

Capacity Building of Communities, Community Networks, and CSOs

Module - 2

Community Networks, Linkages, Partnerships and Coordination

**Community System Strengthening
under NACP - V**



Module - 2

Community Networks, Linkages, Partnerships and Coordination



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75
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Foreword



राष्ट्रीय एड्स नियंत्रण संगठन
स्वास्थ्य और परिवार कल्याण मंत्रालय
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National AIDS Control Organisation
Ministry of Health & Family Welfare
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NACP Phase-V envisages "Keep beneficiary and community in center" of HIV/AIDS epidemic as one of the key guiding principles. This aims to maximum the benefits to its diverse target population in a friendly ecosystem, offering a basket of tailored integrated services across prevention-detection-treatment spectrum. The National AIDS Control Program acknowledges the collaboration and involvement of the communities, people living with HIV/AIDS and civil society organizations as key to elimination of HIV/AIDS related stigma and discrimination and strengthening the HIV response in the country. Under NACP V, Community Systems Strengthening (CSS) as an approach complements NACO's overall vision where every person who is highly vulnerable to HIV is heard and reached out to and every person living with HIV is treated with dignity with access to quality care.

Under CSS, the aim is to identify and build the capacity of the communities, community networks and community organisations to ensure greater meaningful involvement of communities (and their organisations) in planning, implementing, monitoring, and evaluation of NACP. It is expected that these individuals, groups and networks from the community will complement the program through mobilizing the community, increasing demand for NACP services and support in improving the quality of care. NACO, through the model of social contracting already partners with Non-Governmental Organisation (NGOs) and Community Based Organisations (CBOs) for provision of HIV services to our priority populations, and hence, it is envisioned that through further capacity building efforts more community-based organisations will be able to take this partnership to the next level.

The capacity building modules developed under CSS, are designed to equip community, community networks and community-based organisations with the necessary knowledge, skills and tools to augment the HIV response in India. I believe these modules will play a valuable role in increasing the capacities of our communities to work in partnership with the National Program towards achieving the goal of elimination of HIV as a public health threat by 2023.


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सत्यमेव जयते



Preface



राष्ट्रीय एड्स नियंत्रण संगठन
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NACP recognizes the need for community-engaged responses, not just as beneficiaries, but as key partners in action for improving health and well-being. It aims towards elimination of HIV/AIDS related stigma and discrimination. NACP Phase-V, therefore aims to institutionalize the community engagement and meaningful participation at the most granular level in the form of community system strengthening (CSS). CSS will catalase improved health outcomes specifically through strengthening targeted interventions (TI) program, advocacy and rapid response to reducing stigma and discrimination, enhancing treatment literacy, greater involvement of communities in decision making and finally developing structured systems of community-led monitoring (CLM).

Under CSS, creation of the community resource pool at the national and sub-national level is given priority wherein focus is to increase capacities of community, community networks and community based organisations. This is done with the objective to enhance engagement and participation of the community in all aspects of the national program from planning, implementation and monitoring. More recently, substantial contribution is added by the community when engaged through community advisory boards at the district level. While conducting Programmatic Mapping and Size Estimation. Through the principles of GIPA, NACP also recognizes the involvement of PLHIV and affected communities by enabling individuals and communities to draw on their life experiences; thus contributing to reducing stigma and discrimination. Communities also play a pivotal role in enactment of the HIV/AIDS Act 2017 by increasing awareness and creating accountability for furthering the HIV response in the country.

Aligned with the above, the modules have been developed for "Capacity Building of Communities, Community Networks and CSOs" under CSS as part of the Global Fund grant, 2021 – 24. It is intended to intensifies efforts for building capacity and human resources, with the aim of enabling communities and community actors to play a full and effective role alongside health and social welfare systems. The modules are useful not only for the HIV program but can also be referenced by the larger public health programs towards effective community engagement in the country.

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सत्यमेव जयते



Message

The fifth phase of the National AIDS Control Programme, aims to attain the United Nations' Sustainable Development Goals 3.3 of ending the HIV/AIDS epidemic as a public health threat by 2030. This has warranted a focused and stronger attention to community involvement in the HIV response in India. Therefore, community system strengthening lays strong emphasis on building capacity and human resources, with the aim of enabling communities and community actors into full partnership with national health and social welfare systems.

There are new overarching strategies that are employed under NACP phase V which complement ensuring access to testing, treatment and care services. There is attention on developing new generation and integrated communication strategy for prevention, testing, and treatment of HIV and STIs. Focus is also laid on promoting launch and scale-up of social protection schemes by Central/State Governments to mainstream people infected and affected with HIV, including the vulnerable population, towards reducing inequalities and promoting inclusions. To reduce HIV related stigma and discrimination, emphasis is on accelerating the notification of State rules in context of the HIV and AIDS (Prevention and Control) Act, 2017, which is the primary legislation protecting and promoting the rights of people infected and affected with HIV. The community of key population and PLHIV will play an important role by spreading awareness, generating demand and supporting in creating an enabling environment for implementation of these strategies, especially by strengthening the process of grievance redressal mechanism.

These modules support in ensuring that information regarding the rights of the community, access to correct and relevant information regarding the programs under NACP and information on social welfare and protection schemes reaches our priority population. Under CSS, the creation of a community resource pool will complement the National level efforts to accelerate and sustain the national HIV response.

(Dr. Anoop Kumar Puri)



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Message

Under NACP phase V, NACO's vision for community system strengthening (CSS) is to ensure meaningful involvement of PLHIV and Key Populations to support the ongoing HIV interventions by building communities capacities and their systems. It is envisioned as an important strategy to improve the program's impact; effectiveness, efficiency, and accountability through better collaboration. It is envisioned for building capacities for reaching the unreached and hidden groups, dissemination of information, and creating an enabling environment for the reduction of stigma and discrimination.

One of the main components of CSS, is to identify and build the capacities of communities, community networks and organizations, it was envisioned to develop capacity building modules based on the needs of the community. As NACO has always involved the community through constant consultation and conversation, the same process has been followed for the development of the above. The topics covered were identified through the mechanism of community needs assessment and finalized through consultation meetings. The 6 thematic areas identified for the modules are: Advocacy; Community networks, linkages, partnerships, and coordination; Resources Mobilization; Demand Generation; Organizational and leadership strengthening; and CLM & Knowledge Management.

The modules for "Capacity Building of Communities, Community Networks and CSOs" are developed covering a range of topics that can be utilised by stakeholders like SACS and implementing partners working with community, community groups and organisations but also for the communities themselves to increase their knowledge and skills to contribute towards the National HIV program. I believe these modules will contribute to strengthening the roles of our priority populations to achieve the highest attainable standards of health, no matter who they are or where they live.


(Dr. Shobini Rajan)

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Acknowledgment

We strongly believe that the modules developed for "Capacity Building of Communities, Community Networks and CSOs" under CSS as part of the Global Fund grant (2021 – 24) under NACP V will intensify NACO's efforts towards meaningful engagement of the communities in the National HIV response in India.

We are grateful for the valuable guidance provided by Ms. V. Hekali Zhimomi (Additional Secretary & Director General, NACO). Ms. Nidhi Kesarwani (Director, NACO) provided her valuable experience in defining the content for the modules. Dr. Anoop Kumar Puri, (DDG – CST, IEC & MS, NACO), Dr. Uday Bhanu Das (DDG – PMR & Lab Services, NACO) Dr. Shobini Rajan (DDG – TI, BSD and STI, NACO), Dr. Chinmoyee Das (ADG – CST, SI & IT, NACO), Dr. Bhawna Rao (DD – IEC & MS & Lab Services, NACO) and Dr. Saiprasad Bhavsar (DD – CST, PMR & SCM, NACO) and SACS officials for their technical inputs and contribution in developing the modules.

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CBO	Community-Based Organization
CABA	Children affected by HIV/AIDS
CC	Community Champions
CSC	Care and Support Centres
CSS	Community Systems Strengthening
CST	Care, Support and Treatment
CLM	Community Led Monitoring
DAPCU	District AIDS Prevention and Control Unit
DLN	District Network of People Living with HIV
FSW	Female Sex Worker
HIV	Human Immunodeficiency Virus
H/TG	Hijra/ Transgender
HRG	High-Risk Group
ICTC	Integrated Counselling and Testing Centres
IEC	Information, Education and Communication
KP	Key Populations
LWS	Link Worker Scheme
LSE	Life Skill Education
MSM	Men Having Sex with Men
MARPs	Most at Risk Population
NACO	National AIDS Control Organization
NACP	National AIDS & STD Control Programme
NGO	Non-Government Organization
OST	Opioid Substitution Therapy
OVC	Orphan and Vulnerable Children
PLHIV	People Living with HIV
PWID	People Who Inject Drugs
SACS	State AIDS Control Society
SG	Support Group
SHG	Self-Help Group
SLN	State Network of People Living with HIV
SRH	Sexual and Reproductive Health
SSS	Sampoorna Suraksha Strategy
STI	Sexually Transmitted Infections
TI	Targeted Intervention

CHAPTER - 1.0

Introduction, Background and Overview

India is one of the countries in the Asia Pacific region that have recorded significant decreases in new infections among the key populations (KP) and significant increase in providing access to treatment among people living with HIV infection. The strategies adopted by the National AIDS Control Organization (NACO) for prevention, treatment and care have predominantly worked because the National AIDS & STD Control Programme (NACP) has kept the key populations (KP) and people living with HIV (PLHIV) at the center of its response. Working with the key groups, consulting and respecting them as the stakeholders have supported immensely in advancing the response to combat HIV/AIDS and the social ramifications of the epidemic. India in its' fight to end AIDS is at a critical juncture as the fast-track targets and India's commitment to end AIDS by 2030, warrants focused and stronger response from the key players. The key players in this regard are the community members from the key populations such as the female sex workers (FSW), men having sex with men (MSM) and PLHIV. Participation and leadership from important stakeholders in KPs, together with a well-integrated national programme, will propel India toward the global objective of end AIDS by 2030. Towards this purpose the NACP V focuses on Community System Strengthening (CSS) and empowerment and calls for community engagement at different level including cadre of health delivery system, at both NACO and State AIDS Control Society (SACS) level. Community System Strengthening aims to achieve improved health outcomes of NACP specifically for strengthening targeted interventions (TI) program, reducing stigma and discrimination, enhancing treatment literacy, greater involvement of communities in decision making and finally developing structured systems of community-led monitoring (CLM).

One of the main approaches under Community System Strengthening is to develop the capacities of communities and Community Based Organizations (CBO) and Non-Government Organization (NGO). In the year 2021, NACO conducted a series of deliberations with the community members their representatives and national level stakeholders. These consultations pointed out towards the capacity strengthening needs of the community. The national level consultation also brought out the thematic areas on which training could be imparted. Therefore, in order to develop the capacities of individuals and community-based organizations, module-based trainings have been envisaged. This module and five other modules have created to address the related learning needs of the Community Champions (CCs) and CBOs/NGOs in the field of HIV/AIDS prevention program.

CHAPTER - 2.0

Purpose of Module: 2 Community Networks, Linkages, Partnerships and Coordination

This module pertains to community networks, linkages, partnerships and coordination. The purpose of this module is to leverage resources and link KPs to services and support networks that will lead to improved health outcomes.

Target Audience of this module

The target audience of this module are the Community Champions and CBOs/NGOs representing and/ or working for the Key Populations (KPs). The key populations who are defined under the Global Fund CSS framework are those groups that meet all three of the criteria below:

1. The population experiences increased risk or burden of disease due to a combination of biological, socio-economic and structural factors;
2. Access to health services that prevent, diagnose, treatment, or care for these diseases is lower than for the general population; and
3. The population experiences human rights violations, systematic disenfranchisement, social and economic marginalization and/or criminalization.

Based on the above criteria, the KPs are defined by NACO as under:

Female Sex Worker (FSW)

Adult women who engaged in consensual sex in exchange for money/ payment in kind at least once as a means of livelihood in the last six months.

Men Having Sex With Men (MSM)

Adult men who had anal or oral sex with more than one male/hijra partner at least once in the last six months.

Hijra/ Transgender People (H/TG)

Sexually active adult person having more than one sexual partner in the last six months and whose self-identity does not confirm unambiguously to conventional notions of male or female gender roles but combines or moves between these.

People who inject drugs (PWID)

Adult men and women who use addictive substances for recreational or non- medical reasons, through injections, at least once in the last six months.

People Living with HIV (PLHIV)

People Living with HIV who require anti-retroviral therapy (ART) to live a healthy life.

The Community Champions and representatives of CBO/NGO may be from these KPs and some of them may also from the general population. They will constitute the training participants whose capacities will be strengthened under the CSS.

CHAPTER - 3.0

Objectives of Training Module: 2 Community Linkages, Networks, Partnerships and Coordination

The master trainers need to bear in mind that the participants are Community Champions and the representatives of a CBO/NGO and need to build newer linkages, partnerships in order to ensure access to services and rights of the people they work with.

CHAPTER - 4.0

Expected Outcomes

It is expected that after the training, workshop participants will proactively engage in leveraging and networking with the existing systems and other CBOs/NGOs in order to provide maximum support to the KPs. The overall outcomes are as under:

1. Advocacy to ensure accountability and continuous improvement of response to the disease.
2. Functional networks linkages and partnerships between community champion and national programs.
3. Community champions have good knowledge of rights, community health, social environments, barriers to access and develop and deliver effective community-based services.

CHAPTER - 5.0

Principles of the Training Program

The participants of the workshop will be CBO/NGO professionals, activists and community resource persons with varying experience and education. The approaches used for the module cannot be a mere class room lectures kind of one-way interaction; it has to be an approach that respects as well as incorporates their experience, pre-existing knowledge and motivates them to adapt the new learning. Hence, the adult learning approach known as the Andragogy will be utilized for developing these modules. According to Malcom Knowles (Malcolm Shepherd Knowles was an American adult educator, famous for the adoption of the theory of andragogy) an eminent exponent of the adult learning enunciated following core principles of andragogy are:

1. Adults **need to know** why they need to learn something before learning it.
2. The **self-concept of adult** is heavily dependent upon a move towards self-direction.
3. **Prior experiences** of the learner provide a **rich resource for learning**.
4. Adults typically become **ready to learn** when they **experience a need to cope** with a life situation or perform a task.
5. Adult orientation to learning is life centered and they see **education as a process of developing competency levels to achieve their full potential**.
6. The **motivation for adult learners is internal** rather than external.

