

**Supporting Community Action on AIDS in India**

# **Nutritional Support and Health Outcomes in the Context of HIV and AIDS**

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**A report on the impact of nutritional support on the health and quality of life of people living with HIV in home and community-based care and support programmes**





# **Nutritional Support**

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and quality of life of people living with HIV in home and  
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## **The International HIV/AIDS Alliance**

The International HIV/AIDS Alliance is a global partnership of people, organisations and communities working towards a shared vision of supporting effective and sustainable community responses to reduce the spread of HIV and to meet the challenges of AIDS.

Our vision is of a world in which people do not die of AIDS. For us, this means a world where communities have brought HIV under control by preventing its transmission & enjoy better health and quality of life through access to comprehensive HIV prevention, care, support & treatment services, regardless of their gender, religion, class, race, ethnicity, sexual orientation, age, disability, drug use or sex work, backed up by an unbiased system of justice.

In fulfilling our vision, we are contributing towards achieving the Declaration of Commitment on HIV/AIDS of the United Nations General Assembly Special Session of June 2001 and the commitment in June 2006 by the UN General Assembly to the goal of Universal Access to HIV prevention, treatment, care, support by 2010 – in addition to the Millennium Development Goals on HIV and AIDS to halt & reverse the epidemic by 2015.

Established in 1999, the India HIV/AIDS Alliance comprises a country-based Alliance Secretariat in New Delhi, five lead partner organisations (also known as Linking Organisations within the global Alliance) and their networks of over 100 community-based non-governmental organisations and community-based organisations across five states – Andhra Pradesh, Tamil Nadu, Manipur, Maharashtra and Delhi.

In 2007, the Alliance supported over 120 community-based projects through its NGO and CBO partners, to prevent HIV infection; improve access to HIV treatment, care and support; and lessen the impact of HIV and AIDS, including reducing stigma and discrimination, particularly amongst the most vulnerable and marginalised communities key to the epidemic – such as sex workers, men who have sex with men, injecting drug users and adults and children living with HIV.

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# Acronyms

AIDS	Acquired Immuno-deficiency Syndrome
ART	Anti-Retroviral Treatment
ARV	Anti-Retroviral
BMI	Body Mass Index
CSO	Civil Society Organisation
HIV	Human Immuno-deficiency Virus
ICDS	Integrated Child Development Scheme
IEC	Information, Education & Communication
IGP	Income Generating Programme
iNGO	Implementing Non-Government Organisation
LP	Lead Partner
OIs	Opportunistic Infections
PCA	Participatory Community Assessment
PCR	Participatory Community Review
PLHIV	Persons/People Living with HIV
SHG	Self-Help Group
TB	Tuberculosis
WLHA	Woman/Women Living with HIV/AIDS

# Executive Summary

The India HIV/AIDS Alliance established its home and community-based care and support programme with three Lead Partners (also known as Linking Organisations in the Alliance) in Tamil Nadu, Andhra Pradesh and Delhi states in 2000. In turn, these NGOs have worked with networks of implementing NGOs (iNGOs) working at the community level. The overarching goal of the Alliance's care and support programme interventions have been to work towards reducing stigma and discrimination through community mobilisation strategies, improve the quality of life of people living with HIV (PLHIV) and families and children affected by AIDS. A key component of the Alliance's care and support programme, is nutrition support.

This study was conducted with an objective of establishing the effectiveness and efficiency of nutritional support within the home and community-based care and support programme in terms of criteria, outreach, awareness, and knowledge and counselling components. An assessment of client satisfaction levels, minimum defined standards of service, coverage and regional variations were also indicated. Four NGOs were selected in Andhra Pradesh for the study: Vasavya Mahila Mandali (VMM) in Vijayawada, Krishna District; AIRTDS in Tenali, Guntur District; Mahila Mandali in Chirala, Prakasam District, and Green Vision in Visakhapatnam District. In Tamil Nadu, four NGOs were also selected: SSH in Sempatti, Dindigul District; NMCT in Kalapanaickenpalayam, Coimbatore; PACHE TRUST in guidance and supervision of a Principal Researcher, to elicit the information on nutritional support from project beneficiaries including children and adults (both women and men), key community members, anganwadi workers, Government officials and Alliance iNGO staff.

The findings of the study highlighted key aspects relating to the regularity of home visits to adults and/or children living with HIV and nutritional demonstrations by iNGO staff. The study confirmed the satisfaction derived by community members from the outreach and services provided to them. Services are aimed at meeting the food security needs of PLHIV on a priority basis, and include looking at their nutritional needs. Using a community-based approach, food security dealt with through promoting greater community involvement by way of local-level collection of food grain for those most affected from the PLHIV community, specifically rice (known as the "Handful of Rice" initiative). Nutritional demonstrations have also been conducted regularly in various iNGO catchment areas, with an emphasis on encouraging PLHIV and their family members to learn how to prepare nutritious recipes, using locally available low cost ingredients. Through these interventions, myths and misconceptions about the comparative nutritional value of different vegetable and meat-based foods have been addressed. Highlighting the importance of vegetables in daily dietary habits, the iNGOs have also distributed seeds and plants to a few PLHIV for maintaining a kitchen garden that provides

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the opportunity for them to cater to their own needs. The findings of the study also confirmed that social workers and community-based workers operating as home care guides have been the most vital link in addressing the concerns of families and communities about PLHIV nutritional needs also in addition to transferring knowledge about nutrition.

The Alliance LO's NGO staff pays monthly visits to HIV-affected households to inform them about various health issues: for nutrition, they promote a powder mix – an assortment of locally available grains and cereals prepared keeping the nutritional needs of PLHIV in mind. Among the other service components that are provided include vitamin tablets, school uniforms, rice, loans for school fees, and in some instances, a hostel facility for school-going children.

