



Save the Children

2009

A Situation Assessment of Children Affected by AIDS in Nepal



November 2009



HIV-AIDS and STIs
Control Board

National Centre for
AIDS and STD Control



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CREHPA

A Situation Assessment of Children Affected by AIDS in Nepal

Study conducted for

HIV-AIDS and STIs Control Board

Ministry of Health and Population

Baluwatar, Kathmandu

National Centre for AIDS and STD Control

Department of Health Services, Ministry of Health and Population

Teku, Kathmandu

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EXECUTIVE SUMMARY

The main objective of the study is to assess the extent, availability of and accessibility to health care, education, economic and psychosocial support services by children affected by AIDS (CABA) in Nepal. To compare the results, the study also interviewed children having similar socio-economic characteristics (children of families whose HIV status were unknown) which has been referred to in this report as "children of comparable group".

Five districts representing the five development regions and the ecological zones of the country were selected. These districts were: Jhapa (eastern tarai), Parsa (central tarai), Tanahun (western hill), Kanchanpur (far-western tarai) and Doti (far western hill).

The study was carried out in three phases. *Review of existing literatures* related to HIV/AIDS infected children was carried out in Phase I. In Phase II study, *social mapping of the concentration sites* of persons living with HIV (PLHIV) was carried out using rapid assessment technique. In the course of social mapping, the approximate number of disclosed families/persons at each concentration site was determined. This was done through individual interviews with organizational key informants at each district and organizing district level consultative workshops with them.

Phase III of the study was the *community based survey*. The survey interviewed 435 CABA respondents aged 12-17 years or their caregivers (for children under 12 years of age). This sample size was estimated based upon the 'percentage of orphaned and vulnerable children (OVC) not currently attending in school" which was derived from a recently completed survey in Accham district (SC Norway/CREHPA, 2008). An equal number (435) of "other" children aged 12-17 years were interviewed from the same community where CABA lived and having similar socio-economic characteristics (referred to in this study report as "children of comparable group or CCG") for comparison. The sample size was proportionately allocated in the five study districts on the basis of the number of disclosed households estimated by the district based stakeholders.

CABA comprised of those children who were either HIV positive; children with one or more HIV+ parents/caregivers; children who lost one or both parents to AIDS or children living in the house with one or more HIV+ person(s). On the other hand, CCG respondents were selected randomly from the same community. It is possible that CCG could also be affected/infected by AIDS since they belong to the same community where CABA live. However the HIV status of these children or their families/caregivers was not known or undisclosed at the time of the study. Moreover, the present study did not make any attempt to ascertain the HIV status of these CCG families. Coverage of children from such households within the same community helped the researchers to conceal (maintain confidentiality) the HIV status of the children or the family members of the CABA households

The task of identifying the households of these CABA and introduction of the research team to the household member (head of the household) was carried out by the peer educators/community volunteers (assigned by the district based NGOs) who had accompanied the research team. A verbal informed consent was sought from each child in the presence of the peer educator/volunteer for participation in the study. For those CABA who were aged below 12 years, their immediate care giver was interviewed on the child's behalf.

A structured individual questionnaire was administered to CABA and CCG or to their caregivers. A short structured individual questionnaire was administered to the caregivers/head of the households for soliciting information pertaining to socio-economic conditions. Fieldwork (Phase II and III) was conducted between January 26 and March 18, 2009.

Key findings

Background characteristics

A larger percentage of *hill Brahmin/Chhetri* children were represented in both CABA (42%) and CCG samples (45%). *Hill Dalits* constituted about one-third, while over a tenth of the study population were from 'disadvantaged *Janjatis*' (*hill*) and *tarai* ethnic groups. Almost all the respondents were unmarried.

The majority of the CABA (56%) have lost either one or both the parents; CABA were twice more likely to be paternal orphaned than maternal orphaned. Those who have lost both the parents comprised of 7 percent only. The cause of death of parents for most CABA respondents was AIDS-related (81%).

Farming was the main source of income for families in both the groups (54% in CABA and 61% in CCG households). Comparatively, daily wage labour was found to be the source of income for nearly double the proportion of CABA households (25%) as compared to CCG households (13%).

The percentage of CABA households falling under "poor" category (31%) was twice the percentage of CCG households (15%). Families who fall under "poor" category in fact suffer from extreme poverty and hardship. Field observations revealed poverty as one of the basic problems confronted by CABA families. Most of the CABA families stated that they did not have money for basic needs such as food, shelter and clothes and were thus unable to afford treatment/ medication for illness. It was found that the mothers of most paternal orphaned CABA were in ill health. As result, majority of the children interviewed in the study reported that they had to work to support their family and their younger siblings.

