



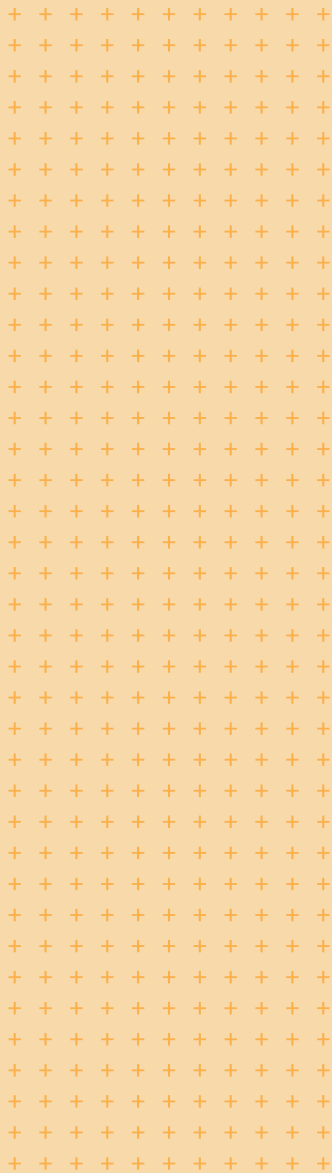
SOCIAL PROTECTION THAT WORKS FOR PLHIV

A COMPENDIUM OF CASE STUDIES FROM 8 STATES



Empowered lives.
Resilient nations.





DISCLAIMER

The views in the publication are those of the authors' and do not necessarily reflect those of the United Nations Development Programme.

DESIGN Simrat Singh

Copyright © UNDP 2011
All rights reserved
Manufactured in India



TABLE OF CONTENTS

INTRODUCTION TO THE COMPENDIUM	02
PROFILE OF RESPONDENTS	04
SUMMARY OF THE STUDY	06
METHODOLOGY	07
GLOSSARY OF TERMS	08
CASE STUDIES	09

SOCIAL PROTECTION THAT WORKS FOR PLHIV

The NACO-UNDP-NCAER study on Socio-economic impact of HIV in India (2006), indicates that people living with HIV (PLHIV) and their households face severe socio-economic consequences including exclusion, marginalization, poverty. They are acutely burdened by increased illnesses, loss of jobs and income, rising medical expenses, depletion of savings and other resources, food insecurity, psychological stress and related morbidity, discrimination, social exclusion and imminent impoverishment that is often irreversible.

+++ Children in HIV-affected households also bear the brunt if they have to discontinue schooling and need to earn in order to augment family income.

Women shoulder a disproportionate share of the impact due to socio-cultural environment. The study indicates that HIV widow households are economically worse off than other HIV households with lower incomes, poorer living conditions, fewer amenities at home with higher borrowings or asset liquidation. Children in HIV-affected households also bear the brunt if they have to discontinue schooling and need to earn in order to augment family income.

There is a clear need therefore to safeguard these individuals and households against declining standards of living, livelihood deprivation and shocks. There is increasing call for support to help mitigate the impact as well as to prevent them from adopting irreversible coping mechanisms such as liquidation of assets and removal of girl children from schools.

According to the Chronic Poverty Report 2008-9, social protection tackles the insecurity trap by protecting poor people

from shocks and reducing their extreme vulnerability; helps them conserve and accumulate assets so that they can improve their livelihoods and productivity; and contributes to transforming economic and social relations in ways that strengthen the longer term livelihood prospects of the poor and the chronically poor¹. Social protection are a set of policies and programmes that can be adopted to address the vulnerability of the poor and protect them from shocks.

In the HIV context, these policies and programmes can be

- ✦ HIV-sensitive: existing policies and schemes which are modified to include PLHIV or pro-active inclusion in the new ones
- ✦ HIV-specific: formulation of policies and schemes which address the needs of PLHIV exclusively.

¹ As quoted in ibid



++ Social protection are a set of policies and programmes that can be adopted to address the vulnerability of the poor and protect them from shocks

Vrutti Livelihoods Resource Centre and Swasti, with the support of UNDP, c tihar, Maharashtra and Nagaland; and a pilot location of Delhi. The study sought to identify strategies that facilitated access to social protection by PLHIV; examine effectiveness of these strategies; draw lessons from what has worked – both the success stories and local innovations; and understand the individual and institutional challenges., The study sought to document success stories of access to social protection.

“Social Protection that Works for PLHIV” is a compendium of twenty such case studies of PLHIV who have accessed social protection schemes. The stories give a glimpse of the lives of beneficiaries, their trials and triumphs, their worries and their hopes. They trace the process of accessing social protection by the applicants and record their experiences. They record the frustrations of the beneficiaries at the

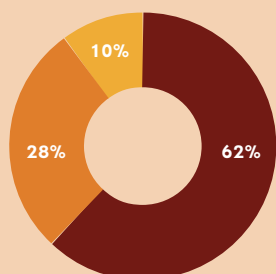
delay, the red tape, and how they have been overcome, how things eventually work out.

This section provides a brief overview of the findings that emerge from the case studies. It is not intended to generalize social protection efforts, achievements or challenges for a state, but to give an insight into various facets of social protection from a beneficiary’s perspective.

PROFILE OF RESPONDENTS

1 AGE DISTRIBUTION OF RESPONDENTS

■ UNDER 30
■ 30-40
■ ABOVE 40



All the respondents of the case study documentation are PLHIVs and most of the respondents are female (67%). Most of the respondents are from the age group of 31 to 40.

Diagram 1 captures the age wise distribution of the respondents

The occupations of the respondents is varied. Close to 28% of the respondents are self-employed involved in income generation activities like running shops, cattle rearing, tea shops, making bangles etc. Occupational profile also includes – drivers, daily wage earners, agricultural labourers, businessmen, NGO workers, housewives, etc. Most of the respondents have accessed nutritional support (40%), followed by pension schemes (23%). Other schemes accessed include – Housing, legal support, financial assistance etc. 60% of the respondents have accessed the social protections schemes with the help of district level networks of people living with HIV (DLNs).

STRATEGIES FOR PROVIDING SOCIAL PROTECTION TO PLHIV

Pro-poor governance is observed in all the states. However, translation of that into policies that recognise the concerns of PLHIV, and adoption of strategies to address them differ. There are exclusive schemes for PLHIV such as double-nutrition in AP and nutritional support from the women development department in Nagaland.

Examples of modification of schemes to include PLHIV eligibility criteria include the Sanjay Gandhi Niradhar Yojana and Antodaya Anna Yojana in Maharashtra. Most schemes, across all states, are being accessed by PLHIV as general population. These include widow pension, subsidized food grains through the public distribution system, housing loans under the Indira Awas Yojana, etc.

ACCESSED SCHEMES, THEIR BENEFITS AND LIMITATIONS

Schemes that cater to cash support, nutritional support, health, housing, livelihood/employment and children's education are popular among PLHIV.

Nutrition support, through public distribution system, Antyodaya Anna Yojana and nutritional support schemes like double nutrition (AP) and Nutritional Support Scheme of the Women Development Department (Nagaland) are schemes that many of the PLHIV access. These enable them to maintain good health and save expenses on food. The limitations reported by some of the beneficiaries include bad quality of grains through the PDS, and not receiving the full benefits as stipulated under the scheme. Only women are eligible for the nutrition scheme in Nagaland leading to discontent among men who

are, therefore, less inclined to be members of DLNs or participate actively in its activities.

Health insurance schemes are extremely relevant and useful to PLHIV. The government implements the Rashtriya Swastha Bima Yojana (RSBY) to provide health insurance to workers in the informal sector. As a result of successful advocacy, the exclusion of HIV was dropped from the scheme. PLHIV are therefore eligible to enrol. Though none of the respondents of the study accessed this scheme, PLHIV in Maharashtra access Star Health Insurance of PSI which provides them cashless hospitalisation. Access to health insurance gives PLHIV a sense of security and peace of mind.

Widow pension is accessed by many women. The scheme provides additional income to beneficiaries. However, many beneficiaries feel that the amount of Rs. 200 is too meagre to make any significant contribution to their well-being and suggest that the amount be increased. Applicants for the widow pension in UP have not received the benefit despite sending in their applications three years ago. Beneficiaries in Delhi complain about the delay in receiving the payment.

The one-time social support to widows, provided in UP and Maharashtra has been useful and help widows take care of many expenses after the death of their husbands.

Beneficiaries in Maharashtra also access the Sanjay Gandhi Niradhar Yojana, a state scheme, to provide financial support to BPL persons who are destitute, handicapped, or suffering from certain illnesses including AIDS. This adds to the monthly income of beneficiaries.

