# Promoting a Home-Based Program Model for Supporting Children Affected by HIV/AIDS: Evaluation of Tumaini Project in Iringa Region, Tanzania

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#### **Acronyms**

AIDS acquired immune deficiency syndrome

ANOVA analysis of variance

COSTECH Commission for Science and Technology

HBC home-based care

HIV human immunodeficiency virus

IRB institutional review board

NIMR National Institute for Medical Research

OVC orphans and vulnerable children

PLWHA people living with HIV/AIDS

SDQ Strengths and Difficulties Questionnaire

USAID U.S. Agency for International Development

#### Introduction

In sub-Saharan Africa, an estimated 12 million children aged 17 and younger have lost one or both parents mainly due to the HIV/AIDS epidemic.¹ In addition, several million other children live with chronically ill and dying parents or caregiver, and others are living with HIV/AIDS themselves. These situations have exposed children to various life threats including dire household poverty, hunger, stigma and discrimination, abuse, and psychological problems. Despite recognition of the magnitude of these challenges, there is little evidence to guide programs designed to address the needs and improve the well-being of orphans and other children made vulnerable by HIV/AIDS.

To address this evidence gap, MEASURE Evaluation, with the U.S. President's Emergency Plan for AIDS Relief funds from the U.S. Agency for International Development (USAID), evaluated four programs targeting orphans and vulnerable children (OVC) — two in Kenya and two in Tanzania. The main purpose of these program evaluations is to find out what program interventions work and which do not work in improving the well-being of children aged 8-14 and their caregivers in households and communities most affected by HIV/ AIDS.

This report presents the post-test findings A Tumain from a 2007 evaluation of the Tumaini visit. home-based care (HBC) program model implemented by CARE and by Family Health International through Consolata sisters Allamano, a faith-based organization, in the Iringa region of Tanzania. This information is useful to government agencies, program staff, and organizations providing services to OVC, to help them make informed decisions on how to meet OVC needs and to reduce their vulnerabilities.



This report presents the post-test findings A Tumaini volunteer reviews school work with a child during a home

MEASURE Evaluation photo by Megan Littrell

#### **Intervention Model**

From 2004 to 2006, CARE International, in partnership with a local sub-grantee, Allamano, implemented the Tumaini home-based care (HBC) program in Iringa district, Tanzania. The Tumaini program provides HBC and support services to people living with HIV/AIDS (PLWHA) and OVC; works to strengthen referral networks; and aims to mobilize and build the capacity of the community to meet the needs of children and their families.2 To meet these objectives, the program employs a number of intervention strategies, including providing HBC and other support services; running kids' clubs; linking the community to an outpatient health clinic within the Allamano Health Center; and providing and ensuring that school-age children have the

necessary school materials (see Allamano/Tumaini Program Intervention Strategies, below).

Although this evaluation focuses on the effects of these four strategies on the well-being of children and caregivers, it is important to note that the program is more comprehensive than this. Other intervention strategies include income generating activities, livelihood skills, stigma reduction and support mobilization, advocacy, health education seminars in communities, other material support (e.g., food, medication), and referrals to complementary services. This holistic approach seeks to benefit OVC and their caregivers directly through these targeted activities, as well as indirectly through the improved well-being of PLWHA and increased capacity of community members to support both groups.

#### **Allamano/Tumaini Program Intervention Strategies**

#### **Providing home-based care and support services**

Home visiting is mainly carried out by trained community-based volunteers, sometimes with Allamano staff present for supervision or to provide other specialized services. The aim of home visiting is to provide home-based care to people living with HIV/AIDS and health education to their families; address stigma and discrimination in families and communities; and to offer counseling, referrals, and material support (i.e., school materials, medication, etc.).

#### Running kids' clubs

Kids' club meetings are organized and run by Allamano volunteers, take place monthly, and are open to all children in the community, including OVC. Participation in Allamano-run kids' clubs is aimed at reducing community stigma and discrimination against families affected by HIV/AIDS and OVC, and to help improve children's social skills, self-esteem, emotional well-being, and other psychosocial outcomes for OVC through peer support and recreational group activities (e.g., songs, plays, etc.).

#### Linking the community to outpatient health clinic within the Allamano Health Center

The program seeks to link families affected by HIV/AIDS to the health clinic at the Allamano Health Center, which provides a wide range of health services. Staff and volunteers ensure that the clinic is accessible and has flexible payment plans. Community members are encouraged to seek health care services, including HIV counseling and testing, professional psychological counseling services, anti-retroviral therapy, as well as other health assistance to families affected by HIV/AIDS. These efforts are geared towards accelerating and strengthening HIV-testing, prevention, and treatment access in the community.

#### Ensuring that school-age children have the necessary school materials

To ensure access to schooling for a majority of OVC, the program provides direct educational support to school-age children on a yearly basis to meet their immediate needs. The Allamano support package includes school supplies, uniforms, and school fees, and is allocated based on identified need. Although Allamano supports children of all age groups, in this study we focused on the necessary school materials (i.e., supplies and uniforms) for primary school-aged children (8-14 years old).

#### **Methods**

#### **Study Setting**

The study was conducted in the Iringa region, located in the southern highlands of Tanzania. Administrataively, the region is divided into six districts: Iringa, Kilolo, Mufindi, Njombe, Makete, and Ludewa. These districts are further sub-divided into 33 divisions, 138 wards, and 703 villages. The study took place in Uwemba, Mtwango, and Ilembula wards (Njombe district) and in Ruaha, Nduli, Mwembetogwa, Mlandege. Mwangata, Mtwivila, Mshindo, Mkwawa, Mivinjeni, Kwakilosa, Kiwere, Kitwiru, Kihorogoto, Kihesa, Ilala, and Gingilonga wards (Iringa district). Iringa region has the second highest HIV prevalence in Tanzania, at 13.4% (compared to the national HIV prevalence of 7%); and the country's highest orphan prevalence, at 17.4%.<sup>3</sup>

Pre-study tasks included consultations with OVC experts and USAID to review study objectives and study design, including sampling; to agree on program information needs; to develop a research protocol and data collection tools; to seek and obtain ethical approval from both Tanzanian and U.S.-based institutional review boards (IRBs); and to select programs and study sites. In addition, visits were made to program sites to meet with staff and local officials to ensure their buy-in, and to gain a better understanding of the Tumaini program, interventions, and key activities.<sup>2</sup>

#### **Study Design**

We applied a post-test study design with a comparison group to evaluate the effect of exposure to the Tumaini program interventions on child and caregiver outcomes. The intervention group was drawn from a list of children (aged 8-14 years old) who had been identified as "the most vulnerable" in the area due to their orphanhood, or because they were living with HIV/AIDS or had parents/ caregivers living with or affected by HIV/AIDS. This

list was obtained from Allamano staff and validated with community volunteers. The study focused on children aged 8-14 years to allow us to examine a wide range of outcomes, including educational and psychosocial outcomes, and because children within this age-range make the majority of those enrolled in the OVC program. A comparison group was drawn from a list of newly-identified most vulnerable children (MVC) in adjacent Njombe district who were scheduled to receive care and support services in the near future from another nongovernmental organization. Children in both groups were identified through the Allamano Health Center, and by MVC committee members who determine which children and families were most vulnerable in their communities.

