REPORT OF THE WORKING SUB-GROUP ON GIPA FOR NACP-IV

The National AIDS Control Programme is committed to the principle of Greater Involvement of People Living with HIV/ AIDS (GIPA). NACP-III made a significant progress in this direction and involved PLHIV and their networks at various stages from programme planning to implementation. NACP-IV will further build up and institutionalize this role of PLHIV in formulating effective national policies, strengthening HIV prevention and scaling up treatment, care and support programmes.

From a handful of selectively open PLHIV in the mid 90s, the PLHIV movement in India has steadily grown in size, visibility and capacity with the emergence of national, state and district level positive networks. Women living with HIV have increasingly become part of the growing group of articulate and informed advocates. They provided strong platforms to PLHIV and facilitated their active involvement in NACP-III.

A. Achievements under NACP III

People Living with HIV have been involved in various important committees and forums including the following:

- National Council on AIDS (NCA) and State Councils on AIDS (SCAs)
- Technical Resource Groups (TRGs)
- Country Coordination Mechanism (CCM)
- Grievance Redressal Committees at the state level

In order to facilitate implementation of GIPA principle, positions of GIPA Coordinators were created in 24 State AIDS Control Societies (SACS) in 2007-08. Currently most of the positions are filled. PLHIV are involved in training programmes, advocacy workshops and outreach activities as resource persons/ positive speakers. A number of them are working as counselors, peer and outreach workers and health care providers under different components of the programme. As partners in the process of mainstreaming, PLHIV and their networks have facilitated leveraging various welfare schemes such as free transport to ART centers, supplementary nutrition, widow pension scheme, legal aid etc. Apart from national level networks, today there are registered networks of PLHIV in almost all states and in about 300 districts. 201 Drop-in-Centres are currently functional primarily through these networks providing psycho-social support, counseling and referral services and linkages to welfare schemes to PLHIV. Grievance Redressal Committees have been formed at the State level to address issues of stigma and discrimination against PLHIV particularly in the context of health care setting.

B. Gaps, Implementation Issues and Challenges:

i. GIPA policy and guidelines yet to be operationalised
ii. Weak technical capacity of GIPA Coordinators, positive networks and staff at Drop-in-Centres

iii. Inadequate understanding of GIPA among various programme implementation staff
iv. Inadequate resources and mechanisms for facilitating GIPA
v. Weak institutional mechanism for grievance redressal
vi. Insufficient involvement of infected and affected children in programmes addressing them
vii. Inadequate mechanisms for information dissemination to PLHIV on their rights and inadequate support to access social and legal protection aids
viii. Minimal involvement of community in programme review & monitoring
ix. District level networks (DLN) of PLHIV yet to be formed in many districts
x. Multiplicity of DLNs in some districts leading to leadership issues and proving to be a challenge to GIPA implementation
xi. Difficulty in finding PLHIV with minimum requisite qualifications to fill up positions of GIPA Coordinators.
xii. Specific monitoring indicators and review mechanisms on GIPA yet to be in place.
xiii. Mainstreaming of GIPA within other institutional settings & health systems remains a challenge.

C. NACP-IV Vision and Priorities

"Meaningful and active involvement of PLHIV in the national response to HIV epidemic from planning to its implementation, monitoring, feedback and evaluation"

Priorities

i. Operationalisation of GIPA Policy Guidelines will be done by organizing national and state level workshops.

ii. Capacity Building:

a) Sustained training and capacity building programmes for registered PLHIV networks at national, state and district levels covering the office bearers may be conducted in the first year of the NACP-IV with refresher in the third year. Similarly annual training of staff at DIC with refresher programmes may be organized. Training components may cover the following:

- Programme and Financial Management
- Accessing services for ART, STI and opportunistic infections
- Drug adherence, nutrition and positive living
- Community Mobilization, Advocacy and Networking
- Accessing social welfare and protection schemes including legal aid
- Special needs of HIV positive women and children
- Leadership development
- and any emerging issues

b) A cadre of trained positive resource persons in every A and B category and priority districts may be raised to effectively represent them in different

forums. About 8-10 positive resource persons in every A and B and priority districts (district advocacy unit) and 8-10 resource persons at the state level may be identified (state advocacy unit) in this regard.

c) Integration of GIPA component in all the training programmes of NACO/SACS/DAPCU/ Development Partners may be ensured. All training modules may be reviewed by an expert committee consisting of concerned programme people and positive persons.

