIDS (26%).

Table 13 Received any counseling care or support from anyone in the past 12 months.

Received any counseling care or support from anyone in the past 12 months ***	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Yes	68.3	285	26.0	101	48.0	386
No	31.7	132	74.0	287	52.0	419
<b>TOTAL</b>	<b>100.0</b>	<b>417</b>	<b>100.0</b>	<b>388</b>	<b>100.0</b>	<b>805</b>

Note: \*\*\* Chi-square value=144.2 and P value=0.000

Province-wise analysis shows that a high majority of CLHIV in Sudurpaschim (89%) followed by Gandaki province (86%) and Lumbini province (79%) reported that they received any counseling care or support from anyone in the past 12 months. On the other hand, only 42 percent of CLHIV in Bagmati province reported receiving counseling care or support in the past 12 months. The percentage of children affected by AIDS who received counseling and support from anyone in the past 12 months were low in all provinces (8% to 50%) (Annex table P7).

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

#### 3.10.1 Heard about HIV

Sixty-six percent CABA had heard about HIV. A significantly higher percentage ( $P<0.001$ ) of CLHIV (82%) than Children affected by AIDS (50%) had heard about it. The major sources of information were family/parents (64%) followed by school (56%), NGOs/training (38%) and radio/television/internet (29%) and health care facilities (23%).

Awareness programs in schools have helped to reduce stigma in the context of schools as compared to before. School-going adolescents in most communities learn about HIV through their textbooks. Nevertheless, one can assume that the knowledge about HIV alone is not enough and that lack of comprehensive sexuality education for adolescents might have encouraged early and unprotected sexual intercourse among adolescents in some communities.

Meanwhile, awareness programs at the community level appear to be lacking, as apparent by the discrimination faced by PLHIV and their children. Caregivers said that they got to know about HIV only after they tested positive through hospitals, CCCs, and CHBC mobilizers. Nevertheless, in some cases, awareness programs have proven beneficial for changing community people's behavior towards people living with HIV.





“ I used to be respected in our community. Nevertheless, later when my neighbors came to know about my HIV status, they did not even buy things from our store. Later, I organized awareness programs for my community people through the support of Maiti Nepal. Nowadays, everyone loves us and cares for us.”

- FGD Participant

Table 14: Heard about HIV

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
HEARD ABOUT HIV ***						
Yes	81.5	340	50.0	194	66.3	534
No	18.5	77	50.0	194	33.7	271
TOTAL	100.0	417	100.0	388	100.0	805
SOURCE OF INFORMATION RELATED TO HIV +						
Television/ Radio/ Newspaper/ Internet	21.2	72	41.8	81	28.7	153
Family/ Parents	62.1	211	67.0	130	63.9	341
School	47.4	161	71.6	139	56.2	300
Community Learning Centers (CLCs)	12.1	41	12.9	25	12.4	66
Adolescents Friendly Health Services (AFHS)	2.9	10	6.7	13	4.3	23
Health care facilities	24.1	82	21.1	41	23.0	123
Friends	5.6	19	17.0	33	9.7	52
NGOs/training	40.0	136	33.0	64	37.5	200
Others	3.5	12	1.5	3	2.8	15
Do not know	.3	1	.5	1	.4	2
Total	100.0	340	100.0	194	100.0	534

+Multiple responses

\*\*\* Chi-square value=89.5 and p=0.000

Province-wise analysis shows a higher percentage of CLHIV of Sudurpaschchim (93%) followed by Gandaki (89%) and Bagmati (87%) were aware of HIV. The awareness is low among the CLHIV of province 2 (44%). It is discouraging to note that only 17% of children affected by AIDS in Province 2 were aware of HIV (Annex table P8).

### 3.10.2 Modes of HIV transmission

In regards to the knowledge on modes of transmission, the most commonly reported modes of transmission were blood transfusions (92%), sharing injections (81%), unprotected sex (72%), and sex with multiple partners (38%).

Table 15 Modes of HIV transmission

Modes of HIV transmission+	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Unprotected sex	66.3	177	80.4	156	72.2	333
Sharing injections	80.9	216	82.0	159	81.3	375
Blood transfusions	92.5	247	90.7	176	91.8	423
Sex with multiple partners	29.2	78	49.0	95	37.5	173
Kissing	3.7	10	5.2	10	4.3	20
Mosquito Bites	3.7	10	2.1	4	3.0	14
Sharing Utensils	.4	1	1.5	3	.9	4
Sharing Toilets	.7	2	2.1	4	1.3	6
Sharing Blades	19.5	52	26.3	51	22.3	103
Sweat/ Saliva/ Breast milk	4.9	13	6.7	13	5.6	26
Mother to child transmission during pregnancy	27.3	73	23.7	46	25.8	119
<b>TOTAL</b>	<b>100.0</b>	<b>267</b>	<b>100.0</b>	<b>194</b>	<b>100.0</b>	<b>461</b>

+Multiple responses

### 3.10.3 Awareness about health facilities providing HIV services

The majority (82%) of children were aware of where people can get services related to HIV. A higher CLHIV (85%) were aware of the service-seeking place than Children affected by AIDS (77%). The difference is statistically significant ( $p < 0.05$ ) (Figure 11 and Annex table 7).

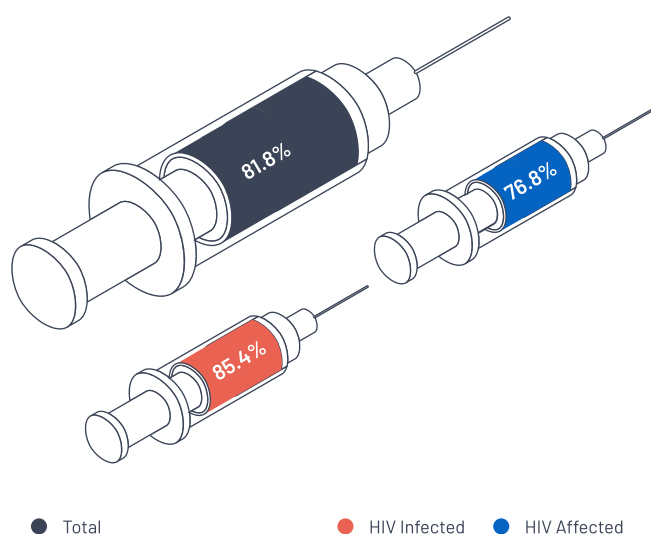


Figure 10 Awareness about health facilities providing HIV services

Province-wise analysis shows that all CLHIV of province 2 and Gandaki province were aware of the health facilities providing HIV services in comparison to only 75% CLHIV in Province 1 and 65% in Bagmati province, Similarly, 88 percent of children affected by AIDS in Karnali province, followed by Sudurpaschim province (87%), were aware of HIV.

### 3.10.4 Knowledge on an organization working on HIV sector

Regarding the knowledge on an organization working in the HIV sector, 76% of CABA were aware of the organization working in HIV-related areas, and more than half (57%) were aware of an organization in community who support distressed families/individual.