Schemes for enterprise support have been accessed in Karnataka through loans for enterprise development. This has provided beneficiaries with a stable source of income. It has meant an alternative source of income to those who could not pursue their former occupation after contracting HIV. One of the beneficiaries who received the loan through

an NGO also gets support for market linkages, a crucial input for sustainability of an enterprise.

Employment is another important source of livelihood and the Mahatma Gandhi National Rural Employment Guarantee Scheme (MGNREGA) is the biggest employment generation programme in the world. Among the study respondents, only one respondent from UP had accessed MGNREGA. There are notifications under this scheme that people who cannot undertake 'hard labour' should be provided work that is not tedious. However, the Panchayat was not aware of such a notification and the beneficiary was unable to get the full benefit of the entitlement as she could not undertake the hard labour expected of her.

A scheme for housing support, the Indira Awas Yojana has been accessed by some respondents in UP, Bihar and AP. Having a roof over their heads is of great value to PLHIV, especially those who have been disowned by their families and left to fend for themselves. However, for the very poor and destitute this scheme is of little use as they do not have land to build the house on, and the amount provided covers less than one third of the construction cost.

PLHIV also access entitlements for their children such as free education and mid-day meals. Many PLHIV value the free education greatly as it will pave the way for a brighter future for their children. One of the respondents has also benefited from accessing a wheelchair and disability pension for her disabled child.

Lack of knowledge is the main barrier to the access of social protection schemes by PLHIV. There is little or no communication on what is available, who is eligible and how the schemes can be accessed. PLHIV get information from friends, neighbours or organisations like DLN and NGOs. This limits universal access of the entitlements by PLHIV.

++ The one-time social support to widows, provided in UP and Maharashtra has been useful and help widows take care of many expenses after the death of their husbands.

SUMMARY OF THE STUDY

EXPERIENCES IN ACCESSING ENTITLEMENTS

PLHIV have mixed experience in accessing the social protection schemes. While on the one hand they receive support and encouragement from organisations like DLNs and NGOs and some pro-active government officials, on the other they also need to deal with corrupt practices, red tape, and perceived and enacted stigma.

Respondents have received support from different sources in accessing their entitlements. The DLNs provide information on schemes and help fill the applications. DLNs often collect applications and submit them in bulk. Some beneficiaries have been approached by department officials or NGO staff informing them of their eligibility for certain schemes and helping them apply. A few have paid a fee for support from people knowledgeable about the schemes and procedures. Support from all these quarters has been very useful and has given the PLHIV confidence to access schemes and eased the process for access.

Many respondents share that the approvals were timely. A few report inordinate delays in getting benefits or need to follow-up constantly before the benefits accrue.

Respondents expressed exasperation over corrupt practices like demand for bribes to hasten the approvals or not releasing the full benefits. One respondent from UP shares her story on how perseverance can succeed in getting full benefits without payments.

For schemes that are accessed as part of the general category, PLHIV do not need

reveal their status. However, perceived or actual stigma are barriers that inhibit them from accessing the entitlements under HIV-sensitive (modified) or exclusive schemes. Respondents in Maharashtra experienced stigma while accessing loans. This can be overcome by collective strength when they approached the officials as a group and demanded accountability. Perceived (fear of) stigma discouraged a respondent from AP to access the double nutrition scheme. Counselling and support from the DLN staff helped her overcome her fears. Delivery of entitlements through DLNs is a possible solution for addressing perceived and actual stigma as is seen in the nutritional support scheme of Nagaland. However, this may be possible only in HIV-specific schemes.

Perceptions of PLHIV on social protection schemes vary with regard to relevance, access, utility and satisfaction. However, there is unanimity on the need for social protection. They also perceive a need for support in accessing schemes and addressing stigma and confidentiality issues. The study finds that there is good intent, but there is still a long way to go to address the vulnerabilities of PLHIV.

++ Respondents expressed exasperation over corrupt practices like demand for bribes to hasten the approvals or not releasing the full benefits.

METHODOLOGY

The study was conducted at the state and the district levels in AP, Bihar, Chhattisgarh, Karnataka, Maharashtra, Nagaland, UP and a pilot location of Delhi. At the state level, the team interacted with senior functionaries of State AIDS Control Societies (SACS), 3-4 state government departments involved in HIV mainstreaming activities, State Level PLHIV Networks, and SACS' Mainstreaming Units to discuss policies, mainstreaming efforts, successes and challenges related to social protection in the state. In the districts, the team visited ART centres and interviewed PL-

HIV to understand access to social protection schemes and their level of satisfaction. They identified 4-7 PLHIV per district to record detailed case studies on their experiences of accessing the schemes and benefits accrued. The team also met with district level functionaries of government departments, District Level Networks, and Drop-in Centres, etc. for their views and experiences on delivery of schemes.

The following table details the states and districts covered and the stakeholders interviewed:

++ The team also met with district level functionaries of government departments, District Level Networks, and Drop-in Centres, etc. for their views and experiences on delivery of schemes.

SOCIAL PROTECTION THAT WORKS FOR PLHIV: COVERAGE IN 7 + 1 STATES

STATE	DISTRICTS	TYPE OF STAKEHOLDERS MET	NO. OF CASE STUDIES	NO. OF ART INTERVIEWS COMPLETED
Bihar	Patna and Katihar	SACS officials, SLN, DLN, Departments – DRDA, Social Welfare, Health and Family Welfare, ICTC Counsellor	7	29
Maharashtra	Mumbai and Thane	SACS officials, TSU, DLN, ART medical office, DAPCU, PSI, AVERT, Departments – MD, NRHM, Ministry of Labour	7	39
Nagaland	Dimapur and Kohima	SACS officials, SLN, DLN, DAPCUs, NGOs, Church Leaders, ART, Departments – Women Development, Social Welfare, Rural Development, Youth Resource and Sports, Agriculture, Food and Civil Supplies, DRDA, Nagaland State Transport	8	11
UP	Allahabad and Gorakhpur	SACS officials, MRU, SIRD, NREGA, Dept of Rural Development, ICDS, SLN, DLN, NGO, ART – MO, Social Welfare Etc	4	6
Andhra Pradesh	Guntur and Anandpur	SACS officials, TSU, DLN, ART Medical Office, DAPCU, DRDA, RDO, Handicapped Cooperative, ICDS, NGOS	7	20
Karnataka	Hassan and Bellary	SACS Officials, TSU, SLN, DLN, ART Medical Officer, DAPCU, Women and Child Dept, NGOs	7	44
Delhi	Central District	SACS Officials, TSU, SLN, DLN, ART Medical Officer, DAPCU, Women and Child Dept, NGOs	4	0
Chhattisgarh	Raipur and Durg	SACS Officials, TSU, SLN, DLN, ART Medical Officer, DAPCU, Women and Child Dept, NGOs	4	41

GLOSSARY OF TERMS

GLOSSARY OF TERMS

Mahatma Gandhi National Rural Employment Guarantee Act. (MGNREGA)	The Act aims at enhancing the livelihood security of people in rural areas by guaranteeing hundred days of wage-employment in a financial year to a rural household whose adult members volunteer to do unskilled manual work
Sanjay Gandhi Niradhar Yojana	Socio-Economic Assistance Scheme providing financial assistance to the destitute. Focus of the scheme is on senior citizens and widows
Antodaya Anna Yojana	Provision of food grains through the public distribution system. The beneficiaries need to enroll through the panchayath or the PDS. The scheme has provision of food grains at a highly subsidized rate of Rs.2/ per kg. for wheat and Rs. 3/ per kg for rice
Indira Awas Yojana	The objective of the Indira Awas Yojana is primarily to help construction/up gradation of dwelling units in rural areas. Indira Awas Yojana is a Centrally Sponsored Scheme funded on cost-sharing basis between the Government of India and the State Governments in the ratio of 75:25
Rashtriya Swastha Bima Yojana	This is an insurance scheme for the people living below the poverty line against the health problems. Only BPL card holders are eligible for the scheme
Star Health Insurance Policy	Health Insurance Policy for PLHIVs in India initiated by PSI. The policy offers cashless hospitalization in over 4000 Star network hospitals
Balasahyoga programme	Balasahyoga is funded by the Children's Investment Fund Foundation and the Elton John AIDS Foundation and is implemented in 11 districts of Andhra Pradesh. The programme reaches out to families of infected children. It is based on the premise that the quality of children's lives will be improved if their parent(s) remain healthy, productive, and able to offer a stable home life.
Sahara Card	ID Cards for PLHIV taking ART for accessing for travel concessions, priority in housing schemes, pensions, etc. provided by Andhra Pradesh State AIDS Control Society
Mainstreaming AIDS	Mainstreaming AIDS is a process that enables development actors to address the causes and effects of AIDS in an effective and sustained manner, both through their usual work and within their workplace. Mainstreaming AIDS is a process that enables development actors to address the causes and effects of AIDS in an effective and sustained manner, both through their usual work and within their workplace. (UNAIDS definition)
District Level Networks (DLN)	Network organization of PLHIVs at the district level