#### **Ethical Considerations**

The research protocol and all instruments were approved by institutional review boards at Tulane University in the United States and at the National Institute for Medical Research (NIMR) and the Commission for Science and Technology (COSTECH) in Tanzania before data collection. Other ethical procedures, including protocols for consent, referrals, and confidentiality, were also put in place before data collection started. For instance, all potential respondents were informed at the study's outset that their participation was voluntary and did not affect their eligibility to receive services from the program. Additionally, participants were informed orally of the purpose and nature of the study, as well as its expected risks and benefits. Because of the high illiteracy rate, verbal consent was requested of participants. Adults provided consent for themselves and the children under their care. Assent was also acquired from children, using child-friendly language to ensure their understanding. If consent and assent were given, the interviewer signed the consent form for the participant. To maintain confidentiality, the

survey cover sheet, which included identifying information, was removed prior to data entry and only unique numerical identifiers were used.

#### **Data Collection**

Four questionnaires were developed, pre-tested, revised, and administered to each OVC household to collect data on the household schedule (roster and other socio-economic factors), caregiver demographics, child characteristics (aged 8-14 years old), and child well-being from the perspective of both the child and that of the child's caregiver. The respondents were the identified children and their caregivers. In 2007, interviews were carried out with 847 OVC households (85.8% of 987 originally selected to participate). Interviews did not occur in the remaining 14% of selected households because of various reasons, including: not eligible, about 6%; could not be located, 2%; residents were not home after three attempts, about 1%; occupant refused or the home did not have a child, about 1%; and other reasons, 4%. A total of 1,104 OVC aged 8-14 years (552 in the intervention area and 552 in the comparison area; 87.3% of those approached), and 845 of their caregivers (429 in Iringa and 416 in Njombe districts) were successfully interviewed. Note that some of the caregivers had more than one child under their care.

#### **Analysis**

The study was originally designed to evaluate the possible effectiveness of the Allamano program interventions on outcome measures for children and their caregivers, using a comparison group. However, initial analyses performed to compare the intervention and comparison groups on key interventions revealed that some children in the intervention group reported having "no exposure" and some in the comparison group reported "exposure" to interventions. About 89% children in the intervention and about 33% in the comparison group had received school supplies from Allamano. In addition, about 60% of children in the intervention group had a volunteer home visit, and only 44% and about

11% had attended a kids' club meeting in the past year, in the intervention and comparison group, respectively. As a result, we decided to examine the outcomes of those "exposed" to any of the four key Allamano interventions and those who were "unexposed," rather than strictly comparing the intervention and comparison group, in order to control for any contaminations among subjects.

Separate analyses were therefore conducted to compare those caregivers or children who had been exposed to an intervention (i.e., volunteer home-visit, a kids' club meeting, heard of Allamano health clinic, or ensuring possession of basic school materials) versus those who had no exposure to the intervention. Regarding the possession of school materials as a key exposure indicator, we compared those OVC whose needs were met (i.e., child had all five necessary school items) versus those whose needs were not met (i.e., child lacking one or more of the basic items). Children's possession of basic items was chosen as a better measure for exposure (met needs) over what they had received because the program only gave school materials to children with unmet needs, while ensuring that all children in the program possessed the basic necessary school materials to attend school. Therefore, an index was developed based on children's responses on whether they had any of the five essential school items (uniform, exercise books, pen, a chair, and a textbook). A "yes" response was scored a 1; a "no" response was scored 0, with possible cumulative scores of between 0 and 5, and a higher score indicating that child had all five basic necessary items for school.

We devised 15 outcome indicators to measure the effects of the four interventions on child and caregiver outcomes. These outcome measures are summarized in the following domains: psychosocial well-being of caregivers (three indicators); psychosocial well-being of children (three indicators); child-caregiver relationship (one indicator); stigma and discrimination (two indicators); child and caregiver's access to basic

needs and rights (six indicators involving access to health services, access to education, and legal protection outcomes). Most of these outcomes measures are scale measurements, and Cronbach's coefficient alpha was employed to estimate their internal consistency (reliability). A Cronbach's coefficient alpha of 0.60 or higher was considered "acceptable."

Descriptive analyses were conducted to compare the unadjusted means and percentages among those exposed and unexposed to the interventions for each study outcome. The relationships between intervention variables and study outcome measures were assessed using one-way analysis of variance (ANOVA) and chi-square tests for continuous and categorical outcomes, respectively. If the relationship was significant (p<0.05), further analyses were conducted to assess whether these differences persisted after controlling for other confounding variables (multivariate analysis) using linear regression or logistic regression, as appropriate. The control variables for caregiver level analysis were: age; marital status (married, widowed, or other); caregiver's reported chronic illness (for <=3 months in past year); household poverty status (wealth assets index); ever attended school; and number of children living in the household. In the child-level analysis, we controlled for child characteristics including age; gender; orphan status (non-orphan, maternal, paternal, or double); relationship to caregiver (mother, grandmother, or other); and number of different homes in which the child lived in the past year.

#### **Strengths and Limitations**

When interpreting the results of this study, one should consider its limitations and strengths. The main limitation was the application of a post-test study design. The absence of baseline data makes any conclusions of the extent of change in outcomes that can be attributed to the program intervention (exposure effects) difficult. Nonetheless, since both intervention and comparison groups were drawn

from existing lists of MVC compiled by MVC committees applying similar national criteria, and were from adjacent districts, they were likely to be equivalent and representative of the OVC that this study intended to survey.