Andragogy reorients adult educators from “educating people to helping them learn”. The methods used may range from isolated instruction within a curriculum or integrated instruction. It may also encompass intentional and unintentional learning situations. The instructions need to be organized by task and present in a manner similar to how it will be used. The learner needs to know why the concept to be learned is important in order for the learner to remain motivated. Despite the learner ultimately having control of learning through self-directed means, the trainer needs to facilitate the opportunities for the learner to experience growth.

CHAPTER - 6.0

Methods of the Training Program

The module covers the subject in great details. The facilitator is required to study the content and if need be research it further and prepare themselves thoroughly. The facilitator can modify presentation to meet the regional need.

This module is further divided into sub-modules with the activities and direct instructions which can be used to explain concepts. During the activity, the facilitator is expected to explain the practical implications of that activity and link it with the content. The facilitator is expected to address specific topics of immediate concern and then expand to how it can be applied in real life situations as well as for various key populations. Much of the content will be applicable to the experiences of the learners therefore a facilitator is expected to engage in active learning, use the learner experience and incorporate key learning on the spot for the better understanding of participants. Facilitator may also engage in cross learning for example learning from the successes of a particular KP group and identifying key strategies that could be incorporated towards other key groups.

CHAPTER - 7.0

Ethics of the Facilitator

Respect for participants

The workshop participants may come from different geographies, life experiences or may be from any KP groups. The facilitator needs to be aware about this diversity and respect all the participants. The respect should translate into his/her/their way of verbal and non-verbal communication. A participant's agency should be fully respected by the facilitator.

Being non-judgemental

The facilitator should make him/her/themselves aware about the diversity of their workshop participants and must be non-judgemental towards them. No participant should be judged on the basis of their sexuality, gender identity, sexual behaviour, being in sex work and their vulnerability to HIV/AIDS.

Equality towards participants

Over and above being sensitive to the diverse participants, a facilitator is also expected to treat all the participants equally. All participants need to be given the equal opportunity to participate and express their views. Participants can be of varied personalities such as introverts and extroverts, sensors and intuiters, thinkers and feelers, judges and perceivers. People from all of these personality type needs to be given equal opportunities to participate in the workshop.

Respecting confidentiality

Team building and group work create a comfort zone for the participants in which participants may share their deeply personal insights and stories. The facilitator has to ensure that post training, they are not sharing these insights by naming any participant. Maintaining confidentiality of the participants and proceedings is an important ethic to be followed by the facilitator.

Module 5	Organizational and Leadership Strengthening
Module Objectives	To enable effective service delivery and advocacy model, maximizing resources and coordinated, collaborative working relationships to maximize impact.
Expected Learning Outcomes	1. Advocacy to ensure accountability and continuous improvement of response to the disease 2. Functional networks linkages and partnerships between community actors and national programs. 3. Community actors have good knowledge of rights, community health, social environments and barriers to access and develop and deliver effective community-based services

Holton, E.F., Swanson, R.A. & Naquin, S. (2001). *Andragogy in practice; Clarifying the andragogical model of adult learning.* *Performance Improvement Quarterly*, 14 (1), 118-143
Andragogy - Malcolm Knowles Submitted by Steven R. Crawford, scrawf@odu.edu at <http://academic.regis.edu/ed205/Knowles.pdf>

CHAPTER - 8.0

2.1 Leverage and Linkages - Support Groups and SHGS

Session: 2.1	Leverages and Linkages- Support Groups and SHGs
Learning objectives of this session	Participants learn about: Participants learn about: • Leverage and Linkages. • Support Groups. • Self-help Group. • Process of linkages and formation.
Duration	1 Hour
Tools	Lecture, Power Point Presentation, Flipcharts, Sketch pen
Methodology	Participatory

Instructions to Facilitators

This session will involve Participatory learning. The facilitator is expected to engage the participants to brainstorm and present their understanding of Support groups & SHGs, Approaches to linkage & formation.

Support Groups

Activity: 1

20 Minutes

Participants are divided into three groups and asked to discuss on indicated questions.

Case Situations:

- Sam has recently been diagnosed with HIV and since his diagnosis, he has been experiencing stress and anxiety. He has also been on OST and is making good progress. His wife Grace feels he needs more social support.
- Raja has lost his job as he was diagnosed as HIV positive during their company annual check-up. He does not understand what to do and is often found sitting alone in his house. He has stopped interacting with anybody.
- Mala is 19 year old girl from a small village in Tamil Nadu. She got married to a 52 year old man working in the city. He sold her to the brothel and now she is forced to work as a sex worker. She is feeling very low and is having fever over past two weeks.
- Paro is a 23 year old transgender woman who makes her living from sex work. After her TB diagnosis, she was advised to undergo HIV test; the result of her HIV test was confirmed to be positive. This diagnosis has caused a major worry in the mind Paro as she is worried that if her Guru Shanthamma learns about her status, she may ask her to leave. Paro thinks about this all the time and has not yet registered for ART. Paro is a TI client of CBO Rainbow Friend, who also have PLHIV support group called Roshini.
- Veena is a 23 year old woman who is diagnosed as HIV positive when she went for check-up for pregnancy. She is very upset and does not know what to do. She joined her husband 2 months ago to stay in a small home at Ghaziabad. He is a truck driver and most of time out on duty. She has lost her appetite and keep crying most of the time. She is scared that she will be thrown out of the house. Laxmi Didi a Social Worker at the urban health center is aware about Veena’s situation. Her son is a volunteer at a PLHIV network.

Questions

- Any support groups in the community that participants are aware of where the KPs \ can be referred?
- How can the support group help the KP?
- How to leverage the support group?



Allow the groups to share their discussion points on these cases for up to five minutes.

Facilitator's Role

The facilitator leads the discussion after the activity and adds information missed. Identify where leveraging and linkage can be created.

Lecture Content for the Facilitator

Understanding Leverage and Linkage

Leverage is the ability to influence situations, people and resources for getting the desired results. In our field of work, not one organization or person is equipped to provide all the possible situations; during such a time in order to provide maximum support to a KP/PLHIV, you seek support from another CBO or Program, that called leveraging. For example: A CBO working with PLHIV leverages social protection and entitlement program to provide maximum support to them. In order to leverage social entitlements, they also provide necessary support for paper work and identification. Process of facilitation enables linkage. Other forms of leveraging is, utilizing discounted rates of medical diagnostics for the benefit of KPs and/ or but not limited to food grains by another organization or charity.

Linkage means the action of joining or linking one thing/entity/people to another thing/entity/ people for the desired support. Change in that linked thing/entity/ people will lead to a change in another thing/entity/people linked to them. Some of the linkage examples are as follows:

1. H/TG linked to the schemes for TG persons.
2. FSWs linked to the livelihood programs.

In the activities that were discussed above, leveraging and linkages were created with the support groups.

Coordination for Leverage and Linkages

To be able to coordinate for leverage and linkages, the Community Champions and CBOs working for KPs and PLHIVs need to be visible to the relevant stakeholders such as officials and health care providers DAPCU, ICTCs, ART centers and even to the community members and CBOs working in the field. The visibility can be achieved by creating a social media handle, web page where they can put a short bio-data and the work they undertake. Other means of visibility are personal interactions with the community leaders/ representatives, opinion leaders and the CBOs. Attending key community and CBO events also enhances visibility.

Co-ordination for leverage and linkages is both communication and interaction based. Writing letters along with the necessary paper work and in person submission, regular follow ups enables coordination. DPACU enables monthly meetings with the CBOs, where key issues can be highlighted. Documentation and clear articulation of the problems and barriers go a long way in achieving the successful outcomes of coordination.

Principles for Leverage and Linkage

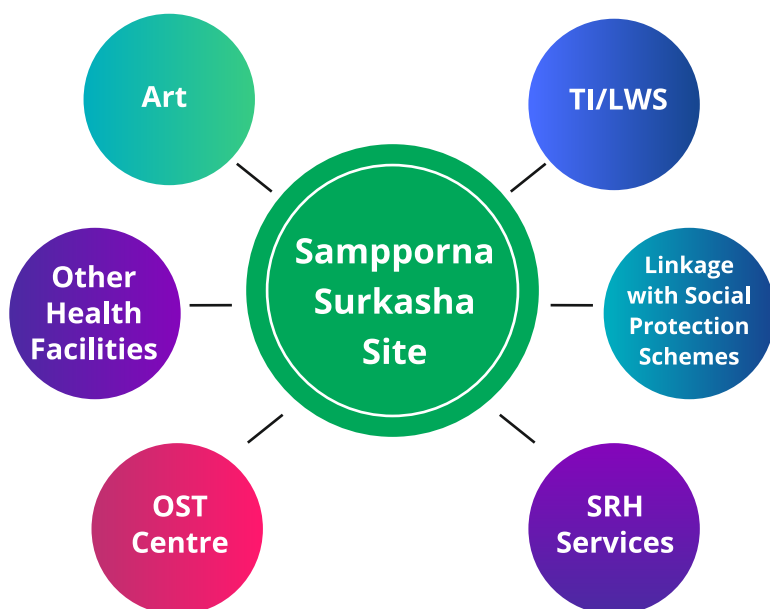
- 1. **Mapping:** Internet search of govt. website, district and city govt. websites, NGO/CBO directories, Websites like India Mart, Just Dial, Practo, CSR organizations or foundations & even the social media handles of stakeholders and institutions that can be utilized. Map the right people and institutions for leverage and linkage.
- 2. **Develop resource directory:** Based on the “Search and Identify” a directory of most relevant resources needs to be made.
- 3. **Connecting:** Once the right stakeholders are identified, then you can start connecting with them for leveraging and linking KPs and PLHIV.

If the search or effort to connect or link fails, then only you proceed towards “creating”, for example: in a place lack of a support group for only PLHIV Women may require a CBO to create a support group for this group.

Leverage and Linkages under Sampoorna Suraksha Strategy

Currently, Sampoorna Suraksha Strategy (SSS) is being introduced at 75 facilities in the first phase, followed by an additional 75 facilities within two and half years in the identified districts/ states. Sampoorna Suraksha Strategy (SSS) is designed to include a holistic set of services customized as per clients’ needs, with strong linkages and referrals with other services and social security schemes, rigorous outreach and follow-ups with clients, leveraging virtual platforms through various apps and other sources. The strategy will undergo mid-course correction and redressal of barriers as they are identified during implementation. The Community Champions and CBOs belonging to districts where SSS is being rolled out should proactively leverage and link KPs and PLHIV under this strategy.

Referral Services under Sampoorna Surkasha Strategy



Support Groups

Lecture Content for the Facilitator

Defining Support Group

Support groups are groups in which you can share your experience, problems and ways to solve them. For many people living with HIV, a support group is the first place where they acknowledge to another person that they are infected and where they come face-to-face with other people who are positive.

Benefits of a Support group

Meeting other people who share the same concerns, fears and medical issues can reduce the power of HIV-related stigma.

In a group, people can:

- Examine what behaviors they want to change.
- Understand how ready they are to initiate change.
- Develop strategies for change.
- Receive reinforcement and encouragement from the group.

Participation in a support group gives PLHIV hope.

Importance of Support Groups

Support groups and organisations help people in many ways:

- They allow people to talk freely and express their feelings and concerns in a safe situation
- People make friends in groups, to call on help and support when the group is not running. People who are excluded by their community can recreate 'family' and community networks through support groups.
- Support group can provide advice and new skills e.g. negotiating safe sex, relationship skills, treatments, dealing with discrimination, immigration, prosecution for transmission, how to manage HIV and side effects.
- Groups provide structure for life: This is particularly important for people who are depressed or feel 'stuck' e.g. because of immigration issues/ victimization.
- Can get a referral e.g. Medical and other services
- Can get practical help e.g. Skill training, financial assistance, help with transport, help with contacting professionals.
- People can see that there are people better and worse off than themselves and being somewhere in the middle can be a comfort.
- Can share in cultural traditions, such as food, talking in your native language, and discussing your religion.
- Can socialise for enjoyment e.g. parties, singing.
- Help with caring for children e.g. through care centre, or helping people to talk to children about HIV.
- Can discuss whether you should tell others about your HIV, as well as how to tell others.

List of support that can be leveraged from Support groups

- Knowledge about the disease.
- Knowledge about care and treatment services.
- Knowledge about treatment adherence, home-based care and opportunistic infections.
- Knowledge on social entitlements.
- Skills on dealing with difficult situations (eg. stigma and discrimination associated with infection).
- Advocacy regarding better policies.

Steps to start a Support Group

Step:1 People

After you have decided that you want to start a support group, identify two or three persons who share your interest in starting (not simply joining) a support group.

Step: 2 Planning

You will need to decide quite a number of things before the first meeting of your group, such as the funds, frequency, location and emphasis of the group. Decide how often your group will meet.

Major types of support groups are as follows:

- Peer Support groups:** Groups led by others with similar interests. Usually these groups are not led by a professional. A professionally led support group: These groups are led or advised by a professional like a social worker or psychologist.
- Discussion group:** Not necessarily a support group, but a group with an educational focus to it. These groups may have a video or a speaker or topic each meeting. These groups may also provide a time where individuals can discuss issues of interest and concern to them to see if others have suggestions or have experienced a similar situation.

Step: 3 Place Decide on a central location accessible via public transportation if possible. With the same location, people always know where to go.

Step: 4 Publicity Publicity is crucial to a beginning support group. It is important to leverage all available media (especially free outlet). Make up a flier announcing the meeting. Give KPs the basics - date, location, time, and a brief description of the purpose of the group. Remember, if you're putting the flyer up in a public place you may have only *2.3 seconds to get a passerby's attention, so use large type and few words. In your flyers, you have to assure people of confidentiality and privacy of such a support group.*

Step:5 Programming

If your meeting is strictly a support group meeting, you will want to go around and check in with everyone and then begin the meeting using whatever model you choose.

