



# SECOND INNINGS...

A Report on Pioneering Responses to Grannies affected by HIV/AIDS  
in Andhra Pradesh, India



**Vasavya Mahila Mandali**

# ORGANIZATION(S) INFORMATION

## Vasavya Mahila Mandali (VMM)

VMM is a non-profit, non-governmental, secular, voluntary organisation working for the all-round development of women, young people and children. VMM is Abbott Fund's Lead Partner in Andhra Pradesh, and implements a home and community-based HIV/AIDS care and support programme through twelve implementing NGOs in Andhra Pradesh. VMM provides technical and financial support to these NGOs to improve the quality of life of children affected by HIV/AIDS, people living with HIV/AIDS and their families.

## Abbott Fund

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*There are the small steps, some with incalculable meaning,  
like two grannies reassuringly grasping each other's hands. . . .*

# ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CAA	Children Affected by HIV/AIDS
CLHA	Children Living with HIV/AIDS
HCGs	Home Care Guides
HIV	Human immunodeficiency virus
IGP	Income Generation Program
INGOs	Implementing Non-governmental organizations
ORWs	Outreach Workers
PLHA	People Living with HIV/AIDS
VMM	Vasavya Mahila Mandali
VMMI	Vasavya Mahila Mandali Implementation unit

# CONTEXT

AIDS is a human tragedy. Since the epidemic in the early 1980s, is estimated that AIDS has caused more than 30 million deaths and orphaned more than 14 million children worldwide<sup>1</sup>. The first AIDS case in India was detected in 1986. Since then, the spread of HIV/AIDS in the country has been swift, with HIV infection reported in all states and union territories. Most of India has a low rate of infection, while the epidemic is most extreme in the southern and north-eastern states. Amongst the states facing an accelerating threat from HIV, Andhra Pradesh is experiencing a crossover of HIV into the general population from high-risk groups. The impact of HIV/AIDS is beginning to reshape societies in hard hit countries like India. In states like Andhra Pradesh where it is visibly emerging and affecting the family dynamics, it is also bound to have long-term effect on the economic scenario.

The epidemic decimates the family, killing young parents and breadwinners and often pushing survivors - grieving orphans and a shrinking pool of ageing grandparents into destitution and mutual dependency. These affected families may collapse, leaving the exhausted and incapacitated elderly to head poverty-stricken households and care for the younger children. At once, the children as well as their grandparents are immersed in devising their own set of coping strategies to handle these

consequent multiple issues - changes in household and family structure, family dissolution, lost incomes and opportunities, forced migration, grief, stress, increased responsibilities and loss of the will to continue living. In addition, their trauma is compounded by the prejudice and social exclusion directed at families affected by HIV/AIDS.

Responding to these multi-level crises is not yet seen as an imminent priority. In the midst of the ever burgeoning programs that disproportionately focus on prevention and awareness activities, there are very few comprehensive programs to address these issues. In this context, it is imperative to realize that the situation of families and \*children infected and/or affected by HIV is large scale and requires concerted efforts of multiple stakeholders.

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<sup>1</sup> RHO Archives: HIV/AIDS – Overview and Lessons learned

# ABBOTT/VMM PROGRAM INTERVENTIONS

In response to this situation, since 2001, Abbott and Vasavya Mahila Mandali (VMM) have been carrying out their pioneer program of Home and Community Based Care and Support (HCBCS) for individuals, families and children infected and/or affected by HIV/AIDS, in association with twelve partner NGOs across eight districts in coastal Andhra Pradesh.

In the course of implementation, VMM noted that the majority of children accessing the program's care and support services are below the age of ten. A considerable number of children have lost both parents and an equally sizeable portion had lost one parent. There were numerous instances wherein the surviving parent was also living with HIV/AIDS (PLHA), and other cases wherein these orphaned children were themselves infected. Another significant group is comprised of children whose parents were both living with HIV/AIDS. The imminent threat of being orphaned and left uncared for was continuously threatening these children<sup>2</sup>. Since their basic rights were no longer protected, most children became highly vulnerable as a result.

The organization probed further to understand the support mechanisms that come into play when a child becomes an orphan or a semi-orphan. In looking back at the families of PLHA and CAA,

they noted that the traditional and extended families pitched in to provide the required care and support for these individuals. In most cases, the grandparents filled in the gap that was created due to the pandemic. Their reaction towards their grandchildren was compassionate and remarkably resilient. However, there was compelling evidence that many were increasingly struggling under the strain and failing to provide completely for their grandchildren's needs. VMM Implementation (VMMI) identified 45 grannies (aged 60 years and above) who were coping with both the loss of their beloved son or daughter and taking on the responsibility of nurturing and caring for their grandchildren.

