

# Think Piece on Livelihood and HIV

---

In the year 2009, an estimated 2.6 million new HIV infections were reported globally and at the end of 2009, an estimated 33.3 million people were living with HIV. Since the beginning of the pandemic close to 30 million people have died of AIDS-related causes. AIDS thus continues to be one of the top killer diseases that creates health shocks on the one hand and increases both social and economic burden for countries.

In 2009, India had an adult HIV prevalence of 0.31%, with the number of people living with HIV (PLHIV) being close to 2.4 million. There is a steady decline in prevalence over the years from 0.41% in 2000 through 0.36% in 2006 to the current level in 2009<sup>1</sup>. Impact of programming in the country over the last three decades or so is visible, with the trend of prevalence stabilising and showing a downward trend. At the same time, issues surrounding vulnerabilities of People infected by HIV are complex in the country and often inadequately addressed. Vulnerabilities existing due to a complex mix of social, economic, political and cultural factors continue to remain a challenge to improved wellbeing of PLHIVs in the country. Of these vulnerabilities, loss of livelihood is a major cause of concern as it pushes individuals and families to poverty and destitution.

## Why focus on livelihood interventions is important for the PLHIVs?

PLHIV, once their status is known, experience increased vulnerabilities which can have a serious impact on their regular income and livelihood. The ILO estimates that at least 26 million people infected with HIV worldwide are aged 15 to 49 years, in the prime of their working lives. In India, 90% of the reported HIV infections are from the most productive age group of 15-49 years which only compounds the threat of HIV to work place in the country. Persons infected and affected with HIV are often subjected to social stigma and discrimination in the workplace and in some cases forced to leave or terminated from employment. In many cases deteriorating health conditions of self or family member/s, in the absence of appropriate support and policies in the work places leads to loss of employment for PLHIV. In such situations, the

***Livelihoods for PLHIV and those affected*** - Ensuring adequate and sustainable incomes and cash flow to the household of the PLHIV

***Vulnerability-*** “The conditions determined by health, social, economic and human factors or processes, which increase the susceptibility of PLHIV to health and livelihoods hazards”