Plan a time for people to meet and greet either before or after the meeting, and make sure that people don't leave without signing up with their address and telephone number. Not only does this keep your mailing list up to date, but it also allows your follow up with your support group members. Minutes of the activities of the support group have to be maintained. Core members have to create a small corpus by contributions from members as well as by applying for support grants.



Sources: <https://healthtalk.org/hiv/hiv-support-groups>
<https://allianceindia.org/beyond-worries-vihaans-plhiv-support-groups/>
<https://socialwork.buffalo.edu/content/dam/socialwork/home/self-care-kit/tips-for-starting-a-support-or-discussion-group.pdf>

Self Help Group

Activity: 2

12 Minutes

The participants are divided into four groups and instructed to discuss the case of some successful self-help group run by the key population.

Case Situations:

- **Paneer HIV Positive Women's Network Trust**, also called **Paneer Poo**, is a registered public charitable trust founded by a team of HIV positive women. Originally it was formed as a women self-help group part of Blossom, who practiced savings and micro credit. It has now turned into a forum for women living with HIV/AIDS in Virudhunagar District who are in need of care, console and counseling support in order to face the social stigma and swim against cultural undercurrents of Indian culture.

- **Mahila Abhivrudhi Samrakshne Samasthe (MASS)** is an institution of ex-devadasis in Karnataka. The ex-devadasi women were trained, formed into small SHGs and taught to manage their own lives. The organization MASS was registered as a Society in 1997 with the Board of Directors made up only by the ex-Devadasi members. MASS currently has a membership of 3,600 and raises funds from several sources. The Government of Karnataka granted MASS a plot of land on lease for its office and other training facilities.

- **Positive Women Network (PWN+)** is an All-India network of HIV positive women, focused on improving the quality of life of women and children living with HIV/AIDS. PWN organizes self-help group and support groups of women living HIV in seven States

- **Swathi Mahila Sangha** is a women led community-based organization which has 13,000-member base in Bangalore. The organisation addresses the needs of every sex worker, especially most marginalized. SMS devoid of any stigma and discrimination, aims to support the equity, equality, dignity, and empowerment of women in sex work. The objective of the organisation is to build capacities of women in sex work by enhancing their knowledge, skills, and attitudes in order to safeguard their lives and livelihood and mainstream the most marginalized women by providing health care services, financial security, social protection services and legal rights.

Allow different groups to share their discussion points on these cases for up to five minutes. The facilitator leads the discussion after the activity and adds information missed.

Facilitator to elicit response from the participants on the following:

Questions

1. What is a Self Help Group?
2. What is the purpose of the SHG?
3. How can this group help the key population in improving economic and health status?
4. What are the steps to form a Self Help Group.

Facilitator leads the discussion and shares the following content.



Lecture Content for the Facilitator

What are Self Help Groups?

Self-help Groups (SHGs) are informal associations of people who come together to find ways to improve their financial stability. They are generally self-governed and peer-controlled.

People of similar economic and social backgrounds associate generally with the help of any NGO or government agency try to resolve their issues, and improve their living conditions. As SHG is an informal group therefore registration under any Societies Act, State cooperative Act or a partnership firm is not mandatory vide Circular RPCD.No. Plan BC.13/PL -09.22/90-91 dated July 24th, 1991.

When is a Self-Help Group a strong and good SHG?

When they have following characteristics in place:

- Regular group meetings
- Attendance
- Savings
- Annual rotation of leadership
- High internal rotation of group funds
- Good repayment rate
- Properly maintained records
- Homogenous members
- Membership between 15-20
- Adherence to rules and regulations
- High member participation activities
- Efficient loan processing
- Basic literacy skills of members

Advantages of Self Help Groups

- **Financial Inclusion:** SHGs incentivise banks to lend to poor and marginalised sections of society because of the assurance of returns.
- **Voice to Marginalised:** SHGs have given a voice to the otherwise underrepresented and voiceless sections of society.
- **Social Integrity:** SHGs help eradicate many social ills such as dowry, alcoholism, early marriage, etc.
- **Gender Equality:** By empowering women SHGs help steer the nation towards true gender equality.
- **Pressure Groups:** SHGs act as pressure groups through which pressure can be mounted on the government to act on important issues.
- **Enhancing the Efficiency of Government Schemes:** SHGs help implement and improve the efficiency of government schemes. They also help reduce corruption through social audits.
- **Alternate Source of Livelihood/Employment:** SHGs help people earn their livelihood by providing vocational training, and also help improve their existing source of livelihood by offering tools, etc. They also help ease the dependency on agriculture.

- **Impact on Healthcare and Housing:** Financial inclusion due to SHGs has led to better family planning, reduced rates of child mortality, enhanced maternal health and also helped people fight diseases better by way of better nutrition, healthcare facilities and housing.
- **Banking Literacy:** SHGs encourage people to save and promote banking literacy among the rural segment.

Self-Help group for Key population

Self-Help Groups is conceived as a strategy to bring together women/ KPs from socially under privileged section of the society and empower them with information and opportunities for economic securities.

SHGs comprise of members who share the following:

- Local context.
- Life situation.
- Crisis

Overall, SHG members help other members while helping themselves.

SHG members who

- come together
- provide non-judgemental support
- provide an “instant identity”
- facilitate community to combat together
- enhance their social skills through participation and
- promote their social rehabilitation.

SHGs, beyond supporting economic activities also provide

- psychosocial support
- entitlement facilitation
- facilitation of credit access
- training for skill building etc.

Handouts

Participants are provided with copies of newspaper on SHG formed by key populations shown

Source:

<https://www.scirp.org/Journal/PaperInformation.aspx?PaperID=72745>

<https://swasti.org/wp-content/uploads/2018/03/HIV-and-Livelihood.pdf>

<http://www.nmdfc.org/WriteReadData/LINKS/g.pdf804d8edd-38c9-4600-8288-6f2d9c2b5a61.pdf>

“Guidelines for implementation of Micro Financing Scheme of NMDFC”



Image: 1

Kolhapur prostitutes' exclusive democracy

VIVEK WAGHMODE

KOLHAPUR, AUGUST 27

PROSTITUTES in Kolhapur have formed an organisation of their own, and elected a seven-member committee on Wednesday with Jyoti Shete as president.

Twenty-three members were contesting and 157 prostitutes participated in the elections to the posts of president, vice-president, secretary, assistant secretary, treasurer and two members.

The initiative for forming the organisation was taken by Pathfinder International's Mukta, an NGO working to empower prostitutes and enabling them to improve and gain greater control over their lives.

Suhel Jamadar, project coordinator of Mukta, said, "All 380 prostitutes enrolled are part of the organisation. The elected committee will run their democratic organisation. The election symbols were the candidates' own photographs. A team from Ashodaya Samithi, an organisation working for prosti-

tutes in Karnataka, is assisting us in this process. It had helped formed such an organisation in Mysore three years ago."

Rupa (name changed), one of the voters, said, "We have got our own platform now to raise issues that concern us."

Jamadar said, "Our work of NGOs for the cause of prostitutes and their children will continue till they get funding from national and international organisations. Sometimes the work stops after they have started several projects. To sustain the work are forming community-based organisations to enable them to fight for their cause. At the initial stage we will act as a guide and provide technical support. Later they will manage on their own," he said.

Votes were counted in the evening. Manda Chavan was elected vice president, while other members on the panel were Mumtaz Desai, Mumtaz Sheikh, Vimal Pawar, Sadhana Kamble and Surekha Pawar.

Formation of Self-Help Group

Activity: 3

12 Minutes

The participants are divided into 3 groups - FSW, MSM and PLHIV and asked to discuss and present the formation of self-help group in their community.

The activity can be concluded with the video of the true story of Lata Mane.



Sources: <https://www.youtube.com/watch?v=5zwxzamPQW0> Youtube link

Lecture Content for the Facilitator

Different Stages of SHG Development

Pre-formation (1-2 months)

Villages are identified where there is great need for intervention. Through the use of Participatory Rural Appraisal (PRA) methods like wealth ranking, village mapping and rapid appraisal of local savings and credit systems, NGOs are able to identify the potential group members in the village.

Formation (2-6 months)

Around 15-20 women collectively decide to form a group. They are motivated to form a group.

They select the group leaders and develop rules and norms for the group. Groups are encouraged to begin savings immediately after the group is formed. The salary for the accountant is initially borne by the NGOs. Group records and accounts are maintained with the assistance of a group accountant. NGOs assist in the group processes, promote an understanding of savings and credit concepts and operationalize the procedures and activities.

Stabilization Phase I (6-12 months)

Groups meet and save regularly. They increase the amount of savings once they gain confidence. They disburse loans among themselves and repay the loans. Repayment ethics are instilled in the members. Individual members who have difficulty with repayments are held accountable by the group. The group often responds by adjusting the repayment schedule or providing financial support to the member until she is capable of paying off her debt.

Group leaders informally interact with the leaders from nearby groups. At this stage of interaction, the group learns various aspects such as rules and regulations, problem solving, systems and procedures from the neighbouring groups. After one or two months of interaction, a cluster association is formed consisting of 15-20 groups from nearby

A cluster association is promoted by 10-20 SHGs which are in nearby villages. The major function of this association is promoting and strengthening the SHGs and giving long-term sustainability to groups by mutual support and cooperation. The association helps/guides the groups to mobilize funds from banks and strengthens the financial and managerial capability of the groups.

Stabilization Phase II (12-18 months)

Groups handle savings and credit transactions on their own. Norms of savings and lending are routinized. Norms are framed to regulate the behaviour of members — penalties are levied for any irregularity. Groups pay the salary of the group accountant.

At this stage, the group will have gained enough experience and discipline to manage the finances but the funds available in the group will be inadequate to meet the increasing demand. The group requires additional funds for supporting income-generating activities. The funds will be mobilized by linking the groups with banks. Some of the groups can get loans from the revolving corpus of the Swa-Shakti project being implemented by the Department of Women and Child Development, Ministry of Human Resource Development, Government of India.

Groups begin to address common issues in their community. These include improving living conditions such as accessing water and electricity, or improving the conditions of the roads leading to the village.

The interactions between the groups are formalized and the cluster association is formed. Regular meetings of the cluster association are held and attended by the leaders of the groups. The association appoints workers to implement their various activities and support the systems at group level.

NGOs reduce their direct interaction with the groups and the responsibilities are transferred to the group and cluster association as much as possible. However, the NGOs are available as resource persons for the groups and continue to provide training and capacity building inputs for leaders and local functionaries appointed by the cluster associations and groups.

Growth and Role Transformation (18-24 months)

During this phase, the linkage with the bank is intensified. If the group effectively utilizes and repays the first loan taken from the bank, it can take the second loan or increase its credit limit. Since limit of the loan amount is high, more members are encouraged to take loans to improve their economic activities. NGOs help in identifying suitable activities and stabilizing existing activities. Cluster associations will initiate special support activities for social and financial development of member groups.

Leaders take on greater responsibility to manage the activities of the cluster association. Groups focus on stabilizing the income generation activities of individual members. Groups form into a block level federation. Federations are formed, owned and managed by the primary groups. At the block level, 100-200 groups may form a federation. The purpose of forming a federation is to ensure sustainability of the groups and to provide continuity and economics of scale for the programme. Federations also establish alternate channels for credit support, especially for satisfying special credit needs of members such as housing, bigger income generation activities, etc.

The federation will appoint its own staff to extend support to the member groups. It will initiate collaboration with external institutions like Rashtriya Mahila Kosh for resource mobilization for further lending to the member groups. Collaboration with the government agencies helps to address the social and community development issues.

Each group independently manages its activities and interacts with banks and cluster level institutions. The older groups extend support to new groups in the nearby villages. They are a source of inspiration for the new groups. NGOs extend support for stabilization of federations of SHGs and formalize linkages with other institutions.



Source: <https://egyankosh.ac.in/handle/123456789/25768>

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10. <https://namati.org/network/member/swathimahilasangha/>
11. <https://www.pwnplus.in/about>
12. <https://www.blossomtrust.org/paneer-poo>
13. <https://www.youtube.com/watch?v=3EX0zo7PXEQ>
14. <https://www.youtube.com/watch?v=uCpYPScIMyY>

CHAPTER - 9.0

2.2 Linkage to Care: Addressing Barriers to Treatment and Adherence

Session: 2.1	Linkage to Care: Addressing Barriers to Treatment and Adherence
Learning objectives of this session	Participants learn about: • Barriers to treatment and adherence. • Encouragement strategies for ART adherence. • Care and Support linkages to help improve adherence . • Leveraging for Adherence support.
Duration	1 Hour
Tools	Power Point Presentation, Flipcharts, Sketch pen
Methodology	Participatory

Instructions to Facilitators

This session will involve Participatory learning. The facilitator is expected to engage the participants to brainstorm and present their experiential understanding the barrier to treatment and adherence and facilitating adherence. This module has pre-decided content which the facilitator is expected to revise beforehand and if need be, refer to the resources mentioned. Activities are conducted before the knowledge sharing via presentation. The facilitator is expected to weave the activity learning in the content.

Barriers to Treatment

Activity: 1

10 Minutes

Facilitator asks the participants what the barriers to treatment are. Note responses on the flip chart.

Facilitator's role:

Facilitator summarizes with the following points if not mentioned:

- Not knowing the status.
- Lack of knowledge.
- Lack of access.
- Stigma and discrimination.
- Fear of being isolated.
- Lack of knowledge about ART.
- Non availability of ART.
- Gender discrimination.



Social Determinants of Health and Root Causes of Non Adherence

Activity: 2

20 Minutes

The participants are divided into four teams. Each team is given a flip chart paper, markers and tape. Each group is instructed to draw a tree on their flip chart. The groups should label the trunk of the tree “Non-Adherence to Care” (for 2 groups) and “Non-Adherence to Treatment” (for the other 2 groups).