In August 2004, a pilot program was initiated for the welfare of these grannies and their grandchildren. Over time, the project with the support of its implementing NGOs identified 380 grand mothers who were taking care of 570 orphaned grandchildren in Coastal Andhra Pradesh. In 2005-06, the concept of Grannies Club was introduced by VMMI and rolled out by the other INGOs in their respective field areas. Currently the program reaches out to 338 members through 26 Grannies Clubs.

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<sup>1</sup> Moving forward - A report on pioneering responses to children affected by HIV/AIDS in Andhra Pradesh, India; Vasavya Mahila Mandali/International HIV/AIDS Alliance 2004

# ABBOTT/VMM PROGRAM INTERVENTIONS

The purpose of this best practices documentation of the Grannies' Clubs is to provide insight into how a relatively simple intervention has created a major support system for grandparents affected by HIV/AIDS. By ensuring a consistent source of human contact and peer support, the Grannies' Clubs have empowered grandparents to not only cope with the loss of their children, but also to deal with the added responsibilities of caring for their grandchildren, many of them infected by HIV.

The document presents a detailed description of the program model and seeks to initiate information sharing through lessons learned in the process of implementing the HCBCS project. Information was obtained from review of the program document and by site visits, including discussions with staff and participants as well as observation of program activities. The primary audience intended for this document includes governmental agencies, international and/or non-profit organizations and civil societies involved in addressing HIV/AIDS related issues.



*Let my smiles spread the message for miles.*



# INTRODUCTION

The sound of gurgling laughter, giggles and blushes as they discuss their crushes and the superstars of their era. Someone suddenly breaks into a melodious song, there are requests for once more and then another request for a dance beat number. A minute of nudging by her peers for the dance guru of the group to give the show stoppers a run for their money. Their mirth is infectious, their chuckles and dimples contagious, and their mood up beat. Who are they? Before one could identify them, suddenly someone is heard sobbing, then howling and ranting off, followed by voices of people showing concern, giving assurance and advice and then again sharing their own grief. They pop up questions, find

answers from within themselves, discuss their \*health concerns, engage in animated talk, share their amusement about their grandchildren's reactions, behavior and responses. Together they resolve to tackle their problems, to ensure the best possible care for \*their families and also do their bit for all. In an instant they would have oscillated you between two extreme emotions of joy and gloom.

.... these are the proceedings of a typical monthly meeting of a Grannie's Club. Welcome to the second \*innings of these oldie goldies who are facing life head on. Raise a toast to their courage, their patience and their spirit of life!!!



# GRANNIES CLUBS

## Grannies Clubs

The Grannies Clubs were initiated as forums for the grandparents of the families infected and/or affected by HIV/AIDS to voice their problems and articulate their needs without inhibitions or fear, and to receive counsel, assurance and guidance.

Through the Grannies Clubs, the project aims to enhance the grannies' acceptance of HIV in their families by offering a community based support structure to assist them in coping with their personal grief and by extending basic social support services to them which will aid them in taking care of their grandchildren, educate them about HIV, train them in child rearing skills (some unique to children affected by HIV/AIDS) and ultimately involve them in program delivery to create a conducive environment within their community. The effort is to empower the grandparents to meet the children's physical and emotional needs as well as their social and intellectual development needs; to nurture them and insure a familial environment so that the risk of their growing into alienated and stigmatized adults is minimized.

In association with other projects, this program is extending holistic support while systematically catering to the following needs of the grannies and their grandchildren:

- Material needs of grannies and children (food, clothing, education support, medical support) - Physical well being
- Skill transfer for sustainable self-help (preventive precautions, taking care of living children by the grannies, by the children themselves (to protect their own selves from opportunistic diseases) - Increased knowledge and skill base
- Psychosocial effect (support systems for the grannies and the children, inputs to grannies to overcome the generation gap and empathise with the children) - Enhanced Psycho-social energy



*Their voices speak volumes for our future plans*

# GRANNIES CLUBS

The Grannies Clubs are exhibiting very encouraging results in terms of improving the enthusiasm and coping capacity of grandparents looking after children infected and/or affected with HIV/AIDS.

- Provides a vent for their trauma, allows them to share and supports their grief processes
- Acts as their bouncing ground and gives them the assurance of physical, emotional and psychological support (in the form of their peers as well as the NGO personnel)
- Restores and strengthens their confidence in terms of handling this issue frontally and to continue living a life of dignity in their respective communities
- Instils a healthy sense of responsibility for their grandchildren's as well as their own lives
- Re-kindles the spirit of life and a hope for a better future



*No hurdles for happiness*

# PROGRAMMING STRATEGIES

**Grannies clubs' fundamentals:** It is common to find most old aged people having no one to talk to or care for them even within their own families. Particularly, old women lack opportunities to make friends and share their concerns in the midst of their household responsibilities. They have restricted mobility, limited exposure and inadequate worldly knowledge.