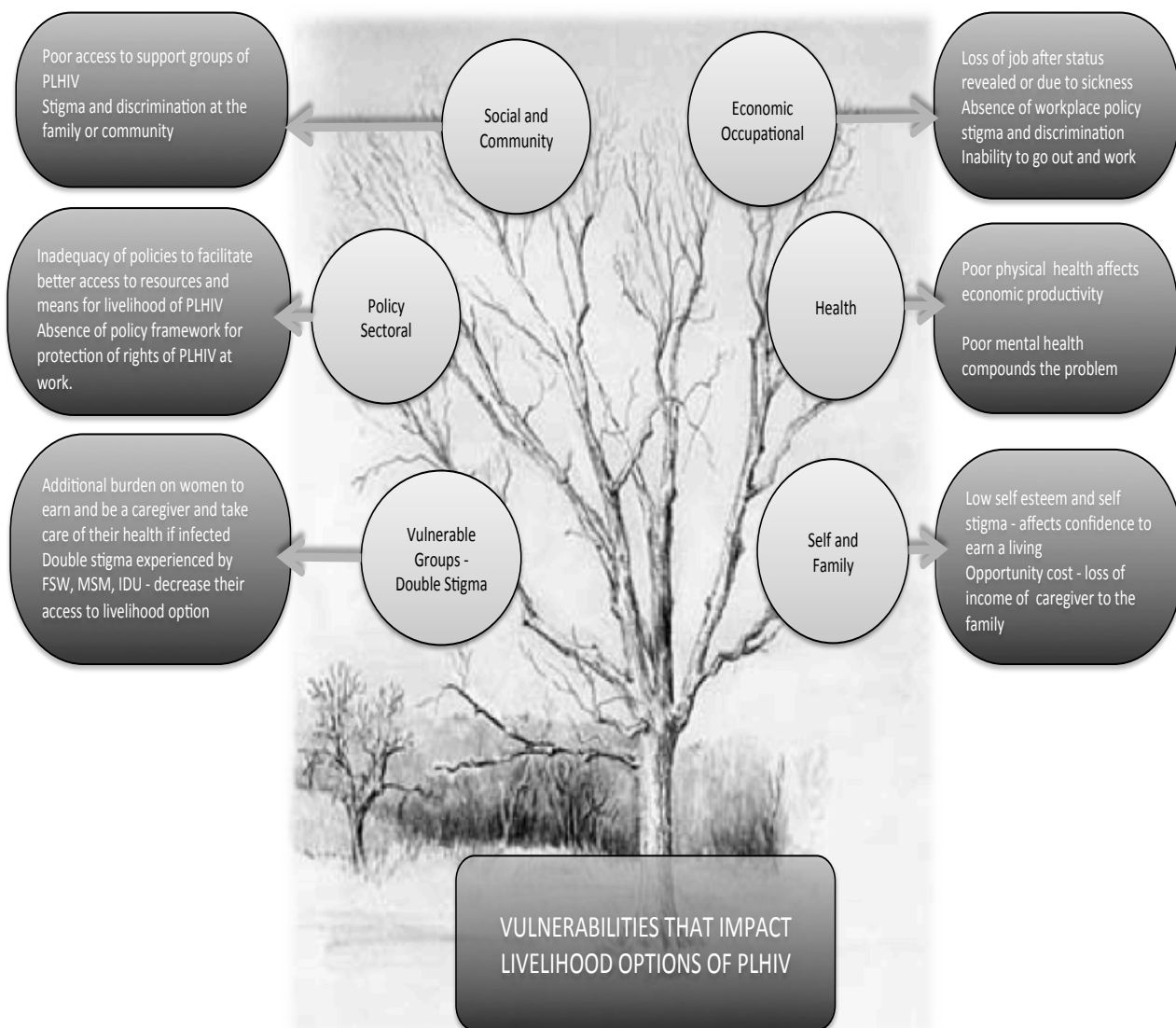
---

<sup>1</sup><http://www.nacoonline.org/upload/HomePage/NACO%20Press%20Release%20on%20HIV%20Estimates.pdf>

lost earnings are greater, as individuals are forced to withdraw from regular employment even though they have many productive years left. The loss of earnings is compounded by the increase in health care needs and expenditure. A study done by UNDP to see the effect of ART on the productive lives of people receiving treatment, conducted in seven states where ART was rolled out in 2004, found that 69% of the respondents felt that after ART their employment plans were affected positively. The study also pointed out that providing ART may not be enough; treatment can only be part of the support package that helps PLHIV to be able to utilize their working abilities and live independent, productive and fulfilling lives.

The impact of HIV on income and earnings of the household are seen both in the loss of employment of the PLHIV due to sickness or termination and loss in income due to absence from work of caregivers.

Some of the important vulnerability factors that contribute to health and livelihood hazards of PLHIV are given in the diagram below:



There are numerous vulnerability factors that negatively affect the livelihood options of a PLHIV as seen in the above diagram. Loss of income along with increased cost of treatment and nutritional needs, further adds to the burden of a PLHIV household.

The recent global recession has continuously depleted resources for HIV and AIDS programming, The total financial resources available for the AIDS response in 2009, was almost US\$10 billion short of what was needed <sup>2</sup> and global response to HIV and AIDS faces a challenge to keep the momentum going and provide quality prevention, care and support services. Besides, another emerging challenge in the current economic environment is decrease in employment opportunities, which further increases the economic vulnerabilities of the PLHIV.

Given these realities and the need for regular income for the PLHIV to meet their escalating expenses, there is a need to plan for a comprehensive and creative livelihood response for those living with HIV and AIDS. This is a critical need for the PLHIV taking into consideration the complexities of vulnerabilities that affect livelihood options as described above.

## Different typologies of Livelihood models for PLHIV tried out in India

The analysis of existing livelihood initiatives in the country show the following five major types of interventions being carried out:



### Model 1: Exclusive Business Unit Employing 2 to 20 PLHIVs

Exclusive business units were started to employ PLHIVs and facilitate improved earning. Models that have been tried in India mostly employed women living with HIV (WLHIV) and they were never the owners of these models. It was mostly floated by NGOs who took on a facilitator's role. The NGO focused on building on the skills the women already had and supported skills transfer through training, professional support in product design, quality control, marketing etc. Most of the units under this model received seed funding as initial investment from a donor agency (bilateral/multilateral/foundations). They functioned as a business unit that shared the profits among women.