- The roots of the tree represent the root causes of non-adherence.
- The branches of the tree represent the consequences of non-adherence.

Facilitator’s role:

Facilitator to give the groups about 20 minutes to draw their adherence trees and encourage participants to think about:

- all of the root causes that affect adherence, including things related to us as people, to our communities and culture, to health services and to the medicines we take.
- what are the social determinants of health impacting adherence.

Facilitator should move around and assist each group.

After about 20 minutes, facilitator to ask each group to present their points and add further using following lecture content:

Lecture Content for the Facilitator

Factors Affecting Adherence

- Lack of knowledge about ART.
- Stigma related to ART.
- Side effect of ART.
- Lack of access to quality care.
- Pill size.
- Following a strict regime.
- Substance abuse including OST.
- Migration.
- Poverty.
- Lack of treatment literacy.

Among the KPs and PLHIV testing, treatment and adherence related factors are determined by the social determinants of Health.



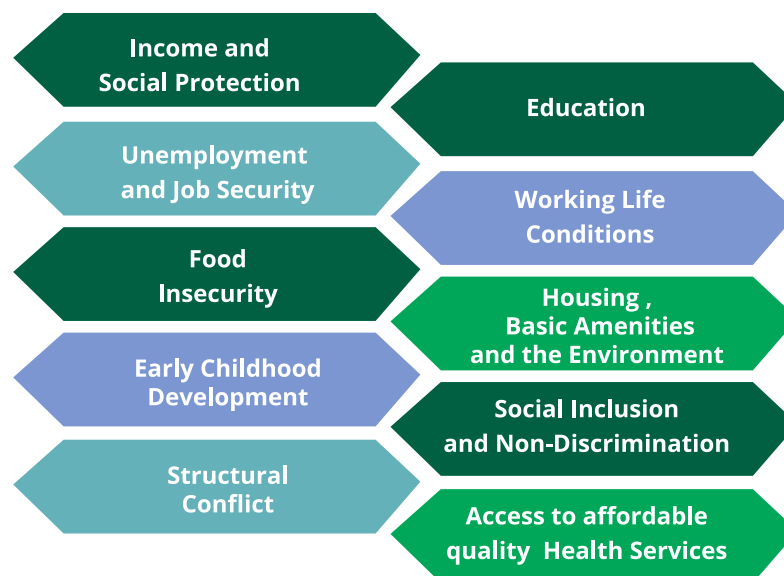
What are Social Determinants of Health?

The social determinants of health are the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics. These circumstances have an impact on the income, health and rights of the people.

Why should we learn about the Social Determinants of Health?

We should learn about the social determinants of health for a simple reason: the challenge of a health problem (for example: HIV is not driven by factors such as the lack of awareness, risk behavior or non-adherence to ART alone, but a multitude of factors which have a serious impact on how a person would access information and services. When Community Champions and CBOs are working to link KPs and PLHIV to various social entitlements, they are trying to address social determinants of health. These factors are presented in the picture below.

Social Determinants of Health



Source:

<https://www.lgbtqihealtheducation.org/wp-content/uploads/2020/12/LGBTQIA-patients-and-SDOH-screening.pdf>

Definition - <https://www.who.int/news-room/questions-and-answers/item/social-determinants-of-health-key-concepts>

Determinants of Adherence to Antiretroviral Therapy among HIV-Infected Patients

Patient and Family - Eg. With regard to children, if the mother (or other caregiver) is infected, then she is struggling with her own illness, psychosocial factors, medication regimens, and most often financial burden due to expenses incurred on her own therapy, child's therapy, and associated cost of medical treatment.

It is known that mothers tend to hide HIV infection status from their children and disclosure is often delayed until adolescence

Stigma-& Discrimination-Related Challenges

Social or family stigmatization and fear of the consequences of revealing HIV infection status to sexual partners are closely related to poor adherence. Family plays a crucial role in any kind of treatment in children or adults. Major issues related to family or caregiver that influence adherence include presence of anxiety; depression; active substance abuse; the presence of HIV infection in another family member. Non adherence due fear of disclosure during times when KPs are in the presence of family/ extended family at their hometown.

Stigma associated with HIV infection or AIDS may be more severe than that of other illnesses, creating barriers to treatment initiation and support for adherence that might otherwise be available

Substance Abuse Related Challenges

Drug use and alcohol consumption are factors that further threaten proper adherences to ART. Studies have consistently shown that active alcohol use and substance use makes it more difficult for patients to adhere to treatment eg. KPs missing a dose because of alcohol consumption (alcohol is highly related to reduced adherence)

Socio-economic Challenges

Poverty having a significant role as a social determinant of HIV/AIDS and the spread of the virus as well as access and adherence to ART treatment

Medication Related Challenges

Fear regarding side effects of medicines, size of pill, dietary restrictions (avoiding samosas and other fried/ spicy preparations), interference of medication schedule with lifestyle (drugs causing dizziness while working).

Health care and Systems related Challenges

Out-of-pocket expenses (for travel etc), health care providers' attitude. Apathy of health care providers – inability to understand that KPs long waiting time and opening hours (start time 9 am interferes with KP work schedule) means loss of daily wage; unavailability of proper counseling services, and social, economic, or psychological support. Lack of privacy of ART clinics and waiting areas.

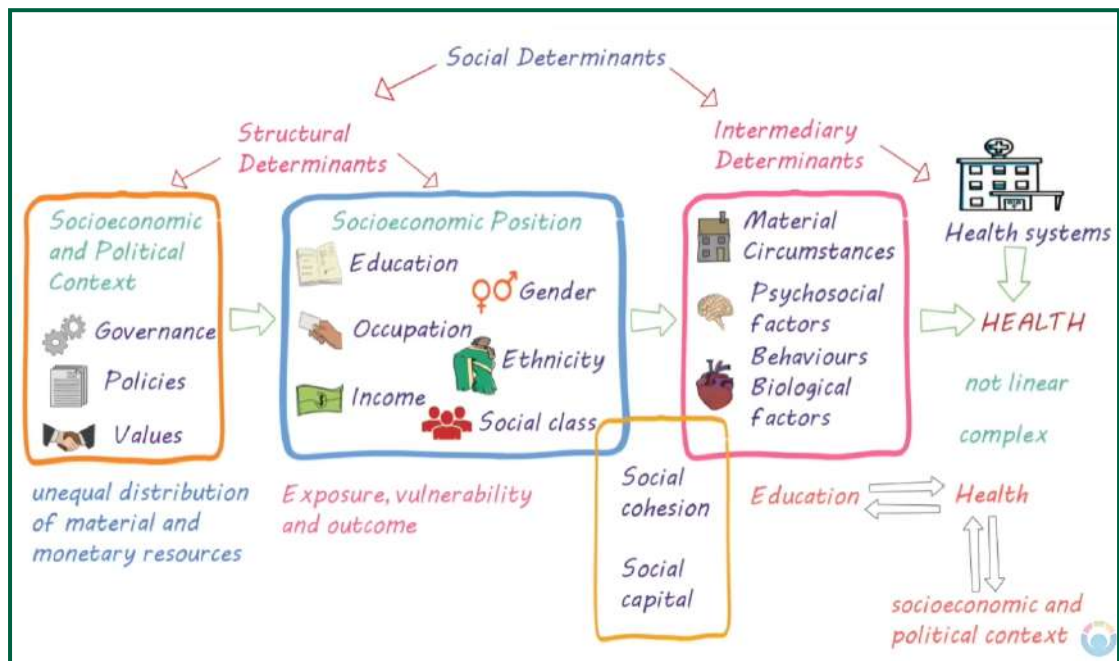
Lack of Efficient Adherence monitoring mechanisms

no centralized data for follow - up across the country.

Political Context

Inadequate focus on laws and policies impacting health of KPs eg. access to SRHR services not available to minors, without parent/ guardian; lack of enabling environment to access social entitlement schemes. Intermittent access to information/ data on HIV/AIDS.

Framework of Social Determinants of Health



Source:

<https://youtu.be/8PH4JYfF4Ns>
Social Determinants of Health

Factors influencing Adherence among Kps

Activity: 3

10 Minutes

The participants are divided into three groups to discuss and present on (H/TG, MSM, and PLHIV)

- Factors encouraging adherence among Key population.
- Encouraging messages for PLHIV to adhere to ART.

Facilitator's role:

The facilitator leads the discussion after the activity. After groups have presented facilitator can conclude with following points:

- Full and correct knowledge about the ART.
- ART=Lifetime commitment.
- Adherence strategies and tips.
- Pill box, alarms, reminder in cell phone.
- social support – partner, family or someone who supports the taking of medication;
- having disclosed being HIV positive;
- trust that the medication works – feel that health status improved;
- trust in health care providers;
- finding out through personal experience that interruption of treatment is not good;
- ability to take the medication routinely; and
- Valuing life.



Activity: 3

10 Minutes

- Anti-retroviral drugs are important to prevent the advancement of HIV, protecting the person from more serious health problems.
- It is important to never fail to take your medication in order to stay healthy, to have energy to work and live normally.
- It is important to continue taking the medication even if you already feel good. This prevents a person from becoming ill and helps maintain a low viral load.
- Taking ARV drugs does not prevent an infected person from transmitting HIV through sexual intercourse, but it can reduce the chances.
- You must use a condom even if you are taking ARV drugs to prevent HIV from passing to the other person.
- Praise them for good adherence.



Counselling for Adherence

Activity: 4

12 Minutes

The participants can be divided into 3 groups (PLHIV, MSM, and FSW) and each can discuss how they can counsel the key population for adherence.

Facilitator’s role:

The facilitator leads the discussion after the activity. After groups have presented facilitator can present following points:

Lecture Content for the Facilitator

Adherence Support to Kps

Step 1:

- Listen to their concerns;
- Do not judge
- Do not advise
- Provide support
- Do not argue

Step 2:

Talk to them about ART

- Goal of ART (U=U); what it does
- Talk about advantages of taking the treatment without fail; full and complete treatment
- Disadvantage of
 - Missing treatment
 - missing a pill;
 - Not regularly testing for CD4 count
 - Not following doctor’s advice
 - Clearing all the doubts regarding ART
 - Talking about side effects and report immediately to the clinic
 - Not taking across the counter medicines



**Activity: 4****12 Minutes****Do's and Don'ts while on ART**

- Importance of regular follow-up
- Ways to remind about taking pills (SMS, reminder in the phone)
- Correct and consistent use of condom
- Importance of nutritious food
- Importance of staying healthy
- Importance of some exercise
- How low immunity can increase the viral load
- Different foods to increase immunity

Step 3

- Helping the client to make realistic plan
- Going through all the issues which they may face and options in dealing with it
- Address of the nearby clinic, places where you get free condom, STI clinic, for injecting drug users where availability of OST
- If they miss to immediately go to the nearby clinic
- If have any other health issue take doctors advise and mention about HIV status
- Condom demo

Step 4

- Appreciate the client if they have adhered to ART
- Without blaming, understand what has made them not be regular
- Support them to overcome any hurdles
- State about the success stories of client from their community who have been regular with ART
- Repeat all points from step 2
- Show concern and care

Linkages and Leveraging for Adherenc

Activity: 5

12 Minutes

Participants are divided into three groups and given one case each. They are instructed to discuss on indicated questions.

Case Situation:

- **Shahana** is a home based sex worker. She is on HIV treatment; her work interferes with her medication regimen. She was told by the doctor that she could have the medication in the evening, after dinner, but she has been unable to keep track of it. That is the time she entertains her clients. Also, after the medication she feels dizzy and has a stomach ache. Whenever she has medication for stomach ache, she doesn't have the ART medication; she feels that it will spoil her liver. Many times, due to heavy drinking, she forgets her dosage. She knows it will affect her health, but doesn't know what to do. She will continue for 3 months with the dosage; then she feels she will stop. Kaun teen mahine se jyada davai leta hae? She has a fungal infection on her inner thigh since the past two weeks that has got aggravated.
- **Mumtaz** who identifies herself as a transgender woman is having a tough time with the site where she goes for Pun – its close to the creek and there are just too many mosquitoes; she has to drink before she even reaches there to bear the discomfort; There are sometimes more than 8 clients; she is not able to use the condom with every client for anal; She gets better paid for oral without condom. She did not reveal HIV status since she tested positive 11 months ago as her Guru will not allow her to be a part of the Dera if she comes to know about her status; Two months ago, she tested positive for TB (there was a swelling in the neck – she has to take medication for 10 months now; She is fed up; She avoids going for her scheduled visit to Link ART centre and avoids calls from counsellor; she thinks – now that I have HIV, i am going to die soon, so why should I bother with all these medications. She is fine with the TB medication; has stopped ART. Anjana, a 32 years old woman, stays with her 14 years old son and husband (alcoholic). He is HIV negative. Anjana was taking ART for the last three years. Her viral load was high. Her husband beats her after having alcohol. He takes care of the rent of the kholi. Her son works at the local hotel as a cleaner; earning is meagre. She is unable to eat adequate meals which gives acidity due to ART. She discontinues her medicine when her discomfort increases and restarts when she feels better.

Questions

- Where will the KP linked for better health outcomes (adherence to medication, viral load suppression, CD4 testing and OI management)?
- What linkages can be established for creating an enabling environment?
- What are the various areas which can be leveraged to increase adherence?