Grandparents affected with HIV/AIDS carry the double burden of their personal trauma and acute stigma within their respective communities. They have little or no knowledge about HIV/AIDS. They have no one to seek counsel from and clarify their doubts, no one to teach them the mechanisms of proper child care and the



preventive measures to be taken to ensure that other family members do not get living. They cannot express their concerns at home lest their grandchildren get adversely affected by their melancholy. Many are filled with diverse emotions: They are angry over their own child for not sharing his/her health status till the deterioration led to death or are filled with contempt towards their son-in-law / daughter-in-law in cases wherein these individuals have passed it on to their respective spouses and children. They are scared to face the community and bear the brunt of society's isolation and stigmatisation, especially in instances where their son/daughter has passed it onto his wife/her husband and respective children. They are overcome with grief and sorrow due to the loss of a dear child / loved one (son/daughter/grandchild). They are apprehensive as to their own future and are overwhelmed by the responsibility (of tending to their own selves and also of nurturing their grandchildren) that has been entrusted to them due to the sudden twist of fate. The last straw is the fact that most of them have no outlet to share their concerns, no support systems to allay their fears and no outlet to uninhibitedly express their varied reactions. Along with their mental strength, they need to pump up their physical stamina. They are compelled to straighten their backs and slog it out at a moment when they are on the verge of giving a rest to their withered and fatigued frames.

# PROGRAMMING STRATEGIES

In response to these issues, the Grannies' Clubs have been formed to function as a common thread amongst grandparents from similar circumstances and problems. Initially most grandparents refused to participate in the Grannies' Clubs for fear that the status of their grandchildren (in the case of children living with HIV/AIDS) might expose them to the sting of discrimination. There are numerous instances wherein some were even unwilling to access related public services due to such concerns. However, patient, consistent support of by the NGO Staff, including Home care guides (HCGs) and Outreach workers (ORWs), helped the elderly to finally come around and join the Grannies' Clubs. These clubs serve as authentic sources of information on all related and useful topics for the grandparents and act as bouncing grounds ready to soak in all their grievances and give them the required advice. They provide the



"In Participatory Community Review, grannies often report quite different needs from those that children identify for them"

grannies an opportunity to share their problems and collectively brainstorm to arrive at feasible solutions, which are then shared with the NGO personnel for their inputs. Thus the Grannies' Clubs are aiding the grandparents in evolving their own coping mechanisms, learning systems and decision making processes.

**Members of Grannies' Clubs:** These clubs are primarily targeted at grandmothers from families affected by HIV/AIDS because, while playing the most important role in caring for HIV infected and/or affected children, these women have very few options to vent their frustrations and share their apprehensions. However, males are also welcome and encouraged to participate in Grannies' Clubs. All grandparents involved in these clubs range in age from 45 to over 70 years.

**Location based Grouping:** The grouping of grandparents has been organised spatially so that grannies in the near vicinity constitute a common group. This has ensured absolute participation of the grannies (with very low absenteeism recorded only in extreme cases of illness) in the monthly meetings despite their mobility constraints. It has helped them to reach out in person to other members faced with emergency situations in their neighbourhoods. Also the proximity of the venue of the monthly meetings has encouraged them to attend regularly and be actively involved in the program interventions.

**Modalities of Monthly Meetings:** Most Grannies' Clubs meet once a month; some meet

## PROGRAMMING STRATEGIES

twice a month. There exists a shared understanding amongst all the members that in addition to the scheduled monthly meeting, they can call for their gathering in case of any emergency. The agenda for a monthly meeting includes discussion about their grandchildren's academic progress, medical status, their own health conditions, demonstration of nutritional recipes and education classes on HIV/AIDS or child rearing. They also discuss neighbourhood affairs



*“Don't worry I am with you”, says Subramanyamma an adult support group member*

and family disputes. They also seek suggestion as regards rearing their grandchildren: how to handle their queries about their deceased or ailing parents and siblings; how to build their capacities to handle stigma; how to reprimand them; how to make them serious about their studies; how to make them self-reliant. In addition, the facilitators also encourage grandparents to participate in recreational activities like dancing, singing and playing games. During the monthly meetings, for at least one or two hours, the grannies enter into a different world of their own. In this short period, they not only share

their concerns, but they also put behind all the grief and gloom that has shrouded them while seeking solace in the comfort of the Grannies Club.