Another related limitation concerns selection bias. The study was initially designed to compare subjects in the intervention and comparison sites, with the assumption that all those in the intervention group would have been exposed to the program components under investigation. However, some children in the intervention group reported being "unexposed," possibly out of choice, suggesting that differences may have already existed between those who self-selected to participate and those who did not. Alternatively, those who chose to receive services may have had an increased need for these interventions and may have been worse off at the start of the evaluation, with respect to the outcomes of interest. Importantly, this evaluation has not covered all of the program intervention strategies that Allamano implements through its Tumaini HBC program. As above, Allamano provides antiretroviral therapy to PLWHA, skills training to youth, health and other services to young children (i.e., under 8 years of age), and their caregivers. For this study however, we focused on evaluating the effects of key interventions provided to children aged 8-14 years, and their caregivers. Children outside this age range, as well as their caregivers who were benefiting from the program, were not included.

A key strength of this study design was that it yielded immediate data on program effects. A non-experimental study design, such as was applied here, is also more ethical as in no instance were services withheld from children or their caregivers. The sample of children under study were comprised of OVC receiving services (the "exposed" group) and a comparison group of OVC schedule to receive the same services in the near future or who were able to access services at the time of study but had chosen not to do so (the "not yet exposed" group).

#### Results

#### **Sample Characteristics**

demographic Table presents the and socioeconomic characteristics of the 845 caregivers interviewed in Iringa region. As expected, the majority of caregivers were female (93.6%). Caregivers had an average number of 3.2 children in their households and had an average age of 44.1 years. One out of every five caregivers (21.1%) reported being sickly for (at least) three months of the past year (a proxy for an HIV-related illness). Most (69.2%) had attended school to some level, and slightly over half were widowed (52.1%). Approximately, 44% of caregivers surveyed lived in poor households (i.e., living in the two lowest wealth quintiles, with two or fewer assets), 33% were living in medium wealth households, and 23.5% were relatively well-off (in the two highest quintiles).4

Household wealth status was assessed using a wealth index derived from a composite measure on a household's ownership of selected assets, including television, radio, bicycles, paraffin lamp, telephone; household living conditions, including roof type; and water source and sanitation facilities.<sup>5</sup> The household living conditions considered were whether the family had a better roof type (iron sheets and tiles), a latrine or toilet, electricity, used coal or paraffin for cooking, and whether they had safe drinking water (from a tap, borehole, or protected well). Each item or goodliving condition was given a score of 1 if "yes" and 0 if "no." The cumulative score for each household was divided into five quintiles (lowest number signifying fewer items owned and hence poorest, and highest score indicative of richest households relative to all other households surveyed). In addition, household vulnerability related to food insecurity was assessed. Food insecurity was assessed using the Household Food Insecurity Access Scale, a nine-item scale designed to measure the prevalence and severity of household

food insecurity, developed by USAID's Food and Nutrition Technical Assistance Project.<sup>6</sup> Results show that a majority of caregivers (88.5%) live in moderately to severely food insecure households.

The characteristics of the 1,104 children in the sample are presented in Table 2. The sample contained roughly equal numbers of boys and girls and the average age of all children was 11.4 years. A majority (85.7 %) were orphaned (maternal, paternal or double). Just under half (46.7%) of children sampled had their biological mothers as their primary caregivers. One in five children (19.7%) reported living in more than one home in the past year, indicative of disruptions in the child's life especially following the deaths of both parents.

#### **Program Exposure**

Figure 1 depicts the proportions of children exposed to selected interventions in the two study sites in Iringa region. The analysis shows that not all children in the intervention area had been exposed to the Allamano interventions, while some of the children in the comparison area had been exposed to one or more of the interventions. It was not clear how these children were able to access the interventions; but as Iringa and Njombe are adjacent districts, it is possible that some children may have moved between the two areas or there had been ripple effects of the program. Also, other organizations may have been providing similar services as Allamano in Njombe. To control for such contamination, in further analyses we focused on comparing children and their caregivers who had been exposed to a particular Tumaini/Allamano intervention strategy, with children and caregivers who had not been exposed to that intervention strategy, regardless of their study group.

Table 1. Description of Caregivers in Sample

Factor	Percent (N=845)
Gender	
male	6.4
female	93.6
Age group (years)	
under 30	11.8
30 to 49	55.4
50 and older	32.8
Mean age = 44.1	
Ever attended school	
yes	69.2
Caregiver ill 3 months in past year	
yes	21.1
Caregiver marital status	
married/living with someone	31.6
widowed	52.1
other	16.4
Number of children in household	
3 or fewer	64.7
more than 3	35.3
Mean = 3.2 children	
Household wealth status	
poorest (1 or no assets)	24.0
poor (2 assets)	19.6
middle (3 assets)	33.0
rich (4 assets)	16.2
richest (5 or more assets)	7.3
Household food security status*	
food secure	6.8
mildly food insecure	4.4
moderately food insecure	46.2
severely food insecure	42.3

<sup>\*</sup> Household wealth status is a composite measure on a household's ownership of selected assets, such as televisions and bicycles, materials used for housing construction, and types of water access and sanitation facilities.<sup>4</sup>

Table 2. Description of Children in Sample

Factor	Percent (N=1,104)
Gender	
male	48.6
female	51.4
Age group (years)	
8 to 11 (mid-childhood)	48.3
12 to 14 (adolescence)	51.7
Mean age = 11.4	
Child's orphan status	
non-orphan	14.3
single maternal orphans	14.0
single paternal orphans	35.7
double orphans	36.1
Child's caregiver or natual parent ill for 3 months in past year	
yes	26.9
Number of homes child has lived in	
one	80.3
two or more	19.7
Caregiver relationship to child	
mother	46.7
grandmother	22.8
other	30.5

Data presented in Table 3 show that of the 834 caregivers who responded, 28.5% (N=238) reported having been visited by an Allamano volunteer at their home. In addition, 48.4% of caregivers reported having heard about Allamano health center and 24.5% (N=206) reported having visited the Allamano clinic to receive services. Data presented in Table 4 show that of the 1,104 children sampled, 27.3% (N=301) reported having attended at least one kids' club meeting, 29.0% (N=323) reported that they had a volunteer visit their home, and 21.9% (N=242) reported having visited the Allamano health clinic. In addition, 57.5% (N=635) of children reported having received school materials (generally uniforms or school supplies), and about 91.6% (N=1,031) reported having at least one of the basic school items with a majority having a desk and a uniform (96.4% and 87.4%, respectively).