Post the presentation, facilitator takes lead and explains the following aspects:

Lecture Content for the Facilitator

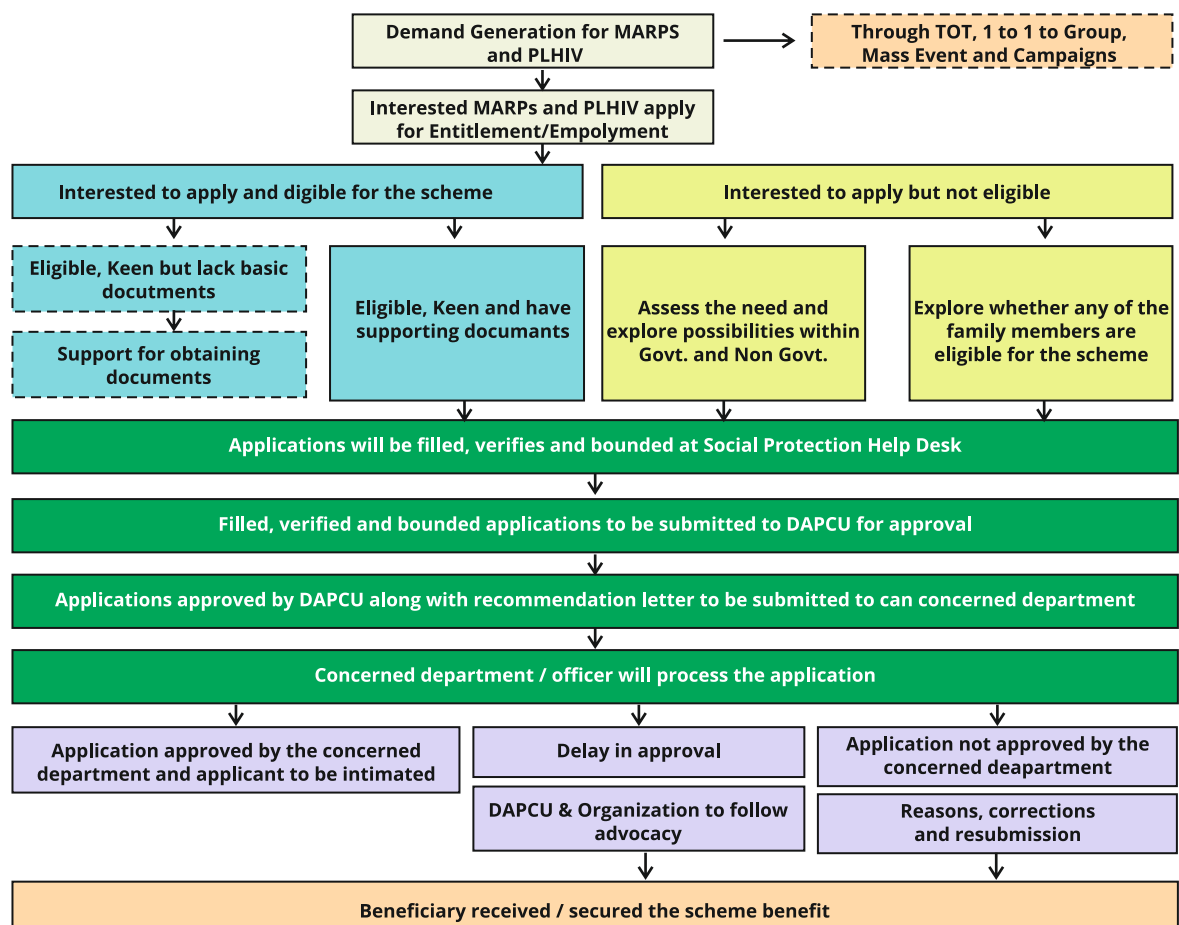
Linkages for HIV AIDS Treatment and Adherence Under District AIDS Protection Control Unit (DAPCU): Single Window Model

- Targeted Interventions (TI)
- Community Based Organizations (CBO)
- State & District Network of Positive People
- Integrated Counselling & Testing Centre (ICTC)
- Sampoorana Surakshaa Clinic
- ART Centre
- LinkART Centre
- Link Workers Scheme (LWS)
- Care & Support Centre (CSC) – (Document on Pan India list to be provided to the participants) - <http://www.naco.gov.in/care-and-support-centres-0>

Social Protection Helpdesk

The social protection helpdesk is established within the existing structure of facilities. The objective of the helpdesk is to sensitize the key population on HIV sensitive social protection generate demand and facilitate access to social entitlements (for example: voter Id card, Adhaar card, ration card, BPL card etc.). HIV social protection schemes are in the areas of nutrition, insurance, free transport, livelihood, housing, pension and other financial assistance, etc.

Social Protection Flow Chart



Areas for leveraging for better health outcomes

The Community Champions, CBO/NGO need to fully leverage following existing programs, institutions and helplines.

- **DAPCU:** Sharing of DAPCU led single window social protection model in all possible platforms in the district; accessing social protection helpdesk at each TI NGO, LWS, ICTC, ART, Link ART, STI Clinic, CSC, and SLN & DLN.
- **NACO Helpline 1097:** The helpline caters to all the population of India and is reachable from any mobile/landline number through a short code toll-free number 1097. Any information regarding HIV/AIDS knowledge, testing information and support services are available here.
- **NACO AIDS APP:** This free app is aimed at spreading awareness about HIV/AIDS and solve any queries of people. This app also has game feature to keep people engaged and aware.
- **Targeted Intervention (TI) Program:** Under the NACP, TIs are focussed on the high risk groups in a targeted manner. KPs can be linked to the TI for availing services which are as follows:
 - **Netreach and Safe Zindagi:** For those KPs who prefer virtual mode of getting information, the portals of these virtual interventions will enable them to get the required knowledge and services in the comfort and privacy of their home.
 - **Opioid Substitution Therapy (OST) under NACP:** OST is aimed at preventing HIV among PWIDs. There are 150 OST centers operational around the country.
 - **Private health sector:** Local lab facilities can be leveraged for confidential HIV testing at subsidized rates; train health workers to provide care and support for HIV AIDS infected KPs; possibility of Public Private partnership; information sharing between public and private healthcare providers to adhere to national treatment guidelines 95 and create data reporting mechanisms for uniform, consistent and cohesive HIV response of National program to reach 95:95:95 goal.
 - **Aanganwadi and ASHA workers:** They can assist in non-health needs of PLHIV and HRGs – linkages with NGOs providing support on Child rights and education.
 - **National, State and District level Networks of People living with HIV AIDS:** They can help in early detection of Partners/ Spouses and children of PLHIV – early initiation of treatment and retention in HIV care. Establishing linkages with projects like Vihaan, AHANA, Svetana.
 - **Technology to scale up testing and service outreach** – eg. eMpower from Vihaan (India HIV AIDS Alliance).
 - **Partnerships for fulfilling housing gaps / employment for people living with HIV** - This can be achieved through DAPCU and other organizations/ NGOS. DAPCU envisages providing not only a programmatic oversight to the HIV/AIDS programme implementation at the district level, but also focusing on mainstreaming and convergence with NHM and other stakeholders.

Services	New & High Priority HRGs	Medium Priority (Maintenance)	Stable (Champions)	HRG PLHIV
Contact (FSW, MSM & TG)	3 times a month	Twice a month	Once a month	Twice a month
Contact (IDU)	4 times a month	3 times a month	2 times a month	3 times a month
Clinic Visit/RMC	Each quarter	Each quarter	Half yearly	Referral to req. health services
HIV Testing	Once in six months	Once in six months	Yearly	-
Condom & Needle Syringes	Yes	Yes	Yes	Yes
Presumptive Treatment	Yes	Need based	Need based	-
BCC	Intensive DIC & Outreach Based	DIC	Hotspot Based	At facility
Priority service for PLHIV	-	-	-	ART Initiation & Adherence, Index Testing

Sources:

<https://youtu.be/CvXGCI8fu5>
Leveraging private health sector

<https://youtu.be/XCG9xGLumRE>
Leveraging couple relationship

<https://clinicaltrials.gov/ct2/show/NCT04298905>

<https://youtu.be/TWp2zkDHmCc>
Leveraging partnership to increase housing/ employment for PLHIV

<https://youtu.be/gN0VcGq7ze0>
Leveraging technology for care

Revamped and revised elements of Targeted Intervention for HIV Prevention and Care Continuum among Core Population
http://naco.gov.in/sites/default/files/TI%20Strategy%20Document_25th%20July%202019_Lowres.pdf

CHAPTER - 10.0

2.3 Coordination and Linkages for Social Entitlements

Session: 2.3	Coordination and Linkages for Social Entitlements
Learning objectives of this session	Participants learn about: • Social protection. • Various schemes for key population. • Alternate livelihood. • SMILE Act, 2022.
Duration	45 minutes
Tools	Power Point Presentation, Flipcharts, Sketch pens
Methodology	Participative

Instructions to Facilitators

This session will involve participative learning. The facilitator is expected to engage the participants to brainstorm and present their experiential understanding livelihood programmes and various Government schemes for key population. This module has pre-decided content which the facilitator is expected to revise beforehand and if need be, refer to the resources mentioned. Activities are conducted before the knowledge sharing via presentation. The facilitator is expected to weave the activity learning in the content.

Activity: 1

5 Minutes

Facilitator to ask the participants if they have heard about Social protection, and if they have what do they understand by the term. The responses of the participants are noted in the flip chart. The facilitators add the definition of the term Social Protection and its relevance for this training

Social Protection

Lecture Content for Facilitator

Meaning of Social Protection

- Social Protection refers to public interventions to assist individuals, households and communities to manage risk better and that provide support to the critically poor.
- Social and legal protection includes access to rights and entitlements which may be in the areas of nutrition, healthcare, shelter, health insurance, legal aid, travel support, pension.

Importance of Social Protection

- HIV and AIDS can push people and households into poverty, in part by reducing household labour capacity and increasing medical expenses.
- Children affected by HIV/AIDS (CABA) have many factors that currently deter or prevent them from benefiting essential health care, education and other social welfare services provided under the Government of India schemes.
- Girls orphaned by HIV tend to be more socially vulnerable and are at enhanced risk of abuse and exploitation.
- In the govt. set up, while the ART is free, there are other costs like transportation, loss of wages during the health consultation days and family expenses. Therefore there is a need for regular income for the PLHIV to meet their escalating expenses.
- National AIDS Control Programme in India, with technical support from UNDP, has been focusing on improving access of the PLHIV to the existing social protection schemes. Efforts have been made to adapt the existing schemes to include PLHIV (HIV-sensitive) as well as to initiate new schemes that directly address the issues of PLHIV (HIV-specific).

By providing Social Protection, some of the aspects of social determinants of health are addressed. This may lead to better outcomes for HIV/AIDS therefore Community Champions and CBOs have to protectively promote social entitlements and encourage KPs and PLHIV to avail these benefits.

Source:

https://www.undp.org/content/dam/india/docs/reducing_vulnerabilities_key_social_protection_schemes_from_a_plhiv_perspective.pdf

[http://www.naco.gov.in/sites/default/files/Guidance%20Note%20-%20DAPCU%20LED%20SINGLE%20WINDOW%20MODEL%20\(3\).pdf#:~:text=%E2%80%9CDAPCU%20led%20Single%20Window%20Model%20for%20Social%20Protection,access%20of%20benefits%20of%20inclusive%20and%20exclusive%20schemes.](http://www.naco.gov.in/sites/default/files/Guidance%20Note%20-%20DAPCU%20LED%20SINGLE%20WINDOW%20MODEL%20(3).pdf#:~:text=%E2%80%9CDAPCU%20led%20Single%20Window%20Model%20for%20Social%20Protection,access%20of%20benefits%20of%20inclusive%20and%20exclusive%20schemes.)



Activity: 2

15 Minutes

The participants are divided into five groups and handed cards which has cases of people living with HIV who have successfully availed social protection of Government of India.

Case Situation:

Chitra is 32-year-old woman who lost her husband to HIV, she has two children and she learns that she is also positive. She is not educated.

Magesh 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. 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.

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.

Savita is a 25 year old agriculture labourer. When Savita was expecting her second child during her 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.

When **Sudha** was 33 years old that her husband died of AIDS, and she subsequently tested positive for the virus. She has 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.

Questions

- How can you help the Kps?
- Under what schemes can they apply.
- Documents required to apply under the said schemes.

Questions

- What seems to be the situation here?

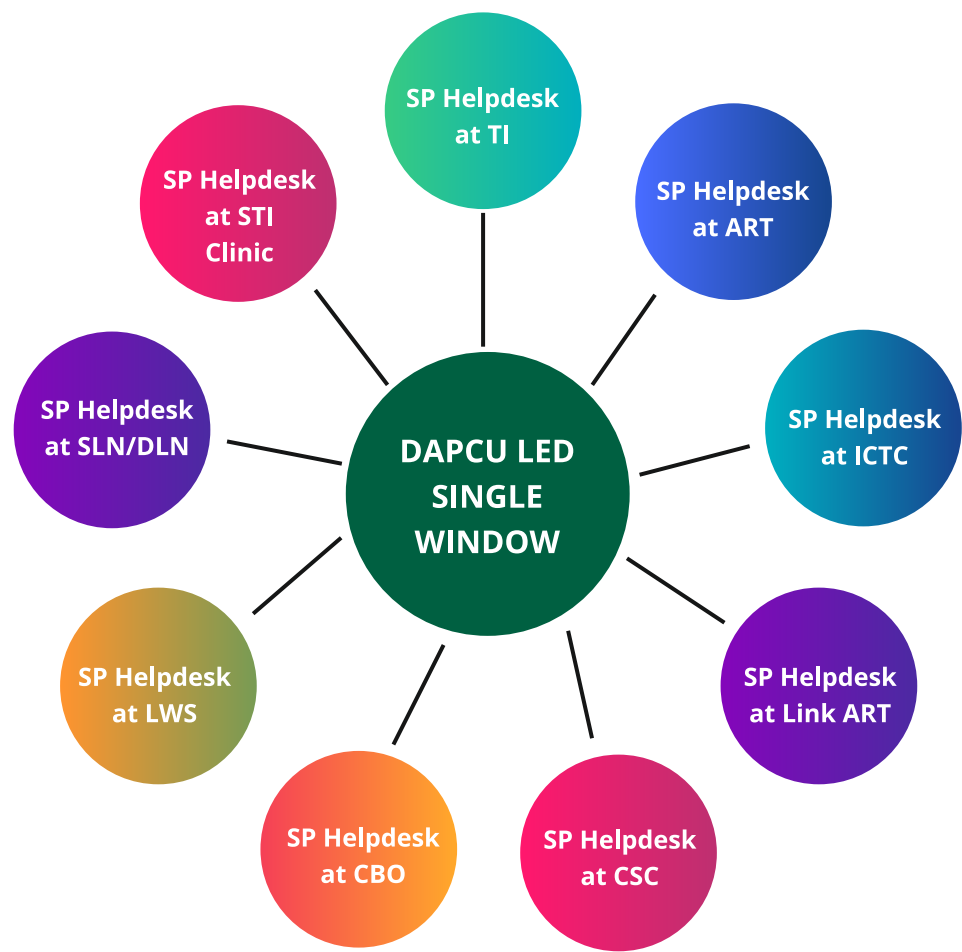


Source:

https://www.undp.org/content/dam/india/docs/social_protection_that_works_for_plhiv_a_compendium_of_case_studies_from_8_states.pdf

Single Window Model

The District AIDS Prevention and Control Unit (DAPCU) led “Single Window” model for social protection is envisaged to improve the accessibility of entitlements and schemes by the infected and affected communities. The single window model intends to facilitate entitlements and schemes provided by the State and Central Government to all eligible People living with HIV (PLHIV), Children Affected by AIDS (CABA) and Most at Risk Population (MARPs)



HIV/AIDS related facilities and services in the district will be provided through service centres for social protection:

- Targeted Interventions (TI).
- Community Based Organizations (CBO).
- State & District Network of Positive People.
- Integrated Counselling & Testing Centre (ICTC).
- Sampoorana (STI) Clinic.
- ART Centre, Link ART Centre.
- Link Workers Scheme (LWS).
- Care & Support Centre (CSC).