Table 16 Knowledge on an organization working on HIV Sector

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Aware about the organization working in HIV related areas *						
Yes	77.2	206	75.3	146	76.4	352
No	22.8	61	24.7	48	23.6	109
Aware about the organization that support to distressed families/individual						
Yes	56.9	152	56.7	110	56.8	262
No	43.1	115	43.3	84	43.2	199
TOTAL	100.0	267	100.0	194	100.0	461

Note: \*=Chi-square value=5.56 and p=0.018

Province-wise analysis shows that all CLHIV of Gandaki and Karnali provinces were aware of the organizations working in HIV-related areas while only 39% CLHIV of Bagmati province were aware of it (Annex table P10).

### 3.11 Effects of COVID-19

Regarding the effects of COVID-19, a fifth of CABA reported that their family members lost their jobs due to the COVID-19 pandemic. A significantly higher ( $P < 0.01$ ) percentage of CLHIV families than children affected by AIDS lost employment because of COVID-19. Among them who lost their jobs, more than half (56%) managed their expenses by acquiring loans, followed by working as a farmer (28%). Similarly, 17% and 19% of CABA managed their expenses through remittance and savings.

#### COVID STORIES

**56%**

Acquired loans

**28%**

Worked as farmer

**17%**

CABA managed  
expense through  
remittance

**19%**

CABA managed  
expense through  
savings

Table 17: Effects of COVID-19

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
LOST JOB FROM ANY OF FAMILY MEMBER BECAUSE OF COVID-19**						
Yes	21.3	89	19.1	74	20.2	163
No	60.2	251	69.3	269	64.6	520
Not applicable (never had a job)	18.5	77	11.6	45	15.2	122
WAY OF MANAGING HOUSEHOLD EXPENSES IN THE ABSENCE OF JOB +						
Remittance	18.0	16	14.9	11	16.6	27
Savings	16.9	15	21.6	16	19.0	31
Loan	57.3	51	54.1	40	55.8	91
Organization paid	10.1	9	9.5	7	9.8	16
Worked as farmer	31.5	28	24.3	18	28.2	46
Do not know	3.4	3	2.7	2	3.1	5
TOTAL	100.0	89	100.0	74	100	163

+Multiple responses

\*\*Chi-square value=9.36 and p value=0.009

Province-wise analysis shows that a higher percentage of CLHIV in Province 2 (52%) reported that their family members lost their jobs due to COVID-19. Similarly, 29 percent of CLHIV in Sudurpashchim province reported their family member lost the job due to COVID-19 (Annex table P11).

## 3.2 Findings from Caregivers

### 3.2.1 Characteristics of Caregiver

The caregivers of CABA were also interviewed in the study to assess the situation of CABA. More than three-fifths (61%) of caretakers were mothers, followed by fathers (27%). Forty-three percent caregivers were aged 35-44 years, followed by 45-54 years (24%) and 25-34 years (20%). Similarly, 69% of caregivers were female, 33% were Brahmin/Chhetri, 27% were Hill Dalits, and 16% were Hill Adhivasi/Janjatis. Likewise, most (89%) followed the Hindu religion, followed by Christian (4%).

61%

Mothers

27%

Fathers

20%

aged 25-34

43%

aged 35-44

24%

aged 45-54

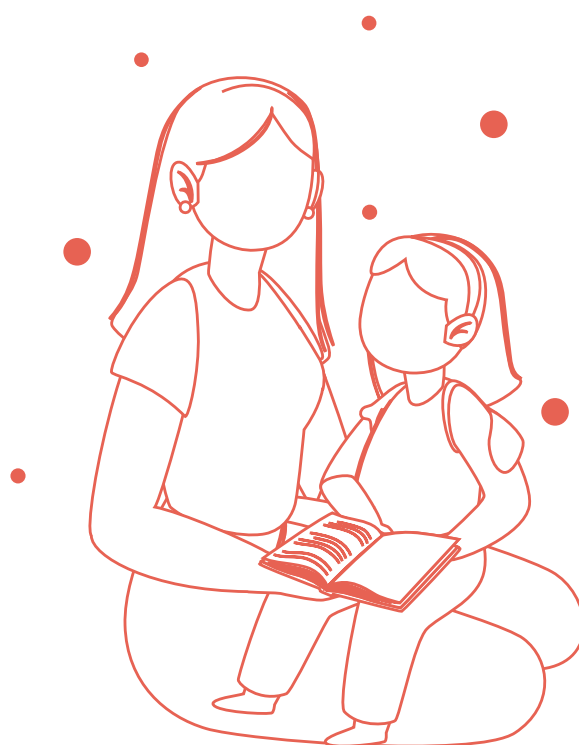


Table 18: Socio-demographic characteristic of caregiver

	Caregiver for				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
RELATIONSHIPS TO THE CHILDREN						
Father	20.3	80	35.3	122	27.3	202
Mother	58.5	231	63.0	218	60.6	449
Sister	3.3	13	.3	1	1.9	14
Brother	2.5	10	.3	1	1.5	11
Grandparents	5.3	21	.6	2	3.1	23
Other	10.1	40	.6	2	5.7	42
AGE GROUP						
Less than 25 years	12.7	50	3.8	13	8.5	63
25-34	18.7	74	21.7	75	20.1	149
35-44	37.5	148	49.1	170	42.9	318
45-54	24.8	98	22.5	78	23.8	176
55-64	3.8	15	2.6	9	3.2	24
65 and above	2.5	10	.3	1	1.5	11
GENDER						
Male	26.6	105	35.8	124	30.9	229
Female	73.4	290	63.9	221	69.0	511
Transgender			.3	1	.1	1
CASTE/ETHNICITY						
Hill Brahmin/Chhetri	30.4	120	35.3	122	32.7	242
Hill Adivasi/Janajati	16.5	65	16.2	56	16.3	121
Hill Dalit	27.1	107	27.2	94	27.1	201
Terai Brahmin/Chhetri	5.6	22	2.3	8	4.0	30
Terai Adivasi/Janajati	12.4	49	11.8	41	12.1	90
Terai Dalit	3.8	15	3.2	11	3.5	26
Muslim	3.8	15	2.9	10	3.4	25
Other caste/ethnicity	.6	2	1.2	4	.8	6
RELIGION						
Hindu	89.9	355	88.4	306	89.2	661
Buddhist	2.3	9	3.5	12	2.8	21
Christian	3.8	15	4.6	16	4.2	31
Muslim	3.8	15	2.9	10	3.4	25
No religion			.6	2	.3	2
Other	.3	1			.1	1
TOTAL	100.0	395	100.0	346	100.0	741

### 3.2.2 Source of income

Regarding the source of caregivers' income, 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 rupees (32%).