CASE STUDY

1 UNDYING COURAGE AND HOPE

11 BETTER HEALTH BETTER LIFE

2 A SECOND CHANCE

12 LOOKING FOR A SILVER LINING

3 PROSPERITY IN ADVERSITY

13 LOOKING FORWARD

4 WHEELS OF CHANGE

14 A WINNING SPIRIT

5 STAYING OPTIMISTIC

15 MAKING IT WORK

6 DRIVING CHANGE

16 RIDING ON HOPE

7 MUCH NEEDED ASSISTANCE

17 FOUNDATION FOR A FUTURE

8 BUILDING BLOCKS

18 FOOD SECURITY

9 REDUCING THE BURDEN

19 FINDING ONE'S FEET

10 SMILING THROUGH THE ODDS

20 EVERY BIT COUNTS



UNDYING COURAGE AND HOPE

+ **NAME** Chitra
 + **AGE** 37 years
 + **DISTRICT** Bellary, Karnataka

Chitra, 37 years old, hails from Bellary district, Karnataka. Up until 2007, her family of four that included her husband and two children - daughter, Meethi and son, Suresh had limited awareness of AIDS and the implications of being HIV positive. It was only when her husband was diagnosed as HIV positive in 2007 and passed away soon after that she realised how it could change their lives. Chitra got herself and her children tested immediately and found out that while she was infected, her children were not. Instead of succumbing to the disease, Chitra chose to fight the condition in order to be there for her children and provide them a secure future.

With the help and encouragement of her friends and neighbours, Chitra applied to the widow pension scheme which required her to submit a copy of her BPL card, income certificate, caste certificate and her husband's death certificate. Close to four months after application to the scheme, she began to receive a monthly pension of Rs.400. Chitra believes the application process was quite smooth and is also satisfied with the scheme as it has supplemented her income.

This was however not the end of Chitra's struggle. Just as she was beginning to cope with her ailment, her son fell ill and gradually began to lose his motor skills. He was unable to walk or even stand. When local doctors could not help, she took him to the National Institute of Mental Health and Neuro Sciences (NIMHANS) in Bangalore where he was diagnosed with progressive muscular dystrophy.

Instead of losing hope, Chitra decided to focus on improving her son's quality of life. First, she needed to ensure he had some mobility and second, she had to get

financial support for his treatment and other incidental expenses. She approached the District Level Network (DLN) for support and guidance. The DLN referred her to the Association of People with Disability (APD), Bangalore where she was able to secure a wheelchair for her son as part of their annual campaign. She is now able to take her son for evening walks in the neighbourhood.

To manage finances better, Chitra decided to secure a disability pension for her son. In order to apply for it she submitted a number of documents including a medical report from NIMHANS, a disability certificate, her BPL card, income certificate and caste certificate. The DLN then helped her reach out to the district welfare officer. After a long wait, the district administration finally cleared her son's disability pension application and Suresh has been drawing a pension of Rs. 400 since 2009.

While these schemes provided her with some respite they did not fully address Chitra's needs. It was important for her to have a stable livelihood. She aspired to start a micro-enterprise - her own 'petty shop' business. She learned from the DLN, Swamy Vivekananda Youth Movement (SVYM) and MCC support group meetings for HIV positive people that that she was eligible to apply for a loan from a nationalised bank through the Scheduled Caste and Scheduled Tribe Development Board. Her being HIV positive was seen as an impediment to repayment of the loan and the bank was reluctant to offer it to her. However, she got her loan approved through the intervention of the DLN and District Commissioner. It took Chitra seven months to receive the money and her loan was finally sanctioned in September 2010. Burdened with an old debt,

she was forced to use the loan to repay it and could not start her petty shop business.

However, Chitra did not give her aspiration to be an entrepreneur. She purchased eight roosters and chicks from the Department of Animal Husbandry, Government of Karnataka. Since then, she has been able to sell one of the roosters for a good price of and is able to use the rest for harvesting and meeting her family's nutritional needs.

Today, in addition to managing her small poultry business, Chitra is also associated with a few local NGOs as a community worker. Her daughter, Meethi is currently enrolled in a pre-university course and has received a three thousand rupee reward for passing her State Board examination. With the help of the disability pension and the wheelchair she has secured for him, her son Suresh is able to enjoy his evening excursions around the neighbourhood.

Chitra's hardwork and determination along with the benefits she has received through the support of government and non-governmental institutions have given her a sense of independence and the confidence to lead her life as normally as possible. She has been able to avail of financial support and credit, secured a wheelchair for her son and has successfully started a small poultry enterprise that is a source of income and also meets her family's nutritional requirements.

++ Instead of losing hope, Chitra decided to focus on improving her son's quality of life.



A SECOND CHANCE

+ NAME Magesh

+ AGE 38 years

+ DISTRICT Hassan, Karnataka

Magesh from Hassan district in Karnataka, is married and has two children – a son and a daughter. Since passing his tenth grade examinations, Magesh has been successfully running a condiments business, which his wife also joined once they were married.

In 2007, Magesh and his family were faced with an unexpected situation when he was diagnosed as HIV positive. Subsequently, his wife tested positive as well while his children remained unaffected. “Even though the news was shocking, my wife and I were able to accept it and we decided that we would continue to live our lives as before,” said Magesh. However, this resolve became difficult to keep up with as his health began to deteriorate. He was constantly tired and suffered from bouts of giddiness, vomiting, and fever. Bedridden for three months, and unable to pursue his business, he started antiretroviral therapy (ART), and began to recover from the illness. Soon he was strong enough to get back to work.

“As my health improved, I realised that the illness had taken a toll not only on my health, but also on my business. To restart my trade I needed financial assistance. An outreach worker that I met at the district level network support meetings introduced me to schemes like the Antyodaya Card and housing scheme, as well as income generation programmes like animal husbandry that I could benefit from. This was truly motivating and I decided to revive my business,” elaborates Magesh.

Magesh applied for a loan to the Devraj Urs Backward Classes Development Corporation. As part of his application he needed to submit copies of his land registration certificate, witness details and signatures, four photographs, income certificate and stamp paper to the processing office. Within two months his loan was approved. Magesh received Rs.15000 to continue the condiments business of which Rs. 5,000 was a subsidy and the balance amount of Rs.10000 was to be repaid in easy annual installments of Rs.3000. An outreach worker from the Swami Vivekananda Youth Movement supported him in accessing the loan.

Though approval was quick, the process was not without its challenges. Magesh spent lot of time and energy in following up with the various agencies involved. He also made some additional payments to expedite the process.

In spite of all this, Magesh is satisfied. “This loan really saved my family. I have been able to revive my condiment business and support my family through the earnings. I generate approximately Rs. 5,000-6,000 per month. Psychologically, I feel much better and the treatment keeps me physically healthy,” he concludes.

++ “Even though the news was shocking, my wife and I were able to accept it and we decided that we would continue to live our lives as before,” said Magesh.



PROSPERITY IN ADVERSITY

+ NAME Kale Gowda

+ AGE 39 year

+ DISTRICT Bellary, Karnataka

Kale Gowda is a 39 year old farmer from Bellary district in Karnataka.

It seemed like his life would never be the same again after he and his wife were diagnosed with HIV in 2004. “The days were very long and uncertainties about our future loomed large,” recalls Kale Gowda. “. However, soon enough, Kale Gowda learned of Jeevan Ashraya, and the District Level Network (DLN) of positive people. “People at the network gave me strength to believe that I was not alone; and there were others to help as well”, he said.

At the DLN support group meetings Kale Gowda learned of social protection schemes like the Indira Awas Yojana- a housing scheme; the Anna Anthodaya Yojana – a scheme for subsidised food grains and; the Prime Minister’s Athmiyata Package – a scheme for buying milch cows. Since he was interested in supplementing his agricultural income he decided to apply for the Athmiyata Package, which gives beneficiaries Rs. 30,000 to buy a milch cow. As per the scheme, the amount is to be split into three parts - Rs. 23,000 towards purchasing the cow, Rs. 1,500 towards its transportation and Rs. 5,500 to build a cattle-shed. On attaining the cow, the beneficiary also receives Rs.10,000 per quarter towards fodder expenses. If the cow delivers a calf, the beneficiary is awarded Rs.25 per day for one and half years towards fodder and incidental expenses.