Barriers faced by the PLHIV in accessing the schemes



Activity: 3

10 Minutes

Facilitator to ask the participant “what are the problems faced by the PLHIV in accessing the schemes.”

Facilitator’s role:

The facilitator leads the discussion. Participants are asked to reflect and facilitator will note down the responses in the flip chart.

Lecture Content for the Facilitator

- Lack of knowledge.
- Absence of valid documents.
- Apathy of the Government officials.
- Stigma and Discrimination.
- Lack of time.
- Repeated visit to the office.
- Have to pay bribe.
- Financial constraints.

The discussion can be summarized using following points:

Every District Level Networks conduct Support group meeting. The basic requirement to be a member of the support group is minimal amount of fees, regular attendance of the meeting, CD4 count report.

Through CBOs awareness drives and advocacy on government schemes, handholding for entitlements can be organized. The Community Champions can help KPs connect with the concerned department for required services.

Partnerships between organizations with shared objectives can lead to combined approaches to community-led service delivery and joint operational support. For example organizations may work together on financial and other resource mobilization, shared planning and delivery of activities and services, shared use of community-based facilities or shared procurement of health and other commodities.



Source:

http://naco.gov.in/sites/default/files/National_%20Report_Social_Welfare_Scheme.pdf

Linkage Role for Community Chmapions, CBO/NGO via Sampoorna Suraksha Strategy

- Currently Sampoorna Suraksha Strategy (SSS) is being introduced at 75 facilities in the first phase, followed by an additional 75 facilities within two and half years in the identified districts/ states.
- Sampoorna Suraksha Strategy (SSS) is designed to include a holistic set of services customized as per clients’ needs, with strong linkages and referrals with other services and social security schemes, rigorous outreach and follow ups with clients, leveraging virtual platforms through various apps and other sources.
- The strategy will undergo mid- course correction and redressal of barriers as they are identified during implementation.
- The Community Champions and CBOs belonging to districts where SSS is being rolled out should proactively leverage and link KPs and PLHIV under this strategy.



CHAPTER - 11.0

2.4 Non-HIV related Health Linkages for Comprehensive SRH Services

Session: 2.4	Non-HIV related Health Linkages for Comprehensive SRH Services
Learning objectives of this session	Participants learn about: • Sexual and Reproductive Health and Rights • SRH needs of KP and PLHIV population • Barriers in SRH services faced by KP and PLHIV population • Understanding transition needs of Transgender persons
Duration	1 Hour
Tools	PPT; Activity; Discussion; Lecture
Methodology	Participative

Instructions to facilitators

This session will involve participative learning. The facilitator is expected to engage the participants to brainstorm and present their understanding of non-HIV related health linkages for comprehensive SRH services and needs of the key populations.

Lecture Content for the Facilitator

Understanding Sexual and Reproductive Health and Rights

Good sexual and reproductive health is a state of complete physical, mental and social well-being in all matters relating to the reproductive system. It implies that people are able to have a satisfying and safe sex life, the capability to reproduce, and the freedom to decide if, when, and how often to do so. To maintain one's sexual and reproductive health, people need access to accurate information and the safe, effective, affordable and acceptable contraception method of their choice. They must be informed and empowered to protect themselves from sexually transmitted infections. And when they decide to have children, women must have access to services that can help them have a fit pregnancy, safe delivery and healthy baby. Every individual has the right to make their own choices about their sexual and reproductive health.



Source:

<https://www.unfpa.org/sexual-reproductive-health#readmore-expand>

What is Sexual Health?

When viewed holistically and positively:

- Sexual health is about well-being, not merely the absence of disease.
- Sexual health involves respect, safety and freedom from discrimination and violence.
- Sexual health depends on the fulfilment of certain human rights.
- Sexual health is relevant throughout the individual's lifespan, not only to those in the reproductive years, but also to both the young and the elderly.
- Sexual health is expressed through diverse sexualities and forms of sexual expression.
- Sexual health is critically influenced by gender norms, roles, expectations and power dynamics.

Sexual health needs to be understood within specific social, economic and political contexts.

Rights critical to the realization of sexual health include:

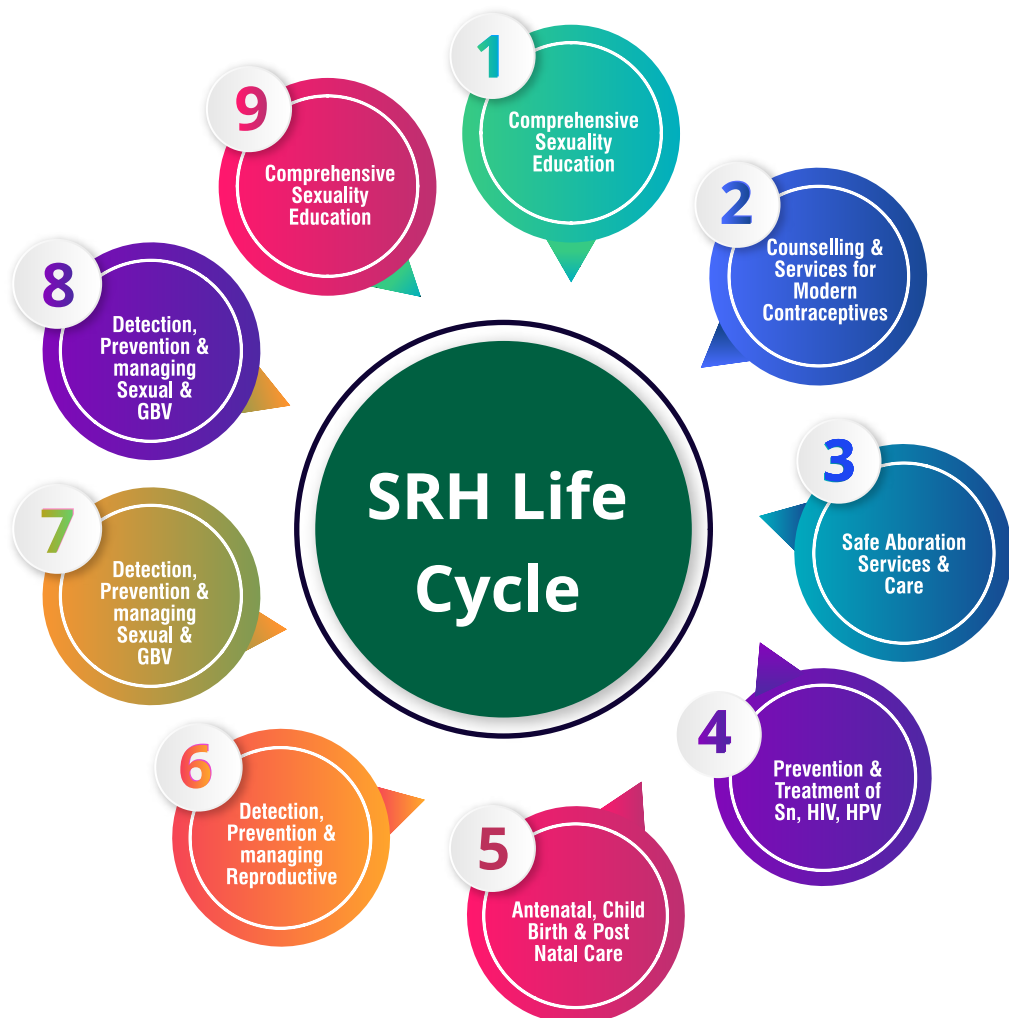
- Rights critical to the realization of sexual health include:
- the rights to equality and non-discrimination
- the right to be free from torture or to cruel, inhumane or degrading treatment or punishment
- the right to privacy
- the rights to the highest attainable standard of health (including sexual health) and social security
- the right to marry and to found a family and enter into marriage with the free and full consent of the intending spouses, and to equality in and at the dissolution of marriage
- the right to decide the number and spacing of one's children
- the rights to information, as well as education
- the rights to freedom of opinion and expression, and
- the right to an effective remedy for violations of fundamental rights.



Source:

<https://www.who.int/teams/sexual-and-reproductive-health-and-research/key-areas-of-work/sexual-health/defining-sexual-health>

Sexual and Reproductive Health Life Cycle



Activity: 1

10 Minutes

Participants are divided into 5 teams and asked to discuss on the SRH needs of:

- A. Female sex workers
- B. Men having sex with men
- C. Transgender / Hizra
- D. PWIDs
- E. PLHIVs

Each team then presents their thoughts.

Facilitator's role:

The facilitator leads the discussion after the activity. After the teams have made their presentations, the facilitator summarises, stating the SRH needs of KPs and PLHIV.



Activity: 1**10 Minutes****Lecture Content for the Facilitator****Why Should Community Champions and CBOs learn about Sexual & Reproductive Health Rights (SRHR)?**

While the KPs and PLHIV have a challenge of HIV, their other needs especially the ones related to sexual and reproductive health are many and require care and services. SRH services often become the entry point for ensuring the health and well-being of communities we work with.

**SRH needs of KPs and PLHIV****(A) Female sex workers**

- Family planning information, counselling and services, including emergency contraceptives.
- Prevention and treatment of STIs (including HIV) and RTIs.
- Antenatal, post-partum and delivery care and infant care.
- Safe abortions and post-abortion care.
- Prevention and treatment of infertility and sexual dysfunction.
- Diagnosis and treatment of cancers of the reproductive system.
- Addressing harmful practices and its affect.
- Addressing gender-based violence against FSW from police, partner, client and others.
- Negotiation skills for condom usage with the clients.
- Cervical cancer related screening and linkage to care.
- HPV Vaccination.

(B) MSM

- Family Planning information and contraceptives (if married to women or bisexual).
- Counselling about various safer sex practices.
- Condom promotion and lubricant usage.
- Counselling for sexual dysfunction, infertility.
- STI and HIV related services.
- Addressing violence from partner, police and family members.
- Facing Stigma and Discrimination challenges

(C) H/TG

- Counselling for gender identity related needs.
- Safer sex practices and behaviour
- Transition counselling, evaluation.
- Feminisation services.
- Sexual reassignment surgery related support and post-operative support.
- Counselling about various safer sex practices.
- Condom promotion and lubricant usage.
- STI and HIV related services.
- Gender based and sexual violence related support services.

(D) PWID

- Family Planning information and contraceptives.
- Counselling about various safer sex practices.
- Condom promotion and lubricant usage.
- Counselling for sexual dysfunction, infertility.
- Safe abortion services.
- ANC, Child Birth and PNC services.
- STI and HIV related services.
- Cross cutting issues emerging from sexuality, gender identity.
- Sexual violence against women PWID.

(E) PLHIV

- Family planning information, counselling and services, including emergency contraceptives.
- Prevention and treatment of STIs (including HIV) and RTIs.
- Antenatal, post-partum and delivery care and infant care.
- Safe abortions and post-abortion care.
- Prevention and treatment of infertility and sexual dysfunction.
- Diagnosis and treatment of cancers of the reproductive system.
- Addressing harmful practices.

**Source:**

<https://www.who.int/hiv/pub/guidelines/sexualreproductivehealth.pdf>

https://nhrc.nic.in/sites/default/files/sexual_health_reproductive_health_rights_SAMA_PLD_2018_01012019_1.pdf

Barriers faced by the KP accessing SRH services

Activity: 2

12 Minutes

Case Situations

Roger is a married man and also secretly have sex with a regular male partner. He has pain while urinating and he goes to a Government STI clinic.

Raba is married and she and her husband are diagnosed with HIV; she does not want to get pregnant and goes to Government hospital to get contraceptive.

Rani is a female sex worker and she is pregnant; she goes to Government hospital for antenatal care.

Abdul is a gay man having regular and casual partners. His regular partner learnt about his sexual behaviour with respect to casual partners. He started hitting him and accused him of cheating. His partner also threatens to out him and is demanding that Abdul has to have sex with him and his friends.

Rosy is experiencing vaginal bleeding and severe pain during sex. She is been advised by her gynaecologist to go to Government hospital for cervix screening. Rosy is also living with HIV.

Barry and Lucy have recovered from their substance use addiction and want to start their family; Lucy is 8 weeks pregnant. There is a strong opposition from their family towards Lucy's pregnancy and they are pressurising Barry and Lucy to abort the child.



The facilitator leads the discussion on barriers and what linkages can be created in case of each of these case situations. Also develop KP and PLHIV wise linkage model for both urban and rural area. Teams are asked to reflect on the output of each group. Facilitator can add points that may have been missed.