**Mixed Groups:** In certain cases, along with grandparents from families affected by HIV/AIDS, the NGOs have included grannies who are unaffected by the virus and/or who are economically and socially disadvantaged. This inclusive approach seeks to remove the fear of stigma amongst the affected and to make the unaffected socially conscious of the issues of those affected by HIV/AIDS. This process also helps to acquaint those grandparents who feel burdened by their responsibilities with the plight of other grandparents who may not be affected by HIV but who are embroiled in their own struggles for existence. The primary goal of these efforts is to put an end to the stigma directed at families affected by HIV/AIDS by creating an example for other community members to follow.

Although most unaffected grandparents in the clubs had heard about HIV/AIDS, they did not have adequate information about it. They were curious to find out more about the disease and to learn about measures to protect their own families, but there were no accessible sources to answer their questions. At the community level, some were also witnessing the hardships of families affected by HIV/AIDS and were motivated to assist in alleviating their pain and trauma. The Grannies' Clubs met the varying needs of all these unaffected grannies and



## PROGRAMMING STRATEGIES

provided an appropriate platform for them to get involved.

**Home visits :** Daily home visits undertaken by the HCGs and ORWs from the INGOs at the community level constitute a core element of the HCBCS program. The HCGs and ORWs are effectively carrying out their responsibility of constantly monitoring and supporting the grannies, right at their door steps. Any grandparent found to be living in a home which is low on resources, particularly food and medicines, is immediately encouraged to visit the project office to obtain the required support. This effort also takes care of those grandparents who have inhibitions about openly sharing their poverty driven needs. In cases where the personnel suspect any of the grandparents or their grandchildren to be suffering from any common ailment, they provide immediate general advice or home remedies. They may also refer them to a doctor for medicine and treatment or, in dire circumstances, accompany them to the nearest neighborhood health centre. When they identify other problems that need specific intervention, they link grannies and their grandchildren to *appropriate* referral partners. In cases where any grannies are bed ridden, they directly deliver food and medicines to them. During home visits, they also inspect the levels of hygiene being maintained in the house and provide basic insights on nutrition, child rearing, and protection measures. Where needed, they also offer social support, eg, help in easing friction between the family, their relatives and neighbours and in reducing stigma by encouraging family

reconciliation and acceptance. At times, they may even assist them with household upkeep. Because of these visits, the HCGs and ORWs develop a close rapport with the grannies, allowing them to more precisely identify the needs and problems



of the grannies and their grandchildren and deliver proper assistance accordingly.

**Networking and ensuring access to social welfare benefits:** Each project implementing partner has established a referral relationship with a variety of service providers including medical practitioners, testing facilities, hospitals, schools, community leaders and representatives,

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corporate houses and government departments. This has been helpful in establishing collaborative initiatives around material aid, access to services, capacity building and advocacy. The results of these initiatives are in turn \*empowering the grannies in caring for their grandchildren.

Since most interventionists were oblivious to the role of the grandparents in providing home care and protection to PLHA and children infected and/or affected by HIV/AIDS, initially there weren't any initiatives or support structures created to sustain these individuals in supporting their distressed relatives. Against this backdrop, one of the first steps taken by this project was to gain an insight into the tasks undertaken by grandparents in HIV/AIDS affected families and provide support accordingly. Initially, many elders were unable to access the government pensions due to the time-consuming bureaucratic processes. However, after the project identified them as the primary bread winners in their respective homes, it was evident that the monthly pension represents their assured source of income. Therefore across all the grannies clubs, the iNGOs have been encouraged to assist the grandparents with the application process to help them in accessing their pensions. Similarly 'Antyodaya', a scheme which ensures a fixed quantity of basic food grains at a minimum price for impoverished families, had not covered many eligible individuals from amongst the Grannies Club members. The iNGOs are currently negotiating with the appropriate government officials to have these individuals included in the 'Antyodaya' scheme.

**Health care facilities:** Integration of provision of general medical facilities along with care and support initiatives has also acted as a significant motivator for the elderly to get associated with this program. After joining the Grannies' Clubs, most of them have realized the importance of



*“When I have to rest it is my duty to care for the family...” says a granny*

taking care of their own selves for the sake of their grandchildren. It is in fact inspiring to see their willingness to support the children persist *in spite of their own incapacities and illnesses.* These facilities have given a significant personal touch to the program interventions simply because the grannies feel that there are people interested in their lives and in *caring for their well being.*

**HIV/AIDS health education** is usually conducted by the NGOs during the monthly meetings of the grannies clubs. The grandparents discuss the health status and the conditions of their grandchildren. They seek suggestions and discuss measures to ensure that their children take medicines regularly. They check on each other regarding strict adherence to the hygiene, health



# PROGRAMMING STRATEGIES

care and nutrition norms prescribed by the medical practitioners and the NGO personnel. In these aspects, the elements of shared experience and shared learning are quite evident.

