

# **Draft Working Group Report on Strategy for Stigma in NACP IV –**

**Date: May 4 & 5, 2011**

## **Members**

1. Mr. Sunil Nanda (Chairperson)
2. Mr. K K Abraham (Co-chair)
3. Ms. Alka Narang
4. Ms. Anandi yuvaraj
5. Mr. Ilannchezian
6. Ms. Prachi Garg
7. Ms. Sweta Das
8. Ms. Varsha Gaikwad
9. Ms. Mihir Samson
10. Ms. Jayaprakash
11. Ms. Enisha Sarin

## **Goal:**

To reduce the impact of stigma and discrimination that affects the quality of life of PLHIV and key populations by developing a comprehensive strategy

## **Background:**

Stigma is recognized as one of the major barriers limiting access and uptake of HIV/AIDS prevention, care treatment and support services. In order to effectively address the problem, it is necessary to understand the causes of stigma and factors contributing to it. Therefore stigma need to be a cross cutting and a core issue for NACP IV. There is a need to create a conducive environment to promote social acceptance and increase service uptake. Programmes such as the Red Ribbon Express have shown that people access services if conducive conditions are created. People came forward openly without hesitation to be tested at ICTCs which were set up at the platforms.

The key driver of stigma is the fear of casual transmission. However myths and misconceptions, shame, blame and judgment related to HIV also need to be addressed along with the fear of casual transmission, for strategies to be effective. There needs to be an open dialogue on the moral dimension of stigma associated with HIV.

Stigma needs to be addressed through awareness creation. Efforts thus far under NACP III have been primarily through mass media campaigns and incorporating S&D into programmes such as Red Ribbon, N.E Campaign, mid media and Folk media.

To draft a robust strategy, evidence needs to be gathered by measuring stigma in a scientific manner and documenting good practices. Initiatives which have helped to increase acceptance within the community and normalize situations need to be documented and replicated. Existing data on stigma from the several studies undertaken by organisations such as FHI and ICRW needs to be reviewed to

understand how best to address S&D within the programme components. Existing tools can be adapted and used to measure stigma scientifically and scale up the stigma programme in NACP IV.

There is a need to design innovative programmes and also address grievances by instituting a legal redressal system. It was suggested that NACO can examine the scope of scaling up successful innovative initiatives such as the World Bank market place strategy.

NACP provides several platforms such as the TI programmes, link workers scheme, SHGs programme and Tribal Action Plan within which stigma reduction components can be integrated. Rural areas can be addressed through migrant interventions and link workers scheme.

**Objective of the strategy:**

The main objective of the stigma strategy is to empower key populations and PLHIVs to access services by focusing on stigma that prevails in different settings such as: self, family, community, health systems, educational facilities and workplaces.

NACO's strategy has to include all settings. The strategy has to be mainstreamed within the existing programmes of NACO. Advocacy initiatives need to be implemented at the community and tertiary level. NACO is already attempting to address self stigma by working with PLHIV networks at district levels.

There needs to be synergy between mainstreaming and GIPA to address S& D. The GIPA coordinator can play a role to ensure that the S&D initiatives are being implemented properly. These need to be monitored at SACS and NACO level by involving civil society and partners.