*The study has demonstrated that the community is highly aware of the benefits of nutritious food for PLHIV in particular, but also for others in general.*

The study has demonstrated that the community is highly aware of the benefits of nutritious food for PLHIV in particular, but also for others in general. Children, as part of various support groups have strongly articulated the advantages of consuming green leafy vegetables as it gives them energy to play and study. One important observation made by both children and adults was a observed decrease in opportunistic infections (OIs) in all those living with HIV because of their routine habit of consuming leafy vegetables and Ragi (finger millet) malt regularly.

The study has shown that after the introduction of care and support interventions in the community, the intake of protein foods and leafy vegetables has increased considerably amongst the beneficiary populations. However, they feel that due to their HIV status, their ability to earn sufficient income has gone down considerably and they are not able to meet their daily nutritional requirements. The communities interviewed felt that if they were trained and engaged in meaningful income generation activities, then they would be able to enhance their income and consequently be able to meet their nutrition needs. Community members have said that iNGOs should strongly advocate with local school authorities to provide at least one midday meal to all PLHIV families and their children, even during holidays to maintain good health.

One suggestion emerging from the study suggests that guidelines for a minimum package of food for PLHIV should be based on an assessment of the requirements. For example, it has been shown that severely ill PLHIV should be taken care of at an organisational level rather than leaving support groups to take responsibility for this. Support groups mobilise the food grains from members of the communities – but, ironically, the communities that these groups rely upon are themselves poor and vulnerable leading to difficulties in securing adequate levels of local food support on many occasions.

In conclusion, the study suggests that home and community-based care and support programmes can and should be scaled up to increase the awareness of low cost locally available nutritious food, to promote the importance of including leafy vegetables in daily diets, and making extensive usage of millet to increase the nutritional quality of food for PLHIV.



# **Home and Community-based Care and Support Programme:**

## **Towards a Critical Review of Nutritional Support Interventions**

The India HIV/AIDS Alliance started its home and community-based care and support programme with three Lead Partners (LPs) in the Indian states of Tamil Nadu, Andhra Pradesh and Delhi in the year 2000. These LPs, in turn, have worked with a network of iNGOs. The overarching goal of the home and community-based care and support programme has been to work towards reducing stigma and discrimination through community mobilisation strategies, improve the quality of life of people living with HIV (PLHIV) and families and children affected by AIDS. Among others, nutrition support services have been an important component of home and community-based care and support programme. The component on nutrition was based on an informed understanding from Participatory Community Assessments (PCAs) that were carried out in operational areas in 2001 and subsequently incorporated a wider spectrum of stakeholders' inputs. The LPs and iNGOs have been bi-annually conducting Participatory Community Reviews (PCRs) which have served to reinforce the importance of food and nutritional component and the enormous burden it places particularly on low-income families.

The Alliance's partners have evolved context-specific strategies to meet the challenges of nutritional care in resource-scarce settings (both in terms of income and knowledge avenues) in both urban and rural areas. These partners have been consistently working with a range of actors like support groups, SHGs, community volunteers, citizen leaders and anganwadi workers to enhance the knowledge levels of PLHIV and their families on the importance of nutrition without losing sight of the importance of wider community support to such initiatives. Alliance partners' interventions seek to address awareness and educational aspects of nutrition for PLHIV. However it also builds on an understanding of the extent of poverty that necessitates direct nutritious food support to PLHIV and affected families especially those facing imminent dangers of high food insecurity or orphaned infants and children. To mitigate the lurking dangers of food insecurity, provision of rice, pulses, cooking oil, cereals, sugar, and jaggery (unrefined sugar) in required quantity is made. In the case of orphaned infants, milk, protein biscuits and ragi powder, for instance, are other provisions arranged on a case-to-case basis. Some of the food grains are locally mobilised from women SHGs, for example, a handful of rice everyday under a community initiative titled Sarvodaya. There are innovative examples where partners have also built vibrant linkages with Integrated Child Development Scheme (ICDS) and midday meals scheme to bring the benefits to eligible infected or affected children.

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**The Alliance's nutritional support has placed due emphasis on education through demonstration and publications.**

The Alliance's nutritional support has placed due emphasis on education through demonstration and publications. Demonstrations have sought to enable people to prepare low-cost locally available nutritional recipes, for example, ragi cakes in coastal Andhra Pradesh. Some vernacular publications, for example, a resource material on nutrition in Telugu are examples of dissemination efforts. As has been highlighted earlier, a deeper understanding of context is crucial to nutritional and food security. There are some innovative examples of promoting kitchen gardens by PLHIV to address nutritional and food security by captive consumption and possibilities for meaningful income generation too.

The study was designed to identify a comprehensive inventory of nutrition-related activities that are currently being undertaken through the home and community-based care and support programme on the basis of coverage scope for expansion and public health importance. This study was also conducted to build a thorough understanding of the home and community-based care and support programme model in relation to nutrition, and to document lessons learned that could be applied to other initiatives.

### **Study Objectives**

- Understand the effectiveness and efficiency of nutritional support under the home and community-based care and support programme in terms of criteria, outreach, awareness, knowledge and counselling components, depth, understand and highlight efforts towards linkages with state/district level departments and/or local self-governing institutions.
- Assess client satisfaction levels in terms of minimum defined standards of service, coverage and regional variations.
- Documenting innovative practices and initiatives in furtherance of not only the nutritional support to PLHIV and their families.
- In terms of adequacy, quality and timeliness of nutritional support, given the nature of resource-scarce settings and gender differentials at the community level.

# Methodology of the Study

Vasavya Mahila Mandali (VMM) and Palmyrah Workers Development Society (PWDS) are Lead Partners of the India HIV/AIDS Alliance in its home and community-based care and support programme. With Abbott Fund support, this programme has been implemented in seven districts of coastal Andhra Pradesh (VMM) and fourteen districts across Tamil Nadu State (PWDS).