CHAPTER - 12.0

2.5 Linking Orphan and Vulnerable Children to Support Services

Session: 2.5	Linking Orphan and Vulnerable Children to Support Services
Learning objectives of this session	Participants learn about: • Participant learn about • The issues of children who are orphan and vulnerable • Linking OVC Children to Care
Duration	30 Minutes
Tools	Power Point Presentation
Methodology	Discussion

Instructions to facilitators

This session will involve participative learning. The facilitator is expected to engage the participants to brainstorm and present their experiential understanding of networking, relationship management and managing community dynamics. This module has pre-decided content which the facilitator is expected to revise beforehand and if need be, refer to the resources mentioned. Activities are conducted before the knowledge sharing via presentation. The facilitator is expected to weave the activity learning in the content.

Activity: 1

10 Minutes

Case Situations

Year 2019

Ronald Hanglem age 34, and his wife **Rose Hanglem**, age 32 live in a small town of Manipur with their two daughters age 12 and 2 years. In past Ronald and Rose were injecting drugs and are now on opioid substitution therapy and are living with HIV. Ronald also has Hep C infection and Rose has XDR TB due to which they are not keeping in good health. Hanglem family does not have any extended family to support them and are in poor financial shape.

Year 2021

Ronald and Rose die in May 2021 due to Covid-19 infection, leaving their daughters, now 14 and 4 years behind. The NGO where Ronald and Rose were linked for support are looking after their daughters, however their future is uncertain as the current NGO is not experienced in working with children and also does not have resources to take care of young girls.

Questions

Assess the situation of daughter of Ronald and Rose
Discuss what needs to be done for these children?
Questions

What seems to be the situation here?
What are the possible reasons for this situation?
What can be done about it?



Case Situations

Shanno, a brothel based female sex worker is living with HIV. She has a 15 old son and a 13 years old daughter. Her son identifies as a girl and is often seen hanging out with local TG/ Hijra women who are also into sex work. Her daughter attends local municipal school. Brothel owner **Shamabai** is aware about Shanno's ill health (she is not adhering to her HIV medication) and unlike other sex workers who were diagnosed with HIV, she has not asked Shanno to leave brothel and allowed her to stay on this condition that she will adopt Shanno's daughter.

Questions

Assess the situation of Shanno's children?
Discuss what needs to be done for her children

Allow different groups to share their take on these cases for up to five minutes.

Issues of Orphan and Vulnerable Children

Lecture Content for Facilitator

Children, irrespective of whom they are born to and where they are, have an inalienable right to survival, protection and development. Parents, society and state institutions have a moral as well as legal responsibility of protecting children's rights. Home is a safe haven for children which comes under tremendous pressure due to their parent's health condition. Children have to shoulder adult responsibilities and often leave their education in order to look after their sick parents or younger siblings. In marginalized sections of the society, children also bear the financial responsibilities of their family. In the year 2021, 64,400 in the age-group 0-14 years were living with HIV. CBOs and NGOs working with Orphan and Vulnerable children have outlined following risks to children of PLHIV:

1. Children if living with HIV/AIDS experience an overall impact on their quality of life due to their HIV status.
2. Children are at a risk of developing health complications if parents are unable to look after them.
3. Children are at a risk of childhood illnesses arising out of lack of nutrition due to poor socio-economic condition.
4. Children are denied survival, protection and development rights when they have to shoulder adult responsibilities.
5. Children are also at the increased risk of being homeless.
6. Children are vulnerable to sexual abuse and trafficking therefore are vulnerable to HIV.
7. Orphan and vulnerable children living with HIV have increased chance of developing mental health related disorders

Support required by Orphan & Vulnerable Children within the framework of "Child Rights"

- Provide temporary shelter to young children and their sick parent.
- Psychosocial support through counselling.
- Nutrition support.
- Linkage to HIV and non-HIV Medical care.
- Education support.
- Life Skills Education (LSE).
- Rehabilitation and reintegration.
- Protection of their family and property entitlements.
- Addressing local level community stigma against OVC children.
- Linkage to social entitlements.
- Linkage to legal agencies and National Commission for Protection of Child Rights



Source:

<https://www.unicef.org/child-rights-convention/convention-text-childrens-version>
<https://data.unicef.org/topic/hiv/aids/emtct/>
https://www.unaids.org/sites/default/files/media_asset/jc637-globalframew_en_0.pdf

Community Champions and CBOs' role in supporting Orphan and Vulnerable Children

- Identifying and assessing children's vulnerability in the PLHIV or KP community.
- Taking steps to protect such children by taking their families in confidence.
- Establishing linkages with NGOs having experience and expertise of working with orphan and vulnerable children living with HIV/AIDS.
- Linking children with existing government schemes that addresses and protect interest and rights of children living in crises.

CHAPTER - 13.0

2.6 Linkage for Mental Health Support

Session: 2.4	Linkage for Mental Health Support
Learning objectives of this session	Participants learn about: • Importance of Mental Health • Provide linkage for Mental Health
Duration	45 minutes
Tools	Power Point Presentation, Flipcharts, Sketchpens
Methodology	Participatory

Instructions to facilitators

This session will involve participative learning. The facilitator is expected to engage the participants to brainstorm and present their experiential understanding of networking, relationship management and managing community dynamics. This module has pre-decided content which the facilitator is expected to revise beforehand and if need be, refer to the resources mentioned. Activities are conducted before the knowledge sharing via presentation. The facilitator is expected to weave the activity learning in the content.

Session Introduction

Ask the participants what they understand by mental health and their responses are noted in the flip chart. The facilitator summarizes with the definition of Mental Health

Defining Mental Health:

Mental health is understood as a state of well-being in which

- A person realizes his or her own potential
- A person can cope with the normal stresses of life
- A person work productively and fruitfully,
- A person is able to make a contribution to her or his community



Activity: 1	10 Minutes
The facilitator divides the participants into four groups and gives them a case each for discussion. They are instructed to discuss what are the behaviors they find not “normal” in these cases. One of the group members is to be nominated by the group to present it.	

Allow different groups to share their take on these cases for up to five minutes.

Case Situation:1

An FSWs aged 29 wanted to change her residence and gave money to the broker for new accommodation. The broker promised to get her a house but her repeated call and messages were unanswered. Later her number was blocked by the broker. She gets anxious and stops eating and does not get sleep; wake up with dreams of being thrown out of house. She stops taking her anybody's call and switch off the phone. She does not cook nor does she come out of her home. She does not accept any clients. She does not accept any clients and fights with her agent.

Case Situation:2

A man aged 32 was cheated by his partner and now the partner refuses to have any contact with him. The partner told him that he is going to get married so wants to end all the relation. The client is unable to accept it and goes and stands outside the building of the partner and keeps calling him. The client was also told by the police not to disturb the partner, but he refuses to listen to anybody and after having alcohol screams and shouts creating disturbance among the residence. He befriends a man with whom he has sex, but the partner was very violent making him sick and scared.

Case Situation:3

A woman aged 52 was not keeping good health for a month, she was advised by her doctor to go HIV testing. She got the result as positive and does not know how to tell her adult sons about the result. She wakes up at night sweating and is not able to concentrate on any household activities. She gets jumpy when somebody touches her. She also gets irritated when anybody asks her if something is wrong. She does not feel like getting up and doing any work.

Case Situation:4

H/TG raised by family with very supportive environment and completed graduation. V applied for a job knowing third gender is recognized by government; got selected by one company as a clerk. First day in the office V was not welcomed by her office colleague. V faced rejection and insult from first day itself by staff; after a month of torture, she quit the job. She has decided to quit home and join a gharana – no hope of societal acceptance; family is very upset and put a condition that is she does so, they would disown her; no property rights will be given to her. She does not know what to do and she makes a fake Facebook account and put her sister's photo. She writes all lie about herself as being a working woman in a big company and doing very well. She gets lot of pleasure and starts living in that world detaching herself from her family and friend.

Case Situation:5

A man who is positive and on ART is suddenly violent with his wife he beats her and tells that God told him to beat her as she will then get away from all the sin she has committed. He says that God talk to him and tell him that is only way human can be pardoned of all the sins.

The man- not the client

Once all the group presentations are over the facilitator shares pointers for warning signals

Lecture Content for Facilitator**Signs to look for**

- KP is unable to sleep or is sleeping the whole day
- KP has stopped going for parties; avoids his friends and family; usual activities – dressing up, watching TV shows, keeping cleanliness
- Having low or no energy - lying down on the bed the whole day; absenting from work/ college; looking as if completely shattered
- Feeling numb or like nothing matters – when you ask him “*kaisa lag raha hae*” answer is – “*kuch nahi lagta*”
- Feeling helpless or hopeless- *Mere haath mei kuch nahi; mera kya hoga?; sab khatam ho gaya.*
- Feeling unusually confused, forgetful, angry, upset, worried, or scared – *Gharwali mujhe nikaal degi, aur mere sar par chat nahi hogi; mera dimaag kam nahi karta – kya karu samajh nahi aata; pata nahi kaise, aaj kal sab bhool jaata hae – kal stove on reh gay, dal jal gayi aur parson galti se darwaaze par lock lagaana bhul gaya. Mere pathi ne mere saath aisa kyu kiya? Mae uski zindagi tabah kar dunga; Mujhe phir se us giraak ke saath jaana hoga- uske niji aang mei juen hae.*
- Yelling or fighting continuously with family and friends – *baat baat par baras padtaa hae – isko har kisis se takleef hae – kisi se bhi nahi banti.*
- Experiencing severe mood swings that cause problems in relationships – *kabhi to bohot acchi banti hae, kabhi lagtaa hae dayan ka roop hae.*
- Having persistent thoughts and memories you can't get out of your head – *mere dimmag se uska khayal jaata hi nahi – bas uska hi chera baar bar mun mei aakar dukh detaa hae* *Hearing voices or believing things that are not true – Tume mujhse aisaa kyu kaha ki tumhare se kitni badboo aati hae? Maene abhi abhi suna aur tum keh rahe ho ki kuch nahi kaha! Mere kya kaan baj rahe hae?*
- Thinking of harming yourself or others – *mae uska jeena haram kar dunga; khud ko khatam karne ke alaawa aur kuch nahi sujhtaa.*
- Not being able to perform daily tasks like taking care of your kids or getting to work or school – *aaj chutti kar lo, mae dabba nahi de sakti; chaar din se office nahi gaya – aaj bhi dil nahi kar raha.*

Activity: 2

15 Minutes

Divide the participants into 4 groups and ask each group to list out 3 issues/ situations where person attempted suicide. Facilitator will talk about the causes, associated risks, signs of suicidal ideation, immediate response, dos and don'ts. Time allotted is 5 mins for discussion and two mins per group for presentation. Once all the group presentations are over the facilitator shares pointers for warning signals.



Case Study

Sumi lives with her mates in Pinjra system of Mumbai. She is in this trade for last few years. She is young and in demand hence most of her clients hire her on contract for month or more and take her with them to outstation locations. She is very scared to go out with such clients for long days as they force her to go with multiple men, they do not use condoms and also beat her. She drinks a lot and also adds cigarette ash to the drink: *“nashaa accha chadtaa hae; sab sehne ki himmat aati hae”* She has no help or support in the new place and finds herself helpless. She doesn't take interest in anything and mostly talks that she doesn't want to live like this: *“aisa jeena bhi kya jeena”*.

She has been getting into frequent fights and gets violent over small things. Sometimes she suddenly starts crying.

Four days ago, she gave away her favorite dress to Anusuya and said, *“iski ab mujhe zaroorat nahi”*. While going to the temple, she suddenly started walking in the middle of the road – people started shouting and Anagha pulled her towards the side.

Yesterday, she was very gloomy and stayed in bed all afternoon; today she is singing and ironing her clothes and laughing at the Kapil Sharma show jokes on You- Tube.

Discussion: The case is expected to tap underlying suicidal ideation of Sumi, with a lace of depression. She has hope to live a better life and will lead a good life if she gets support from someone).

Lecture Content for Facilitator

Signs to look for:

- Excessive sadness or moodiness: Long-lasting sadness, mood swings, and unexpected rage; unmotivated
- Hopelessness: Feeling a deep sense of hopelessness about the future, with little expectation that circumstances can improve; feeling trapped
- Sleep problems.
- Talking about suicide — for example, making statements such as *"ab jeene ka dil nahi,"* *"kash jab mae bahar jaau mujhe truck kuchal de "* or *"ab kya reh gaya...sab khatam ho chuka hae"*
- Winding up – giving away personal belongings; prized possessions; saying goodbye as if never going to meet again
- Having mood swings, such as being emotionally high one day and deeply discouraged the next
- Increasing use of alcohol or drugs
- Doing risky or self-destructive things, such as using drugs or driving recklessly.

Lecture Content for Facilitator

The Facilitator will share appropriate responses for providing emotional support:

Immediate response suggested:

- Directly speak to the individual and ask if she feels suicidal.; ask the person if they have any plan to commit suicide. ; ask if she has tried before; extract a promise- *"aisa kuch bhi karne se pehle ek baar mujhse milogi/ baat karogi promise karo"*
- Don't be judgemental.- *"aisa mat karo; ye paap hota hae"*
- Alert near and dear ones that you feel that the person is at risk (other cohabitants etc)
- Try and see that the person is not left alone for some days.
- Give them motivational materials to read or watch. – prayer book; watsaap video msg
- Connect them to support group, let them feel that they are not alone.
- Encourage professional help. – *"Ek didi hae; bohut accha lagega unse milkar; mae lekar jaa saktaa hu; vishwaas kar; ek baar milke dekho"*

Activity: 3**10 Minutes**

Ask the participants if any the above symptoms are visible where the person should go; whom should he/she consult?.

If the group have not come out with the reply that the person should consult a psychiatrist/ psychologist, facilitator must suggest this and also explain that all the Government hospitals have a psychiatric department and many NGOs also have visiting psychiatrist.

The participants are divided into three groups and they discuss the factors leading to substance abuse among PLHIV, FSW, and MSM. They present their discussion and the facilitator summarises the discussion.