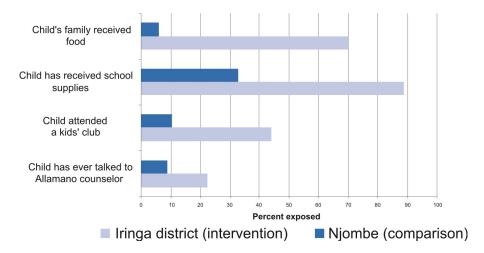


Figure 1. Percent of children exposed to selected program services, by study group.

Table 3. Percent Distribution of Caregivers by Intervention Exposure and Intensity

Intervention Type	Percentage (N=834)
Caregiver had home visit by	20.5
Allamano volunteer (N=238)	28.5
Length of volunteer visit	
(among those with visit)	
<ul> <li>Less than 30 minutes</li> </ul>	27.3
<ul> <li>30 minutes</li> </ul>	35.7
<ul> <li>Longer than 30 minutes</li> </ul>	37.0
Average time per visit = 40.0 minutes	
Caregiver perceptions concerning quality of services by volunteer	
<ul> <li>Volunteer gives good advice</li> </ul>	90.3
<ul> <li>Services are a big help</li> </ul>	
to family	82.0
<ul> <li>Satisfied with things the</li> </ul>	
volunteer does	86.2
<ul> <li>Volunteer visits often enough</li> </ul>	63.4
Caregivers who had heard about	
Allamano Health Center (N=418)	48.4
Caregivers who had visited Allamano	
Health Center in past year (N=206)	24.5
More than one visit to Allamano	
Health Center in past year (among	
those with any visits)	86.7

## Effects of the Home-Visiting Strategy on Caregiver and Child Outcomes

As described earlier, the Tumaini program staff trains community-based volunteers to conduct home visits on a regular basis, to provide home-based care and support to OVC and their families within their communities. This section examines the program's effects on caregiver and child outcomes.

#### Psychosocial Well-being of Caregivers

The psychosocial well-being of caregivers was measured using four outcome indicators (positive, negative, marginalization feelings, and perceived community stigma). Positive feelings (alpha=0.72) and negative feelings (alpha=0.81) sub-scales were extracted from the psychological domain of the World Health Organization's quality of life instrument,5 which was used to measure caregivers' psychological health. Each sub-scale has four items, with possible scores ranging from 1 to 5, where a higher score is indicative of positive perceptions of quality of life. Positive feelings scale items included how much caregivers enjoy life, how much caregivers experience positive feelings in their lives, how positive caregivers feel about the future, and if caregivers generally feel content. Caregivers' negative feelings were measured by responses to four questions (extent to which any feelings of sadness or depression interfere with the

Table 4. Percent Distribution of Children by Intervention Exposure and Intensity

Intervention Type	Percentage (N=1,104)	
Child's home visited by Allamano volunteers/staff (N=323)	29.0	
Child has visited Allamano (N=242)	21.9	
Reported frequency of visits to the Allar Health Center in past year	mano	
<ul><li>On ce</li><li>Twice</li><li>Three times or more</li></ul>	44.6 12.8 42.6	
Child reported attending at least one kid's club meeting in community or school (N= 301)	27.3	
Reported frequency of attendance at kid's club (among those with any attendance)		
<ul> <li>Every month</li> <li>Every other month</li> <li>Three or four times a year</li> <li>Less than three times a year</li> </ul>	56.7 7.4 10.7 25.2	
<ul> <li>Kids' club a ctivit ies most enjoyed by</li> <li>Traditional songs and dances</li> <li>Learn ing good behavior</li> <li>Learn ing to help with chores</li> <li>Other</li> </ul>	child 39.3 15.3 14.0 31.4	
Child reported having received at least one school item (N=635)  Item reported received	57.5	
<ul> <li>(among those who received)</li> <li>School uniform</li> <li>Pens/pencils/textbook</li> <li>School bag</li> <li>Other</li> </ul>	94.2 91.5 47.7 28.3	
Child reported having at least one of the necessary school items (N=1,031)  Item reported (among those with at lea	91.6 st one item)	
<ul> <li>School uniform</li> <li>Exercise books</li> <li>Pens/pencils</li> <li>Textbook</li> <li>Desk/chair</li> </ul>	87.4 75.5 72.5 5.9 96.4	

caregiver's everyday functioning; how much do feelings of depression bother the caretaker; how worried does the caretaker feel; and how often does the caretaker have such negative feelings as despair, anxiety, or depression). The mean scores for positive feelings for those exposed to volunteer home visits and non-exposed groups were 2.5 and 2.3, respectively. After controlling for confounding factors however, the effects of home visiting exposure were reduced to a non-significant level. When the negative feelings scale was used to measure caregivers' feelings, home visiting showed no significant effects.

Feelings of marginalization among caregivers were assessed by a five-item scale (alpha=0.80) previously used among youth-headed households in Rwanda.<sup>7</sup> The five items on this scale ask if people speak badly about the caretaker or caretaker's family; do people make fun of the caretaker's situation; would people rather hurt the caretaker than help the caretaker; does the caretaker feel isolated from others in the community; and does the caretaker feel that no one cares about him or her. The possible rating for each item ranged from 1 to 4, with higher scores indicating higher marginalization. The results show that caregivers whose homes were visited by a volunteer felt more marginalized compared to those not visited (mean scores of 2.36 and 2.25 for exposed and non-exposed, respectively). After controlling for confounding variables, this statistically significant effect of home visiting persisted (p=0.05).

Caregivers' perceived negative community attitudes towards HIV-affected families (PLWHA and OVC) was assessed using a new three-item scale (alpha=0.67). The scale was based on caregivers' responses to whether the community rejects orphans; whether the community rejects families affected by HIV/AIDS; and whether people are jealous of the services given to orphans and families. The possible scores ranged from 1 to 4, with higher scores indicating more community stigma and discrimination towards HIV-affected families. Results show that caregivers exposed to home visiting had a higher mean score than those not visited (mean scores were 2.5 versus 2.3, respectively; p<0.001). This association persisted even after controlling for other confounding variables. This finding suggests that caregivers who received home visits from an Allamano volunteer feel that other people in the community have negative attitudes towards those affected by HIV/ AIDS. This finding was unexpected, given that part of the reasoning for volunteer home visiting was to help reduce stigma and discrimination in the household and in community towards PLWHA and OVC. To understand this relationship better, we examined individual items of the scale and their statistical relationships to home visits. Results show that those visited held significantly higher mean scores, meaning that they felt more strongly than those not visited, that the community rejects HIV-affected families, and that people are jealous of services provided to OVC and their families (Figure 2) (p<0.001 for both items). However, no significant association was found between home visits and the "whether the community rejects orphans" scale item.