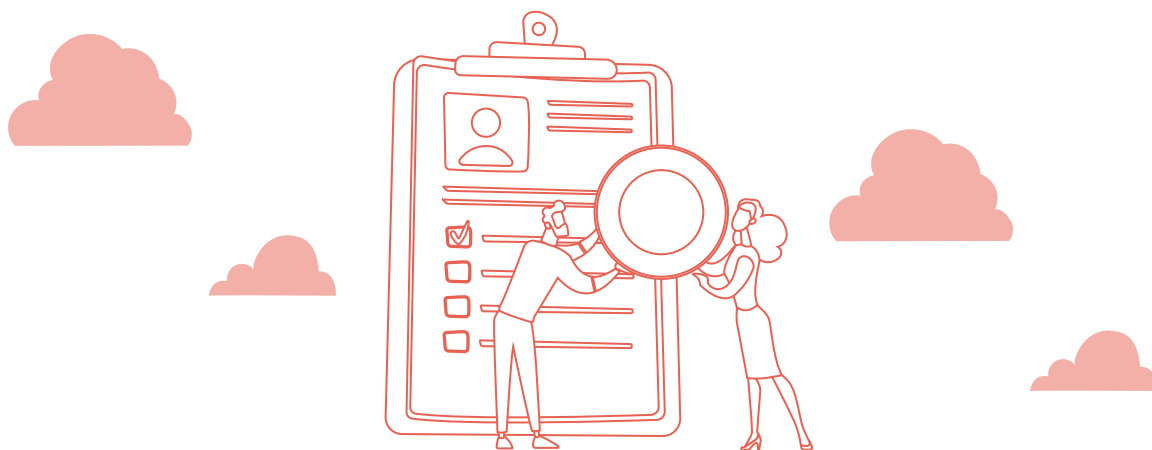
Table 19: Source of income

	Caregiver for				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
SOURCE OF INCOME						
Agriculture	38.7	153	30.9	107	35.1	260
Business	10.1	40	6.4	22	8.4	62
Craftsmanship (skilled labor)	6.3	25	13.6	47	9.7	72
Govt. service	.5	2	1.7	6	1.1	8
Private service	10.6	42	14.2	49	12.3	91
Daily wages	23.3	92	23.1	80	23.2	172
Household works	5.3	21	6.1	21	5.7	42
Does not work	1.3	5	1.7	6	1.5	11
Others	3.8	15	2.3	8	3.1	23
MONTHLY INCOME OF HOUSEHOLD/FAMILY						
Below Rs. 5, 000	37.0	146	32.1	111	34.7	257
Rs. 5, 000-10, 000	29.1	115	34.4	119	31.6	234
Rs. 10, 001- 20, 000	20.8	82	24.0	83	22.3	165
Rs. 20,001- Rs. 30, 000	4.1	16	6.4	22	5.1	38
Above Rs. 30,000	2.5	10	1.2	4	1.9	14
Do not know	4.6	18	1.2	4	3.0	22
Don't want to answer	2.0	8	.9	3	1.5	11
TOTAL	100.0	395	100.0	346	100.0	741

Qualitative findings also showed that the economic situation of CABA is not good. Most of these children are from economically poor backgrounds whose parents are daily wage earners, agricultural laborers, or migrant workers. Mothers are the primary caretakers of CABA in most cases, among which single mothers hold a staggering count. Those who have lost both parents are either cared for by their relatives or sent to care homes. Some older CABA who have lost their parents are even compelled to take care of their siblings.

Due to their impoverished condition, CABA are deprived of basic needs and a decent standard of living. While they hardly get to eat three meals a day, protein-rich foods like milk, eggs, and meat are luxury items they cannot afford.





“ I have been providing them by earning as much as I can, although I have a fragile financial condition. I have not been able to send them to good schools and give them warm clothes in this winter.”

- FGD participant

As they survive with a minimum amount, savings are barely possible. Many caregivers said that they take loans from others during emergencies.

“ My father is very old and does not let me do any work. He is scared that I might die if I start working as I am under medication. He receives 12000 rupees once in every four months as an old-age allowance, and we survive with that amount.”

- CTP graduate

### 3.2.3 Level of education of caregivers

It was found that 36% of caregivers were illiterate, followed by basic level education (32%), non-formal education (14%), and secondary education (12%). Only six percent of caregivers had higher secondary level education.

Table 20: Level of education of caregivers

Level of education of caregivers	Caregiver for				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Illiterate	36.5	144	35.5	123	36.0	267
Non-formal education	15.9	63	11.6	40	13.9	103
Basic(1-8)	28.6	113	36.4	126	32.3	239
Secondary	11.4	45	12.4	43	11.9	88
Higher secondary	7.6	30	4.0	14	5.9	44
<b>TOTAL</b>	<b>100.0</b>	<b>395</b>	<b>100.0</b>	<b>346</b>	<b>100.0</b>	<b>741</b>

### 3.2.4 Status of biological parents

More than half (56%) of the children had biological parents alive, followed by only a mother alive (30%). Similarly, 8% had none of their parents alive, and the proportion was higher among CLHIV (12%) than Children affected by AIDS (8%).

Table 21: Status of biological parents

Biological parents of the child alive	Caregiver for				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Both are alive	47.6	188	64.7	224	55.6	412
Only mother is alive	30.4	120	30.1	104	30.2	224
Only father is alive	9.6	38	2.0	7	6.1	45
Both are not alive	12.4	49	3.2	11	8.1	60
<b>TOTAL</b>	<b>100.0</b>	<b>395</b>	<b>100.0</b>	<b>346</b>	<b>100.0</b>	<b>741</b>

### 3.2.5 Accessibility of health services

Seventy-five percent of caregivers of CLHIV stated that they visited health facilities every month for taking the ARV/ART treatment. Similarly, 15% and 7% of caregivers mentioned that they visited health facilities once every two months and three months, respectively. Similarly, the majority of caregivers mentioned that primary caregivers were responsible for the child's medication, his/her hospital visits, and taking care when he/she fall ill, and 73% of caregivers visited Government Hospital for treatment and other medical illness, followed by the private clinic (10%) and Health post (10%). Similarly, 44% of caregivers stated that it took up to 30 minutes to reach a health facility where the child usually visits, followed by 31-60 minutes (26%) and 61-120 minutes (21%). Similarly, 66% of caregivers stated that the child visited the nearest health facility (60% Children affected by AIDS and 73% CLHIV). The reasons for avoiding the nearest health care facility were also explored, in which the major reasons were unavailability of required service (51%), expensive service (25%), and low quality of service (10%).

Sixty-six percent caregivers mentioned they were satisfied with the services provided at the health facility, while 19% were very satisfied, while 5% were dissatisfied with the services (6% CLHIV, 3% Children affected by AIDS). Likewise, 8% caregivers said they sometimes faced stigma or discrimination by doctors or staff at the hospital. Regarding the deprivation of health service or treatment, 26% children were deprived of a health service or treatment because of financial limitations.