The programme has been implemented in different phases over the past six years. For the purpose of this study, implementing NGOs (iNGOs) that have completed four years of home and community-based care and support were purposively selected, keeping in view that four years is a sufficiently long period of to take stock of the impact of programme implementation components in beneficiary communities. Based on this criteria, Table 1 shows details for the specific NGO intervention areas selected for the study:

**Table 1: Implementing NGOs selected for the study in Andhra Pradesh and Tamil Nadu States**

Sl. No	iNGO	Location	District	State
1	Green Vision	Vizag	Visakhapatnam	AP
2	VMM Care & Support	Vijayawada	Krishna	AP
3	AIRTDS	Tenali	Guntur	AP
4	Mahila Mandali	Chirala	Prakasam	AP
5	AIRD-V	Valliyoor	Tirunelveli	TN
6	NMCT	Kalapanaickenpalayam	Coimbatore	TN
7	PACHE TRUST	Ponmeni Jayanagar	Madurai	TN
8	SSH	Sempatti	Dindigul	TN

Taking into account the objectives of the study, focus group discussion checklists and guidelines were developed at VMM in collaboration with participating NGOs. A total of five focus group discussion checklists and one interview schedule were developed for the purpose of study. In addition to this, a structured discussion with NGO staff was also arranged. Focus group discussion checklists were developed for children support groups (children 8-18 Years), Women and men living with HIV/AIDS, men living with HIV/AIDS, community leaders and anganwadi workers and ayas. Interview schedules were prepared and administered for health care providers and government officials notably PHC Staff. Structured discussion with social workers and field staff from among the NGO staff was part of the methodology.



# Study Findings in Andhra Pradesh and Tamil Nadu

## A Stakeholder's Perspective

### Children

Discussions with the children highlighted that they have a good understanding about the importance of food. They were of the view that all types of vegetables including leafy ones and seasonal fruits are good for health and should be consumed to the extent possible and available. Foods like ragi (Finger millet<sup>1</sup>) or preparations made with ragi or with any millet are also good for health. Foods like eggs, meat, chicken, and fish are nutritious foods as well. However, children said that these are costly and hence they are often not able to afford them. In essence children felt that locally available inexpensive foods offer sufficient nutrition and works out to be cost-effective for them. Community has gained much of this knowledge from NGO social workers and by attending the nutrition classes at the field office and by also participating in demonstrations. Inspired by the information and knowledge shared by outreach workers, many of the community members have participated in the support group activities and underwent community training on nutrition. In addition to this children in some parts of AP affirmed that Aola (or Amla, the Indian gooseberry) is good as it contains more Vitamin C and is also economical. They also added that Ragi Java, Ragi Sankati (Ragi balls) can also be prepared with Ragi flour, which is nutritious food.

Children often discussed the 'popular grandmother recipes' e.g., carrot halwa (carrot pudding) which they emphasised were also nutritious. Nevertheless the children also highlighted that at the same time they also liked the recipes endorsed by local NGOs e.g., laddus made with nutritious mix and milk.

PLHIV families are also taking fruits, fish and eggs once or twice in a week. They are eating leafy vegetables and other vegetables every day. Home-prepared ragi malt has become very common item for all the family members. No special food is cooked for any body. Food cooked in the house, is eaten by all, however children are given preference. Children in many areas affirmed that due to the poor economic condition in their families, most of them are not able to afford required nutritious food.

The social workers have demonstrated several recipes of which ragi malt and curries using leafy vegetables are common. The usual process of preparing ragi malt is simple and easy to learn. Ragi malt is prepared by soaking the ragi seeds for an hour or so followed by sun drying and then grinding it to powder form. The ragi powder is then added to the boiling water and finally

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<sup>1</sup> Finger millet is especially valuable as it contains the amino acid methionine, which is lacking in the diets of hundreds of millions of the poor who live on starchy staples such as cassava, plantain, polished rice, or maize meal. Finger millet can be ground and cooked into cakes, puddings or porridge.

jaggery is added to it. For preparation of ragi laddu, jaggery milk and ragi powder are added and mixed thoroughly and is made shaped as round or spherical balls. They can be easily preserved for a week's time. Instead of milk, vanaspati (hydrogenated vegetable oil) or ghee (clarified butter) is added in the preparation, which can be preserved for a longer duration.

Regular visits and counselling by the social workers has ensured enhanced consumption of nutritious food as a result of which children are able to participate in school games and are regularly attending the school which they could not do earlier. Children of the age group 1-5 years get supplements at Anganwadi centres whereas in schools midday meals are provided to all the children in the age group of 6-13 years.

In the children group meetings there are discussions around nutrition, food and recipes. Importance of green and other vegetables and how to support themselves and others are also being discussed.

Support groups collect rice, clothes and books during door-to-door visits once in three months. During the visits the support groups are able to collect about 80 kilogrammes rice and Rs. 500 per family. With the help of social workers, the collected materials are distributed to needy households. Support groups are also helping orphans to consume nutritious food at least once a day. The groups are conducting awareness rallies through songs that convey messages of nutrition and health care.

Notably the PLHIV covered by the iNGOs in their respective areas are ordinarily made available two kilogrammes of ragi malt, 500 grammes of peanuts, one kilogramme dal, one kilogramme jaggery, 200 grammes dates which is in addition to 10-15 kilogramme rice collected from the community every month. Contents of kit varied from NGO to NGO but cereals, pulses and ragi were by and large conspicuously present in most locations.

Children highlighted that in some places, a few civil society organisations or hospitals are also making nutrition supplements available that has helped to meet gaps somewhat e.g., a hospital in Nellakottai in Tamil Nadu was not only making available some nutrition powder, vitamin tablets and tonics but are also conducting monthly health check-up for all PLHIV, including children.