### Model 2: Support Net: Credit Linked Self Help Groups

This is the Self Help Group (SHG) model adapted to PLHIV context. SHGs made up of PLHIVs were formed across the state in different districts with a federation at the centre with a managing role. Two models – one in Tamil Nadu and other in Kerala were implemented and managed through the District Level Networks (DLNs). They were mostly exclusive PLHIV groups of men and women. Beyond supporting economic activities, these models tried to provide psychosocial support and entitlement facilitation. Key components of the models included, SHG formation, facilitation of credit access, training for skill building etc.

### **Model 3: Employment Facilitation**

In this model attempts were made by PLHIV networks to facilitate access to local employment opportunities for the members of their networks. This model included skills training and job placement services. What has really worked is the personal rapport built by the facilitating agency with the employer to deal with issues of absenteeism due to illness. In this model much better sustainability is guaranteed.

The attempts at modeling this approach have been limited except for some efforts by Positive Women Network (PWN+), Indian Network of Positives (INP+) and DLN in facilitating local employment opportunities for network members. PWN+ is initiating an idea of Public Private Community Partnership with industry (Suzlon and others) and Ministry of Women and Child Welfare for facilitating employment of PLHIV.

### **Model 4: Micro Enterprise Promotion with Credit and Skill Building**

There are significant number of initiatives on enterprise promotion to support livelihoods of PLHIV and those affected. The different initiatives provide micro credit, capacity building for PLHIV on micro enterprise (including exposure visits) and strengthening the district level networks to manage enterprise, provision of one time small grant, community owned regulated micro financial institution models, provision of secure saving, field based supervision of activities, focus on initiating enterprise through neighbourhood groups etc.

### **Model 5: Social Protection and Entitlement Facilitation**

Social protection is designed to reduce poverty, inequality and vulnerability of specific population groups. In India, both inclusiveness and exclusivity is stressed for specific groups like PLHIV. In practice, information on and access to schemes and awareness among beneficiaries are reportedly very poor and actual evidences of the same remain unavailable. Access is the key issue resulting from lack of awareness both among officials and beneficiaries, stigma, bureaucratic procedures, corruption and other constraints.

## **Summary of Lessons Learnt**

Some of the lessons offered by the existing livelihoods promotion initiatives are:

- **Institutional backing for business incubation is absolutely essential:** Given the vulnerabilities faced by PLHIV, institutional base for business incubation is essential to conceptualise and establish enterprises owned or operated by PLHIV. Enterprise by PLHIV require external support from other organisations during the incubation period.
- **Scalability and sustainability comes from business leadership and long term plans:** Strong leadership support has been at the core of successful business units of PLHIV. There is need to recognise and nurture the great

enterprising attribute that some of the PLHIV widows facilitated by NGOs have demonstrated.