**Education support:** Most grannies aspire to see their grandchildren educated. They realize that it is the best resource that can insure a better future for the children in their absence. The iNGOs support them in their endeavours by enrolling their children in schools and periodically following their academic progress. When resources are mobilized through other projects, the organization's personnel ensure that these children are given priority in terms of provision of educational supplies, uniforms and toys.

**Resource mobilization:** iNGOs are soliciting contributions from individuals, households, enterprises and businesses in their field areas, including the neighborhoods of \*families affected and/or infected by HIV/AIDS. Material contributions include food, \*clothing, and supplies. The members of the Grannies' Clubs are also involved in these \*support mobilization activities. Some actively participate in gathering resources from \*their respective communities; others have been linked with self help groups who collect \*food grains from amongst their members and hand them over to these grannies. One extraordinary example involves a work site where all the community residents are day wage migrant labourers, where the partner NGO has been able to collect rice every month grandparents and their grandchildren infected and/or affected by HIV/AIDS.

**Legal support:** The iNGOs are also involved in activities geared to help grandparents in securing and passing on assets and property that legally belongs to the child. Many cases include situations where the grandparents are opposed to a parent's wish to pass on the inheritance of the child's parent to the child. Most of the grandparents are unaware that the grandchildren have an equal share in their property. This situation is especially grave in cases where the children belong to their daughter. Since women's property rights are barely acknowledged in India, it requires quite a strong stand to ensure that the child is given what he/she is rightfully entitled to. NGO staff members assist the grandparents in writing their assets and property in the name of the children, and, when required, the organizations also support them in filing suits and participating in legal proceedings.

At times of need, the project offers basic subsistence needs to the grandparents and their families. Simultaneously, it is also making efforts to reduce the grannies' dependence on them by involving community in all the activities, by stimulating the government to provide social support services and by educating the elderly about their rights and the mechanisms of accessing those services that are due to them. Such long term perspectives which involve these individuals as active participants in improving their own lives are crucial in mitigating the adverse impact of their circumstances.

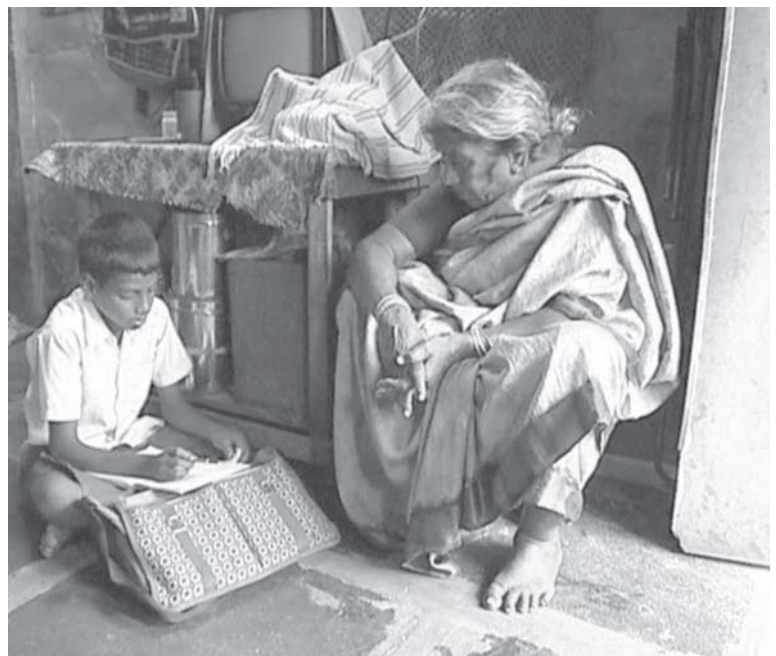
## PROGRAM OUTPUTS

**Peer Support systems – enhanced mental peace:** In this project, supporting grief processes is significant because the Grannies' Clubs provide the space and a facilitating environment for the grandparents to open up and share both positive and negative emotions in a healthy and liberating way. The monthly meetings ensure that they allow time exclusively for their own selves. They consider the Grannies' Clubs to be temporary getaways that cheer them up and empower them to courageously face their daily challenges. They have been able to settle internal conflicts, overcome fears and inhibitions and handle their trauma because of the support extended to them by their peers. This common platform has facilitated interactions with others who are undergoing similar traumatic situations. Most share that they saw their problems diminish when others narrated their woes. They are learning from each other's experiences and drawing strength from their collective wisdom.

Some of them share instances when they were short of food grains for the next meal. While they used to feel helpless and unable to handle such difficult situations, they now consider themselves to be in a better position because of their support system created through the network of Grannies' Clubs. Some of the grannies feel that their negative experiences have brought them together and through sharing their negative experiences, they are now enjoying certain opportunities and support which other women of their age and backgrounds do not have access to. Their appreciation is well evident in that most of the grannies who are daily wage labourers and street hawkers willingly give up half a day's work and their respective earnings

to religiously attend their club meetings. They gratefully acknowledge the program interventions and the contribution of the Grannies' Club to their lives.