Children want to go a step further with the idea of support groups for children living with HIV by widening their remit to form a larger club of all children which includes support for all poor children. Children expect NGOs to start local children clubs so that they would be able to support a wider circle of all poor children in getting access to nutritious food and also to help them to be regular to school through proper counselling. Children, in many NGO locations, also reported being steadfast about their personal hygiene. This was evident in their regular routine in terms of taking bath, cutting nails and washing their hands with soap before every meal and after defecation.

Children reported no gender preference in the household, but some mothers prefer to serve meals to father first and later giving preference to children in keeping with cultural norms.

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## **Women**

Women have been associated with the programme from the outset and have developed good rapport with the iNGOs. Respondents expressed satisfaction that the NGO staff make regular visits to families once a fortnight and educate them about nutritious food. Regular consumption of green leafy vegetables, other vegetables and fruits such as banana, Jamun<sup>2</sup> (Indian blackberry or Java Plum) are seen as keeping them healthy. Preparation of ragi malt is demonstrated at the centres as well as during home visits. Demonstrations are conducted to prepare various nutritious recipes using locally available low cost food – during which women in communities learnt that ragi malt is wholesome and can be a healthier alternative to commercial cold soft drinks during summers. The major perception is that regular consumption of ragi java has generally contributed to good health. Women affirmed that under the Integrated Child Development Scheme (ICDS), pregnant mothers, lactating mothers, and preschool children are supplied with food and also that school-going children are provided with lunch in the school. They further affirmed that VMM's partner NGOs are supplying two kilogrammes of ragi, one kilogramme of wheat flour and 250 grammes of jaggery (unrefined sugar used in large parts of India, also popularly known as Gur) and groundnuts in small quantities for preparing nourishing food.

As for personal hygiene, women have acquired knowledge about benefits of sticking to a regimen and routine that includes taking bath twice daily, keeping the house, immediate surroundings and the area around the well or hand pump clean, washing hands before every meal, cleaning vegetables before cooking, using mosquito nets, washing hands with soap after defecation, for example.

Dealing with myths and misconceptions has been an important aspect of nutrition-related interventions in the home and community-based care and support programme. For instance, there exists a popular notion amongst women that papaya is not good for pregnant women because it is seen as having properties that are 'hot' and that heat caused can lead to abortion. Through regular exchange of ideas and knowledge, these age-old notions have sought to be addressed.

Under the home and community-based care and support programme, women have formed support groups. Support group denotes a group consisting of people affected/living with HIV/AIDS who come together to provide emotional and psychosocial support to each other in order to boost their confidence and sense of belonging. As members of support groups and as individuals, women are propagating the importance of nutritious food. They reported receiving a good response from other women in their locality and said that not only PLHIV households but also other households have gained the knowledge of cooking low-cost nutritious food in their households.

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<sup>2</sup> The juicy fruit-pulp contains resin, gallic acid and tannin; it tastes usually from acid to fairly sweet. All parts of Jamun or java plum tree can be used medicinally and it has a long tradition in alternative medicine.

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programme.*

All the women were unanimous in their view that their economic status had reduced drastically due to their HIV positive status. However, after following the advice of the social worker, they started to eat more nutritious food, therefore improving their health condition and being able to actively work again to earn some money (though not on the same scale as they used to earn before being affected by HIV and AIDS) – although this is mostly spent on nutritious food and buying more eggs and fresh foods. Indirectly, this regular intervention has also helped in reducing the stigma towards these women to a certain extent, and the women reported that compared with earlier times, their community members are now more sympathetic and understanding towards those living with HIV.

Most of the women SHG members are undertaking various activities like conducting group meetings, showing empathy to PLHIV, giving moral support to them and also supplying rice for the needy. Women are also members of support groups and doing similar service with greater interest. So far, they have not come across any problems in carrying out their services to the community.

The women in most places additionally expressed that they need some vocational training and financial help so that they can earn more to spend for nutritious food rather than depending on the grant from the NGOs. PLHIV believe that self-reliance is the best way of gaining confidence and respect and that this can be achieved if they have access to sustainable means of income generating programmes (IGP) for starting their own enterprises.

## **Men**

Adult men in the study communities reported knowing the local NGOs and their interventions over the last five to six years. Their knowledge about the NGOs is based on a general understanding that these organisations conduct awareness camps and meetings to motivate people living with HIV (PLHIV), mainly on nutrition and sanitation, and that care and support is provided to affected children and family members. They reported that NGO staff and social workers also periodically pay home visits and explain about nutritious food to the household. During home visits and camps, it is frequently highlighted that the community is eager to know the advantages of nutritious food in general but more particularly for PLHIV. Keeping in mind the interest of communities and families, the NGO staff have frequently been using the nutrition demonstration as a mode of enhancing learning. This has significantly led to improving their knowledge about the importance of nutrition in the context of HIV and has also enhanced their understanding about low-cost locally available sources. The results of these demonstrations have led to some perceptible change in the health conditions of PLHIV after consuming nutritious food. This has, in turn, impacted the capacity of PLHIV to work more gainfully. In effect, both the knowledge and practice aspects of community-level interventions are visible.

It was clear that nearly 50 per cent of the respondents had been taking nutritious food while the rest were not able to do so due to financial constraints. This situation rooted in a vicious circle of poverty poses an extremely difficult

*Most of the women SHG members are undertaking various activities like conducting group meetings, showing empathy to PLHIV, giving moral support to them and also supplying rice for the needy.*

situation for the neighbourhood, the larger community and the intervening local NGOs. Many of the respondents are members of self-help groups (SHGs) and/or support groups. In regular meetings of the SHGs and support groups, the members often discuss government programmes to address HIV/AIDS. They generally tend to concentrate on issues of drug distribution particularly Anti-retroviral drugs (ARV) but in the process, nutrition sometimes remains beyond the ambit of their discussions. The groups however, largely feel that government intervention in the area of nutrition support is needed today more than ever before but also that these should be backed by a concerted long-term plan of action.