1. Stress related to their issues like
 - Stigma and discrimination
 - Non-Acceptance by Family
 - miss guidance on homosexuality by untrained doctors
 - Lack of self-awareness especially about sexual orientation [who I am by sexually]
 - Shame and guilt feeling
 - Poor access to health care due to social stigma and sexual practices
 - Low self esteem
2. Peer pressure
3. Force by the client
4. Fight with partners
5. Relationship problems
6. Personality disorder
7. Violence from partner, police, local gundas
8. Financial problems

In addition to the psychiatric department of Government hospitals there are NGOs working for substance abuse for example Kripa Foundation.

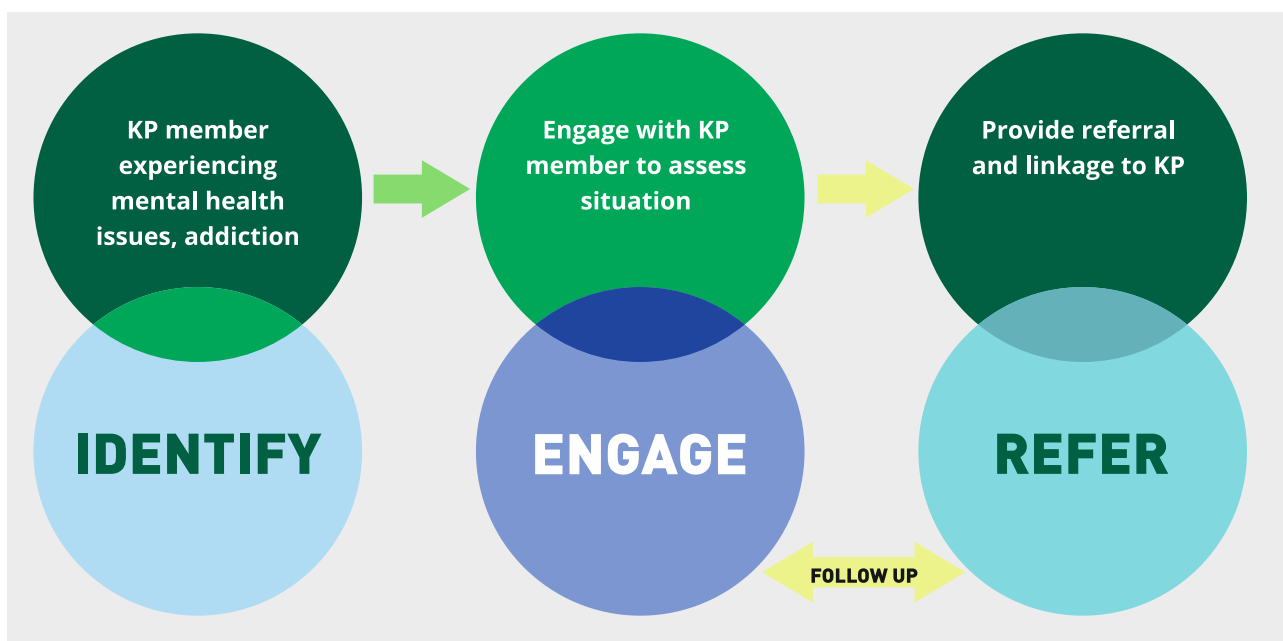


Lecture Content for Facilitator

Signs to look for:

- Excessive sadness or moodiness: Long-lasting sadness, mood swings, and unexpected rage; unmotivated
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- Winding up – giving away personal belongings; prized possessions; saying goodbye as if never going to meet again
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- Doing risky or self-destructive things, such as using drugs or driving recklessly.

IER Role of Community Champions and CBOs



Community Champions and CBOs have to bear in mind that while a KP member is dealing with mental health or addiction related challenges, his/her/ their other unmet health and social needs might be co-existing, thus they will need to proactively work to address those needs. This could be done by them by providing assisted or unassisted referral and linkage to care. Both Community Champions and CBOs will have to develop their district level resource directory for being able to provide referrals and linkages.

Linkages and Referrals by Community Champions, CBOs



Annexure

Examples of Schemes, implementing agency and Documents required for various schemes for PLHIV

1. Indira Awaas Yojana is a Government of India social welfare program to provide housing for the rural poor in India.

Implementing agency : Flagship scheme of the Ministry of Rural Development implemented by District Rural Development Agencies (DRDAs) / Zilla Parishads on the basis of allocations made. The Gram Sabha will select the beneficiaries

Documents Required

- Caste Certificate
- Ration Card
- Any other documents specified by the Gram Sabha

2. Prime Minister's Rozgar Yojana (PMRY) Prime Minister's Rozgar Yojana (PMRY) provides self-employment to educated unemployed youth. The scheme aims at assisting eligible youth in setting up self-employment ventures in small-scale industry, service and business sectors.

Implementing agency: At the grass root level District Industries Centre Small Industries Service Institute located in the metropolitan cities are the implementing agencies for the scheme

Documents Required

- Proof of date of birth (SSC certificate or transfer certificate from school where one studied).
- Certificate of qualification (academic and technical).
- Ration card or any other proof of residency for three years (such as residential certificate issued by an MRO).
- Experience certificate, if applicable.
- Income certificate issued by an MRO of the concerned mandal.
- Caste certificate issued by an MRO, if applicable
- Driving license, in case the candidate is applying for motor vehicles.
- A copy of the Proposed Project Profile.

3. Mahatma Gandhi National rural Employment Guarantee Act (MGNREGA):

Mahatma Gandhi National Rural Employment Guarantee Act (MGNREGA) is a social security scheme launched by the Government of India, which seeks to provide employment and livelihood to rural workers in the country. MNREGA is an employment scheme that aims to provide social security in rural India by guaranteeing a minimum of 100 days of paid work per year.

Implementing Agency:

Gram panchayats, district panchayats, line departments (PWD, Forest Dept.) and NGOs. A Programme Officer is to coordinate the implementation of NREGS at the block level.

Documents Required for NREGA Job Card

- Aadhar Card
- Ration card
- Bank account
- Passbook
- Passport size photo

4. Swarnajayanthi Gram Swarojgar Yojana (SGSY): Swarnajayanthi Gram Swarojgar Yojana is an employment programme designed to stimulate self-employment activities and ensure that every assisted below poverty line (BPL) family – Swarojgar – is able to earn a minimum monthly income of Rs. 2,000/- within three years.

It aims to achieve this objective by encouraging families to engage in income-generating activities and by providing assistance through a combination of wages, technical capacity building and a package of financial assistance that includes institutional credit and subsidy

Implementing Agency: SGSY is being implemented by the District Rural Development Agencies (DRDAs), with the active involvement of Panchayati Raj Institutions (PRIs), the Banks, the Line Departments and the Non-Government Organizations (NGOs).

5. Swarna Jayanti Sahakari Rozgar Yojana (SJSRY) The key objective of the scheme was to provide gainful employment to the urban unemployed or underemployed through the setting up of self-employment ventures or provision of wage employment.

Implementing Agency: Department of Urban Development

6. National Maternity Benefit Scheme : The objective of the scheme is to improve pregnant women nutritional intake during the pregnancy.

Implementing agency:

- Nagar Palikas
- Hospitals
- Primary health centre
- Anganwadi centres

Document required:

- White Ration card
- BPL card

7. Janani Suraksha Yojana: The scheme has been designed to encourage poor women to opt for institutional deliveries that contribute to the reduction of infant and maternal mortality.

Implementing Agency: National Rural Health Mission

Documents Required

- Ration card

8. Rashtriya Swasthya Bima Yojana (RSBY): The objective is to provide protection to BPL households from financial liabilities arising out of health shocks that involve hospitalization.

Document required:

- Ration card

9. Antyodaya Anna Yojana (AAY): AAY was a step in the direction of making TPDS aim at reducing hunger among the poorest segments of the BPL population. The main objective of this scheme to target those population who sleeps without two square meals a day.
Implementing Agency: Public Distribution system

Documents Required

White Ration Car

10. Free Transport to PLHIV for ART

Some of inclusive and exclusive schemes operational in various states in India, which have high relevance for PLHIV:

[Inclusive – PLHIVs included in the existing social protection schemes. Exclusive – Social protection schemes that are exclusively made for addressing specific needs of PLHIV]



Sources:

https://www.allianceindia.org/wp-content/uploads/2014/09/AllianceIndia2014_hiv_compendium_.pdf
https://www.undp.org/content/dam/india/docs/hiv_sensitive_social_protection_a_four_state_utilisation_study.pdf

Sr. No.	Name of the State	Name of Scheme	Ministry/Dept. responsible	Remarks
1	Gujarat	Tibibi Sahay (Medical Help)	Dept. of Social Justice and Empowerment	Inclusive Scheme
2	Andhra Pradesh	Apathbandhu (Accident Insurance) Scheme	Govt. of Andhra Pradesh	Inclusive Scheme
3	Odisha	Chief Ministers Relief fund	Govt. of Odisha	Inclusive Scheme
4	Uttar Pradesh	Mukhyamantri Garib Arthik Madad Yojana (Chief Minister's Financial Assistance Scheme for the poor)	Govt. of Uttar Pradesh	Inclusive Scheme
5	Karnataka	CABA Financial Support	Dept. of Women and Child Welfare	Exclusive Scheme
6	Karnataka	Star Health Insurance Scheme	PSI	Exclusive Scheme
7	Nagaland	Nutritional Support for Women	Directorate of Women Development, Govt. of Nagaland (State)	Exclusive Scheme
8	Goa	Dayanand Social Security Scheme for PLHA	Dept. of Social Welfare, Govt. of Goa	Inclusive Scheme
9	Tamil Nadu	Orphan and Vulnerable Children Trust	Govt. of Tamil Nadu	Exclusive Scheme
10	Andhra Pradesh	Sahara Card	APSACS	Exclusive Scheme
11	Odisha	Mo Kudiya (My Hut) Housing Scheme	Ministry of Rural Development	Inclusive Scheme
12	Rajasthan	Palanhaar Scheme for CABA	Government of Rajasthan	Exclusive Scheme
13	Rajasthan / Karnataka	Palak Mata Pita Scheme (Scheme for people who adopt HIV positive orphans)	Government of Rajasthan and Karnataka	Exclusive Scheme
14	Assam, Gujarat, Karnataka, Himachal Pradesh, Maharashtra, West Bengal, Goa, Sikkim	Travel Concession on road transportation to PLHIV for ART	Ministry of Surface Transport and States and private sector	Exclusive Scheme
15	Gujarat, Karnataka, Maharashtra, Mizoram, Punjab, West Bengal	Orphanages	Ministry of Women and Child Development	Inclusive Scheme



Source: <https://swasti.org/wp-content/uploads/2018/03/Social-Protection.pdf>

Example of Aastha Parivar Alternative Livelihood Programme Alternative Livelihoods

Aastha Parivar Alternative Livelihoods Program aims to create a self-sustaining method of income generation for the CBOs and the key population (KP) sex workers within their communities.

The project has been running since the organization's inception and offers alternative livelihood possibilities to sex workers and their children through educational courses. To date, we have facilitated a range of practical courses including; making and selling chocolate, phenyl, agarbattis, chutneys and other goods; as well as training in mehndi, tailoring and beautician services.

Additionally, vocational training is offered to CBO members on management and income generation skills. So far, over 600 community members have been trained in vocational skills, with many going on to start their own small businesses to support themselves and their families.

Courses Offered Under the Alternative Livelihoods Program:

- Practical Courses:
- Kolhapuri chappals
- Rakhi making
- Lantern making
- Chocolate making
- Phenyl
- Agarbattis
- Imitation jewellery
- Vocational Courses:
- Mehndi
- Tailoring
- Beautician
- Management
- Income Generation



Source:
<http://aasthaparivaar.org/our-work/alternate-livelihood/>

SMILE scheme- Support for Marginalized Individuals for Livelihood and Enterprise

Key Points

About: SMILE scheme is set to provide welfare and rehabilitation to the Transgender community and the people engaged in the act of begging.

Objective: SMILE Scheme aims to provide comprehensive welfare and rehabilitation measures to the Transgender community and the people engaged in the act of begging.

Ministry: SMILE Scheme is a central sector scheme, designed and being implemented by the Ministry of Social Justice and Empowerment.

Fund Allocation: The Ministry has allocated Rs. 365 Crore for the scheme from 2021-22 to 2025-26.

SMILE scheme- Key Features

National Portal & Helpline: It will provide necessary information and solutions to the problems of the Transgender community and the people engaged in the act of begging.

Sub-Schemes under SMILE Scheme: There are two sub-schemes under the SMILE Scheme- Central Sector Scheme for Comprehensive Rehabilitation for Welfare of Transgender Persons' and 'Central Sector Scheme for Comprehensive Rehabilitation of engaged in the act of Begging'.

SMILE scheme- Sub-schemes

Central Sector Scheme for Comprehensive Rehabilitation for Welfare of Transgender Persons: It provides Scholarships for Transgender Students studying in IX and till post-graduation to enable them to complete their education.

It has provisions for Skill Development and Livelihood under the PM-DAKSH scheme. Through Composite Medical Health, it provides a comprehensive package in convergence with PM-JAY supporting Gender-Reaffirmation surgeries through selected hospitals.

The Housing facility in the form of 'Garima Greh' ensures food, clothing, recreational facilities, skill development opportunities, recreational activities and medical support etc. to the Transgender community and the people engaged in the act of begging.

The Provision of Transgender Protection Cell in each state will monitor cases of offenses and ensure timely registration, investigation and prosecution of offences.

The National Portal & Helpline will provide necessary information and solutions to the Transgender community and the people engaged in the act of begging when needed.

Central Sector Scheme for Comprehensive Rehabilitation of engaged in the act of Begging: It will focus on Survey and identification, Mobilization, Rescue/ Shelter Home and Comprehensive resettlement.



Sources:

<https://www.adda247.com/upsc-exam/smile-scheme-a-scheme-for-transgender-and-beggar-community/>

Notes

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Hindustan Latex Family Planning Promotional Trust

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Uttar Pradesh - 201307

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