**Improved rapport between the grannies and the children:** Due to the generation gap, grandparents often lack the understanding of what is happening with their grandchildren, their trauma, their individual difficulties and disorders, their coping strategies and the ways in which they express their grief. The Grannies' Clubs have given them a broader scope to view the children's needs and aspirations. Interactive sessions involving both children and the grandparents have given them new insights into their children's issues and greater understanding of their behaviour and responses. In fact most



*Adherence to treatment, a boon for schooling*

## PROGRAM OUTPUTS

grannies acknowledged that through their Grannies' Club experience, they have transformed their relationship with their grandchildren. They sing, dance and play with their grandchildren and have become friends with them.

### **Improved health status of the children:**

Grandparents meticulously practice the nutritional demonstrations given by the NGO personnel. They are also very precise in following the medication schedules prescribed for both the children and themselves. They exchange suggestions and continuously update their knowledge of providing proper care for both infected and affected children. During their monthly meetings, they share strategies to ensure the intake of medicines by their grandchildren, discuss each other's preparations and exchange cooking tips.

### **Increased coping strength and crisis management skills:**

The grannies share that after becoming members in the Grannies' Clubs, their coping strategies have increased manifold. They no longer buckle under pressure. Despite their inadequacies, ill-health and poverty stricken status, they are not willing to send their wards to hostels. They also refuse to place their grandchildren in institutional care despite being urged to do so by their unaffected children who may even offer to provide for them sans the children. They have also gained the capacity to support others in need. When any member is undergoing a crisis, illness or emergency, they often pool their limited resources and intervene to handle the situation. Grannies recollect many instances wherein when one of them was sick, other members took care of the grandchildren and cooked food for the children as well as for

the sick person. In extreme cases, they also take on the responsibility of informing the NGO personnel and seeking professional help as required.

**Socially responsible grannies clubs:** The grannies are highly motivated to speak about the HIV/AIDS issue and are actively involved in promoting HIV/AIDS awareness in their neighbourhoods. They are very conscious about educating their unaffected children and grandchildren about the perils of the disease and prevention strategies. Most grannies have also been trained as DOTS providers and are actively involved in administering DOTS. As such they are active educators in TB prevention and treatment as well. Whenever they spot any individual with even the slightest of symptoms, they extend referral services and urge them to get tested. The grannies share that they do not want any individual to suffer because they were too late in getting themselves tested due to ignorance or fear. The organizations believe that, over time, these small efforts by the grannies will lead to a larger positive impact in their community.

One grandfather, whose son died of AIDS several months back, still continues to attend the Grannies' Club meetings. His family was approached by the organization and invited to participate in their programs. However, out of fear that his positive status might get revealed, his son did not avail the services until the last stages when it was too late. Although the realization dawned late on his family, he has resolved to ensure that no one undergoes the misery that his son endured especially when services are available to treat and deal with the

## PROGRAM OUTPUTS

infection. So he continues to forgo his pay for a day in order to attend the monthly meetings, participate in the deliberations and promote HIV education and prevention.

As is evident from these examples, the grannies and grandfathers who participate in the Grannies' Clubs are much more than humble oldies caring for their grandchildren. They have in fact evolved into crusaders in the fight against HIV disease.

**Re-strengthened social ties and improved living environment:** The Grannies' Clubs have assumed the role of being extended families for each member of the association. After their 'Affected with HIV' status disrupted social ties with their relatives and neighbours, the Grannies' Clubs offered them the solace and support mechanisms to strengthen their position and confront their weakened external relationships with newly discovered optimism.

**Reduced stigma and discrimination:** The approaches of forming mixed groups and involving community members in the program interventions have all borne fruit. Most of the grannies express that they are now more comfortable sharing the HIV status of their grandchildren in their neighbourhoods because they no longer fear any form of discrimination. There are also many reported instances wherein the grandparent or the child had fallen sick and the community members rushed to inform the project office and help was ushered in immediately. Thus, the combined efforts of the social workers and the grandparents have created a supportive environment and sensitized the community to empathise with their needs.

