

Report of the NACP-IV Working Sub-Group on Stigma

Stigma and discrimination associated with HIV/AIDS are major barriers that prevent access to prevention, treatment, care and support services. The NACP III Guiding Principles laid emphasis on creation of an enabling environment wherein those infected and affected by HIV could lead a life of dignity. The major initiatives taken during the NACP-III which challenged the issue of stigma and discrimination are as follows:

- (i) Multi-media mass mobilization campaigns such as Red Ribbon Express (RRE) which involved positive networks for campaign outreach and generated a strong community dialogue on the issue.
- (ii) Spots on radio and TV with messages by celebrities on the issue of stigma and discrimination; special episodes on the issue of stigma in long format radio and TV programmes such as “Kalyani Health Magazine” and TV serial “Kyunki Jeena Isi Kaa Naam Hai”.
- (iii) Folk media performances in rural areas with focus on stigma and discrimination.
- (iv) Sensitization of medical and para-medical staffs on stigma during training programmes; inclusion of stigma and discrimination components within the sensitization programmes for grassroots workers such as SHG, AWW, ASHA, ANM and members of PRI; advocacy and sensitization programmes for parliamentarians, legislatures, faith based leaders, judiciary, police and other stakeholders; media sensitization programmes for journalists on stigma free reporting.
- (v) Involvement of PLHIV as positive speakers at various national and international forums, training programmes and advocacy workshops.
- (vi) Linkages established between various service centres and positive networks; setting up of Drop-in-Centres to provide platform for psycho-social support to PLHIV in the districts and to facilitate access to services.
- (vii) Formation of grievance redressal committees in the states to address the issue particularly in medical settings.
- (viii) Involvement of PLHIV in various mainstreaming programmes and in leveraging several Government welfare schemes to mitigate the impact of the epidemic on PLHIVs.
- (ix) Prompt actions taken through concerned authorities in case of reports of stigma and discrimination.

1.1 Key Issues & Gaps:

- Stigma and discrimination was not addressed as a “core” programme issue
- As stigma operates at subtle psychological level and is influenced and reinforced by negative societal norms, it has always been a challenge to address it. Stigma reduction programmes require better understanding of local social practices and norms which reinforce negative behaviours and key drivers of stigma such as fear, myths and misconceptions, shame, blame and judgment related to HIV also need to be addressed
- There is a need for a holistic approach to address stigma at self, family, community and institutional levels.
- Mainstreaming initiatives taken to sensitize grassroots functionaries, law makers, policy makers, police and other stakeholders were not uniform across the states and generally lacked follow-up.
- Grievance redressal mechanism remained weak.
- The need has been felt for a strong legal framework to address rights violation and violence.
- There was a lack of documentation of successful initiatives and evidence based replication.

- Capacity building initiatives such as mentoring and leadership to strengthen PLHIV to address stigma and discrimination need to be strengthened.

2.0 Recommendations for NACP–IV

2.1 Vision:

“NACP-IV will build up an environment where everyone can access services for prevention, treatment, care and support without fear or prejudice and is not stigmatized or discriminated in any sphere of life on account of HIV or AIDS or being a member of marginalized communities”.

2.2 Programme Priorities

While NACP-IV will further build up and strengthen the initiatives taken up during NACP-III, the efforts will focus on the following:

- Creating an overarching enabling environment which reinforces positive attitudes and practices at the societal level
- Addressing
 - Self- stigma among PLHIV and MARPs
 - Stigma in family settings
 - Stigma at health care settings
 - Stigma at workplaces
 - Stigma at educational institutions
- Protecting and promoting the rights of PLHIV, marginalised and vulnerable populations by reviewing and developing policies and legal instruments.

The interventions to address stigma and discrimination will have greater focus on women in view of the evidence that women are more likely to be stigmatised and discriminated if they are HIV positive or belong to marginalised communities.

2.3 Geographical Priorities

While high prevalence areas will receive greater attention, the strategy will be to reach out to all states and vulnerable areas with anti-stigma measures irrespective of prevalence

2.4 The anti-stigma messages will focus on:

- Allaying fear of casual transmission which is considered as the key driver of stigma
- Myths and misconceptions, shame, blame and judgment related to HIV
- Pre-existing stigmas which often reinforce stigma faced by PLHIV such as against socially marginalized and vulnerable groups (e.g., IDUs, MSM, sex workers).
- There is no difference between “us” and people living with or at risk of HIV infection
- With appropriate lifestyle changes and the advent of ART, an HIV positive person can continue to lead a productive life, has the right to continued employment
- Community empowerment, legal rights, gender inequities and positive prevention