**Caregiver-Child Relationship** — The caregiver's feelings towards a child was assessed using a subscale with four items (alpha=0.81) taken from

the 2000 U.S. Census Bureau Survey of Income and Program Participation (SIPP), which was designed to collect information from individuals and households in the United States. <sup>8,9</sup> The four-scale items related to parents' feelings towards their children include whether the child is much harder to take care of than most children; does the child do things that really bothers the respondent; does the child take up more of the respondent's time than expected; and does the repsondent feel angry with child. Possible scores range from 1 to 4 with higher scores indicating more negative feelings. Results showed that volunteer home visiting was not associated with a caregiver's feelings towards the children within their care.

Access to Health-Care Services for Child and Caregiver — The caregivers' access to health care services was measured through a self-reported response by caregivers on whether they had ever gone to Allamano for health services. Approximately 65% of those visited by an Allamano volunteer or staff member had visited the Allamano center for health care services, compared with only 28.7% of those not visited by a volunteer. Even

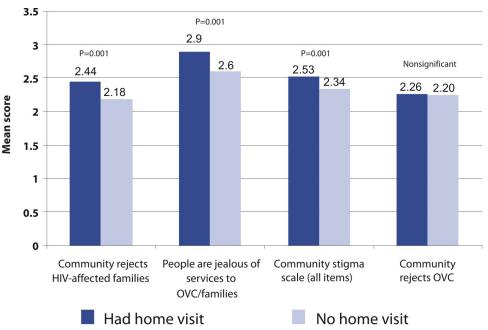


Figure 2. Caregivers' perceived negative community attitudes towards HIV-affected families and OVC (mean scores) by volunteer home visit status.

after controlling for potential confounders, those visited by a volunteer were five times more likely to seek health care services at the Allamano center than those not visited (Exp(B)=5.33; p<0.001). Similarly, the child's access to healthcare services was measured via caregivers' responses to a question on whether the child had ever sought health care services from the Allamano center (yes=1or no=0). Results showed that children with a home visitor were twice as likely (Exp (B)=2.4) to have gone to the Allamano center than those who were not exposed to home visiting (p<0.001), all else being equal.

Child's Legal Protection Outcomes — Child's legal protection outcomes were assessed using two indicators: designation of an alternate caregiver for the child and whether the child has a birth certificate (national identification document). Legal advice is among the other essential services that Allamano volunteers and staff provide to their clients by, for instance, helping caregivers identify and designate an alternate caregiver for the child, in case of their absence, and ensuring that children have an identity document, such as a birth certificate. Child legal protection was measured by the caregivers' responses to the question: "Have you designated an alternate caregiver for the child if something happens and you could nolonger do so?" and "Does the child have a birth certificate?" Overall about 36% of all children had a birth certificate (N=394), and 13.5% had a designated alternate caregiver (N=149). Further analyses showed that children whose homes had been visited by an Allamano volunteer were more likely to have a birth certificate than those who had not been visited (42.6% and 33.6%, respectively; p=0.02). However, this relationship lost statistical significance after controlling for other confounders. There was no significant association between exposure to home visiting and a child having a designated alternate caregiver.

**Social Networks of OVC** — The effect of a home visitor on the child's social support networks was measured using the adult support scale developed

and described in Boris et al. (2006).<sup>10</sup> The scale contains four questions for children: "Do you have an adult in your life that you trust to offer you advice?"; "Is there an adult who would go with you to authorities if you needed?"; "Do you have an adult in your life who comforts you when you feel down?", and "Do you have an adult in your life that you can always depend on?". Possible responses range from 1 for strongly disagree to 4 for strongly agree, with higher scores indicating greater adult support. The internal consistency of this scale (alpha) is 0.73. Results show that children whose homes were visited by a volunteer felt that they had more support from adults compared to children whose homes were not visited (mean scores were 3.5 versus 3.4, respectively). The relationship remained statistically significant even after controlling for confounders (p<0.001).

Psychosocial Well-being of Children — The impact of home visiting on the psychosocial well-being of children was assessed using selfesteem indicators including family-relationships and global self-esteem (self-worth) subscales of the widely-used self-esteem questionnaire, a youth-specific instrument.<sup>11</sup> The familyrelated self-esteem subscale assesses a child's perception regarding his or her family's favorable or unfavorable attitudes toward the child, and it had six items (alpha=0.80): "Are you happy about how much your family likes you?", "Are you too much trouble to your family?", "Do you get in trouble too much at home?", "Do you feel OK about how important you are to your family?", "Do you get along as well as you would like to with your family?", and "Does your family pay enough attention to you?". The global self-esteem subscale measures what a child thinks of self and what image he or she has have of himself or herself (attitude towards self) and has eight items (alpha=0.70): "Are you happy with the way you can do most things?" "Do you sometimes think you are a failure?", "Are happy with yourself as a person?", "Are you the kind of person you want to be?", "Do you often feel ashamed of yourself?", "Do you like being just the way you are?" "Are you as good a person as you want to be?", and "Do you wish you had more to be proud of?". Each item was scored on a fourpoint scale ranging from 1 for strongly disagree to 4 for strongly agree, with reverse coding for the opposite items. For each subscale, higher composite score indicates positive self-esteem. Results showed that children in households that were visited by a volunteer had slightly higher family-related self-esteem scores (child felt valued in the family) than those not visited (total scores of 21.3 and 20.9, for visited by volunteer and not visted, respectively; p=0.02). However, the difference was not significant after adjusting for potential confounders. Home visiting had no significant effect on the child's global self-esteem (attitudes towards self); total scores were 21.6 for those visited and 21.2 for those not visited.

#### **Effects of Participating in a Kids' Club**

The aim of the Allamano-run kids' clubs is to help improve children's social skills, self-esteem, emotional, and other psychosocial outcomes for OVC and to reduce community stigma and discrimination against families affected by HIV/AIDS and OVC. This section presents its effects on child outcomes.