**Renewed vigour and hope amongst the grannies:** The Grannies' Clubs have done much in terms of building the members' camaraderie, particularly their grandchildren's HIV status. Their anxiety, which was often driven by a sense of isolation from their community and apprehension about their grandchildren's well being and future, has been diminished considerably. This reduced anxiety has translated into better emotional and even physical health for the grandparents. Most grandparents were highly apprehensive and worried about the future of their grandchildren after their demise. The behavior of their extended family only worsened their anxieties which often adversely accelerated their ageing process. However their association with the NGO and the Grannies' Clubs has given them confidence that their grandchildren will be looked after and adequately supported after their death. This platform has greatly supported and re-energized them. Some of the Grannies' Club members are very old. Their physical stamina is on the decline and they are no longer able to work. However, many report that their mental strength has taken a surge through participation in this peer support group. One of the grannies even quipped that it has added a few more years to her life! For most, it has rekindled their desire to live longer in order to care for their grandchildren.

It is difficult to express in words the full impact of the Grannies' Clubs as it is reflected in the spring that has come back into faltering steps, in the glint that has made its way into tired eyes, in the peace that fills them behind wrinkled faces and shrunken bodies and in their eagerness to set the date of their next meeting: "Well, how soon do we meet again???!!"



## LESSONS LEARNED

- Despite the disintegration of the joint family model replaced by the current norm of nuclear families, traditional social security systems, particularly grandparents, are serving as the primary safety nets for families and children affected and/or infected by HIV/AIDS. This holds true even in cases where the grandparents have little or no income and had been counting on being supported by the very son or daughter who died of AIDS. Even grandparents who had been deserted by their children show up to help the family cope with this catastrophic situation which has affected the entire family. Ultimately, intentions, emotions and relations reign supreme over inadequate resources and capacities.
- Those who have suffered are the best advocates and campaigners for the issues of HIV/AIDS. Despite their age and accompanying physical, mobility, and energy constraints, most members of the Grannies' Clubs have assumed voluntary and significant roles in HIV/AIDS prevention activities. It is quite inspiring to see grandparents whose children and grandchildren had died of AIDS continue to participate in the club meetings and prevention activities because they consider it their moral responsibility to remain active in this movement. Their age, in fact seems to be their advantage. They speak openly about issues of HIV/AIDS on every possible occasion, sometimes even at social gatherings and community functions. Neighbors and friends near and far are willing to take their counsel and confide their problems to them. Grannies are playing an active role in extending referral services. They persevere even when their advice is falling on deaf ears because they are determined to prevent others from having to experience that which so devastated their own lives.
- Complementary to the Grannies' Clubs, it is essential to organize interactive sessions which include their respective spouses. This helps ensure that grandfathers get involved and share the child rearing responsibilities with the grannies. This also allows them to discuss each other's issues and concerns and facilitates shared understanding and distribution of tasks involved in managing the household, e.g. family finances, household chores and caring for the grandchildren.
- In the initial stages of the program, some iNGOs had extended assistance for IGP. However, since the members in those clubs were elderly, they found it difficult to handle the additional financial responsibilities which resulted in bad debts. Currently this component is currently on hold while the project staff is exploring ways of re-introducing a revised version of this component based on the socio-economic profile of the grannies.
- Due to geriatric problems, the aged grandparents find it very difficult to bridge the generation gap and meet the physical demands and emotional needs of children. Some have a weakened memory and their understanding prowess is diminished. They exhibit strong resistance and often take a long time to introduce even nominal changes suggested by the NGO personnel. Although these are not huge hurdles, the staff needs to be well oriented and prepared to deal with them with patience and understanding. The grandparents are themselves remarkably patient. They are willing to devote all the

## LESSONS LEARNED

time necessary and are able to learn if they have a good teacher. The HCGs and the ORWs will need only have to frequently repeat their lessons and periodically check progress at the home front in order to help them succeed in their second innings.

- This concept of a peer support group has been successful primarily because of the organizations' efforts to establish a close rapport and maintain a personal touch with the grandparents. Through partnerships with other institutions, internal projects and networking initiatives with various service providers, the program has been able to provide assistance to alleviate both urgent needs and basic subsistence requirements of these most vulnerable households. It is important to recognize that a peer support group for individuals where the majority is constantly dealing with the challenges of food security would not be productive. Only a comprehensive and holistic intervention as exists in this program can create a long term positive impact.



*She says "Aim high in hope"*

# CHALLENGES AND RECOMMENDATIONS

## Challenges :

- Physical disability of the grandparents could not make them attend for the meeting as they could not walk. As most of the grandparents are single they always require support to walk. Hence either out reach worker or volunteer or grandchild to hold up grandparents to reach to the meeting venue.
- The hearing impairment or the inertia among grandparents is influencing during the process of meetings, as they could not understand the matters discussed during the meeting.
- It is time-consuming for an out reach worker to facilitate the Grannies club meeting as the grandparents want to discuss all the issues and concerns. If the meeting is planned and end up as time bound the grandparents become dissatisfied with abrupt closing and do not show interest to attend for the next meeting.
- Societal attitudes of looking down the geriatric age group has affected to initiate grannies clubs in some of the villages hence the grannies clubs were initiated with middle age and grandparents in the initial stages then in due course it is meant for grandparents.
- The messages given during meetings are hard to understand if it is given like in other interventions with children or youth. The facilitator has to go to their level of communication. Utmost patience with specific communication skills are required to facilitate grannies clubs otherwise it is very difficult to form and strengthen.