#### ARV/ART TREATMENT





Table 22: Accessibility of health services

	Caregiver for				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
FREQUENCY OF VISITING A HEALTH FACILITY FOR TAKING THE ARV/ ART TREATMENT						
Monthly	75.4	298				
Once every 2 months	15.2	60				
Once every 3 months	6.6	26				
Others	2.8	11				
CARETAKER FOR THE CHILD'S MEDICATION, AND TAKES CARE OF HIM/ HER WHEN HE/ SHE FALL ILL						
Primary caregiver	93.7	370	71.7	248	83.4	618
Other family members	2.3	9	2.0	7	2.2	16
Child themselves	2.3	9	.6	2	1.5	11
Others	1.8	7	25.7	89	13.0	96
HEALTH FACILITY FOR THE TREATMENT AND OTHER MEDICAL ILLNESS						
Health Post	6.6	26	13.6	47	9.9	73
Primary Health Care Centers (PHCs)	1.3	5	1.7	6	1.5	11
Government Hospital	82.0	324	61.6	213	72.5	537
Private Hospital	2.8	11	5.2	18	3.9	29
Private Clinic	5.8	23	15.3	53	10.3	76
HIV Testing Centers	1.3	5			.7	5
I don't visit health facilities at all	.3	1	1.2	4	.7	5
Others			1.4	5	.7	5
TIME TAKEN TO REACH THE HEALTH FACILITY WHERE THE CHILD USUALLY VISITS						
Up to 30 minutes	35.7	141	53.2	184	43.9	325
31-60	30.1	119	21.1	73	25.9	192
61-120	22.3	88	18.5	64	20.5	152
More than 2 hours	11.9	47	7.2	25	9.7	72
Nearest health facility visited by child						
Yes	60.3	238	73.4	254	66.4	492
No	39.7	157	26.6	92	33.6	249
REASON FOR AVOIDING THE NEAREST HEALTH CARE FACILITY						
Fear of being identified	8.3	13	3.3	3	6.4	16
Due to felt stigma	2.5	4			1.6	4
Staff is unfriendly	2.5	4	2.2	2	2.4	6
Service is expensive	17.8	28	37.0	34	24.9	62
Required service is unavailable	56.1	88	43.5	40	51.4	128
Low quality of service	10.8	17	7.6	7	9.6	24
Others	1.9	3	6.5	6	3.6	9

	Caregiver for				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
SATISFACTION WITH THE SERVICES PROVIDED AT THE HEALTH FACILITY						
Not at all	.3	1	.6	2	.4	3
Dissatisfied	6.3	25	2.6	9	4.6	34
Neither satisfied nor Dissatisfied	9.9	39	9.2	32	9.6	71
Satisfied	65.3	258	68.5	237	66.8	495
Very satisfied	18.2	72	19.1	66	18.6	138
FACED STIGMA OR DISCRIMINATION BY DOCTORS OR STAFFS AT THE HOSPITAL						
Always	.3	1			.1	1
Very Often	2.8	11	1.4	5	2.2	16
Sometimes	9.4	37	6.1	21	7.8	58
Rarely	5.3	21	4.0	14	4.7	35
Never	82.3	325	88.4	306	85.2	631
THE AMOUNT REQUIRED EACH MONTH FOR ACCESSING HEALTH SERVICES						
Up to 500	52.2	206	53.2	184	52.6	390
501-1000	26.1	103	21.1	73	23.8	176
More than 1000	21.8	86	25.7	89	23.6	175
THE CHILD HAS EVER BEEN DEPRIVED OF A HEALTH SERVICE OR TREATMENT BECAUSE OF FINANCIAL RESTRICTIONS.						
Yes	25.3	100	25.7	89	25.5	189
No	74.7	295	74.3	257	74.5	552
TOTAL	100.0	395	100.0	346	100.0	741

### 3.2.6 Knowledge on HIV status of parents and children

Thirty-seven percent caregivers reported that the child's HIV status was not disclosed (Figure 12). Likewise, 58% caregivers stated that the children disclosed their parent's HIV status (61% CLHIV, 54% Children affected by AIDS) (Annex Table 7).

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

“ I have not shared the HIV status of my daughter to her because I am afraid that she might disclose it to other people.”

- FGD participant

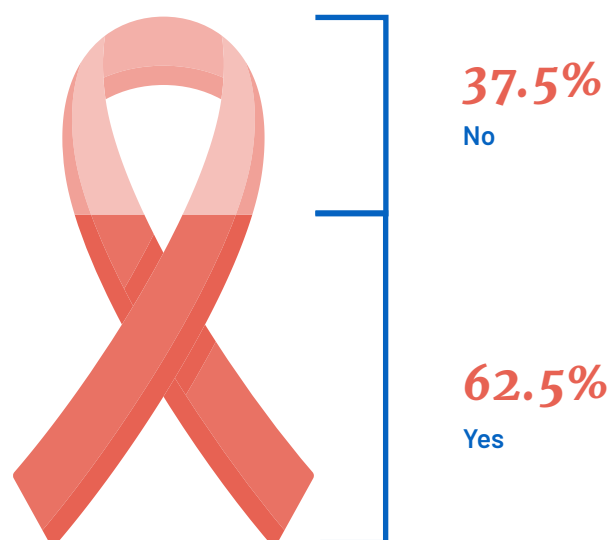


Figure 11 : Disclosure about the child's HIV status to the child

### 3.2.7 Worries about the responsibility of children

The study found that 31% caregivers mentioned that older or adult siblings of children would be the child's caretaker if the primary caretaker will not be able to due to health problems, followed by mother (15%) and father(13%). 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 sick children (54%).

Table 23 Worries about the responsibility of children

	Caregiver for				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
CARETAKER FOR THE CHILD, IN THE FUTURE, IF YOU WILL NOT BE ABLE TO DUE TO HEALTH PROBLEMS						
Mother	9.9	39	21.7	75	15.4	114
Father	13.9	55	12.4	43	13.2	98
Mother's parents	6.6	26	7.5	26	7.0	52
Father's parents	3.5	14	2.3	8	3.0	22
Paternal uncles/ aunts	4.6	18	4.0	14	4.3	32
Maternal Uncles/ aunts	1.8	7	2.3	8	2.0	15
Older or adult siblings of children	33.2	131	28.9	100	31.2	231
Institution/ Orphanage	3.8	15	3.8	13	3.8	28
No one	12.7	50	11.8	41	12.3	91
Others	10.1	40	5.2	18	7.8	58
Total	100.0	395	100.0	346	100.0	741
WORRIES ABOUT RESPONSIBILITIES AS A GUARDIAN FOR THE CHILD						
Yes	96.7	382	96.2	333	96.5	715
No	3.3	13	3.8	13	3.5	26
Total	100.0	395	100.0	346	100.0	741
WORRIES THE MOST+						
Money to send children to school/daycare	84.6	323	91.3	304	87.7	627
Money for food	56.5	216	62.2	207	59.2	423
Money for clothes	44.5	170	49.2	164	46.7	334
Housing or money for housing	32.5	124	35.7	119	34.0	243
Other financial concerns	63.4	242	57.7	192	60.7	434
Caring for a sickly child	65.2	249	41.1	137	54.0	386
My poor health or old age, physical limitation	40.1	153	31.8	106	36.2	259
Other	10.7	41	11.1	37	10.9	78
TOTAL	100.0	382	100.0	333	100.0	715

+ Multiple responses

### 3.2.8 Information about the ownership of property

Sixty percent caregivers currently own property by themselves or their spouse. Regarding the type of property, 89% and 84% of caregivers own land and housing, respectively.