In order to apply for the scheme, Kale Gowda needed to go through the veterinary

doctor in-charge of his village. Further, he was required to obtain membership to the local dairy association which could be done by assuring that he would provide milk to the local dairy center. As part of his application he then submitted an identity proof, a letter confirming his membership, and a document from banks certifying that he had no running loan against his name.

Despite providing all the relevant documents, Kale Gowda received no information on the status of his loan. Upon getting in touch with the bank manager he found out that his loan had been refused and the bank was unable to cite a legitimate reason. Kale Gowda, a few other applicants and the DLN approached the bank as a group and insisted on a written document stating that the bank would not provide them a loan. It was only after three years of constant follow up and persistence that Kale Gowda’s loan was finally sanctioned.

Kale Gowda and other co-applicants set out to visit the neighbouring district of Tiptur to identify suitable milch cow breeds and make their purchases. Once he had selected the cow, he was required to provide bank details and a photograph of the cow. The bank then sent a Demand Draft payment directly to the seller.

Today Kale Gowda earns approximately Rs.2000 every fortnight from the dairy enterprise. This additional income helps him cover travel costs to the ART center and also helps him meet other financial requirements.

“As I grow older it is becoming increasingly difficult to manage my plot of farming land. I think it is much better to invest in cattle and I am already thinking of buying one more cow in a few months,” he shares.

++ “The days were very long and uncertainties about our future loomed large,” recalls Kale Gowda.”



WHEELS OF CH ANGE

+ NAME Subbalaxmi

+ AGE 43 years

+ DISTRICT Chickmagaluru, Karnataka

Subbalaxmi, 43 years old, hails from Chickmagaluru district of Karnataka. Six months after her marriage she was betrayed by her husband and asked to leave his house. Subbalaxmi was left with little choice but to return to her father where she began to help him run his business of repairing and renting bicycles. After her father's demise she started to run the enterprise independently and it became the source of her livelihood.

In early 2010, Subbalaxmi learned that her husband had died of HIV. Her neighbour, who was a "person living with HIV" (PLHIV), suggested that she get herself tested. She tested positive for HIV and her CD4 count was also low so she was required to start antiretroviral therapy (ART) immediately. She also learned about the District Level Network that supports PLHIV and joined the network. Attending the network support group meetings boosted her confidence as she saw her peers leading their lives with courage and a positive spirit. Following the death of her husband, Subbalaxmi became eligible for the 'Widow Pension scheme' from the government. She applied for this scheme with the assistance of a 'local documenter' - a person who helps people access schemes for a fee. She paid him a fee of Rs.500 as service charges and Rs.200 for local travel to help her with the application. Within 6 months she began to receive Rs.400 each month and used this money for ART visits and other health related expenditure.

Once at the District Level Network meetings an employee of a faith based organisation – the Chickmagaluru Multipurpose Service Society (CMSS) informed members that it was providing loans to PLHIV for enterprise generation. Subbalaxmi applied by submitting her ration card and her husband's death certificate and was sanctioned an interest free loan of Rs.5000 to expand her cycle shop business. This money helped her add two more cycles to her assets and increase her earnings. After one year she is supposed to repay the principal amount on a monthly basis. "Now I can smile because I earn enough to take care of my needs through my cycle shop and the widow pension," she says.

Unfortunately, the team learnt that a few days after their visit Subbalaxmi passed away at the Victoria Ladies Hospital. Her illness had not been properly diagnosed and on account of discrimination she was treated by multiple doctors and health facilities. Subbalaxmi's story is similar to so many PLHIV. Such instances call for reflection upon whether the discrimination against positive people is a greater killer than the virus itself.

++ Attending the network support group meetings boosted her confidence as she saw her peers leading their lives with courage and a positive spirit.



STAYING OPTIMISTIC

+ NAME Kamlini

+ AGE 37 years

+ DISTRICT Thane, Maharashtra

Kamlini, aged 37, was a housewife with a teenage daughter. However, her life changed forever in 2007 when her husband tested positive for HIV and passed away soon thereafter. As a police constable he used to earn Rs.4800 per month. Suddenly, Kamlini now the head of her small household and HIV positive found herself left with no immediate earning prospects.

Kamlini had heard about NTP+ (Network for Thane Positive People) and became a member. She also got a job as a peer development officer with NTP+ and now earns Rs. 2,200 per month. Further, the District Level Network provided her the support she needed to pick up the pieces of her life and gain confidence so that she could live positively.

“Through the network I found out about schemes for those living below the poverty line (BPL). I applied for the Sanjay Gandhi Niradhar Yojana. I visited the local municipal office with a friend and a network member, filled the forms, and presented the required documents,” shares Kamlini

Kamlini disclosed her HIV status to the officials and found out that they were very cooperative and helped her apply to the scheme. She had to submit copies of her ration card, death certificate of her husband, birth certificate of her daughter, income certificate, and antiretroviral therapy (ART) card.

“Soon my application was approved and I started receiving the benefits. It was easy and smooth, it did not take too much time

or effort and there were no hidden costs either,” she says with relief. Under this scheme Kamlini now gets a benefit of Rs. 750 every month.

Kamlini also availed of the Star Health Insurance Policy under which she is entitled to cashless hospitalisation when the need arises. She had to submit a copy of her ART card and CD4 count report to a policy agent from PSI, an NGO working in HIV.

As with the Sanjay Gandhi Niradhar Yojana, she faced no difficulties in accessing this scheme. “The Star Health Insurance Policy is a good plan for PLHIV through which they can avail benefits for any kind of hospitalisation. All PHIV should get this benefit”, she concludes.

++ Kamlini disclosed her HIV status to the officials and found out that they were very cooperative and helped her apply to the scheme.



DRIVING CHANGE

- + **NAME** Prem Prakash
- + **AGE** 34 years
- + **DISTRICT** Thane, Maharashtra

Prem Prakash, 34, resides in Thane district of Maharashtra. He used to work for a private sector company and drew a monthly salary of Rs.5000. He happened to attend a health camp in Bhiwandi and watched a street play on HIV/AIDS and this got him thinking. Having engaged in high risk behaviour, he decided to get himself tested. Prem Prakash found out he was HIV positive and soon after his wife too tested positive for the virus.

Prem learned of NTP+ a network of and for positive people and the couple decided to join the network. Prem got involved in various activities of NTP+ and became a peer educator. Through the network he became aware of the schemes for people below the poverty line. To avail these benefits, he visited the local municipal corporation office where he also disclosed his HIV status to the officials. He was met with cooperation and the officials helped him access the schemes. In 2008, he applied for the Sanjay Gandhi Niradhar Yojana by submitting copies of his ration card, income certificate and antiretroviral therapy (ART) card. He now receives Rs. 600 per month under this scheme. He also acquired the Antyodaya Ration Card in the same year and can purchase grains at a subsidised rate of Rs. 2 per kilogram for rice and Rs. 3 per kilogram for wheat.

Soon after, in 2009 Prem was informed that the Samaj Kalyan (Social welfare) department was allotting free stalls in the local market for scheduled castes. Being eligible, he went to the department, found

out all the information about the scheme and submitted the necessary documents – ration card, caste certificate. He has been allotted a place for a stall in Nehru market but has not yet started an enterprise in the market so far. Further, he also accessed the Star Health Insurance Policy which makes him eligible for cashless hospitalisation should the need arise.

Prem found that most of the social entitlements were easy to access without stigma. He is of the opinion that apart from the Star Health Insurance Policy, the other entitlements do not contribute significantly to reducing financial vulnerability. However, he is happy nonetheless that these are available for PLHIV and are easily accessible.

Prem established a rapport with several key people from the relevant government departments in the process of applying for the social entitlement schemes. He then started helping other people apply for social protection schemes for a fee and realised that this part time occupation would be a good source of additional income. It also gave him the opportunity to learn more about the schemes and build relationships with many more government officials. Further, his own HIV status helped him establish credibility with the PLHIV.

As his earnings from this part time occupation increased, he resigned from his job and decided to take this up fulltime. He now earns Rs.7000 a month. He enjoys this work and provides free services to PLHIV. He also continues to provide voluntary services to the network.

++ Prem learned of NTP+ a network of and for positive people and the couple decided to join the network. Prem got involved in various activities of NTP+ and became a peer educator.



MUCH NEEDED ASSISTANCE

+ NAME Savita

+ AGE 25 years

+ DISTRICT Guntur, Andhra Pradesh

Savita is a 25 year old agriculture labourer residing in Guntur district in Andhra Pradesh. In mid-2010 she was expecting her second child when, after a routine pre-natal check-up she was informed that she had tested positive for HIV. Following this her husband, a wall painter, was tested and also found to be positive.

“For days on end I would be depressed and would quarrel with my husband. Finally I realised that I could not go on like this. It was my fate and I had to accept it. So I picked up the pieces of my life and moved on. But I still worry about my future and that of my two sons,” she laments.