- The grandparents that are members of grannies clubs face severe food insecurity due to unproductive age group and lack of support from other family members owing to urbanisation and industrialisation. Due to slum clearance in some of the urban areas like Vijayawada and Visakhapatnam, it led to forced nuclear family system.
- Sickness of grandparents is leading to inability to take care of the orphan grandchildren. Hence grandparents are traumatised in upbringing the children.

## Recommendations :

- One of the major problems faced by the grandparents in the upkeep of children infected and/or affected by HIV/AIDS is inadequate resources and capacities. It is imperative that there are home and community based care and support initiatives to identify these inadequacies and to then design and implement strategies aimed at filling the gaps while strengthening the existing resource base.
- The Grannies' Club project experience strongly suggests that in order to ensure long term positive impact, home and community based care and support interventions for families affected by HIV/AIDS should focus on enhancing the economic resiliency of each household. Primary caretakers need to be empowered and thus should be provided with the means and support necessary to counter the basic challenges of livelihood and survival.



# CONTACTS

- (AIRTDS)Action for integrated Rural and Tribal Development Social Service Society**  
Kattevaram, Tenali mandal,  
Guntur District, Andhra Pradesh  
Tel : +91 8644-225739; 233755; 325249.  
Cell :+ 919347007761  
Email : airtds@airtds.org  
Web : www.airtds.org
- College/Community Network Centre, Department of Social Work**  
DNR College Association, Bhimavaram,  
West Godavari District, Andhra Pradesh  
Tel : + 91 881 6223774  
Cell :+ 91 98 481 44181  
Email : socialworkdnr@yahoo.com  
Web: www.dnrcollege.com
- Green Vision**  
Door #. 31-31-22 Saibaba street,  
Dabagardens, Visakhapatnam-530020,  
Andhra Pradesh  
Tel : + 91 891 2561801  
Cell : + 91 98 495 99505  
Email : greenvision@sify.com
- Kolleru Rural Development Service Organisation (KRDSO),**  
24A-20-17, Ashok Nagar, Near Andhra Bank,  
Eluru, 534002, West Godavari,  
Andhra Pradesh  
Tel : + 91 8812 227198  
Cell : + 91 944 0653935  
Email : krds@yaho.com
- Mahila Mandali**  
Station Road, CHIRALA-523155  
Prakasam District - Andhra Pradesh  
Tel : +91 8594 232632  
Cell : + 91 98 49991691  
Email : mahilamandaliclx@sify.com
- Needs serving Society**  
Markandeyanagar, Veaver Colony  
Chilakapluripet 522 616  
Guntur District, Andhra Pradesh  
Tel:+ 91 8647 253581, 257496, 259105, 251138  
Cell :+ 91 98 481 65335  
Email : ch\_eswaraprasad@yahoo.com  
needsservingsociety@gmail.com
- Rakshana**  
Door #. 22-15-24  
Thomaspeta, Chirala-523155  
Prakasham District, Andhra Pradesh  
Tel : 91-08594233453  
Cell : + 91 98 481 26064  
Email : rakshana\_in@rediffmail.com
- Swamybabu & Vajramma Charitable Trust (SVCT),**  
Narasannapeta  
Srikakulam, Andhra Pradesh  
Tel : + 918942 76013  
Cell : + 91 944 1468072  
Email: swamyvct@rediffmail.com
- Serve Train Educate People's Society (STEPS)**  
Door # 3-689, Nagari Street,  
Srikalahasti-517644,  
Chittoor District, Andhra Pradesh  
Tel : + 91 8578 222563  
Cell : + 91 9390028595  
Email : stepshcbcs@gmail.com
- Vasavya Mahila Mandali (VMM)**  
Vasavya Nagar, Benz Circle  
Vijayawada-520010, Andhra Pradesh  
Tel : +91 866 2473056  
Cell : +91 98 49081733  
Fax : +91866 2473056  
Email : vasavyamm@sifi.com  
Web: www.vasavya.com



For more copies of this report,  
please contact:

Vasavya Mahila Mandali  
Benz Circle  
Vijayawada 520 010  
Andhra Pradesh  
Tel : +91 866 2473056  
Fax : +91 866 2473056  
Email : [vasavyamm@sify.com](mailto:vasavyamm@sify.com)  
Website : [www.vasavya.com](http://www.vasavya.com)

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