Most of the PLHIV noted that due to their ill health some of them are earning far too less with the consequent serious difficulties in supporting their families and running their households. Before being infected with HIV they used to work regularly and for longer hours. Reduced income acts as an impediment in adhering fully to the advice of community workers of NGOs with regard to nutritious food. Even in the face of mounting financial burden accompanied or aggravated by dwindling incomes, the PLHIV have to think about their children's future and, expressed worries about having to find income to be able to save a small amount for them.

*The contribution  
of local doctors  
and volunteers in  
providing proper  
guidance to all  
PLHIV has been  
commended  
by a number of  
stakeholders.*

### **Government Functionaries**

Government officials have exhibited an informed understanding about the interventions of NGOs working with the communities. While the interventions of NGOs in relation to government primarily relates to identifying PLHIV and helping them access treatment and other services from the hospitals, it is also known that they are also educating the PLHIV about the importance of nutritious food. They have also spread awareness among the community members about HIV/AIDS and helped in reducing stigma.

Government teachers have benefited from the knowledge about HIV that they have gained from NGOs. This is attributed to the equitable and fair treatment meted out to the children living with HIV in regard to access to midday meal. The contribution of local doctors and volunteers in providing proper guidance to all PLHIV has been commended by a number of stakeholders. With the supply of nutritious mix by NGOs supplemented by proper guidance on preparing nutritious meals with locally available low-cost foodstuff, there is a perceptible change in the health status of PLHIV. As a consequence, OIs are found to be less in HIV-infected people.

However, it is widely felt that governmental efforts are not adequate to mitigate the overall impact of HIV that the affected poor families have to bear. The contention is that PLHIV families should be adequately supported by government to meet the food security issue. In relation to PLHIV and their families, hunger is often the major day-to-day niggling issue.

There is a strong understanding among government officials about the need for a strong NGO intervention in the area of HIV particularly in the area of addressing the nutrition-related needs of PLHIV. One important assertion

### **Nutritional Support**

made by government functionaries related to their unequivocal support to the NGO efforts in community-level programme implementation. Government beneficiaries have largely been appreciative of the care & support efforts directed towards to the children living with HIV not just in relation to nutrition and nutritional awareness but also such important aspects as education and allied provisions.

Integrated Child Development Scheme (ICDS) anganwadi teachers and ayas (helper) attended the training camps conducted by VMM where they came to know the facts about HIV/AIDS, Tuberculosis (TB) and other related infections. The trainings have helped them to understand the issues of PLHIV and educate the community about HIV and AIDS leading to conditions where discrimination between children is addressed and that children are treated equally. They recounted some stories of initial resistance that they encountered from the community but at the same time asserted that with rising awareness about HIV and AIDS among the community, there is waning resistance from the community with the result that they are gradually allowing their children to mix and play with children living with HIV.

At the ICDS centres, the ICDS functionaries do not differentiate between children except Grade III and IV, who are eligible to get additional ration as per scheme guidelines. Children falling in Grade III and IV are recognised as severely malnourished. Children affected by AIDS who fall in Grade III or IV as per scheme guidelines also get additional ration as do all other Grade III and IV children.

The ICDS functionaries are aware that NGOs are providing food to PLHIV families. As they have been trained about the importance of nutrition, there is a reasonable level of understanding that pregnant women need more food and that too nutritious food. In addition to that they informed that pregnant women need to take iron and folic acid tablets for 100 days, as most of them are anaemic. They also refer all pregnant women for Ante-natal care.

## **Key Community Persons**

Key community persons are generally referred to as people in a community who are widely recognised as citizen leaders or opinion leaders within or outside the formal power structure having the capacities to influence perspectives and views at the local level. Key persons of the community know about NGOs activities for the past two years. Majority opined that green leafy vegetables, other vegetables, carrots and seasonal fruits are good for health and they should be included in daily diet. Some recipes prepared with ragi millets are also good for health. NGO social workers are giving demonstrations in their centres to educate the community, especially PLHIV in the preparation of ragi malt. They felt that implementation of nutrition programmes for PLHIV is a big issue and that the government should plan and implement more comprehensive services for PLHIV. While the NGOs are doing their bit with the help of whatever little resources they can generate in combating the problem, a strong response will require that government looks into the available models on nutrition and intervene through a more sizeable response. Key members of the community

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see themselves as better placed to mobilise small community-level support for PLHIV as is evidenced by the fact that they have been encouraging the community to donate rice, dal, and even small amounts of money for the cause of extremely poor PLHIV.

## Examining the Intervention Approach

### Nutrition Counselling and Food Demonstrations

Nutrition counselling with a view to raise nutritional awareness has been an important component of home and community-based care and support programme. This is also supported by food demonstrations to bring home an appropriate method of preparations of some easy-to-make nutritious recipes designed for overall improvement of community nutrition.

*Nutrition counselling with a view to raise nutritional awareness has been an important component of home and community-based care and support programme.*

The child participants in focus group discussions highlighted that they comprehended the fact that mixed diets promote good health. Some mentioned the specific contribution of foods like carrots for healthy eyesight. The role of nutritious foods like egg, meat, chicken, and fish was repeatedly mentioned but at the same time the question of affordability has been a dominant and recurrent argument. It is established that the concept of inexpensive, locally available foods nutritious is acceptable to the community in more practicable ways than one.