Feelings and Social Behavior of Children —The effects of kids' club meetings on a child's feelings related to community, family, and self; and on social skills; was assessed using five multidimensional indicators: family-related and global (self-worth) self-esteem discussed earlier, two subscales from the Strengths and Difficulties Questionnaire (SDQ)12 (emotional symptoms and pro-social behavior); and the child's perceived negative community attitudes towards PLWHA and OVC. A series of analyses comparing mean scores in these five outcome areas between children exposed and not exposed to the kids' club meetings were conducted. Results show that there was no association observed between kids' club participation and self-esteem for both measures (family-related and self-worth).

The emotional problems and pro-social behavior subscales measures the child's negative attributes and positive behavioral attributes, respectively. The two indicators were obtained from the SDQ, which has five subscales that are usually used to screen for different dimensions of child behavior: emotional symptoms; conduct problems; peer relationship problems; hyperactivity/inattention; and pro-social behavior. 12 In this analysis, children's emotional problems were measured by caregivers' responses to the following items (alpha=0.71): whether the child complains of headaches, stomach aches, or feeling sick; whether the child seems worried; whether the child is unhappy, depressed, and tearful; whether the child is nervous in new situations; whether the child loses self-confidence; and whether the child has many fears or becomes frightened easily. Possible scores ranged from 4 to 32, with higher scores indicating more emotional problems. Results show that the children who had participated in a kids' club meeting had fewer emotional problems compared to those who had not attended kids' club (total scores were 11.7 among those for attending and 12.0 among those not attending). Even after everything else was held constant, kids' club participation had a positive and significant effect on the child's emotional well-being (p<0.05). Pro-social behavior was assessed using caregiver's responses to the positive SDQ five-items (alpha=0.62): whether the child is considerate of other people's feelings; whether the child shares toys, pencils, and food with other children; whether the child tries to help if someone is hurt, upset, or sick; whether the child is kind to other children; and whether the child offers to help adults or children.

Each item was scored from 1 to 3, with a possible cumulative score ranging from 5 to 15, and with higher scores indicating more cooperative and desirable behavior. Children who participated in kids' club meetings had better social behavior than those who had not attended in the past year (with scores of 14.1 for those attending versus 13.7 for not attending). The significance of the effects

of attending a kids' club meeting persisted after controlling for confounding factors (p<0.05).

Further analyses on frequency of exposure (i.e., the number of times a child attended kids' club meetings in past year) was conducted to examine if there was a dose-response relationship. Frequency was measured by the response to the question: "How often did you attend the kids' dlub in the past year?", and coded as monthly; every other month, or four or fewer times a year. The children who attended a kids' club monthly had fewer emotional problems (scoring 11.7) as measured by the SDQ subscale compared to others (those who attended every other month scored 12.0 while those who attended four times or fewer a year scored 12.5). Nonetheless, these differences were not statistically significant. Similar patterns were observed for pro-social and global self-esteem but they were also non-significant.

Children's perceptions of negative community attitudes towards HIV-affected families (PLWHA and OVC) were assessed using the same three items as for caregivers (as previously described). However, the reliability of this scale for the children's data was marginal (alpha=0.59) and

below our set alpha coefficient (0.60). Using individual scale items, results showed that kids' club participation had a significant effect on children's perceptions that people in the community were jealous of the services given to HIV-families, including orphans (Figure 3). Children who had attended kids' club had a higher mean score than those who had never attended (mean scores 2.7 for those attending versus 2.4 for those who had never attended, p<0.001). These effects persisted after controlling for confounders. No significant differences were observed when using the other two scale items (whether the community rejects orphans and whether the community rejects HIV-affected families).

**Social Support Networks of OVC** — Social support networks for OVC were assessed using two indicators: adult support and social isolation scales. Adult support was measured as previously described. Children who had attended kids' club meetings felt that they had more adult support in their lives than those who had not attended (mean scores were 3.5 for those attending versus 3.4 for those not attending). This difference was statistically significant (p<0.001), even after controlling for other confounding variables. Social

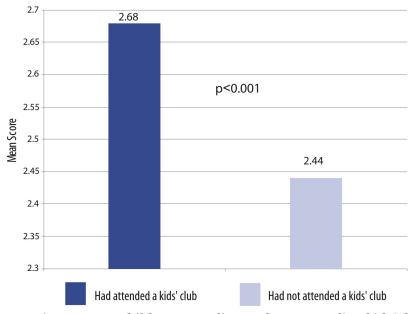


Figure 3. Perceptions among children attending and not attending kids' clubs that people were jealous of services to OVC and families.

isolation was measured by five items (alpha=0.80) from the KIDSCREEN social acceptance subscale (bullying), which evaluates children's feelings of social isolation.<sup>13</sup> The items are measured by children's responses to five questions: "How often do you play alone because no one wants to play with you?", "How often do other kids pick on you?", "In the past four weeks, have you been afraid of other girls/boys?", "Have other girls/boys made fun of you?", and "Have other girls/boys bullied you?". The results show that kids' club attendance had no significant effect on the children's feelings of social isolation.

# Effects of a Health Clinic Linked to the Community on Health Outcomes

The Tumaini program is based at Allamano Health Center, which is strongly linked to the surrounding communities through trained volunteers who conduct health education, counseling, referrals, and other basic health services at community, household, and individual levels. This study compared those who have "ever heard" of and those who have "not heard" of the Allamano Health Center.

Caregivers' health status was assessed using caregivers' responses to the question: "How is your health?" Possible scores ranged from 1 to 5, with higher scores indicating very good health. Caregivers who had heard of the Allamano center reported significantly better health than those who had not (mean scores 3.4 among those who had heard versus 3.2 among thsoe who had not, p=0.001). This relationship persisted after controlling for confounders (p=0.05).

#### Caregivers' Access to Health Care Services —

This outcome indicator was measured by a self-reported response by caregivers to the following question: "How easily are you able to get good medical care?" Caregivers who had heard of the Allamano Health Center reported easier access compared to those who reported no knowledge of the center (mean scores 2.5 for those who had heard of the center versus 2.4 for those who had

not; p=0.01). However, this difference disappeared after controlling for confounding factors.

Children's health status and their access to services were examined based on caregivers' reports regarding the health status of the children in their care and whether they felt that the children needed any health services that they was not receiving. For these two child-health outomes, no significant differences were observed between those children whose caregiver had heard of the Allamano Health Center and those who had not.