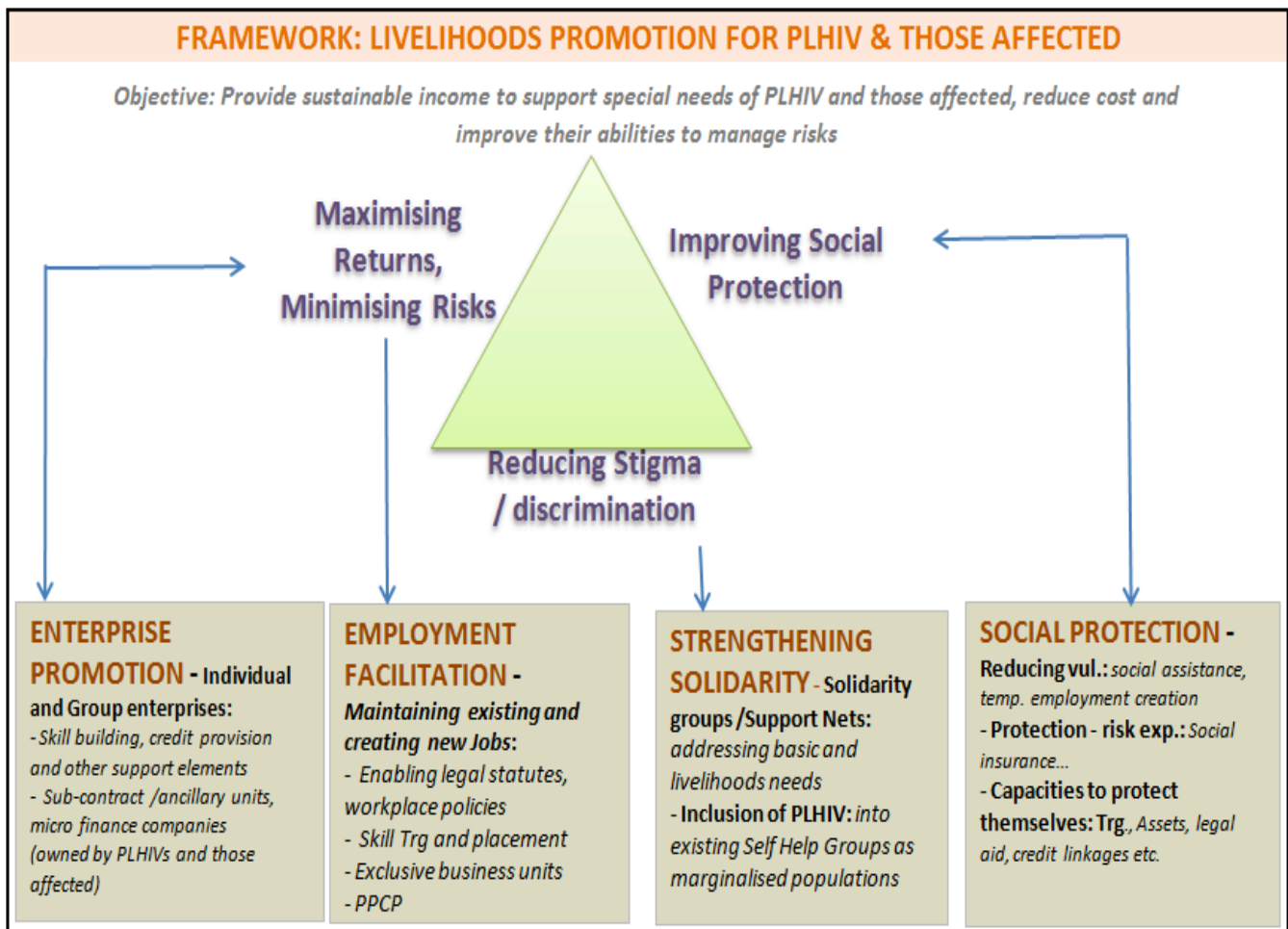
- **Replication of SHG model in HIV sector is beset with problems:** As it violates the principles of affinity and homogeneity. The HIV binding factor may not be sufficient to keep the group together. The pilots (by INP+, PWN+ and MYRADA) have been able to address the solidarity and basic needs to some extent, but the livelihood needs still require more work on the models.
- **Employment has better chance of providing secured livelihoods to PLHIV than enterprises:** Employment in supportive working environment have proven to be a lesser risk option for PLHIV to earn their livelihoods. However, a larger number of donor supported initiatives in the country focus on enterprise promotion rather than employment facilitation.
- **Models that can promote economic empowerment with HIV prevention:** Swathi Jyoti, which is being implemented within the Pragati Project (partnership project of Swasti and Swati Mahila Sangha) in Bangalore among Sex Workers shows best practice in facilitation of easy and cost effective credit without any collateral to the extremely vulnerable group of female sex workers. The Swathi Jyoti economic empowerment model brings forth the important link between economic empowerment and HIV prevention.
- **Enterprise enabling and associated collaborations and skills are needed:** The DLN's role is critical in enabling enterprises and facilitating social protection and other livelihoods options. However, necessary skills are not yet evident. In the Council of People Living with HIV in Kerala (CPK+) model supported by UNDP, positive attitude of Municipal and District Panchayat Officers helped their enterprise initiatives enormously. Therefore, a collaborative process is essential to livelihoods augmentation.
- **Effective social protection for PLHIV requires three pronged action:** To enable PLHIV to benefit from social protection schemes requires them to be able to access to mainstream programmes and schemes (inclusiveness), modifications to existing social protection schemes to make PLHIVs better eligible to seek the benefits and also design of schemes exclusively for PLHIV which can appropriately address their requirements.