Food demonstrations appear to have served the intended purpose. Children could readily narrate the method of preparation of nutritious food, which they had observed during demonstrations. Many often referred to the preparation of ragi malt recipes as well ragi balls with details or steps of preparation. Awareness of children regarding the nutritional utility of local foods was well registered by children as was evident from their statements during focus group discussions.

As for women participants, who were familiar with the NGOs, nutrition counselling was found to be a very useful activity in the project. Apart from information on locally available nutritious fruits, they appreciated the demonstrations presented at the centre as well as at their homes.

The women also highlighted some of the health, hygiene and nutritional aspects including personal and environmental hygiene which they came to know during health and nutrition counselling sessions. Counselling was also instrumental in clarifying to them some aspects relating to traditional beliefs and myths, for example, on the use of papaya.

In spite of the poor attendance of men in focus group discussions, men did make some references to the counselling and demonstration sessions held as part of the project. They also referred to the camps and meetings conducted for their motivation. An important observation made by men related to the basic concept that nutritious food brought about health improvement. At the same time, they reported the difficulties in fully implementing such knowledge because of systemic financial constraints.

Community leaders referred to the nutrition counselling rendered by NGOs and cited nutritious food such as greens, seasonal fruits which were good for health. They also highlighted that demonstrations were conducted at the centres to apprise community on nutrition.

Describing the activities of NGOs, the government officers stated that there is an important role of NGOs in counselling and educating the community members regarding nutrition and health with particular emphasis on HIV/AIDS. Low cost of nutritious foods specifically locally available ones were said to be covered in counselling and demonstration sessions.

### **Improvement of Home Nutrition**

Children were happy with diet profile at the domestic level and this was echoed by most of the children interviewed. They mentioned that in addition to the foods usually consumed at home, depending on the feasibility they also include fruits and eggs once or twice in a week. The consumption of leafy and other vegetables was more regular. Home made ragi malt has been found as a recent entry in the family menu. Most primary stakeholders affirmed that demonstrations have helped them and that it has led to increased consumption of ragi malt and nutritious curries with green leafy vegetables at home.

Women affirmed that they have made it a habit to have nutritious items like ragi java as an integral part of their daily food intake. However it is the transfer of this knowledge in the general population which gives a greater sense of satisfaction. The respondents affirmed that in addition to people living with HIV (PLHIV) households the information on importance of nutrition using locally available foodstuff has also percolated to the general population in the neighbourhood. To this end, a number of households particularly in some coastal areas of Andhra Pradesh have raised kitchen gardens which help them in providing good nutrition to the family.

### **Impact on Health with Nutrition Support**

Children stated that intervention had enabled them increase consumption of nutritious food. In an oblique reference to the consequent improvement of health, children stated that they are attending the school regularly and they are also taking part in school games which they used to find difficult earlier. In their opinion the other family members are also more regular in going to the work which has resulted in better earnings.

Women were of the view that PLHIV are deriving notable benefits from the nutrition support programme. They said that consumption of nutritious food has brought about definite visible changes in their health. They are able to work more actively and earn some money though that is not equal to what they were earning prior to contracting HIV. However they added that they need additional income to support them effectively and consume more nutritious foods such as eggs and meat products so that they can remain healthy and strong.

Men referred to the awareness camps in which information about nutrition and sanitation was discussed. Apart from hygiene aspects they mentioned facts

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presented regarding leafy vegetables, other vegetables and fruits, but with emphasis on food for PLHIV. While they had not known earlier much about nutrition, they stated they came to know that all foods were in fact beneficial particularly leafy vegetables.

As for health benefits of exposure to nutrition, men said they were able to work for more hours. Cyclerickshaw pullers, for instance, stated that they could paddle nearly 50 kilometres a day as compared to 20 kilometres earlier.

Government health officials at ICDS centres and anganwadis stated that as a consequence of regular supply of nutritious food by NGOs coupled with the advice on preparation of nutritious supplements based on local foods, an encouraging change was evident in the health status of PLHIV. They indicated that OIs were observed less frequently in infected persons.

### **Provision of Supplements and Energy Rich Foods**

Child participants stated that distribution of rice and medicines apart from books and uniform was undertaken by other civil society organisations like Rotary Club through the concerned local NGOs. It was noted that two kilogrammes of ragi malt, 500 grammes of peanuts, one kilogramme of dal, 500 grammes to one kilogramme of jaggery, 200 grammes of dates etc were provided to all PLHIV every month apart from 10-15 kilogrammes of rice contributed by community members. It was noted that the types of ingredients varied a little from place to place, for example, wheat flour and groundnuts also appeared in certain places as items made available to PLHIV. However in most of the places cereals, pulses and ragi were the items that were commonly made available to the PLHIV.

Anganwadi workers and the ayas stated that their linkage with NGOs working on nutritional issues targeting PLHIV families is of an ongoing nature. These functionaries are able to reinforce NGO educational efforts because of their training in nutrition. These functionaries are particularly well placed to comprehend and strengthen the community response especially those of pregnant women. Pregnant women are periodically informed of the need to consume more nutritious food as well as consume iron and folic acid tablets for 100 days. Referral services were provided to pregnant women and were referred to ante natal clinics. The knowledge of HIV among these functionaries ensures that there is no discrimination in reaching out to children living with HIV with benefits of the scheme and this goes a long way in ensuring that the schemes are accessed in accordance with the letter and spirit.

Community or citizen leaders highlighted that a major contribution of local implementing NGOs is towards encouraging the larger community to contribute towards the food and nutritional security of the poor PLHIV. Local resource mobilisation in terms of both money and essential foodstuff has been the dominant mode of ensuring food security. However, it came out clearly that such public donations can only be an exercise in filling up some gaps in the short term but ultimately it is the government support that can address the systemic gaps with a long term view on effectiveness, outreach and sustainability.