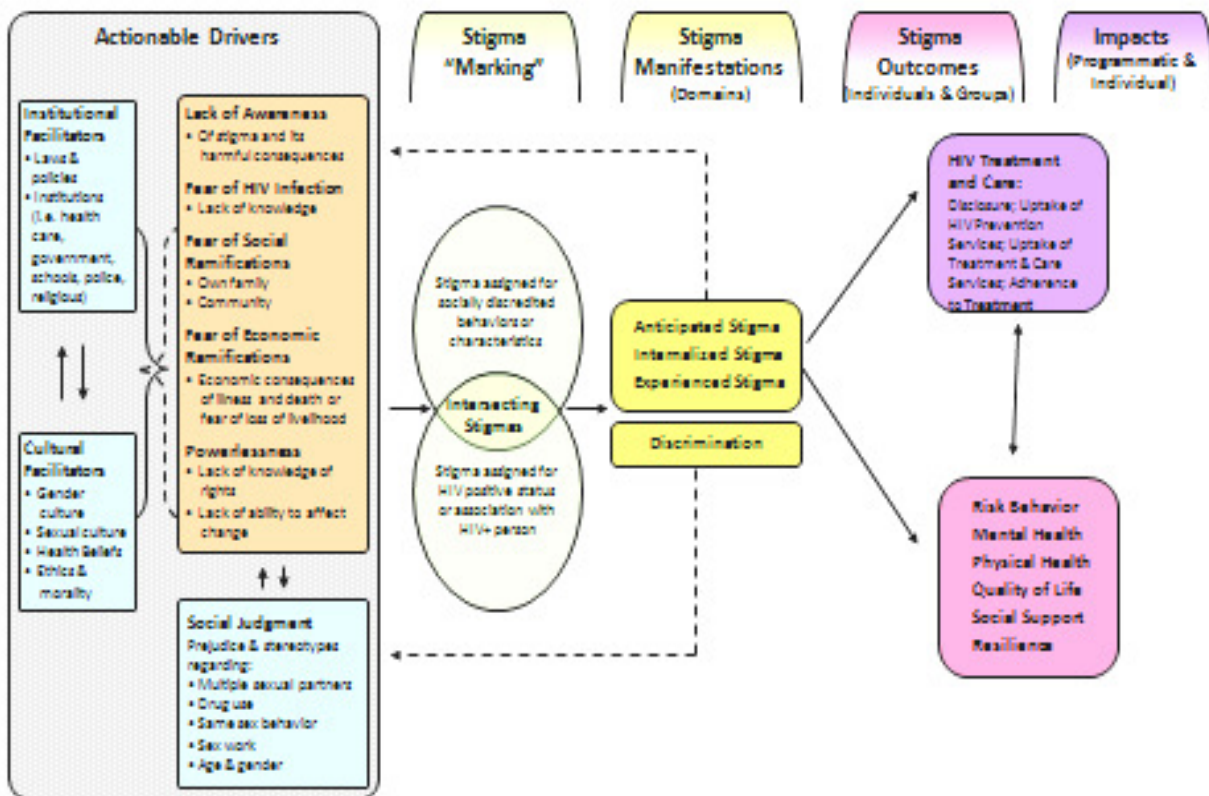
**Guiding principle of the stigma strategy**

- Be based on Human Rights and Gender lens
- Include populations of various sexual minorities groups, IDUs and Sex workers
- Ensure gender equity and equality – in terms of programmes and projects and resources
- Create enabling environment by instituting laws, policies and advocacy
- Promote positive cultural and social behaviours, beliefs, practices, attitudes and values that guide the programmes and policies
- Be evidence based and result oriented in a strategic manner

**Approaches**

- Convergence as an approach to address stigma by integrating HIV within the health programme
- Leverage partnerships, synergies and linkages
- Focus on capacity development of institutions and individuals
- Ensure evidence based programming
- Emphasize on community participation and involvement
- Strategy should be developed in a context specific manner

## Reducing HIV Stigma & Discrimination: A DRAFT Framework for Program Implementation & Measurement



The group suggested considering the above framework which depicts the key actionable factors that drive and facilitate HIV stigma, the marking of individuals or groups as socially unacceptable based on behaviors, characteristics and/or HIV status, which manifests for individuals and groups in several ways (domains) as a guiding map while developing the strategy.

### Target Audience to be addressed:

Primary	Secondary
PLHIV and Key Populations	General population
Families affected by HIV	Policy Makers including Police, Judiciary
Societal Leaders/Opinion	Panchayat Members
Media	Community Leaders
Health Service providers	Gatekeepers
Educational Institutions	Programme planners and implementors
Decision/Policy maker	Private sector
	Faith based organizations

## Objectives and key strategies

**Objective 1:** To protect and promote the rights of PLHIV and Key vulnerable population and enhance social acceptance

### Suggested Strategies

- Integrate stigma reduction component within the existing interventions of NACO, SACS and their partners.
- Create platform at national, state and district level to address issues related to PLHIV
- Strengthening community based services implemented by PLHIV and vulnerable populations such as DICs, TI run by CBOs
- Identify the key drivers of stigma and develop evidence informed strategies to address them at individual, family and community level, **and institutional level**
- **Developing** and **adapting** various tools that measure stigma and discrimination including PLHIV Stigma index tool and Pop Council Check list and ICRW tool