Savita enrolled with the Prevention of Parent to Child Transmission (PPTCT) unit at the government hospital and received the appropriate treatment, counselling and drugs for her condition. Since all precautions were taken she hopes that her younger son, 3 months of age, does not have the virus.

Through the PPTCT unit, Savita was put in touch with a volunteer from SHIP, an NGO that operates the district level network for positive people. “The volunteer from SHIP informed me about the double-nutrition scheme that I can access through the Anganwadi and suggested I apply. Initially I was hesitant since I felt that if others knew that I was taking double nutrition, they would also know that I was HIV positive. However, the volunteer convinced me to access the scheme as I needed nutritious food to remain healthy.”

The SHIP volunteer also helped me apply for the scheme. She asked me for a few personal details and filled out a form. She then accompanied me to the Anganwadi centre where I had to show my antiretroviral (ART) therapy card. A week later I started getting the benefits – 2 kilograms of a nutrition mix and 4 eggs every week for me and my elder son. The Anganwadi worker has also been very kind to me. She knows that I am positive but does not discriminate against me. Since the Anganwadi centre is close to my house there are no other costs for accessing the benefits of the scheme. I have been accessing this scheme since 10 months and I get the full benefit of my entitlement,” she shares.

Savita is happy with the nutritional support she receives since it has contributed to her good health and has enabled her to continue working. She has heard about another nutritional scheme provided by an NGO and also of loans available for micro-enterprises but she is currently not keen on applying for any scheme that will need her to leave the village to access the service.



++ “The volunteer from SHIP informed me about the double-nutrition scheme that I can access through the Anganwadi and suggested I apply.



BUILDING BLOCKS

+ NAME Nandini

+ AGE 28 years

+ DISTRICT Guntur, Andhra Pradesh

Nandini, aged 28, is a resident of Guntur district in Andhra Pradesh. She recalls clearly that day in 2006 when, after an ante natal care (ANC) visit for a routine check-up during her second pregnancy she was referred to the Prevention of Parent to Child Transmission (PPTCT) for testing. She tested positive for HIV and subsequently, her husband Ramu, an auto driver, also tested positive.

Their troubles began soon after the couple tested positive. Ramu's family disowned them and they were forced to live separately in a small portion of the family house. Since, Nandini had some land registered in her name, a programme volunteer of the Balasahyoga programme from the antiretroviral therapy (ART) centre suggested that they apply for a housing loan from Andhra Bank under the Indira Awas Yojana Scheme. Applicants needed to have the original land registration papers in their name and a ration card. The Balasahyoga volunteer helped them through the application process and Nandini received the loan after submitting all the requisite documents, including the original land registration papers.

"The process is a bit tedious," says Nandini. "It took three to four days to apply for the loan and we had to get signatures from the Ward Commissioner, Tahsildar and the Mandal Revenue Officer and fill out several details in the application form. Since the land was in my name I had to go personally to these offices with my one month old child to get all the signatures. It would have been easier for me if they had allowed someone else to complete the

formalities on my behalf.”

It took four to five months for the loan of Rs.40000 to be sanctioned. The money was released in four instalments, with each instalment being released only after physical verification of the construction progress. So the first instalment was released only after they had built the foundation. Nandini is not very happy about this. “They should first release the instalment, verify its proper utilisation and only then release the subsequent instalment. This ensures that we don’t have to worry about funding for each stage of the construction,” she says. She also reports that she has received Rs.5000 less than the sanctioned amount and she guesses that the shortfall is due to expenses incurred by the bank for processing the loan.

Two years after receiving the loan, in 2009, Ramu passed away. He was supporting the family until his death but now the responsibility of raising her two sons fell entirely on Nandini’s shoulders and she started working as an agricultural labourer, earning Rs.60-80 per day. “It is a struggle to work and raise a family alone while dealing with HIV at the same time,” she shares. “It is usually difficult to get clean drinking water at the fields. This leads to frequent health problems. Hence, while others are able to put in 25-30 days a month, I am able to work for only 15-20 days because of my health.”

“How beneficial has the loan been to me? Well, it is difficult to build a house with Rs.40000 and we have spent three times the amount to complete the construction. So the amount is clearly not enough. Even if poor people own some land they may not be able to take benefit of this service. I do not make enough money to support the family and repay the loan so the land registration papers remain with the bank. However, I am pleased that I have a roof over my head. It gives me a sense of security and I am also

spared the recurring expenditure of paying rent. This has been a huge benefit for me.”

In addition to the housing loan scheme, Nandini has also accessed support for her children. “Before Ramu’s death my elder son, Sesidhar used to study at a private school. Now I can no longer afford to send him there and have moved him to a government school where he gets education and mid-day meals free of cost,” she says. My younger son, Eswar accesses the nutrition scheme at the Anganwadi,” she adds. “The Balasahyoga volunteer informed me of this scheme and I visited the Anganwadi centre and spoke to the social worker. Once I told her I was HIV positive, I had no problems in accessing the scheme for my son. It is a good scheme since my son gets nutritious food,” she says. Initially Eswar was receiving food under the double nutrition scheme. However, there was a modification to the scheme and double nutrition was provided only to HIV infected children. Since he is HIV negative, he was moved to the single nutrition scheme.

In addition these social entitlements, Nandini has also recently for widow pension and for the Sahara Card at the antiretroviral therapy (ART) centre. Having successfully received government support, Nandini now provides information to other PLHIV and motivates them to apply for their entitlements.

The entitlements that Nandini has received, especially the housing loan and educational support, have been beneficial to her and her family. She feels that the government should consider some way to provide entitlements to those who migrate from some other locations, especially widows, and those do not have ration cards, voter ID cards, or other such identity documents.

++ Their troubles began soon after the couple tested positive. Ramu’s family disowned them and they were forced to live separately in a small portion of the family house.

REDUCING THE BURDEN

+ NAME Jaya

+ AGE 21 years

+ DISTRICT Guntur, Andhra Pradesh

Jaya, 21, lived in the Guntur district of Andhra Pradesh with her husband, Ravi and two sons. Ravi worked in a *mirchi* (chilli) yard in Guntur.

“Ravi kept falling ill. I thought that it was due to the heavy workload at the chilli yard,” she explains. However, she was unaware that Ravi had tested positive for HIV in 1999. He kept this a secret for three years and frequently visited nearby town of Mangalgiri to take treatment at a private hospital. Finally, in 2002, Ravi took Jaya to the hospital and too tested positive.

“I was devastated. Nine years ago the stigma was so much higher than it is today. I was also worried about my children’s future. Although, I started taking treatment with my husband at the private hospital, it was extremely painful and I I was unable to tolerate the pain and swelling that came with the high dosage of medicines,” she says. Further, the treatment was very expensive and they spent Rs.30000 every three months on it. Ravi earned Rs.20000 per month during peak season and Rs.10000 per month during the lean season. Since they were living in a joint family, Jaya’s in-laws also extended financial support to them.

The couple had also heard about a traditional healer in another town – Bapatla. They approached him for treatment and he gave them a powder that resembled tea and one flower. He asked them to mix this powder in water, keep the flower in that water overnight, filter it and drink this every

++ “I was devastated. Nine years ago the stigma was so much higher than it is today. I was also worried about my children’s future. Although, I started taking treatment with my husband at the private hospital, it was extremely painful and I I was unable to tolerate the pain and swelling that came with the high dosage of medicines,”

day in the morning. The couple took this medicine for one year.

In 2004, Ravi died of AIDS. Jaya took up a job at the *mirchi* yard and used to earn Rs.80 per day depending upon the quantity of the work done. She bought a sewing machine through support group loans organised by the district network and earned additional income through tailoring. Since mid-2010, she works with the Balasahyoga programme as a Family Case Manager where she has to go across to villages and motivate and follow-up on PLHIV. Though it requires some travel, she finds this job physically less burdensome than the previous one. She also earns more money than she used to.

After Ravi's death, Jaya's was informed of the widow pension scheme and the Ward helped her access it. Her application was cleared within 3-4 months and since then a municipal officer comes to the government school in her locality and issues her the monthly pension amount of Rs. 200. If she is unable to collect the money, she is paid in the subsequent month. She uses this amount to pay a life insurance policy premium that will secure her children's education in the event of her death. "I hope my children will recognise and appreciate my efforts in ensuring that they get a good education," she says.