2.5 Addressing Stigma & Discrimination at Self, Family and Community level

- Counselors at ICTCs, ART centres, CCCs, TIs and DICs will be trained and encouraged to address self stigma and positive living during inter-personal counseling sessions with PLHIV & Key Populations with special focus on women and children.
- Participation of grassroots functionaries such as SHGs, AWW, ASHA, ANM, PRIs and community leaders in HIV programme will be strengthened and they will be trained and involved as stakeholders in anti-stigma measures at community level through process of mainstreaming. .
- Initiatives such as Gram Sabhas taking anti-stigma oath and NGOs/ CBOs passing anti-stigma resolutions will be promoted.
- PLHIV representation in local bodies/ platforms such as Village Health & Sanitation Committees (VHSC), District Health Committees, Village School & Education Committees etc will be promoted particularly in high prevalence and highly vulnerable states/ districts. They will act as watchdog in ensuring that there is no stigma and discrimination faced by PLHIV and marginalized communities in accessing services relating to health and education.
- Advocacy with political leadership, faith based organizations, mainstreaming organizations and media will be intensified for building up overall supportive environment. Positive role models will also be used in this advocacy initiative.
- Mainstreaming interventions will be strengthened to ensure access of PLHIV and marginalized communities to livelihood and social security schemes without fear and prejudice. The infected and affected communities will be involved in leveraging these schemes.
- Police and law enforcing agencies, judiciary, bar associations will be specifically sensitized on the issues concerning PLHIV and marginalized communities including sex workers, MSM and IDU.
- Positive resource persons/ speakers will be involved in various trainings and campaigns to promote positive living concepts.
- Community Support Groups will be formed to facilitate creation of overall supportive environment, provide psycho-social support in case of incidents of stigma and discrimination and linkages to appropriate grievance redressal authorities.

Legal services and environment

- Sensitization & advocacy initiatives will be taken for leveraging free legal aid for PLHIV, particularly women & children as part of mainstreaming with NALSA, SALSA & DALSA and by involving judiciary, bar associations etc.
- Legal literacy programmes will be developed for 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 redressal and crisis mechanism
- HIV Bill needs to be taken up which will go a long way in addressing the issue by providing a legal framework.

2.6 Addressing Stigma & Discrimination at Institutional Levels

i. Health Care Settings

The interventions will be directed through the departments of health, state / district health societies, hospital management, medical and paramedical (HIV and non HIV related services), health care settings under public sector undertaking, media and health insurance providers by undertaking the following activities;

- Training programmes for health care providers including doctors, nurses and para-medical staff need to be reviewed and standardized to include a component on addressing issue of stigma and discrimination.
- Medical councils and medical associations will be actively involved in sensitisation programmes for doctors.
- Allaying fears of HIV transmission during discharge of duties and availability of Universal Safety Precautions to health service providers will be prioritised. IEC materials for doctors on Universal Safety Precautions will be developed, distributed and displayed.
- Role models among service providers will be identified and promoted.
- Anti-stigma mandate will be included within Citizens Charter in health care institutions and District Health Committees, Rogi Kalyan Samities etc.
- Chief Medical & Health Officer of the district and Superintendent of the hospital will be made responsible for taking immediate action in case of report of stigma and discrimination from any health care institution in the district.
- Linkages with service delivery units (Prevention, treatment and care and support) with networks and CBOs/NGOs will be strengthened by involving infected and affected people in follow-up of cases, cross-referrals, nutrition, drug adherence, positive living, positive prevention and delivery of quality services.
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ii. Educational Institutions

- Efforts will be made that specific directives are issued by Departments of Education at the national and state levels to all schools that no child can be denied admission/ removed from the school on account of being infected or affected by HIV.
- Right to Education Act will be appropriately invoked to address issue of stigma and discrimination in educational institutions.
- The training components under AEP and RRC will reinforce messages against stigma and discrimination.
- Teachers training programmes such as B.Ed. and M.Ed. etc. may include a small module on HIV including the issue of stigma and discrimination.
- PLHIV may be included in Village School & Education Committees.
- Advocacy with school principals, parent teachers associations, officers of departments of education, NCERT, SCERTs, examination boards etc. will be done on sustained basis for effective stigma and discrimination measures in educational institutions.

iii. Workplace

Work place interventions are crucial to address stigma & discrimination at government & non government/ public and private organizations involving both organized & un-organized sector. The involvement of trade unions, management, business confederations and HR associations is crucial. The interventions are:

- Mainstreaming activities with industry and business confederations will be strengthened.
- Efforts will be made in partnership with M/o Labour & Employment that more and more organizations adopt National Policy on HIV/ AIDS and the World of Work and implement it. Technical help will be provided to organisations in this effort.

- Advocacy with board, management, HR and trade unions/ associations will be undertaken.

IEC interventions to address stigma and discrimination:

- IEC campaigns will be designed to address the issue through mass media, mid-media and outdoor campaigns. Celebrities and role models will be involved for message dissemination.
- Efforts will be made to identify and promote folk troupes drawing artists from the affected communities for public performances.
- The communication and social mobilization initiatives will aim at generating community dialogue and discussions around myths and misconceptions, shame, blame and judgmental values related to HIV and reinforcing positive attitudes and practices.
- Communication tools and packages with rights based approach will be developed by involving infected and affected communities to address the issue.
- Gender sensitive campaigns to address S&D amongst women and other gender sensitive populations will be undertaken.

vi. Media

Advocacy workshops for national and regional media on HIV/ AIDS reporting and using correct terminology will continue to be conducted. Media visits to programme sites will be organized.