# Effects on Child Outcomes of Having the Essential School Materials and Supplies

To ensure access to schooling for a majority of OVC, the Tumaini/Allamano program provides direct educational support to school-age children to meet their immediate needs including regular school attendance and help in their psychosocial well-being. The Allamano support package includes school supplies, uniforms, and school fees that are allocated based on identified need.

Child's Access to Education — A child's access to education was assessed using two outcome indicators: child is still attending school and child is regularly attending school. Regular school attendance was measured by a caregiver's response regarding the number of days a child had missed school in the week preceding the survey. If the survey was conducted during school holidays, a caregiver was asked about the number of days the child missed school in the week before holidays started. Possible responses for number of days missed ranged from 0 to 5. Results showed that a significantly higher proportion of children exposed to the program through home visits and kids' clubs were still attending school compared to those not exposed (99.7% versus 91.9%, and 97.7% versus 92.8%, respectively; p<0.001). Numbers were too small for any further analysis. In examining the contributions of program interventions to regular school attendance, results showed that exposure to home visits, kids' clubs, and having the necessary school materials made no significant difference on a child's regular school attendance status.

Child's Psychosocial Outcomes — The effects of having the necessary school materials on a child's self-esteem (family-related and global self-esteem scale) were assessed. Results showed that possession of school materials was related to better self-esteem scores. Children who had more school items felt that their families valued them more compared to those who had fewer school materials (total scores were 21.2 versus 20.5; p<0.002). Furthermore, having the necessary school supplies was also positively associated with enhanced self-worth (as measured by the global self-esteem subscale) among children in the exposed group (scores of 22.4 versus 20.8; p<0.001). Both relationships remained significant after controlling for confounders (Figure 4).

Child's Perceptions of Negative Community Attitudes towards HIV-Affected Families — Results also showed that children who had the necessary school materials felt that there were fewer negative attitudes towards PLWHA and OVC in the community compared to those who reported having fewer school items (p<0.001), even after controlling for other confounders (Figure 5).

Adult Support — Results show that children's feelings of adult support increased with the increasing number of basic school supplies in their possession (mean scores ranging from 2.8 to 3.7, for those with zero and five basic items, respectively). The relationship is statistically significant (p<0.001), even after controlling for other confounding variables. Figure 6 shows that a child's perceptions of adult support increases with the number of school necessities the child reported having.

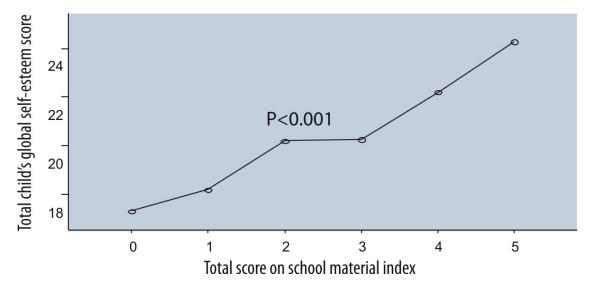


Figure 4. Relationship between having basic school materials (index) and child's total global self-esteem score (self worth).

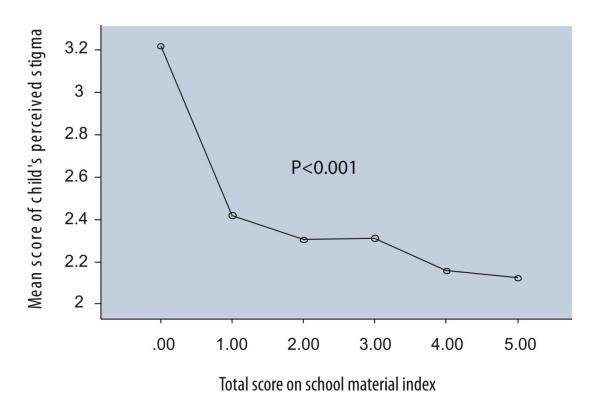


Figure 5. Relationship between possession of basic school materials and child's perceived negative community attitudes towards HIV-affected families.

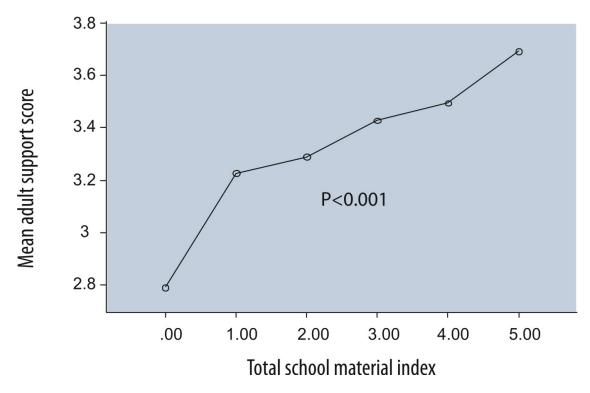


Figure 6. Relationship between possession of basic school materials and adult support.

#### **Discussion and Conclusions**

In this report, we presented the effects of theTumaini program (HBC Allamano) on measures of well-being for OVC and their caregivers in Iringa region, Tanzania. Analysis was guided by the expectation that clients who had been exposed to any of the program interventions would fare better than those who had not been exposed. Even though some of the interventions were at community and household levels, the outcomes were expected to be observable at the caregiver and child levels. The analysis showed mixed effects of the program interventions on children's and caregivers' psycho-social support networks, access to health care, legal protection, community stigma, and child educational outcomes. Although the differences in scores between exposed and non-exposed groups vis-á-vis some indicators were not statistically significant, most analyses indicated a positive pattern of the effects of current interventions on child and caregiver outcomes.

Results of this evaluation confirm that home visits conducted by trained volunteers can contribute to better psychosocial outcomes and increase access to basic services, including health care and legal advice for clients. Indeed, over 90% of caregivers visited by volunteers agreed that "they liked what the volunteer did for them" and many agreed that volunteers "do not visit enough." This implies that, in addition to providing psychosocial support to caregivers and children during home visits, volunteers provide clients with good information, encouragement, and other necessary support to enable them to seek the services they need including health care at Allamano Health Center. Also, having an accessible health clinic at Allamano may have enabled caregivers (who were aware of the clinic) to seek health care services.