Table 24 Information about the property

	Caregiver for				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
OWNERSHIP OF PROPERTY CURRENTLY BY YOU AND YOUR SPOUSE						
Yes	57.0	225	63.3	219	59.9	444
No	41.5	164	35.8	124	38.9	288
Do not know	1.5	6	.9	3	1.2	9
TOTAL	100.0	395	100.0	346	100.0	741
OWN PROPERTY+						
Land	86.2	194	90.9	199	88.5	393
Housing	84.4	190	83.1	182	83.8	372
Money	8.9	20	12.8	28	10.8	48
Materials property (Furniture, kitchen utensils, etc.)	31.6	71	33.8	74	32.7	145
Others	1.3	3	2.3	5	1.8	8
TOTAL	100.0	225	100.0	219	100.0	444

+Multiple responses

### 3.2.9 Use of money received from a CASH transfer program

The study also explored the use of money received from CTP from the caregivers of CLHIV. The most common areas to spend the money on were school (82%), food (58%), and the medical sector (51%). It is discouraging that only 7% of caregivers mentioned that they had enough money for covering the child's medical expenses related to HIV.

Table 25 Use of money received from a CASH transfer program

	CLHIV	
	%	N
<b>AREAS YOU SPEND THE MONEY THAT YOU GET FROM CASH TRANSFER PROGRAM+</b>		
For food	58.2	230
For medical	51.1	202
For school	81.8	323
Other specify	7.6	30
<b>HAD ENOUGH MONEY PROVIDED FOR COVERING THE CHILD'S MEDICAL EXPENSES RELATED TO HIV</b>		
Yes	7.3	29
No	92.7	366
<b>TOTAL</b>	<b>100.0</b>	<b>395</b>

+Multiple responses

### 3.3 DAC Findings

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

#### 3.3.1 Context

The CTP was rolled out in Nepal before the promulgation of the new Constitution of Nepal, 2015 and before the local level elections of 2017. With the adoption of a new constitution, a three-tier governance system was introduced with national, provincial, and local governments. Before this, coordination was done between CCC, District Public Health Office (DPHO), and municipalities or VDCs for implementing CTP. However, the change in federal structure added the need to coordinate with ward level too. The process is lengthier and has shortcomings. The most immediate effect is seen during the formation of the CABA committee. The frequent turnover of government officials at the local level has made it difficult for the CABA CTP implementers to select appropriate representatives. The positions in the committee sometimes remain vacant for a long time, and they will have to acquaint the new member with the context, progress and challenges time and again. Coordination at the local level has also raised an issue of confidentiality. Some people who have not disclosed their HIV status in the community do not want to enroll their children in CTP because they fear that their status might be revealed to others.

“ If such information is leaked to the ward head, it might be used in a wrong way as political representatives might not take the sensitivity of the issue that seriously.”

– KII Respondent

Besides these issues, there has been continued support from the local and provincial level government to coordinate and implement the program.

#### 3.3.2 Relevance

The CABA CTP was initiated to provide cash support to children infected with HIV/AIDS when no national social protection programs were directed at them. Although other organizations are working on the issue, most of them focus on the awareness and treatment of HIV, distributing education materials once in a while, and providing counseling services to the infected ones. Few local level governments are also providing small amounts for supporting the infected children. However, these programs appear uneven and do not provide uniform educational or nutritional support to the children throughout the year. Given the situation and the needs of CABA in Nepal, CTP has been considered to be significant by providing cash support to children all over the country every month till the age of 18.

#### 3.3.3 Effectiveness

The program has been able to include all children infected by HIV/AIDS across the country except those who do not have birth certificates and also the ones whose parents do not want to enroll their children in the program because of their lack of confidence in the maintenance of confidentiality regarding their HIV status.

The amount being provided to children every month has not increased since the beginning of the program. It is insufficient for covering most expenses of a child. However, it has provided relief to children affected by AIDS families to some degree.

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

– KII Respondent

The program has improved the nutritional as well as the educational status of the children living with HIV. Families spend most of that amount on buying food or educational materials for children.

“ Those 1000 rupees was used for my tuition classes and lunch.”

– CTP graduate

“ Because of 1000 rupees they have received, people who were able to afford only 1 kg of rice can afford 5 kg now”.

– KII respondent

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. Most CABA come from lower-class backgrounds who can hardly afford three meals a day and good education. They go to government schools and hence use the amount for buying school uniforms and stationery.

CTP has successfully linked cash support with other treatment and care programs that jointly have enhanced CABA health and living status. It has encouraged access to HIV testing, CHBC, and ART services through which CABA receives HIV-related services free of cost. CABA and their family have been involved in the National Health Insurance program in the districts where the scheme has commenced for other health services.

### 3.3.4 Impact and Changes

A close relationship between CTP and the surge of health services-seeking behavior among people has been observed. The program and other ART and counseling services have encouraged CLHIV and their parents to take their medicines regularly. By boosting morale and upgrading their living standard, CTP has changed their perception and increased acceptance of their HIV status. It has indirectly helped them realize that they can live a normal life if they consume medicines regularly.

CTP has enabled children to stay in school till the age of 18. There are cases where even those who have severe economic conditions have been able to continue their education with the 1000 rupees support they obtain from the program.



“ In our community, we had a 14-year-old whose household economic condition was very pathetic because of which the child had no choice but to work. However, with the CABA program and its 1000 rupees monthly allowance, the child started to go to school.”

– FGD respondent

It is evident that CTP has supported children in their education. On the other hand, we can also see the evidence in which CTP graduate were facing difficulty to manage the expenses of education and also for food after the end of CTP. So, the end of CTP after 18 years also negatively impacts the lives of children in the absence of any other supporting programs.

## CASE STUDY I

**H**ari Prasad (name changed) from Dailekh was 15 years old when he was enrolled in the CTP. The CQTP allowance amount helped him to buy educational materials and nutritional foods. But it has been 18 months since he received his last allowance. When asked about the difficulty faced after the end of CTP, he said, “Currently, I am in grade 12, and it has been difficult to bear the cost for my education. I have been facing difficulty in education and getting nutritional food after the money from CTP has stopped.” It is challenging to manage all the expenses for a family like Hari’s, whose average monthly income is just 5–6000 rupees. Agriculture and labor work are the main income source of the family. They also take loans to manage family expenses.

Explaining the situation of adolescents in the community after the end of CTP, he said, “Many 18+ youth drop out of education after they stop getting cash transfer. Many start working as daily wage labor along with their parents.” He also added that government and organizations should provide free education and skill development training for the 18+ youth who do not receive cash transfers.

## CASE STUDY- II

**M**ina Rai (name changed) is 19 years old, and she stopped receiving the cash transfer one year ago. Mostly, she used the amount from CTP for college fees and sometimes for food as well. She mentioned that she faced problems in managing educational expenses after the end of the CTP. “Though I am studying in a government school, I need to pay certain fees every three months, and I also need to purchase books and copies. With the end of the CTP, there has been difficulty to pay fee regularly to the college. We take a loan to pay the fee.” So, she thinks such a program needs to be continued because many are forced to leave their education to go to India for foreign employment after CTP.