vii. Institutional set-up

- (i) Grievance Redressal Mechanism will be created to address cases of stigma and discrimination against PLHIV as follows:
 - GIPA TO/ Coordinators at NACO and SACS will examine and investigate the cases of stigma and discrimination as per the timelines prescribed under the GIPA Policy Guidelines. They will maintain data of the cases received their brief description and action taken.
 - District AIDS Control Officer will be responsible for addressing the stigma and discrimination cases in a district and will ensure action as per the recommendation of NACO/ SACS
 - Chief Medical & Health Officer of the district or the nodal officer for HIV programme in the district will be responsible for immediate action in emergency health situations.
 - Though stigma and discrimination are cross cutting issues, the mainstreaming units in NACO and SACS may coordinate the efforts in this direction.

viii. NRHM Integration

- Provision of and adherence to use of Universal Safety Precaution kits for service providers
- Sensitization and Training on providing HIV related services and stigma prevention
- Ensuring provision of HIV related services and institutional provision to address stigma and discrimination against PLHIV, KPs and affected communities
- Zero Tolerance on stigma against PLHIV, KPs and affected communities within institutions.

- Citizens Charter to state zero stigma approach and provision of services to PLHIV under all health care institutions and Rogi Kalyan Samities.

ix. Monitoring & Evaluation

- One focal person may be identified in every programme division to ensure that recommendations on addressing stigma and discrimination are incorporated in implementation of the concerned programme.
- PLHIV and marginalized communities may be suitably represented in the TRGs, Grievance Redressal Forums and programme review mechanisms at field levels for effective monitoring of measures to combat stigma and discrimination.
- Various tools that measure stigma and discrimination such as PLHIV Stigma index tool need to be developed and adapted
- Baseline, midline and endline evaluation studies will be conducted to measure impact of interventions.
- While every programme component will have indicators on stigma and discrimination, the suggested indicators are:
 - % of people ready to share food and clothes with PLHIV
 - % of people ready to allow PLHIV to stay in their area/ village
 - % of people having no myths or misconceptions about HIV/ AIDS
 - % increase/ decrease in number of complaints relating to stigma and discrimination by Grievance Redressal Forums
 - % of complaints on which actions were taken by the Grievance Redressal Authorities
 - % of Training modules incorporating component of Stigma & Discrimination
 - % of staff (programme officials, doctors, counselors, paramedical) outreach functionaries (PEs, ORWs), frontline workers (AWW, ASHA, ANM, PRI members etc.) trained on S&D issues
 - % of PLHIV networks trained on dealing with S&D issues
 - % of facilities linked to PLHIV networks for follow-ups etc.
 - Number of hospitals adopting and displaying anti-stigma charters/ policies
 - Number of organizations adopting Workplace Policies
 - % Gram Sabhas taking anti-stigma oaths

x. Capacity Building:

- Training programmes for all functionaries implementing NACP should include component on stigma and discrimination. Special trainings to counselors will be provided on rights based counseling and dealing with issues such as stigma at self, family and community. Within the TI programme – all PE, ORWs, Counsellors etc need to be sensitized on S&D and its impact and how to address such issues.
- Capacity of PLHIV networks/groups at the national, state and district levels will be built up on how to deal with issues of stigma and discrimination at different levels i.e. self, family, community and institutional levels.

Annexure I: List of Participants

Member Convener: Mr. Mayank Agrawal

1. Mr. Sunil Nanda (Chairperson)
2. Ms K.K. Abraham (Co-Chair)
3. Dr. Ravi Verma
4. Ms. Sweta Das
5. Dr. Umesh Chawla
6. Ms Nandini Kapoor Dhingra
7. Ms. Kanmani Chandran
8. Mr. Mihir Samson
9. Ms. Prachi Garg
10. Mr Shantamay Chatterjee

Annexure II: Terms of Reference

- Take stock of efforts so far and identify needs of people living with HIV/AIDS.
- Deliberate and recommend approaches for an expanded role of PLHIV and their networks in maximizing synergy between prevention, treatment, care and support
- Suggest framework and institutional mechanisms for implementation of GIPA at various levels
- Review role of Drop-in-Centres for providing psycho-social support to PLHIV and linkages with services and suggest measures for improvement
- Suggest approaches including measures for addressing stigma and discrimination in various setting – health care, work place, educational institutions, community, family etc.
- Suggest strategies for addressing the needs of positive people including those of women and children
- Identify possibilities for special welfare measures for PLHIV to mitigate the impact of infection on them
- Assess the technical support needs and suggest capacity building plans for SACS, DAPCUs, NGOs, positive networks, law implementing agencies and other stakeholders for strengthening GIPA
- Review the legal framework in relation to prevention and care services for PLHIV
- Suggest measures for providing legal support and protection and creating an enabling environment for people and families affected and infected with HIV/AIDS
- Suggest mechanisms for redressal of grievances of PLHIV
- Review existing ethical guidelines for research programmes (bio-medical & social), prevention & treatment including vaccine trials
- Design a strategic approach for GIPA, Stigma, ethical and legal issues under NACP – IV.
- Suggest innovations in implementation
- Explore the possibilities of integration activities with NRHM

Deliverables: Draft Report with Annexure

Time frame: 6-8 Weeks