School enrollment

The present study showed a high level of school enrollments among both CABA (93%) and CCG (95%) who were aged 12-17 years. However, some gender disparity in current school enrolment within CABA and among CCG was evident. Comparatively, however, current school enrolment was higher among CABA boys (87%) than the CABA girls (75%). This was also true to some extent for CCG (93% boys 'vs' 85% girls). Caste factor in school continuation (current enrolment) was also evident from the study. For instance, children from *Dalit* community had comparatively lower school enrolment (78 % CABA and 85 % CCG) when compared to children from *Brahmin/Chhetri* castes (88% CABA and 94% CCG) and the *Janajati* children (82% CABA and 94% CCG).

Access to health facility

A higher percentage of CABA boys (64%) than the CABA girls (44%) had received health attention for the illnesses (general illnesses) they had suffered in the past six months (preceding the survey). In contrast, no gender disparity in receiving health attention was evident in CCG (62% boys 'vs' 63% girls). The findings show that the possibility of a girl born to a CABA family to receive health care attention when sick was much lower than a girl born to a CCG family. Likewise, better educated (lower secondary and above levels) CABA are more likely to receive health attention (62%) than those who are either illiterate (40%) or low literate (primary education level) (47%). These differences are observed even in CCG respondents.

It was encouraging to find the majority of the CABA (52%) and CCG (52%) respondents rating the behaviour of the provider as "polite". Less than 6 % of the CABA and below 1% of CCG children felt the provider's behaviour to be rude or impolite. On the other hand, one in six caregivers (17%) considered provider's behaviour as "impolite" because the providers discriminated them due to their low economic status. Two in three CABA also felt that the provider acted impolitely due to their family's (parents') HIV status.

Family capacity and food intake

Less than half (48%) of the CABA respondents perceived that their economic status was same as those of their neighbours. Likewise, two-fifths (42%) of the CABA respondents and slightly higher percentage among caregivers of CABA (47%) perceived that their economic condition was worse to that of their neighbours. On the other hand, the percentage of CCG respondents who felt that they are better off than their neighbours was twice higher than that of the CABA respondents (18% vs. 9%).

The large majority of the CABA (97%) and CCG respondents (96%) reported about consuming food two to three times a day and no difference on the type of staple food consumed by them. However, consumption of supplementary food such as milk, meat, egg, and fruits was rare among CABA than among CCG.

Stigma and discrimination

Stigma and discrimination related information was solicited from CABA respondents only. The study has shown that the majority of CABA had experienced discrimination in their life. The common forms of discrimination faced by them were avoidance; insult/disgracing remark, separation of bed and separation of dinning plates and utensils. A higher percentage of girls (39%) have reported about facing discrimination than the boys (34%). Moreover, more HIV infected girls (53%) than counterpart boys (33%) aged 12-18 years have reported of experiencing discrimination. The study has also shown that "*Dalit*" boys were more likely to experience discrimination than the "*Brahmin and Chhetri*" boys. This is evident from the fact that 22% of the "*Brahmin/Chhetri*" boys perceived discrimination as against 35% among "*Dalit*" boys.

CABA respondents reported that they had experienced least discrimination at a health facility and within the family (6%). They are more likely to face discrimination from the community (49%) and to some extent from their peers (28%). The nature of discriminations were in the form of avoidance (65%), insult/disgracing remarks (53%) and giving separate dinning

plates/ utensils, separate seat and separate bed to sleep. Discrimination within the community was mainly in the form of avoidance, making disgracing remarks and asking to sit separately from others.

Psycho-social issues

Children infected with HIV are more likely to experience fear and isolation when they are left alone in the house. Within the HIV infected children, more girls (76%) than boys (56%) tend to experience fear and isolation when left alone. The extent of experiencing fear and isolation are high in double orphaned children; much higher among the girls (79%) than in boys (54%). Feeling of fear and isolation increased with increase in education level. Out of 67 CABA boys studying in the primary level, close to two fifths (39%) have expressed of having such feelings, as against 51% and 48% of those studying in the lower secondary and secondary levels. Similar trends (increase in feelings with increase in education levels) are observed in CABA girls also.