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## **Training**

Training camps and meetings are an important means of enhancing the capacities. Such initiatives are periodically organised by implementing NGOs. Participants are generally exposed to the fundamentals of HIV and AIDS, co-infections, STI and related aspects. The knowledge of these aspects has not only helped in participants becoming effective peer educators but in also internalising that it is a serious development problem and should therefore be viewed as such. It has also helped in a growing realisation that all response to the issues around HIV and AIDS must have a human face. This learning imbibed over a long period of time has helped not only face the community resistance with conviction and gumption but has also helped reduce stigma and shame considerably over a period of time. One of the direct outcomes of training can be seen in the area of enhanced nutritional well being of PLHIV. Members of the PLHIV families though felt that the new emphasis of NGO-supported training should focus on skill building of family members that directly helps augment income.

## **Community Resource Mobilisation**

Women and children are part of the support groups. These support groups as well as the individual community members are helping in propagating the principles of nutritious food. In conducting the activities of support groups, the members make an effort to cover all the households in a locality and not just the PLHIV households.

Support groups undertake house-to-house visits, collect rice as well as books and stationary. It was reported that during each such visit on an average around 75-80 kilogrammes of rice as material contribution and Rs. 500 in cash are mobilised. The allocation and distribution of locally mobilised resources to the households is done on the basis of a perceived understanding of support group members about the priority needs of families in distress or urgent needs. In particular orphans benefit from these efforts as they are provided nutritious food at least once a day.

Apart from directly contributing to nutritional improvement of the community, the support groups also propagate nutrition concepts through organising awareness rallies and using songs as a medium for disseminating information.

One oft-repeated assertion made in some groups was that the government was concentrating more on treatment component with little or no emphasis on nutrition. This lopsided emphasis lessens the overall impact in terms of avowed quality of life as treatment access without a minimum level of nutritional support for the poor PLHIV does not meet the intended purposes a great deal.

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# Recommendations

The study findings have highlighted several issues, particularly those related to the significant impact that nutrition has had on improving the overall health of people living with HIV (PLHIV). However, the findings also indicated that the poverty situation, further compounded by HIV, affects PLHIV households in many ways which are more often harsh and vicious than those not affected by HIV and AIDS. One overwhelming challenge for communities and civil society organisations is to design and sustain interventions that can address the issue of nutrition on a sustainable basis. Building on the study findings, some of the key recommendations include:

## **Greater Awareness Building and Understanding about Nutrition and HIV**

The findings have highlighted the need for creating more awareness about the nutritional issues that afflict PLHIV. While a lot of meaningful efforts have been directed towards building an overall climate of understanding on HIV and AIDS, it must be understood that it is an unfinished agenda that needs to be maintained and continued. Unless this continuity is ensured, some of the gains made so far could be lost. Securing basic human rights for PLHIV is directly commensurate with the level of community awareness and acceptability of the issues surrounding PLHIV and HIV-affected families. Self-help groups, support groups and a host of other community-based formations can and should play a more decisive role in enhancing wider community awareness. The Alliance and its partners' experience has demonstrated time and time again that ensuring community participation in the design, implementation and monitoring of a programme has very significant impact on the results. This approach to programme design and implementation should be considered as instrumental in developing nutrition and HIV programmes.

## **Promoting Robust Income Generating Programmes (IGPs)**

People living with HIV (PLHIV) and their families have widely understood the importance of nutritious food in their daily diets and have made significant efforts to adopt new nutritional practices. However, the poverty scenario compounded by HIV and AIDS in many areas continues to adversely affect the nutritional objectives of community level interventions. Given these realities, it has become important to have nutritional interventions woven into a robust and context-specific IGP component – a lesson learned early in the Alliance's care and support programme. The need, however, is to integrate this lesson and replicate the model more widely. In designing IGP support in this way, it helps affected families to develop diversified livelihood opportunities resulting in more income – and ultimately, helping them to translate this into improved health outcomes for PLHIV through nutritional means. While communities have

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acknowledged and appreciated the initiatives taken by the Alliance's home and community-based care and support programme in regard to nutrition, the common thread in all suggestions from study recipients across the two states was that the NGOs should conduct further training programmes on nutrition education to highlight the nutritive values of different foods. They also suggest that this would give a sustained push to developing locally-specific income generation programmes in order that gaps can be addressed in achieving better nutrition for poor PLHIV. Moreover, this study has shown that PLHIV and their families not only link IGP with enhancing their nutritional status but also see it as a major contributing factor to greater self-reliance, self-respect and human dignity.

## **Advocating for Food Security**

In most cases, the study noted that PLHIV study participants found it difficult to afford nutritious food or were dependent on community donations for a regular intake of nutritious food. The Public Distribution System (PDS), for example through ration shops, has the mandate to provide a regular supply of food grains at an affordable rate to all those who qualify. However in many areas, the effectiveness and responsiveness of the PDS is open to question, even though it is a key institutional arrangement established by the government to ensure food security of the poor and vulnerable. It is paramount that this system works for its intended purposes as the effective, transparent and responsive functioning of the PDS is directly linked to improving its overall governance. Therefore, it is important to strengthen community level advocacy initiatives and to build a strong local coalition to address accessibility issues for PLHIV on a sustained basis. This approach, working at both district and state levels, can work best with a wider coalition of civil society organisations working closely together to address the issue of food security and thus advocating to ensure the effective functioning of such vital social security measures

## **Institutionalising Nutritional Learning within the Community**

A measure of success is always to see the knowledge of a particular subject or skill being translated into practice. A measure of the success of the Alliance's home and community-based care and support programme has been the large number of PLHIV families who have attended the nutrition demonstration programmes and are now routinely preparing nutritive diets with low cost locally available foodstuffs. Although the nutrition demonstration initiatives have primarily targeted PLHIV and their families, they have not excluded other community members in the vicinity and the further success of the programme has been the observation that such community members also participate in nutrition demonstrations alongside the PLHIV. Their participation not only contributes to sensitising the immediate neighbourhood about the special nutritional needs of PLHIV but it also helps build a measure of broad understanding about the overall importance of low cost nutrition especially among the poorest. Thus, it is not only PLHIV families who can benefit from such initiatives and put their learning into practice but all families in the community. It is important that the wider participation of the community at large is seen as absolutely important and therefore should be proactively pursued for greater institutionalisation of learning on nutrition in the community – and as a mechanism for reducing stigma and discrimination towards those living with HIV.