## Policy Recommendations and Strategies

The National AIDS Control Program (NACP) phase-3 and upcoming phase-4 (2012 onwards) should incorporate the agenda of livelihoods promotion for PLHIVs and those affected. One of the main causes of inadequate and not so effective livelihoods work for PLHIV is the lack of due emphasis to the agenda at national and state levels. NACP can provide a framework of actions on livelihoods to SACS, District Level Networks and Civil Society Organizations working with PLHIV and MARP.



The strategic intent for livelihood promotion of PLHIV in the country should focus on three pillars: Enhancing Livelihood and maximizing returns, Reducing Social Discrimination and Improving Access to Social Protection as given in the diagram below.



Making PLHIVs 'secure' on livelihood front should be an important element of the national HIV programme. The framework of livelihood support for PLHIV thus cover four strategic approaches viz. **Enterprise Promotion**, **Employment Facilitation**, **Strengthening Solidarity** and **Entitlement Realization** through improved access to Social Protection (**EESE**) which in their totality and in different combinations can address diverse livelihoods needs of different type of PLHIV and those affected, in the country. The specific nature and combination of support to each typology of PLHIVs will need careful thinking and alignment.

### 1. Employment Promotion

**Employment** is the safest bet for livelihoods promotion of PLHIV, given the vulnerabilities involved. But due to poor health condition and stigma and discrimination in the workplace, PLHIVs are forced to quit jobs or are some time thrown out of their jobs. Therefore it is crucial to create a facilitatory environment that will help to keep the PLHIVs in the current job. Denial of employment to the HIV infected person merely on the ground of her/his HIV status is arbitrary and unreasonable and infringes the requirement of Article 14

(Right to Equality) as well as Article 21 (Right to Life) of the Constitution of India. Employers still feel it is a burden to take HIV positive people on their rolls. Therefore through adequate legal support and formulation of workplace policies the employment status of the PLHIV should be protected. Also support could be provided through skill building training as well as local placement based on the current skills and capacities of PLHIV. This will improve PLHIV's access to employment opportunities. Besides this, exclusive business units for PLHIV, as well as Public Private Community Partnership Model should also be tried out to facilitate access to employment for PLHIV.

## 2. Enterprise Promotion

Enterprise is profit oriented and influenced and affected by market conditions. Supply and demand are the key areas which entrepreneur needs to be familiar with. While the basic principles of enterprise are same across geography and context, peculiarities remain, for different products in different contexts. While planning enterprise promotion for PLHIV, it is important to bear in mind that the enterprises are difficult to set up and success rates are low; also that not everybody wants to be an entrepreneur and that businesses have risks and failures and need to be carefully planned. Given these risks it is important to provide business development support to the PLHIV for planning enterprise. Following key steps need to be considered before initiating the enterprise promotion for PLHIV

Step 1: Understanding the context and markets

Step 2: Need assessment and business planning

Step 3: Building capacities

Step 4: Promotion and branding

Step 5: Integration

## 3. Reducing Stigma and Social Discrimination

The PLHIVs face stigma within families, communities and at work places. Social discrimination can severely limit the participation of PLHIVs in the market e.g. PLHIVs (once their identity is known) may not easily get loan for starting an enterprise. Eateries started by them may not get customers. Therefore, in order that livelihood options can be successfully implemented, creating the right environment is crucial. It is important to undertake steps to reduce social discrimination, which will improve access of PLHIV to employment/income opportunities and provide sustainable livelihood options. Stigma can be reduced by working towards strengthening solidarity among PLHIVs as well as through sensitization of stakeholders and general public.

## 4. Social Protection

Beyond livelihood promotion and reducing stigma and discrimination, it is also important to facilitate access to social protection schemes that exist in order to reduce the vulnerabilities of PLHIV, enhance their self-esteem and improve access to livelihood opportunities. Three types of social protection strategies



/instruments are: Reduce Vulnerabilities, Protection from Risk Exposures and Enhance Capacity to Protect Themselves.