**Objective 2:** To empower PLHIV to access quality services

- Create effective linkages with service delivery units (Prevention, treatment and care and support) with networks and CBOs/NGOs including legal clinics
- Developing projects and programmes that improve the positive living concepts such as positive prevention, peer counseling and positive speakers, role models (like survival kit )
- Enhance and strengthen the linkages with social welfare schemes –by mainstreaming through relevant ministries
- Document and adopt successful innovative stigma reduction projects
- Scale up the Collectivization initiatives to strengthen the CBOs and PLHIV networks
- Develop and institute capacity development programmes such as mentorship and leadership initiatives/projects
- Institutionalized interface between policy makers and PLHIV networks

**Objective 3:** Generate evidences to design polices and programmes

### Suggested Strategies

- Document and publish good practices and challenges limiting scale up
- Adapt existing tools to scientifically measure the stigma and discrimination
- Document human rights violations experienced by PLHIV and key populations by
- Review and analyze existing research and evidence to understand the relationship between stigma and discrimination
- Involve PLHIV and key populations in monitoring programme implementation (community monitoring mechanisms) as well as to help design and execute research studies.
- Design innovative programmes to address stigma related issues

**Objective 4:** To measure the impact of stigma reduction programmes by developing and reviewing existing indicators.

### Suggested Strategies

- Review and standardize the impact assessment tools and develop systems at state and national level to evaluate interventions and assess their impact on reducing stigma and discrimination to strengthen common understanding of effective approaches and practices

- New measureable indicators need to be developed –process and outcome indicators through community participation at all level
- Periodic reviews need to be conducted to assess the impact of various stigma reduction programmes
- Review and scale up PLHIV Stigma Index projects based on successful initiatives such as the stigma index programme in Tamil Nadu

**Objective 5:** Ensure a rights based approach by reviewing and developing polices and legal instruments

**Suggested Strategies**

- Review existing laws that impede access to prevention and treatment programme by perpetuating stigma
- Develop district and state level task force to address stigma and document the human rights violation issues.
- Institute legal redressal mechanisms
- Develop legal literacy programmes by providing domain specific ((healthcare, workplace, gender laws, reproductive, education) Information on rights and entitlement to increase awareness among PLHIV, Key populations and establish linkages with redresses and crisis mechanisms
- Scale up sensitization programmes for various populations such as health care providers, judiciary, work place at all levels – on an on going basis
- Review, adapt and scale up the impact of legal clinics being set up based on the assessment
- Assess impact of parliamentarian forum and revitalize with renewed progress agenda including drafting new laws and reviewing existing laws that impede access to HIV programmes- state level
- Accelerate the enactment of the pending HIV/AIDS Bill since 2006.
- NDPS and ITPA acts to be amended to provide legal protection for people carrying out Targeted Intervention Programmes
- Ensure the use of existing legal systems to prevent stigma and discrimination in various settings such as health care, educational institutions, community and family
- Every institution (including work place, health care and education institutes) should follow the policy of reasonable accommodation to address special needs of PLHIV.
- Free legal counseling and support through legal aid cells for PLHIV by creating linkages and building capacity
- BAR association should be sensitized and provided adequate training/information (lawyers/judge)
- Dissemination of policy commitment, codes of ethics and codes of conduct to facilitate greater compliance

**Indicators- Areas**

Need to evolve and standardize indicators that can document and measure stigma and discrimination across NACP IV.

- Need process indicators –gender and sex disaggregated
- PLHIV friendly facilities – at service delivery points
- Access to entitlements to various social schemes-HIV sensitive schemes vs HIV specific schemes
- Treatment denial linked to universal precautions
- Redressal mechanisms - no of reported cases of service denial –reported and addressed
- No of public institutions having work place policies including HIV in place .e.g positive discrimination employment schemes

- HIV Bill enacted in the parliament by 2012

### **Strategies for addressing stigma in different settings:**

#### Self Stigma amongst PLHIVs

- Empower PLHIVs by involving them at every level of decision making
- Set-up redressal mechanism to ensure protection of rights
- Provide rights based counseling and linkages to services, networks and referrals through ICTCs
- Address mental health issues by linking with existing services
- Strengthen referral services and create linkages with existing services
- Strengthen DIC as a platform to address self-stigma
- Explore and identify opportunities for PLHIV networks to establish interface/interaction with policy makers to sensitize and influence policy and programmes
- Ensure community mobilization and collectivization

#### Stigma from home, neighborhood and community

- Domestic violence care centers (engage WCD dept for addressing the needs of social protection/rehab of the women children affected/infected by HIV)
- Increased number of shelter care homes for orphans/infected children