### 3.3.5 Monitoring and Evaluation

A CABA committee of seven members has been formed in every district, including a representative from DPHO, HIV focal person, one HIV positive person, local government officials, and other stakeholders. One of the functions of this committee is to monitor the program in the district, carry out joint home visits with the local government representatives every 3-4 months to investigate if the money is being used properly, and understand the situation of the beneficiaries. They take a checklist with them and also prepare a report for each visit. However, due to the insufficient budget allocated, the committee has not performed this function for quite some time now.

Apart from that, CHBC mobilizers and other implementing organizations conduct home visits to check up on their health status and provide counseling services. Follow-up is sometimes also done through the phone.

### 3.3.6 Challenges

CCC representatives and concerned stakeholders have reported many challenges they have faced during the implementation of the project. Difficulty in enrollment of CABA in CTP due to lack of birth certificate is one of those. Many CABA caregivers are single mothers who lack citizenship documents because of cross-border marriages and other cultural reasons. This directly impacts their children because they cannot have a birth certificate or have a bank account- both necessary conditions for enrollment in CTP. In such situations, the child has been registered for CHBC services only and not in CTP.

Many infected and affected children are deprived of HIV-related services due to their place's difficult geography and remoteness. It is troublesome for those living in remote areas to travel from distant and open a bank account to enroll in the program.

Those who haven't opened up about their HIV status to others in the community hesitate to create an account in the bank with the fear of their status being disclosed.

“ We have found that the bank has not been able to maintain confidentiality and that they have been asking uncomfortable questions to the service users.”

-KII Respondent

Another challenge that was observed is the misuse of money by family members.

“ In few cases, parents have used the allowance for household expenses and some to drink alcohol. The number of which the allowance is being misused is around 7 out of 67.”

- KII Respondent

Likewise, the coordination between the implementing non-government organization (NGO) or CCC, DPHO, and local government has been particularly affected due to the lack of policy, budget, and appropriate plan at the government level.

### 3.3.7 Sustainability

In 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 of CTP. They fear that such support will be stopped after the termination of the project. Since the support is only provided till the age of 18, those above 18 are left with a dilemma regarding continuing their education.

“ 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

After 18 years, the needs and expenses of children increases, but when the cash from the CTP program also stops, their situation becomes worse. It is not guaranteed that everyone living with HIV can work after reaching 18 because of their health and social situation. Even when they are, it is hard for them to get a job because of the stigma and discrimination attached to HIV.



“ Age of children increases but their situation remains the same. Cutting them off from CTP when they reach 18 affects them, and therefore, CTP should be accompanied by skill development programs to increase their employment possibilities.”

-KII Respondent

### 3.3. 8 Lessons Learnt

#### Promising Practices

- The modality of implementing CTP through a partnership with CCCs and local NGOs has proven effective by reaching out to every district of the country. The program has been able to link the cash support with other available health and treatment supports to CLHIV in the community.



- CTP has included CLHIV regardless of gender, social, or economic background, which has been incredibly beneficial to the marginalized class.
- The HIV status of children is not disclosed to anyone by the implementing organization, which has helped enroll children in the program.

#### Areas to be improved

- Cash support of only one thousand rupees per month is not sufficient for meeting the needs of CABA.
- Cash support is only provided to CLHIV and not to the affected children. The household situation of affected children is not that different from the infected ones. An infected child may have siblings who are not infected. Though their health status may differ, they share the same economic condition affecting every child in the family in almost the same way. Both CLHIV and affected children have infected parents, primarily single mothers who face hardships in finding a job because of their status, alongside various social and cultural restrictions imposed upon women. In such circumstances, the money provided is insufficient. It is impractical for parents to discriminate against their children on food or education. When 1000 rupees is only a little help to one child, the question arises- how much it can do when it is further divided into two or more in the same household.

“ When Children affected by AIDS see that their siblings are getting support and they are not, they feel discriminated.”

- KII Respondent

- When a child reaches 18 years of age, he/she no longer becomes eligible to get support from CTP. This has affected infected adolescents above 18 years negatively. The program also does not provide support to help them in this transition phase.
- The requirement of the birth certificate has deprived many CLHIV of getting enrolled in the CTP.
- Impractical budgeting and lack of effective coordination between the stakeholders have contributed to the inconsistency in monitoring by the CABA committee.

## CHAPTER IV

# CONCLUSION & RECOMMENDATIONS

### 4.1 Conclusion and discussion

The assessment showed the overall situation of CABA in Nepal is gradually improving compared to past years due to many interventions focused on CABA, such as CTP, which has contributed to improving the living standard of CABA to some extent. Findings showed that the healthcare-seeking behavior among CABA was good as most of them visited health facilities in case of any illness, and more than a fourth usually visited health facilities once a month. It has helped improve the nutritional and educational status of the children as families spend most of the amount for buying food or educational materials for children. Likewise, the majority of CABA were satisfied with the health services. However, few CABA were also dissatisfied with the health services and faced stigma or discrimination by doctors or staff at the hospital, as shown by qualitative and quantitative findings, which cannot be overlooked. 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. Another similar study (CREHPA, 2009) also showed that the majority of CABA had school enrollments. The CTP has also aided many children in school by helping to pay their fees, buy stationery, uniforms, or lunch.

Regarding the dietary behavior 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. So, although improving, the nutritional status of CABA children needs to be worked upon as more than two-fifths of CABA also mentioned they had some problem with managing food.

Despite improvement in certain areas, the assessment showed that CABA is still deprived of

psychosocial well-being as much faced fear about different issues, had experienced many unpleasant feelings such as feeling ashamed, low self-esteem, and even some had the feeling of suicide. A study conducted in five districts of Nepal (CREHPA, 2009) showed that children infected with HIV were more likely to experience fear and isolation when left alone in the house. On the other hand, another study (Raphael et al., 2000) showed that children receiving sufficient support from family, peers, and others are psychosocially strong and are less likely to be depressed. Qualitative findings also showed that stigma and discrimination related to HIV are persisting in society. Some studies showed that not only PLHIV but other people associated with them might face discrimination too. A survey conducted in 2003 (Parker and Aggleton, 2003) showed that both PLHIV and associated people like family members and related groups face discrimination and prejudices.

The findings obtained from caregivers showed that nearly half of the children and seven out of ten caregivers had obtained counseling care or support from anyone in the past 12 months. An overwhelming majority of the caregivers mentioned they worry about the responsibilities as a guardian for the child. In this regard, caregivers mostly worry about sending children to school/daycare, money for food, clothes, and caring for sick children. Similarly, only less than a tenth of caregivers mentioned that they had enough money to cover the child's medical expenses related to HIV. Hence, to conclude, despite improving the situation of CABA and the notable effectiveness of CTP to upgrade their living status, many aspects should be pondered upon to uplift their quality of life further. Some of these issues include psychosocial wellbeing and improved nutritional status.