In 2009, at a support group meeting organised by the District Level Network, Jaya learned about the National Family Benefit Scheme for widows. All the support group members who were eligible applied for the scheme as a group at the Guntur Municipality office by submitting copies of their ration card, income certificate, voter card, husband's death certificate and ART reports. "The application process was easy for me because I am educated. For women who are not educated it may be much more

difficult," she says. It took twenty months to receive the benefits from this scheme. Eight months after submitting the application, they received a bank deposit slip. But it was only a year after providing the slip that the applicant actually received the scheme amount of Rs.5000 and Rs.600 interest. "The amount given is quite good. However, it would be much more useful if the amount was increased to Rs.10000," says Jaya

While sharing some of the limitations of the various schemes, Jaya mentions that the overall awareness of schemes is low. "Take me for instance," she says. "In spite of working for the last six months in the organisation I don't know of all the schemes that are available for PLHIV. So, how will other community members know of their existence?" she remarks. In addition to low awareness, she also expresses that delays in sanctioning schemes reduce their usefulness. "Despite the shortcomings, the schemes are relevant to our needs. The benefits we receive do not completely solve our problems but reduce some of the burden," she concludes.

++ She uses this amount to pay a life insurance policy premium that will secure her children's education in the event of her death. "I hope my children will recognise and appreciate my efforts in ensuring that they get a good education," she says.



SMILING THROUGH THE ODDS

+ NAME Yhuni Kesen
+ AGE 24 years
+ DISTRICT Nagaland

Yhuni Kesen, 24, was diagnosed with HIV in January 2009 when she was hospitalised for a kidney ailment. Her parents and relatives were informed of her status and their immediate reaction was disturbing. “My father was so angry when he learned that I was HIV positive that he wanted to have me discharged from the hospital without even completing the treatment”, she recalls. Her family members started wearing gloves while attending to her needs and kept a distance from her. Yhuni’s parents were ashamed of her for maligning the family name in the village. Her childhood friends avoided her saying, “she has a dreaded disease”. The villagers avoided her out of fear that they would catch the disease through the air. She felt she was a burden to her family and was so depressed and lonely that she had no desire to live. Yhuni’s health also deteriorated tremendously during this period.

At this time Mr. Abel, a board member of KNP+ (Kohima Network of Positive People) told her about a vacancy for an Outreach Worker for PLHIV at FPAI (Fulfilling Peoples Aspiration India) in Kohima. Yhuni had very little hope of getting the job, but nevertheless applied. When she found out that she was selected for the job, she was elated. “I was so happy I forgot all about my miseries. I even forgot I am HIV positive,” she says. Yhuni joined office in March 2009, and opened a new chapter in her life.

One of the key factors that that changed her health condition was the nutritional support she received through the District Level Network’s (DLN) Women

Development Department. When her health deteriorated and she had to start antiretroviral therapy (ART), it was crucial that she maintained a healthy diet which neither she, nor her family could afford. At that time the nutritional support came as a great boon. In order to access the scheme she had to register at the DLN by paying a ten-rupee membership fee, and had to also submit her HIV test report, ART book and CD4 count report. Once she was a member she had to attend support group meetings and participate in training programmes. Now twice a year she receives 35-40 kilograms of rice, 15 kilograms of dal, and 5-10 kilograms of ghee. In addition, every month she receives six packets of Paustic – a nutritional supplement.

Yhuni is now a happy woman and thanks the FPA India for giving her a job, the DLN for all their help and the Women Development Department for the nutritional support. “Without them,” she exclaims, “I don’t know what would have happened to me.”

With her much improved health; Yhuni is able to work effectively at FPAI. She supports her brother’s education and occasionally sends money or food items like sugar, meat, tea leaves, fruits etc. to her family. She is also able to save money that she would otherwise spend on buying essential nutritional items. Since her health has improved expenditure related to health care has reduced. She is also able to regularly pay ten per cent of her salary to her church. Now her family and community have accepted her and she is invited to share her messages at important occasions. She motivates her peers to live with a positive spirit and shows them by her example that HIV does not mean the end of life.

++ With her much improved health; Yhuni is able to work effectively at FPAI. She supports her brother’s education and occasionally sends money or food items like sugar, meat, tea leaves, fruits etc. to her family.



BETTER HEALTH BETTER LIFE

+ NAME Ava

+ AGE 28 years

+ DISTRICT Kohima, Nagaland

Ava, a 28 year old from Kohima in Nagaland was married and led a very normal life up until 2004, when at the time of her son's birth she found out that was HIV positive. Subsequently, her husband also tested positive. Learning of her HIV status changed Ava's life dramatically. She began to have several conflicts with her husband and her marriage eventually ended in a divorce.

While Ava revealed her and her son's HIV status to her immediate family, she was not willing to share it with others. Her parents provided her emotional support but were unable to extend financial help. Ava now realised that she would need to fend for herself and her HIV infected baby all by herself.

Ava came to Kohima seeking a job and was employed as a maid at a leading hotel. However her health deteriorated. On account of her and her son's frequent health setbacks she had to quit the job at the hotel. She also started antiretroviral therapy (ART). During this period, she survived on the savings she had made while working at the hotel. However, as finances began to run dry, Ava struggled to make ends meet.

At this time, Ava heard about the nutrition support schemes from the Kohima District Level Network (DLN) staff. She was asked to register with the DLN to access the schemes from the Department of Women Development. To register with the DLN she paid a ten-rupee membership fee and showed her HIV test report, ART book and CD4 count report. Once she registered with the DLN, she had to attend support group meetings and participate in training programmes on a regular basis.

Ava received nutritional support from the Department of Women Development. The nutritional support consisted of 35-40 kilograms of rice, 15 kilograms of dal and 5-10 kilograms of ghee every six months. In addition she received three packs of Paustic – a nutritional supplement every month. She also received a monthly widow pension of Rs. 200.

To access these schemes, she did not spend any money, except the DLN registration fee. The network collected the nutrition quota on her behalf Ava picked it up from the network in Kohima. With the DLN as an intermediary, she did not have to reveal her status to any government official or experience stigma.

Ava is extremely happy with both the schemes as they have contributed to some improvement in her personal life. With a nutritious diet, the ART medication has a better impact on her health as well as that of her son's. Owing to her improved health, she has been able to start a micro-enterprise of selling kitchen items.

In addition to the nutritional support and widow pension, Ava also receives educational support for her son from the Nagaland Women's Voluntary Association which covers his school fees. Earlier she had to borrow money to educate her son. But now, she is out of debt and continues to support her son's education.

Ava confesses that she is not eligible to receive the widow as it was meant for widows who are 35 years and above. However, the NNP+ and DLN made a special consideration in her case and approached the department to relax the age criteria. She is very grateful to the Women Development Department and to the DLN for the benefits she is availing today. "Because of their support I have been able to keep good health and send my son to school. However, I feel sorry for my son. It was not his fault," she regrets.

++ With a nutritious diet, the ART medication has a better impact on her health as well as that of her son's. Owing to her improved health, she has been able to start a micro-enterprise of selling kitchen items.

“Although I get only 10 kilograms of rice, one kilogram of dal, one kilogram of ghee and 24 poustic packets every month; for a poor person like me it means a lot,” says Akuno.

² Funded by UNDP under the mainstreaming initiative in the north-east.

LOOKING FOR A SILVER LINING

+ NAME Akuno
+ AGE 36 years
+ DISTRICT Nagaland

Akuno, from Nagaland is 36 and a mother of four.

“I found out that I am HIV positive in 2007, when I was treated for fever and water formation at the back of my body. My husband passed away when my youngest daughter was just couple of months old. My health is very weak, I often get sick, but what will become of my children if I don’t work?” she says..

Akuno is a dynamic and enterprising woman. However, her ill health comes in the way of her performing to her full potential. Of late she has also been losing her left eye vision.

She had acquired a loan of Rs.20,000 from the ‘Entrepreneur Associates’² and started a Chinese restaurant selling momos and chowmein. But due to poor health she moved to running a poultry enterprise by taking an additional loan of Rs.5000. Since then, Akuno has been able to repay the loan and run her household successfully. Akuno is a beneficiary of the nutritional scheme and of the destitute widow pension from the Department of Women Development. Further, she gets educational support for one of her daughters from Nagaland Development Outreach (NDO), a development wing of Nagaland Baptist Church Council (NBCC). She is also supported by the Positive Living Centre of the Catholic Relief Service (CRS) who provide her medicines and other nutritional support. Akuno says the support she is

receiving has helped her immensely given she is the sole bread winner of the family. “Although I get only 10 kilograms of rice, one kilogram of dal, one kilogram of ghee and 24 poustic packets every month; for a poor person like me it means a lot,” says Akuno.

At the time of taking the interview, Akuno was very weak and deeply concerned about the future of her children. She is grateful for all the support she has received, but also wishes that there were employment schemes for HIV affected people.

She hopes that in the event of her death, her eldest son, who is now 22 years old, will find a job and look after his sisters.