iii. While PLHIV participation at various forums already achieved during NACP-III such as TRGs, NCA, SCAs, CCM and Grievance Redressal Committees at State levels will be continued, it may be further expanded to other forums such as JIRM.

iv. Grievance Redressal Mechanisms at national, state and district levels may be fully institutionalized and existing Grievance Redressal Committees at the state levels may be strengthened.

v. It will be ensured that the DICs are accessible to all positive persons including those from marginalized communities. Also DICs specific to women and children for districts with high PLHIV population may be considered in order to ensure wider access to services for women & children living with or affected by HIV.

vi. IEC materials will be developed specifically to address PLHIV issues such as treatment, drug adherence, nutrition, rights and responsibilities, linkages to services, welfare schemes, legal aid etc. through participatory mechanisms by involving them in material development process. It will be contextualized to serve local needs.

vii. Technical guidance may be provided for formation of DLNs in the districts, particularly A and B and with sizeable PLHIV population, where they are non-existent.

viii. PLHIV networks will be linked to service delivery centres such as ICTC, ART, STI centres and CCCs to facilitate follow-up on issues of LFU tracking, nutrition, drug adherence, quality services without stigma and discrimination etc.

D. Changes suggested for institutional set up

- Provision of GIPA Technical Officer (TO) at NACO to ensure integration of GIPA in various national and state programmes.
- Constitution of GIPA Technical Advisory Groups (TAG) at NACO and SACS
- Creation of Grievance Redressal Mechanism to address cases of stigma and discrimination against PLHIV

    i. 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.

ii. 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
iii. 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

Expansion of Drop-in-Centres

DICs will be established in all 'A', 'B' and those 'C' or 'D' category districts in the country where PLHIV population is sizeable. DICs functioning will include:

- Providing a platform for psycho-social support where PLHIV can gather and share their feeling and concerns
- Providing counseling on drug adherence, nutrition, opportunistic infections, STI treatment etc.
- Providing linkages to PLHIV to various services for care and support available in the area and promote positive living
- Providing linkages to PLHIV to Government welfare and social protection schemes through mainstreaming with the concerned departments in the district
- Assisting in LFU tracking
- Organizing income-generation and community activities
- Facilitate GIPA in the district

- Provision of separate spaces for men and women may be made in the DICs.
- In case, there is already one DIC in the district and the registered number of HIV positive people in the DIC exceeds 400, a second DIC may be considered but only for women. However, the sanction for second DIC will depend on other factors including number of active PLHIV in the existing DIC, its geographical coverage etc. An assessment team may constituted by NACO/ SACS to ascertain the need for second DIC in a district.
- Support Groups of PLHIV may be formed in the DICs and by the DLNs for providing psycho-social support to PLHIV from general population and marginalized communities particularly for those who are in distress.

E. NACP IV Focus Areas:

a. Quality

- Quality of PLHIV participation at different forums will be improved through training and capacity building of PLHIV networks so that they can effectively present their issues and advocate on them
- At least one model DIC will be developed in each state with A or B category districts through direct handholding by SACS. The model can be replicated in other districts.
- Quarterly reviews of the quality and access to services may be conducted in the district through involvement of DAPCU/ PLHIV networks and DICs

b. Innovations

- Annual conventions of PLHIV networks and DICs may be organized at the state level under the umbrella of SACS to facilitate sharing of best practices.
- National level conventions facilitated by NACO may be organized to share best practices from the states on GIPA.
- A small corpus of fund may be earmarked as “Innovations Fund” to promote innovative activities by PLHIV networks/ forums.
- Linkages with various women forums and facilities in the districts may be established for WLHIV
- Innovative models such as ‘Jeevan Deep’ in Gujarat involving PLHIV in mainstreaming process may be considered for replication in other states suitably.

c. Integration/ Convergence

- PLHIV should be involved as community advocates for developing linkages with other ministries/ departments and stakeholders for leveraging social protection and welfare schemes for PLHIV.
- PLHIV may be taken as special invitee in Village Health & Sanitation Committees (VHSC), Rogi Kalyan Samitis and District Health Committees (DHC).

d. Activities that can be integrated with NRHM

i. Grievance Redressal Mechanism within health care settings
ii. Engaging PLHIV networks in programmes & services like awareness building, LFU tracking and outreach
iii. Involving PLHIV as special invitee in Village Health Sanitation Committees (VHSC) and other levels- District Health Committees and DAPCU.