### **Broader Recommendations**

- Programme designs should address the key vulnerabilities of PLHIV without which, livelihoods promotion for them will continue to be a major challenge.
- Repayment of loan has been a major challenge. This is the result of *ad hoc* approach to livelihood programmes in many of the models currently being implemented in the country. Therefore, there is a need for more systematic approach to livelihood promotion, which should include appropriate market study, planning, proper systems, linkages, provision of technical assistance etc.
- Poor systems of monitoring have affected performance and effective follow up of many of the models.
- Those PLHIV who are associated with DLN have better quality of life as a result of access to a support system. A study is needed to assess exclusion of the marginalized PLHIVs, who are not part of a support network and who have limited access to services and support.
- Integrated livelihood programme that ensures participation of both infected as well as general community will work better because:
  - Integrated support inputs are essential for the success of livelihoods programming.
  - Groups with only PLHIV programme could fail - due to several health related issues they face.
- Need to effectively involve local government for funds and other support
  - PLHIV issues are not on the development agenda for local bodies - if that can be done, then lot more funds can be mobilized, and effectiveness of programmes can be enhanced.
- It is important to have national and state level guidelines to implement livelihood programmes for PLHIV.
- Key essentials:
  - Making network work in most situations
  - Bridging trust deficits among networks, NGOs
  - Business ideas to initiate networks (between District Networks and NGOs or other organizations) which can be translated into enterprises
  - Innovations - requiring pilot scale experimentation
  - Replicable models, in specific settings, that can reach scale

### **Delivery Model and Institutional Roles**

Delivering livelihoods for PLHIV and those affected require structures to translate the policy intent to concrete actions. The existing structure at national, state and district level should be able to administer and facilitate the livelihoods promotion strategy. The following diagram briefly captures the proposed approaches of institutional role within the NACP to deliver livelihood-focused programmes for the PLHIV.

<b>Delivering Livelihoods for PLHIVs: Institutions and their Roles</b>			
	<p><b>Ministry of Health and Family Welfare with NACO</b>  <i>guide, facilitate, develop models at pilot scale, support scale-up mechanisms, monitor, advocate and document</i></p> <p><b>Agenda Setting, Governance, Steering, Coordination</b></p>	<p><b>Central Ministries</b></p> <p>Support to MoHFW and NACO in its mainstreaming efforts; involving Ministry of Rural Development, Ministry of Labour and Employment, Ministry of Women and Child Welfare...</p>	
<p><b>UNDP, UNAIDS, Donors</b></p> <p>Technical and financial support to the government in building better livelihoods strategy and actions on the ground</p>	<p><b>Mainstreaming Wing at NACO</b></p> <p>Augmentation of skills in the unit with a Sr. Livelihoods Expert - Twinning Mainstreaming division with the task of both social protection and overall livelihoods</p>	<p><b>Technical Resource Group - Livelihoods</b></p> <p>a steering group involving livelihoods experts along with health professionals; design and monitoring of livelihoods interventions</p>	
<p><b>State AIDS Control Societies and Mainstreaming Resource Units</b></p> <p>Guide and steer the implementation of livelihoods strategy; facilitate design of social protection initiatives; mainstream with various arms of the Govt.</p>	<p><b>Technical Resource Group in High Prevalent States</b></p> <p>Design and monitoring of livelihoods work in the state</p>	<p><b>Network of Positives</b></p> <p>Guide and steer the implementation of livelihoods strategy; facilitate design of social protection initiatives; mainstream with various arms of the Govt.</p>	<p><b>State Government Departments</b></p> <p>Support to SACS and Network of positives in their mainstreaming efforts; involving various relevant departments /government bodies</p>
<p><b>District Level Networks</b>            (working with local government, Panchayats)</p> <p>Design livelihoods prototypes, Engage with NGOs, community based organisations for implementation of selected prototypes, monitor and evaluate, develop capacities at district level for livelihoods promotion, converge and integrate interventions with Panchayats and other arms of the government</p>	<p><b>Civil Society Organisations</b></p> <p>Design livelihoods prototypes, Engage with DLNs -build their capacities, implement or support implementation of livelihoods initiatives...</p>		<p><b>Private Sector, Academic /Research Institutions, others</b></p> <p>Skill building for PLHIVs, CSR donations, design and fund social protection measures, Support the initiatives of DLNs and NGOs, providing research inputs, knowledge base and expertise to the interventions</p>