Akuno’s story reflects the fears of hundreds of PLHIV who have access to schemes and support for their present day problems but are constantly weighed down with worries for the future of their children and other dependent family members.

LOOKING FORWARD (13/20)

+ NAME Sudha

+ AGE 33 years

+ DISTRICT Guntur, Andhra Pradesh

It was in 2006 when she was 33 years old that Sudha's husband died of AIDS, and she subsequently tested positive for the virus. She resides in the Allahabad district of Uttar Pradesh and of her three children, one of her sons is positive while the daughter is negative.

When the villagers and her relatives learned that Sudha was HIV positive they disowned her. They would not sit with her; she was not invited to celebrations and religious functions. She was forced to leave her job of cooking mid-day meals at the primary school. "*Mere haath ka bana khana school me nahi khate* (they don't eat food cooked by me in the school)," she rues. She was careful to keep her son's status a secret, fearing that he too would face the same stigma, his studies would be affected and that he could even be expelled from school.

In 2008 Sudha heard about ANP+ and became a member. Through the network she was able to access antiretroviral therapy (ART) services and social protection schemes. She applied for the Bimari Upchar Sahayata Yojana in 2010 which provides free medical aid to BPL families by submitting a photocopy of her ration card, income certificate, caste certificate, account number, ART centre registration card and a stamp paper of Rs.100. "The application process was easy and smooth. My application was approved within five months and I did not have to pay any extra money to receive approval," she shares. Once her application was approved, Sudha received a sum of



Rs.5000, which she spent on medicines and her daughter's marriage.

While Sudha is satisfied with the Bimari Upchar Sahayata Yojana, she has yet to receive approval to the widow pension which she applied for three years ago.

Sudha strongly feels that because of increased awareness on HIV, and increased empowerment of PLHIV, they are able to exercise their socio-economic and political rights. She hopes that in the future she is able to avail the benefits of other social protection schemes such as the widow pension and Indira Awas Yojana.

++ When the villagers and her relatives learned that Sudha was HIV positive they disowned her. They would not sit with her; she was not invited to celebrations and religious functions.



A WINNING SPIRIT

+ NAME Amita Devi

+ AGE 30 years

+ DISTRICT Gorakhpur, Uttar Pradesh

Thirty-year old Amita Devi hails from Aigatpur Mohta, a small village in Kampergang taluk of Gorakhpur district in Uttar Pradesh. Her husband, Radheshyam who worked as a helper in Mumbai contracted HIV after engaging in high risk behaviour and before he realised it he had passed on the infection to his wife. After three months of treatment at the Benares antiretroviral therapy (ART) centre, Radheshyam passed away on 4th February 2007.

When Amita informed her father-in-law that his son was no more, she was asked not to return home. Disowned by her in-laws, Amita turned to her sister, Deepa, a teacher, for support. Deepa stood firmly by her sister and agreed to help her economically, even choosing to not get married until Amita could find a way to support herself. Amita's resolve, reinforced by Deepa's selfless support, gave her the strength to stand on her feet, fight against social discrimination and access the entitlements that were her right.

Amita joined the Drop-In Centre (DIC) as a female counsellor. The village pradhan informed her that she was entitled to the widow pension scheme on account of the untimely death of her husband. She also heard from the social welfare department that she could apply for widow pension. She accessed these schemes in 2006, with the support of the pradhan and the District Level Network (DLN). Along with the application form, she needed to submit a photo, her husband's death certificate, and a copy of her BPL card. She also had to open a bank account with the local bank. She received a one-time payment of Rs.20000 as social support and draws Rs.1800 every

six months as widow pension. In 2007, she applied for the Indra Awas Yojana (IAY) and was allocated funds through which she has been able to build a house for herself.

But accessing these schemes was not easy. It took over one year to receive benefits from the social support and widow pension schemes and over two years to be allocated the funds from the IAY. Amita had to make frequent rounds to various government departments during this time. She was compelled to pay Rs.5000 in addition to the regular costs to get the funds under the social support scheme IAY released. When she applied for IAY the DLN members asked her not to give any extra money to access her entitlements. They supported her and gave her the confidence to keep pressurising the department to approve the funds without extending any extra payment. Finally two years later, in 2009, she was allocated funds under IAY. "I now know that we can access entitlements without any additional payments if we are persistent and in future I will not pay anything more than specified when I access any scheme. I will also share my experience with other PLHIV and support them to receive the full benefits of their entitlements," she assures.

The benefits have helped Amita tremendously. She has been able to repay the debt raised for her husband's treatment and is also able to afford medicines for herself. "*Abhi mujhe dava ke liye kisike samne haat nahi failane padte hai*" (I no longer have to ask others for money to buy medicines). She now has her own house and is able to live an independent life.

While discussing the efficiency of the application process to these schemes, she feels the time taken between application and actual approval is too long. She requests the government to implement a system wherein PLHIV will get priority in accessing the benefits of the government schemes.



++ The benefits have helped Amita tremendously. She has been able to repay the debt raised for her husband's treatment and is also able to afford medicines for herself. "*Abhi mujhe dava ke liye kisike samne haat nahi failane padte hai*" (I no longer have to ask others for money to buy medicines)

++ “Although I get only 10 kilograms of rice, one kilogram of dal, one kilogram of ghee and 24 poustic packets every month; for a poor person like me it means a lot,” says Akuno.

MAKING IT WORK

+ NAME Rita
+ AGE 26 years
+ DISTRICT Katihar, Bihar

Rita, 26 years old, resides in the Katihar district of Bihar. In mid-2008 her husband fell ill and tested positive for HIV. He was subsequently asked to get his wife tested and Rita too tested positive.

Rita knew little about the virus when she found out about her HIV status. She thought that it meant she was going to die very soon. While the couple revealed their status to the family Rita was hesitant to share this information with others. During this time, she came across Manoj Pardesi of INP+ at a meeting. His overall appearance and good health inspired her and she realised that she too could live a long healthy life.

In May 2009 Rita was offered a job as a counsellor at the Drop-In Centre (DIC). At this point her husband was very ill and did not have a job. He passed away in June 2010, leaving her as the only earning member of a family of four – herself, her old mother-in-law, and two sons aged 6 and 8 years.

In 2010 during the “janaganana” (Census) Rita was told that her family qualified for a “Red card”. The officials noted her details and soon the card was delivered.

Further, she was informed by the Ward Commissioner’s office that she qualified for the widow pension. They collected all the necessary documentation – application form, photographs, ration card – and soon an account was opened for her in the post office. The first pension has not yet been credited to her account so far, but she has

received Rs.600 to buy blankets – provided by the Chief Minister for widows.

“The amount is too little,” she muses. “If we received at least Rs.500 as pension it would be much better.”

Her sons study in a government aided school. “The education there is not very good and I have engaged a private tutor at home. They get free books and meals at the school, but they don’t like the food served in school and either carry food from home, or buy food from outside,” she shares.

Rita is relieved that she has the job at the DIC. However, that too is not entirely secure. The DIC contract is annual and this March if the funding is not renewed, she will be out of work. “I worry about what might happen,” she says. “I have studied only till the eighth grade and getting another job might not be easy. I am the only earning member of the family and I have to look after my family and my health while keeping my commitments at work.” She feels that some secure livelihood options need to be made available for women who are HIV positive in order to help them continue leading a normal life.

RIDING ON HOPE

+ NAME Meera

+ AGE 42

+ DISTRICT Uttar Pradesh

Meera who hails from Uttar Pradesh runs a small tea shop in her village to support herself and her 14 year old son. “My husband died in 2006, five years after he tested positive for HIV. He was working as a tailor in Mumbai where he contracted the virus. I also tested positive thereafter,” she shares.

After her husband’s death, Meera decided to spare no effort to support her son. She was earning Rs.800 per month and needed to increase her earnings. She had heard of the widow pension and the Mahatma Gandhi National Rural Employment Guarantee Act (MNREGA) through the Gram Panchayat and applied for both schemes. She is yet to receive approval for the widow pension but was more successful with her MNREGA application and got a job card made through the panchayat.

However, when the time came to allot work to her – instead of light jobs she was offered heavy manual work like excavating soil from the channel. Her health did not permit her to take up such kind of work. She spoke to the DLN President and requested that he intervene her behalf. The President informed the panchayat of a government resolution that PLHIV should be given light work, but the panchayat did not relent, explaining that they had received no such communication, and that Meera should be treated as any other person who applied for work under the scheme. With no other option Meera completed the job given to



her with the help of her son and managed to earn Rs.1400.

“I want to provide my son a good education and I am grateful for any opportunity I get to earn some money. But 14 days of work is hardly enough to make a significant difference to me. If the government orients the gram panchayat and other officials at the district level to provide PLHIV with light work under MNREGA, it will be easier for us to access our benefits,” she says..