- **Method**

I. Inclusion of DLN representatives in District Health Committee and DAPCU Committees
II. Sensitization & capacity building of health care service providers on HIV services, GIPA and stigma
III. Monitoring jointly by SACS & NRHM on to strengthen HIV & related services to PLHIV & KPs

F. Involving PLHIV in Programme Monitoring and feedback

- A district level coordination mechanism led by DAPCU or CMO/ District AIDS Officer may be established for taking stock of quality of service delivery and access to welfare schemes. Review meetings at least once in three months with staff at the service centres (ICTC. ART, STI, CCC, DIC), DLN and district level mainstreaming partners may be held on the issue.
- PLHIV may be included in various review missions including JIRM.

- PLHIV as members of various committees and forums will be provided opportunity to participate in activities from planning, implementation and monitoring of HIV programmme.
- Regular interface will be established with PLHIV and their networks to ascertain their needs and the programme gaps specially concerning WLHIV and CLHIV.
- DICs will be encouraged & involved in gathering of evidences and documentation of innovation and best practices.

G. Monitoring & Evaluation

The progress of GIPA as a programme component needs to be monitored against a set of indicators. Quarterly review visits by SACS officers to DICs will be helpful in improving performance and strengthening capacity of DICs. Complaint/ suggestion boxes to be put up in the DICs that may be opened by DAPCU/ district health committee /SACS representatives will help to ascertain the quality of services in the DIC and feedback on other PLHIV related issues in the districts. The following monitoring indicators are suggested:

i. Percentage of district level networks covered through training
ii. Percentage of state level networks covered through training
iii. Percentage of DICs covered through training
iv. Number of training modules incorporating GIPA in training curriculum
v. Percentage of number of grievances/ complaints received and addressed at district level/ state level/ national level
vi. Frequency of meetings of NCA/ SCA/ TAG
vii. Follow-up on decisions taken in the meetings of NCA/ SCA/ TAG
viii. Number of policy directives issued on GIPA
ix. Number of national/ state/ district level forums having PLHIV representation
x. Number of district level review meetings organized on GIPA
xi. Number of state level review meetings organized on GIPA

Key indicators for DIC monitoring

i. Percentage of positions filled
ii. Percentage of PLHIV to the total number registered who visited the DIC in last quarter
iii. Provision of separate spaces for men or women exists or not
iv. No. of PLHIV counseled on drug adherence, nutrition etc. in last quarter
v. No. of LFU cases tracked by the DIC in last quarter
vi. No. of PLHIV provided legal aid through mainstreaming in last quarter
vii. No. of PLHIV linked to income-generation schemes through DIC in last quarter
viii. No. of PLHIV linked to social protection schemes such as widow pension etc.
ix. No. of PLHIV linked to free transport scheme

Independent evaluations may be undertaken of the DICs in 2nd and 4th years of the NACP-IV. The overall programme may be evaluated by measuring progress on identified indicators and through interviews and FGDs with different stakeholders.

H. Timeframe

S.N.	Activity	Time Frame
1	Training of programme staff, SLNs, DLNs & DIC national & state level on GIPA Policy	1st Yr of NACP IV
2	Training of national, state and district PLHIV network office bearers	1st Yr of NACP IV with refresher in 3rd Yr
3	Training of DIC staff	1st Yr of NACP IV with refresher in 3rd Yr
4	Identification of 8-10 PLHIV resource persons in every A & B and other priority districts and their training	Within 1st Yr of NACP IV
5	Integration of GIPA component in all the training programmes of NACO/SACS/DAPCU/ Development Partners- All training modules to be appropriately modified	To be completed within first year of NACP-IV
6	Establishing Grievance Redressal Mechanisms at national, state and district levels	Within first six months of NACP-IV
7	Assessment of requirement of new DICs	Within first six months of NACP-IV
8	Establishing new DICs	To be completed in first two years of NACP-IV
9	District level meetings of DAPCU, DLN, DIC, District AIDS Prevention Officer and staff at the service centres to review the access to services and welfare schemes	Every quarter
10	Review visits to DIC by SACS officers	Each DIC to be covered every quarter
11	DIC evaluations	2nd and 4th years of the NACP-IV

Annexure I: List of Participants

Member Convener: Mr. Mayank Agrawal

1. Mr. Sunil Nanda (Chairperson)
2. Ms Kaushalya (Co-Chair)
3. Ms. Alka Narang
4. Dr Eric Zomawia
5. Ms Nakshinaro Ao
6. Dr Bijendra Singh
7. Ms. Neha Chauhan
8. Mr Shantamay Chatterjee
9. Ms Mekhla Pothana
10. Mr Raman Chawla
11. Ms Daksha Patel
12. Dr. Meenal Mehta

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