## 4.2 Recommendations

The study team has come up with the following recommendations based on both quantitative and qualitative findings:

### 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.

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# ANNEX TABLES

*Annex Table 1: Faced any stigma or discrimination by doctors or staffs at the health facilities*

Faced any stigma or discrimination by doctors or staffs at the health facilities	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Always	.5	2	0	0	.3	2
Very Often	1.5	6	.6	2	1.1	8
Sometimes	7.3	29	4.6	15	6.1	44
Rarely	1.5	6	3.4	11	2.4	17
Never	89.1	353	91.4	296	90.1	649
<b>TOTAL</b>	<b>100.0</b>	<b>396</b>	<b>100.0</b>	<b>324</b>	<b>100.0</b>	<b>720</b>

*Annex table 2: Fear about certain things in last 12 months*

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
IN LAST 12 MONTHS, FEAR ABOUT BEING GOSSIPED						
Yes	11.5	48	7.7	30	9.7	78
No	88.5	369	92.3	358	90.3	727
IN LAST 12 MONTHS, FEAR ABOUT BEING VERBALLY INSULTED						
Yes	8.9	37	7.5	29	8.2	66
No	91.1	380	92.5	359	91.8	739
IN LAST 12 MONTHS, FEAR ABOUT BEING PHYSICALLY HARASSED						
Yes	2.6	11	2.3	9	2.5	20
No	97.4	406	97.7	379	97.5	785
IN LAST 12 MONTHS, FEAR ABOUT BEING PHYSICALLY ASSAULTED						
Yes	2.4	10	5.7	22	4.0	32
No	97.6	407	94.3	366	96.0	773
TOTAL	100.0	417	100.0	388	100.0	805

Annex Table 3: Experienced of feelings by CABA in last 12 months

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
IN LAST 12 MONTHS, EXPERIENCED FEELING ASHAMED						
Yes	16.5	69	8.2	32	12.5	101
No	83.5	348	91.8	356	87.5	704
IN LAST 12 MONTHS, EXPERIENCED FEELING GUILTY						
Yes	5.0	21	2.3	9	3.7	30
No	95.0	396	97.7	379	96.3	775
IN THE LAST 12 MONTHS, EXPERIENCED FEELING LONELY						
Yes	12.7	53	5.9	23	9.4	76
No	87.3	364	94.1	365	90.6	729
IN LAST 12 MONTHS, EXPERIENCED FEELING ANGRY AT ONESELF						
Yes	20.4	85	9.0	35	14.9	120
No	79.6	332	91.0	353	85.1	685
IN LAST 12 MONTHS, EXPERIENCED FEELING ANGRY AT OTHERS						
Yes	27.1	113	16.2	63	21.9	176
No	72.9	304	83.8	325	78.1	629
IN LAST 12 MONTHS, EXPERIENCED FEELING LOW SELF-ESTEEM/ SELF-WORTH						
Yes	14.1	59	7.7	30	11.1	89
No	85.9	358	92.3	358	88.9	716
IN LAST 12 MONTHS, EXPERIENCED FEELING SUICIDE						
Yes	1.7	7	1.3	5	1.5	12
No	98.3	410	98.7	383	98.5	793
TOTAL	100.0	417	100.0	388	100.0	805

Annex table 4: Experience of exclusion from social gathering or activities

In the last 12 months, have been excluded from social gatherings or activities (p<0.05)	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Yes	8.9	37	5.2	20	7.1	57
No	91.1	380	94.8	368	92.9	748
<b>TOTAL</b>	<b>100.0</b>	<b>417</b>	<b>100.0</b>	<b>388</b>	<b>100.0</b>	<b>805</b>

Annex Table 5 : Experience of stigma or discrimination

	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
HAVE EXPERIENCED DISCRIMINATION OR STIGMA FROM NEIGHBORS						
Yes	6	26	5.2	20	5.7	46
No	93.8	391	94.8	368	94.3	759
HAVE EXPERIENCED DISCRIMINATION OR STIGMA FROM FRIENDS						
Yes	5.5	23	3.9	15	4.7	38
No	94.5	394	96.1	373	95.3	767
HAVE EXPERIENCED DISCRIMINATION OR STIGMA FROM FAMILY MEMBERS						
Yes	4.8	20	4.4	17	4.6	37
No	95.2	397	95.6	371	95.4	768
HAVE EXPERIENCED DISCRIMINATION OR STIGMA FROM ANYONE						
Yes	3.1	13	2.6	10	2.9	23
No	96.9	404	97.4	378	97.1	782
TOTAL	100.0	417	100.0	388	100	805

Annex Table 6: Ever experienced any type mistreatment

Ever experienced any type mistreatment +	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Physical	2.4	10	1.8	7	2.1	17
Emotional	8.6	36	7.5	29	8.1	65
Sexual	1.2	5	.8	3	1.0	8
None	91.8	383	91.8	356	91.8	739
<b>TOTAL</b>	<b>100.0</b>	<b>417</b>	<b>100.0</b>	<b>388</b>	<b>100.0</b>	<b>805</b>

+Multiple responses

Annex table 7 :Aware about the place where people can get service related to HIV

Aware about the place where people can get service related to HIV	Type of children				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
Yes	85.4	228	76.8	149	81.8	377
No	14.6	39	23.2	45	18.2	84
<b>Total</b>	<b>100.0</b>	<b>267</b>	<b>100.0</b>	<b>194</b>	<b>100.0</b>	<b>461</b>

Annex table 8: Knowledge on HIV status of parents and children (For CLHIV only)

	Caregiver for				Total	
	CLHIV		Children affected by AIDS		%	N
	%	N	%	N		
DISCLOSED ABOUT THE CHILD'S HIV STATUS TO THE CHILD YET						
Yes	62.5	247				
No	37.5	148				
DISCLOSED ABOUT THE PARENT'S HIV STATUS TO THE CHILD YET						
Yes	60.5	239	54.3	188	57.6	427
No	39.5	156	45.7	158	42.4	314
TOTAL	100.0	395	100.0	346	100.0	741

## Province wise Tables

Table P1: Ever had an illness in the past one month by Provinces

	HIV infected		HIV affected	
	Yes	No	Yes	No
Province 1	37.5	62.5	36.0	64.0
Province 2	43.8	56.3	41.5	58.5
Bagmati province	20.7	79.3	23.9	76.1
Gandaki Province	36.1	63.9	32.4	67.6
Lumbini province	39.5	60.5	33.3	66.7
Karnali Province	51.9	48.1	42.3	57.7
Sudurpashchim province	39.8	60.2	27.6	72.4
Total	36.2	63.8	32.0	68.0
N	151	266	124	264

Table P2: Faced any stigma or discrimination by doctors or staffs at the hospital by Provinces