*A measure of the success of the Alliance's home and community-based care and support programme has been the large number of PLHIV families who have attended the nutrition demonstration programmes.*

## **Enhancing the Participation of Men**

The study has confirmed the observation that the participation of women and children in the Alliance's nutritional initiatives has been a strong element in the overall success. However, the participation of men needs to be given a new direction. Intensive counselling with men to drive home the importance of nutrition would lend a impetus to the overall efforts. For example, strengthening the networks of home care guides or a network of volunteers to target men (or even to involve men as volunteers) will go a long way in strengthening the home and community-based care and support programme in general.

*Linkage with key concerned government agencies and functionaries as well as with the local self-governing institutions has been a strong point of nutritional interventions.*

## **Linkage with Key Government Agencies and Local Institutions**

Linkage with key concerned government agencies and functionaries as well as with the local self-governing institutions has been a strong point of nutritional interventions. Looking at the present level of appreciation of each others' contribution to strengthening nutritional outcomes in their respective domains, the present level of linkage building has to be sustained. For all practical purposes, linkage building with government must be viewed as work in progress and must be pursued in the same breadth. This can perhaps only be done through a process of open and regular communication based on mutual trust. This approach also takes into account the fact that indeed all players – government agencies, local self-governing institutions and civil society – have their own strength and limitations that needs to be worked upon. While forging strong linkages with government and local bodies is definitely a sine qua non for effective interventions at the community level, it also poses a number of context-specific challenges. These challenges have to be overcome with a sense of purpose based on experience and critical appreciation of each other.

# Conclusion

The lack of adequate and balanced nutrition has had a devastating effect on people living with HIV, in terms of their response to HIV-related treatment and overall health outcomes. In the case of children, the impact has been even more devastating simply because children have added nutritional demands for their growth and development. Lack of adequate nutrition increases the risk of opportunistic infections (OIs) related to HIV and prolongs recovery from acute illnesses. Moreover, research on those infected with HIV has showed a direct association between weight loss and an increase in OIs. Therefore, promoting normal growth in children and preventing weight loss in adults should be of utmost priority when planning nutritional interventions for PLHIV.

With this evidence in mind, the India HIV/AIDS Alliance established its home and community-based care and support programme with three Lead Partner NGOs in three states. In addition to other services provided within the care and support package, nutritional support has been a central component of the programme. The key to this intervention and others within the home and community-based care and support programme is the NGO field staff and the home care guides/volunteers who work on a day-to-day basis to reach as many of the intended recipients as possible within a community. The underlying concept is not just to inform and educate but also to ensure that learning is translated into improved nutritional practices across the community. To involve all family members and the community in responding to the nutritional needs of PLHIV, social workers together with the formation of support groups and SHGs bring about improved awareness and understanding about the importance of nutrition and preparation of nutritious food using locally available materials. Social workers encourage community members to participate in income generation and undertake skills building activities to raise incomes thereby enhancing the financial capacities of PLHIV and their families to secure adequate food providing them with higher levels of nutrition.

The nutritional intervention has been instrumental in demystifying many popularly held beliefs at community level; for example, that meat has superior nutritive values and that leafy vegetables contain little or no nutrition. Regular demonstrations on low cost recipes have also helped to overcome this and to explain the nutritive values of most leafy vegetable in relation to meat. People in the community have now come to understand the relative advantages of different food items in terms of their health benefits. Through adopting and adapting this knowledge, PLHIV have reported marked improvements in their health status. In cases where their CD4 count has remained stable or has improved relatively over a period of time, PLHIV have attributed it primarily to improved nutritional status.

Lack of adequate nutrition increases the risk of opportunistic infections (OIs) related to HIV and prolongs recovery from acute illnesses.

*The study has provided some key recommendations that will help to consolidate the accomplishments of the Alliance's care and support programme and provide signposts for addressing the challenges that still act as barriers to effective delivery.*

The study has provided some key recommendations that will help to consolidate the accomplishments of the Alliance's care and support programme and provide signposts for addressing the challenges that still act as barriers to effective delivery. It is important to further widen and deepen awareness efforts in the community and to ensure full community engagement in programme design, delivery and monitoring. This will further help in institutionalising nutritional learning within communities. However, as has been well documented in other settings, poverty and reduced incomes are the biggest obstacles to achieving nutritional outcomes. Therefore, robust income generating programmes which are sustainable by and within communities are potentially a solution to addressing this situation. Equally important is to continue to build strong linkages with relevant government agencies and departments as well as local self-governing bodies to augment and raise the pitch for collaborative action. Community-led advocacy to ensure the responsive and accountable functioning of public institutions is a sine qua non of 'real' benefits that can percolate to the community.

The rights of PLHIV to lead a dignified life and building their capacity to secure their basic human rights is central to the Alliance's home and community-based care and support programme approach. However the capacity of PLHIV and their families must be combined with wider awareness and perspective building among various stakeholders particularly with the community, civil society organisations and government at different levels. This requires partnerships and linkages between these diverse stakeholders to ensure that institutional and cultural barriers are dismantled in order to improve the quality of life of the people living with HIV.

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