#### Health Care Settings and Providers (both public and private)

- Facilitate stigma reduction initiatives at health care settings to ensure stigma free service delivery
- Train, sensitize and build capacity of health care providers by reviewing and standardizing training programmes to include a component on stigma reduction
- Developing PLHIV friendly service delivery points for facilitating stigma reduction activities
- Build role models
- Ensure the practice of universal precautions within the hospital settings
- Availability/Accessibility of positive prevention (birth control etc)
- Special care and annual check up for HIV+ women, e.g., Pap-smear and annual OI test must be made available for women (WLHIV)
- Convergence with NRHM e.g., for OI services
- Health emergency to be addressed within 24x7
- Early launch of helpline and IVRS
- Operationalization of emergency health care for women and children

#### Educational Institutions

- Advocacy and awareness sessions with various bodies such as Management, Parents and teachers, SHG, PTA and school mentoring committees
- Awareness of right to education
- Media campaigns to address stigma in educational facilities
- Networking with various educational departments and ministries

#### Workplace

- Strengthen networking with business confederation and agencies
- Advocacy with board, management, HR and associations and trade union

- Legislate the HIV/AIDS Bill
- Mainstream with the department of labour on National Workplace policy
- Mass media campaigns
- Promote Role Models
- Involve of PLHIV as positive speakers

#### Advocacy with Media (print media and electronic media)

- Review existing guidelines for media to ensure sensitive reporting
- Conduct advocacy workshops with media houses
- Availability of updated media toolkit
- Advocacy with media in publishing right information on HIV/AIDS issues and using correct terminology
- Timely reporting on stigma issues
- Regular involvement of media in PLHIV network programs

#### Legal Redressal and Grievances

- Ombudsmen body at the district level which will be responsible to deal with issues of discrimination at health settings, family and institutions.
- Pilot mediation groups at the village level to address family and social grievances (headed by women). Representatives from the community will be part of this group.
- Empower Panchayats/Gram Sabha to mediate and negotiate regarding issues related to PLHIV.
- Strengthen state level grievances redresses mechanism (set up as per supreme court order) headed by Principal Secretary of Health.
- GIPA officers must regularly follow up grievance redresses from districts and ensure specific reporting mechanism with details for pending complaints with details of duration of pending complaints.
- District level committees for grievances redressal may headed by CMO - popularize redressal mechanism through nodal officers of state ART centers
- District Magistrate shall address/monitor PLHIV issues every month.

#### Communication

- Mass media campaigns like Public service advertisements on TV and radio internet and mobiles and local cable services etc.
- Develop innovative communication approaches that facilitate engagement (RRE)
- Information packages developed for specific populations
- Use of social networking sites to promote
- Leveraging new IT enabled networks to create awareness on care, support, treatment and prevention services
- Use of Folk media especially in the rural areas
- Films along with facilitated discussions on stigma to create awareness
- Using village health committee to empower PLHIV
- Developing appropriate package on stigma reduction and make available at different levels

## Recommendations:

- i. Address S & D in a comprehensive manner rather than in a piecemeal manner. Identify all possible settings at both rural and urban areas and also populations most at risk of facing stigma such as key populations like FSWs, TG, MSM and IDU. This would require identifying all relevant stakeholders at the state and district levels and sensitize them. For example at the district level – the SHGs, teachers, panchayats, NGOs, police etc. Uniform messages need to be developed and disseminated.
- ii. Training provided by STRC must include a component of S&D – Training modules to be reviewed to integrate a stigma component and also include a positive speaker as part of the training
- iii. Within the TI programme – all PE, ORWs, Counsellors etc need to be sensitized on S&D and its impact
- iv. The Village Health committee which is a mandate under the Link workers scheme can be used as a platform to promote S&D initiatives,
- v. Besides grievance redressal, crisis response mechanism also needs to be instituted as there is a need to create an enabling environment by building trust.
- vi. SACS need to develop capacity to implement and measure impact of stigma reduction programmes especially amongst the HCPs, educational staff, PLHIVs and other community settings etc including HCP in private hospitals.
- vii. Each state needs to develop a baseline and develop interventions accordingly
- viii. District and state level task force needs to be set up comprising of lawyers, social workers, policy representatives, teachers, corporate representatives. Community members to address and redress stigma related issues.
- ix. To encourage workplace HIV programmes – corporate sector can be awarded for incorporating HIV policy programmes with S&D component.