	HIV infected					HIV affected			
	Always	Very Often	Sometimes	Rarely	Never	Very Often	Sometimes	Rarely	Never
Province 1	2.2	6.7			91.1	4.5			95.5
Province 2	2.1	14.6			83.3	4.4			95.6
Bagmati province		5.5	2.2		92.3	7.8			92.2
Gandaki Province	5.9	5.9	11.8		76.5	17.9	10.7		71.4
Lumbini province	2.4	7.1			90.5				100.0
Karnali Province	3.7	18.5	7.4		70.4	11.1	11.1		77.8
Sudurpashchim province		1.8	1.8		96.3	1.1	6.5		92.5
Total	.5	1.5	7.3	1.5	89.1	.6	4.6	3.4	91.4
N	2	6	29	6	353	2	15	11	296



**Table P3: Education by Provinces**

	HIV infected		HIV affected	
	Yes	No	Yes	No
Province 1	93.2	6.8	93.5	6.5
Province 2	92.5	7.5	95.3	4.7
Bagmati province	98.9	1.1	89.1	10.9
Gandaki Province	91.4	8.6	92.6	7.4
Lumbini province	100.0		97.2	2.8
Karnali Province	100.0		100.0	
Sudurpashchim province	100.0		95.4	4.6
Total	97.5	2.5	94.4	5.6
N	383	10	321	19

**Table P4: Excluded from a social gathering**

	HIV infected		HIV affected	
	Yes	No	Yes	No
Province 1	4.2	95.8		100.0
Province 2	6.3	93.8	3.8	96.2
Bagmati province	13.0	87.0	10.4	89.6
Gandaki Province	8.3	91.7	8.8	91.2
Lumbini province	9.3	90.7		100.0
Karnali Province	7.4	92.6	3.8	96.2
Sudurpashchim province	8.9	91.1	6.0	94.0
Total	8.9	91.1	5.2	94.8
N	37	380	20	368

**Table P4: Excluded from a social gathering**

	HIV infected		HIV affected	
	Yes	No	Yes	No
Province 1	4.2	95.8		100.0
Province 2	6.3	93.8	3.8	96.2
Bagmati province	13.0	87.0	10.4	89.6
Gandaki Province	8.3	91.7	8.8	91.2
Lumbini province	9.3	90.7		100.0
Karnali Province	7.4	92.6	3.8	96.2
Sudurpashchim province	8.9	91.1	6.0	94.0
Total	8.9	91.1	5.2	94.8
N	37	380	20	368

Table P5: Ever experienced any type mistreatment

	HIV infected				HIV affected			
	Physical	Emotional	Sexual	None	Physical	Emotional	Sexual	None
Province 1		2.1		97.9		4.0		96.0
Province 2	2.1	2.1		97.9	1.9	1.9		96.2
Bagmati province	3.3	6.5	2.2	93.5	3.0	11.9	3.0	86.6
Gandaki Province		8.3		91.7	2.9			97.1
Lumbini province	9.3	7.0	7.0	97.7		2.4		97.6
Karnali Province		14.8		85.2		15.4	3.8	84.6
Sudurpashchim province	1.6	14.6		85.4	2.6	11.2		88.8
Total	2.4	8.6	1.2	91.8	1.8	7.5	.8	91.8
N	10	36	5	383	7	29	3	356

Table P6: Ever faced fear when left alone

	HIV infected			HIV affected		
	Yes	No	Never stayed alone	Yes	No	Never stayed alone
Province 1	22.9	41.7	35.4	6.0	48.0	46.0
Province 2	43.8	31.3	25.0	34.0	37.7	28.3
Bagmati province	15.2	43.5	41.3	14.9	32.8	52.2
Gandaki Province	16.7	47.2	36.1	14.7	35.3	50.0
Lumbini province	34.9	53.5	11.6	19.0	40.5	40.5
Karnali Province	7.4	44.4	48.1	15.4	46.2	38.5
Sudurpashchim province	27.6	61.8	10.6	17.2	50.0	32.8
Total	24.7	48.7	26.6	17.5	42.5	39.9
N	103	203	111	68	165	155

Table P7: Received any counseling care or support from anyone in the past 12 months

	HIV infected		HIV affected	
	Yes	No	Yes	No
Province 1	58.3	41.7	8.0	92.0
Province 2	60.4	39.6	15.1	84.9
Bagmati province	42.4	57.6	7.5	92.5
Gandaki Province	86.1	13.9	29.4	70.6
Lumbini province	79.1	20.9	11.9	88.1
Karnali Province	55.6	44.4	50.0	50.0
Sudurpashchim province	88.6	11.4	48.3	51.7
Total	68.3	31.7	26.0	74.0
N	285	132	101	287

**Table P8: Heard about HIV**

	HIV infected		HIV affected	
	Yes	No	Yes	No
Province 1	83.3	16.7	42.0	58.0
Province 2	43.8	56.3	17.0	83.0
Bagmati province	87.0	13.0	35.8	64.2
Gandaki Province	88.9	11.1	47.1	52.9
Lumbini province	74.4	25.6	47.6	52.4
Karnali Province	77.8	22.2	65.4	34.6
Sudurpashchim province	92.7	7.3	75.0	25.0
Total	81.5	18.5	50.0	50.0
N	340	77	194	194

**Table P9: Aware about the place where people can get service related to HIV**

	HIV infected		HIV affected	
	Yes	No	Yes	No
Province 1	75.0	25.0	57.1	42.9
Province 2	100.0		77.8	22.2
Bagmati province	64.5	35.5	75.0	25.0
Gandaki Province	100.0		75.0	25.0
Lumbini province	81.5	18.5	45.0	55.0
Karnali Province	92.9	7.1	88.2	11.8
Sudurpashchim province	95.3	4.7	87.4	12.6
Total	85.4	14.6	76.8	23.2
N	228	39	149	45

**Table P10: Knowledge on an organization working on HIV Sector**

	HIV infected		HIV affected	
	Yes	No	Yes	No
Province 1	75.0	25.0	52.4	47.6
Province 2	91.7	8.3	66.7	33.3
Bagmati province	38.7	61.3	83.3	16.7
Gandaki Province	100.0		75.0	25.0
Lumbini province	70.4	29.6	35.0	65.0
Karnali Province	100.0		88.2	11.8
Sudurpashchim province	92.5	7.5	86.2	13.8
Total	77.2	22.8	75.3	24.7
N	206	61	146	48

Table P11: Lost job from at least one family member from COVID

	HIV infected			HIV affected		
	Yes	No	Not applicable	Yes	No	Not applicable
Province 1	22.9	75.0	2.1	20.0	80.0	
Province 2	52.1	43.8	4.2	47.2	52.8	
Bagmati province	22.8	54.3	22.8	28.4	67.2	4.5
Gandaki Province	22.2	66.7	11.1	17.6	79.4	2.9
Lumbini province	16.3	62.8	20.9	19.0	64.3	16.7
Karnali Province	29.6	25.9	44.4	11.5	38.5	50.0
Sudurpashchim province	7.3	69.9	22.8	2.6	79.3	18.1
Total	21.3	60.2	18.5	19.1	69.3	11.6
N	89	251	77	74	269	45

# STUDY TEAM

## **TWG MEMBERS**

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