++ After her husband’s death, Meera decided to spare no effort to support her son. She was earning Rs.800 per month and needed to increase her earnings.



FOUNDATION FOR A FUTURE

+ NAME Biraj

+ AGE 25 years

+ DISTRICT Katihar, Bihar

Biraj, 25 years, is a driver who lives in the Katihar district of Bihar. He fell ill in early 2010 and was found to be HIV positive. His wife also tested positive and he hopes that their 13 month old baby is free of HIV when it is time for him to be tested. Biraj's parents are aware of the couple's HIV status and accepted them. He currently faces no stigma at home or in his neighbourhood.

Ritu, the DLN counsellor explains, "In many families the HIV positive status of the son is accepted since he has certain responsibilities as a son. Once the son passes away the same support may not be given to the daughter-in-law." As for the society, she says that the stigma is coming down as the number of detected cases grows – "*Yeh bimari chipti nahi hai, kitna chipayenge?*" (This illness cannot be hidden, how far can we hide it?).

Biraj has had a BPL card since 2006 after he got married. The process of obtaining the card was smooth. His father had initiated and followed through on it. It took about six months from application for him to get the card. He shares an interesting story of misuse. "In 2006 some officials from the department came to our house and told us that money had been allocated to us and that they wanted to check whether we had received it. I told them that I did not get any money. The photo on the application was also not mine. The officials made further enquiries and confirmed that there had been misuse. Now we use the card to get rations from the fair price shop. Though the quantity given to us is about a kilo lower than what we are entitled to, the quality is fine."

Initially after testing positive Biraj remained quite ill, but since he has started antiretroviral therapy (ART) his health is improving. He continues to be a driver. His employer knows that he is positive and there has been no change in his remuneration on account of his status. But he is not happy with his job. "As a driver I earn about Rs.60 per day and I have to stay in the car the whole day. *Hum to business karna chahate hai* (I want to run a business). That way I can spend more time with my family, earn more and it will not be as tedious as being a driver." Biraj has recently been allotted Rs.45000 under the Indira Awas Yojana (IAY) to build a house. Block officials came to his house and told him he was eligible for funds under the scheme to build his own house. They helped him with the application and he has no complaints against the process.

While the application has been approved, the money has not yet been transferred to his account. Biraj plans to use some part of the money allocated to start a business. On hearing this, Rajkumar, the DLN President, cautions him, "you will not get the entire amount in one instalment. It is released in three parts and each subsequent instalment is released after checking the utilisation of the previous one. Even this amount is not enough to build one house, so how will you manage to build a house and have business capital to spare?" Biraj does not reply.

Biraj is not aware of other schemes that his wife or child may be entitled to. Lack of knowledge is one of the main causes of limited access to entitlements. Biraj is satisfied with the process of accessing entitlements. He accesses subsidised rations and so far this has been useful. However the benefits from the IAY have yet to come in and it is too early to gauge how far this support will be useful and how it will impact Biraj and his family.

++ Biraj is not aware of other schemes that his wife or child may be entitled to. Lack of knowledge is one of the main causes of limited access to entitlements.

++ Now,
thanks to the AAY
card, Harihar's
family receives 35
kilograms of rice
at only a rupee
per kilogram.
Sugar and salt are
also provided at
subsidised rates.

FOOD SECURITY

+ NAME Harihar Babu
+ AGE 35 years
+ DISTRICT Durg, Chattisgarh

Harihar Babu, 35 years old, lives in Bhilai Durg district of Chattisgarh. A taxi driver, earning Rs.10,000-12,000 per month, he would frequently travel out of station. In December 2007, following a bout of weakness he underwent an HIV test and tested positive, and in January 2008 began anti-retroviral therapy (ART). His wife, Premrata too tested positive in June 2008 but his son is free of the virus. When he tested positive his wife stopped eating and talking to him, but their relationship returned to normal after a few days. Fearing stigma, he has not shared his HIV status with anyone else.

Long distance driving soon became difficult for Harihar and he began work as a private driver to a doctor, earning a monthly salary of Rs.4,000. The illness and reduced salary put the family in severe financial distress. His wife got in touch with Drop-In-Centre (DIC) staff and other PLHIV PLHIV after testing positive. Soon she got a job in a targeted intervention project through which she earns Rs.5,500. This has helped support their family.

A number of PLHIV in the Durg district are part of the District Level Network and visit the DIC regularly. Harihar and his wife also joined the network. "I got to know of different services for PLHIV after joining the DLN. Those PLHIV who are not linked to the DLN have little awareness of the services and schemes that they can benefit from", he says.

In June 2010, Harihar heard about the Antyodaya Anna Yojana (AAY) from the DIC staff. The couple submitted a proof of residence as well as a copy of their ART cards to the DIC staff. They received the AAY card in December 2010. The first time Harihar went to get ration the shop keeper refused to give it and asked for the signature of the Food and Civil Supplies Officer. He reported this to the DIC who sorted the matter. Harihar accessed the AAY scheme in January 2011. "We did not spend a single paisa in getting the AAY card," he reports. He feels that the card should be made available through the DLN as PLHIVs have little understanding of the various procedures and have no time to approach different entities to get the card made.

Now, thanks to the AAY card, Harihar's family receives 35 kilograms of rice at only a rupee per kilogram. Sugar and salt are also provided at subsidised rates. However, kerosene is not available. Harihar hopes that this will reduce the financial burden as he will end up saving Rs.500-600. He notices that the card does not have his photograph and thinks it is probably to maintain confidentiality.

While he is happy with the benefits he has received, he mentions that since the distribution dates for each commodity differ, he has to go more than once each month to the fair price shop. He also feels that in addition to the current ration they should also receive oil and pulses.

FINDING ONE'S FEET

+ NAME Priya

+ AGE 27 years

+ DISTRICT Delhi

Priya, 27 years of age lives in Delhi. In 2008 her husband fell critically ill and it was on his deathbed that she learned that he was suffering from AIDS. She was asked to get herself and her two sons tested. She and her younger son tested positive for the virus and the elder one tested negative. Her life has been a never-ending struggle ever since.

After testing positive, Priya took up a job in a factory. Though this provided her with a degree of financial security, her social security was under threat as her in-laws began harassing her. They would disclose her HIV positive status to the neighbours and keep her clothes and vessels separately from those of other family members. Finally they asked her to take her two sons and leave their house. Priya moved into her father's house, but here too her brother and sister-in-law did not want to support her. Her father was sympathetic, but could do little to help. Finally her brother agreed to let her stay provided she pays rent.

With help from her neighbours Priya took the bold and courageous step of filing a case of domestic violence against her in-laws. Following this, the in-laws plotted to take custody of her children by convincing her to sign a paper that the children were staying with their paternal family with her consent. She has been unable to get her sons back ever since.

Meanwhile, the stress and illness forced Priya to discontinue work. Soon after, she heard about the widow pension scheme from

some neighbours. She filled the form and got it signed by the Member of the Legislative Assembly (MLA) of her area, and submitted it at the pension office with identity proof, address proof, and death certificate of her husband. Then she opened an account in a nationalised bank and has been drawing a pension of Rs.1000 over the past year.

"It took eight months for my application to be approved. Though the pension is usually not released in time, I get it at the stipulated time on important national holidays like Republic Day, Independence Day, and Gandhi Jayanti. It is not a very large amount, but since I do not have a job right now, it is useful to pay rent and a few other expenses. I feel better now and I am also looking for another job," she shares.

++ Her In-laws would disclose her HIV positive status to the neighbours and keep her clothes and vessels separately from those of other family members. Finally they asked her to take her two sons and leave their house.

She asked the official if she was entitled to any additional benefits as a PLHIV and he was rude to her, said that they did not deal with such people and asked her not to talk about it.

+ **NAME** Suhasini
+ **AGE** 36 years
+ **DISTRICT** Delhi

Suhasini heard about the widow pension scheme through neighbours after the death of her husband. She picked up the application form from the pension office, was able to get it signed by the MLA of the area and then submitted it along with an identity and address proof and her husband's death certificate. Further, she opened an account with a nationalised bank. It was when she went to submit her form for the widow pension that she understood the real impact her condition would have on her life.

Suhasini now periodically receives a pension of Rs.1000. However, there is very often a delay in the release of the payment. She also applied for a BPL card by

Suhasini feels that it would be useful to have some schemes that support the education of HIV infected children. Providing the children food as well as some assistance to earn a livelihood would be really helpful as they may be denied jobs on account of their HIV status.

UNITED NATIONS DEVELOPMENT PROGRAMME

55, Lodi Estate P.O. Box 3059, New Delhi 110003, India

EMAIL: info.in@undp.org

WEBSITE: www.undp.org.in