Social protection system

Knowledge was low about organizations working on HIV/AIDS sector or individual/groups those provided support to distressed families/individuals. Less than a half (49%), of the CABA, one-tenth (11%) of care-givers of CABA and a quarter (23%) of CCG reported that they knew about organization working for HIV/AIDS. Extent of knowledge is found to be directly proportional to the age of the respondent in both the cases (CABA and CCG). Older CABA (15-17years) were more like to be aware of organizations working for their cause. Few CABA (13%) have become members of a social organization working in HIV/AIDS sector. Interestingly, 16 % of the CCG have said that they are members of an organization working on HIV/AIDS.

The majority of CABA children (60%) were unaware about any place where they could find psycho-social support. One-third (32%) of them stated NGO as the place for such support. One-eight (12%) of CABA respondents cited hospital as a place for psycho-social support. Similarly, an insignificant proportion of the respondents reported private clinic, HP/SHP, youth clubs and FCHVs as a source of support.

Knowledge and access to HIV AIDS related information and service

Knowledge regarding the mode of transmission of HIV was high among both the categories of children. However, misconceptions prevailed among these children regarding mode of transmission of HIV. For instance, a significant percentage of the CABA (30%) and CCG (41%) believed that HIV could be transmitted by mosquito bites; or perceived that HIV cannot be infected to a person if he/she does not indulge in sex (53% CABA 'vs' 52 % CCG).

Parents (59%) formed the main source of information on HIV/AIDS among CABA. On the contrary, school teachers (57%) and friends (52%) formed the main sources of information about HIV/AIDS for the majority of the CCG respondents. Radio and TV as sources of information were cited by less than a third of the CABA and about two-fifths of the CCG respondents.

Awareness about VCT centres was found to be high among CABA respondents than the CCG respondents (59% vs.35%). It was encouraging to find that almost all respondents could correctly name the place or organization running a VCT service in the district (93% CABA and 90% CCG).

RECOMMENDATION:

Education

- Sensitization programs focusing on the rights of CABA to education in a discrimination-free environment should be conducted to reduce existing discriminatory practices against CABA students in schools. School children, guardians and teachers should be encouraged to play more pro-active roles to reduce the feeling of isolation and neglect in school environment;
- Periodic monitoring by external agencies such as DACC, DoE, INSEC, and local civil society organizations should be carried out in every school to prevent discriminatory practices and take necessary actions against the school authorities;
- Although the study does not show worse scenarios on discriminatory practices in education against CABA, it is high time for the government and concern stakeholders to introduce intervention programs focussing on universal education;
- Children orphaned due to AIDS as well as the girl child from a HIV status disclosed family should be given free education up to secondary level in all categories of schools (public and private schools). In addition, the government should provide monetary incentives (scholarships) to CABA in order encourage the caregivers to send their children to school on regular basis.

Health care

- There is a need to engage community based health providers and community leaders to ensure that no child is deprived of health attention on the basis of sex (gender-based discrimination) or HIV status of the child or her/his family members. CABA families should not stigmatized or discriminated against while seeking health care at a health facility;
- Health sector (MoHP) should work closely with other sectors (Ministry of Education and Sports; Ministry of Women, Children and Culture, etc.,) to reduce discriminatory practices and ensure better health care attentions for CABA children and their families including transportation incentives for receiving regular dose of Anti-retroviral drugs from a health facility.

Care and support

- Policies on the child care must be developed in the best interest of a CABA, bearing in mind that he/she should be raised in a caring family environment and is able to attend school. Sending CABA to a child care center should be discouraged by the community. Child care center should be the last place for a child to live.
- Community-based awareness campaigns are necessary to protect the rights of child born in a HIV positive family. Policies and Directives are needed to safeguard the rights of the

CABA and take punitive actions against those in the community propagating discrimination against a HIV positive child.

Elevating economic conditions

- Since most CABA families live in worse economic deprivation, children of such families are found to be extremely malnourished and need supplementary diet and health attention. To ameliorate the condition of CABA families, at least one of the caregivers in a family be provided with skills and seed funds for income generation such as goat and pig rearing, poultry farming, commercial vegetable farming, etc. which have proved to be commercially viable than the conventional skill development training programs.

Psycho-social supports

- A coordinated effort from the government and civil society organizations working in HIV/AIDS sectors is needed to establish psycho-social counselling and support services in the place PLHIV community and CABA live and work everyday;
- Provisions should be made for greater involvement of local community leaders and PLHIV community to reduce vulnerability, stigma and discrimination and strengthen the capacities of the communities to respond to HIV/AIDS and other human rights priorities.