Results revealed that having school necessities was not associated with children's educational outcomes (enrollment and regular attendance). These findings are intriguing, as many OVC programs

including Tumaini are geared towards removing obstacles to school enrollment and attendance by providing school necessities (e.g., supplies and uniforms). However, almost all children aged 8-14 years interviewed were attending school (perhaps because the Tanzanian Ministry of Education does not charge fees for primary schooling, and provides scholarships for secondary and tertiary education to the most vulnerable children). Future inquiries on educational outcomes should look at other constraints on performance (i.e., grade level) over school attendance (i.e., child still in school and regular attendance). It is also important to note that children who had all necessary school supplies had better psychosocial outcomes and positive feelings, and that they felt more adult support than those who were lacking or had fewer such materials. Having the necessary school items was significantly associated with enhanced selfesteem scores and more feelings of adult support among children, even when holding confounders constant. This result suggests that in assisting school-age OVC with the minimum necessary school supplies and meeting their immediate needs improves their psychosocial outcomes. Indeed, there is growing evidence showing that OVC experience psychosocial distress as a result of losing a parent and having reduced access to basic necessities compared to how they lived before the parent died or how their peers live.<sup>14</sup> However, very little is known about the mechanisms through which possession of school necessities operates to influence children's psychological outcomes. It is possible that possession of these basic school materials is a proxy for feelings of belonging (i.e., that they appear more like other children or that society cares about them), and hopefulness about their future life prospects.

Analyses examining the effects of kids' club participation on child psychosocial outcomes revealed fewer benefits for children who attended compared to those who had never attended a club meeting. Kids' club participation was expected to be most effective on improving self-esteem, social life, and in reducing stigma and discrimination-related feelings children. However, among the only positive psychosocial outcomes among children potentially attributable to the kids' club intervention were reduced emotional problems and improved social behavior.

Results also show a negative effect of program exposure on children's and caregivers' perceptions of

community stigma towards families affected by HIV/AIDS in their communities. The group exposed to home visiting felt that there was more stigma and discrimination towards PLWHA and OVC when compared to those who were not exposed. These negative results were unexpected, suggesting that perhaps the issue of stigma and discrimination have not yet been adequately addressed within these communities. However, this could also be indicative of a "self-imposed"

"Losing a loved one, children losing a parent or having a chronically ill parent (HIV-positive), generates self-pity and self discrimination among the affected family members. This kind of stigma is very hard to take away compared to the stigma from others in the community that our program typically addresses."

Allamano staff member

stigma" that PLWHA and OVC may be experiencing feelings of self-pity and distress from their HIV situation and, as a result, may start perceiving other people as being judgmental of them. The current OVC program has been designed to address the "socially imposed stigma" due to the social stereotypes and prejudice from community or household members, but not "self-imposed stigma," which may require a different program approach. Indeed, an Allamano staff member noted that PLWHA and OVC feel

and behave in accordance with how they think other people see (perceive) them, and that those who feel a strong stigma may isolate themselves. This could also be one of the unintended outcomes of the program. A home visit by someone known to support people in the community affected by HIV/AIDS may inadvertently direct stigma towards beneficiaries.

# Programmatic Implications

These findings have policy and programmatic implications. The Tumaini model is a home-based care and support program that is linked to a health center aimed at providing comprehensive services to PLWHA and others most affected by HIV/AIDS. Evaluation findings have highlighted that some of the program's interventions are effective in producing their intended outcomes, while others require further investments if they are to become effective. Based on findings, the following programmatic recommendations are offered.

Home visiting is potentially an effective strategy but must be implemented cautiously to avoid negative outcomes. In general, home visiting by trained volunteers or Allamano staff had positive effects on some outcomes for caregivers and children. Increasing the numbers of volunteer/ staff visits so that participating households can be visited more often, and more new households visited, thus, benefiting more beneficiaries. However, this strategy could also lead to negative outcomes including feelings of margilization and discrimination among clients in the community perhaps because of their HIV-positive status. We would recommend that this component continue to be strengthened and scaled up as part of the OVC program intervention strategy, but at the same time find ways within the local context to avoid the potential negative consequences for beneficiaries. These mechanisms may include intensified community sensitization about HIV/ AIDS and counseling PLWHA in support groups for encouragement.

New strategies to address and reduce selfimposed stigma are needed. Findings from this study indicate that people directly affected by HIV (PLWHA and OVC) may be experiencing a "selfimposed stigma." However, current programs are designed to reduce "socially-imposed stigma," i.e. stigma coming from the community. Thus, programs should develop a stigma-reduction strategy that addresses both kinds of stigma, particularly for PLWHA. The starting point could be to explore the issues further and brainstorm new strategies with PLWHA/beneficiaries in focus groups. These new approaches should then be used to strengthen existing sensitization and mobilization strategies aimed at reducing social-stigma and discrimination.

The kids' club intervention strategy should be reviewed and improved. Psychosocial support activities are a critical component of programs designed to assist children affected by HIV/ AIDS. The kids' club meetings aim to address the psychosocial needs of OVC by providing a forum to address stigma and discrimination, social isolation, low self-esteem, and anti-social behaviors. However, the kids' club component of this program generally did not result in better psychosocial outcomes for children. We recommend that an alternative kids' club model and curriculum that is more attractive and accessible to children (i.e. child-friendly and fun) be developed and tested by programming experts. Program designers should also consider other ways to increase the frequency of attendance. Kids' clubs may have been less effective than expected as only a few children were attending as often as expected (i.e., twice a week). We suggest involving parents and caregivers in designing, planning, and setting meeting schedules of the clubs to encourage participation. The goal is to have children's participation in kids' clubs with the full support, knowledge, and approval from their parents/caregivers.

Establish referral linkages between communities and designated local health centers. Findings show that a majority of caregivers served by Allamano had

visited the Allamano Health Center for services, including counseling and HIV testing. An HBC visiting strategy, combined with a referral system that is linked to a specific clinic staffed by trained professionals able to address cases beyond the volunteers' capacity, appears effective. We recommend that programs establish referral relationships between specific communities and local health care centers to facilitate follow-up and enable client monitoring.

As part of psychosocial support for OVC, programs should ensure that school-age children have the necessary school materials to attend school. As part of the overall care and support strategy, programs should ensure that children of

school age have the basic school necessities to make them feel supported and hopeful for the future. This strategy was effective beyond expectations in helping the children in this study feel better about themselves and that society cares. Ensuring that children have the necessary school supplies had positive effects on children with regard to self-esteem as well as perceived adult support networks. Therefore, in addition to providing family counseling and other essential services to children, ensuring that school age children have their school basic needs met is essential to their overall well-being.

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