Stigma Busters: Empowering and enabling local governance to work towards stigma-free Gram Panchyat

Swasti Health Resource Centre

Because of high levels of stigma and discrimination, people living with HIV (PLHIV) rarely participate openly in community-level political and social discussions that affect the implementation of programmes, schemes and policies. Until now, the potential for Panchayat Raj Institutions (PRIs), India’s local governing bodies, to influence community perceptions and responses around HIV-related stigma had not been utilized. This project was successful in training and mobilizing Gram Panchayat (GP) members to lead stigma reduction efforts in five communities and to create a platform for ongoing dialogue between the Panchayat and PLHIV. This initiative was part of a larger effort to adapt and pilot test a global stigma reduction framework to the Indian context. 1

Implementation

Knowing the community

Swasti conducted a mapping exercise to understand the power structure within the Panchayat system and the roles, needs and aspirations of its members as well as of other key stakeholders. These included health department representatives, teachers, Anganwadi workers, the police and other local leaders. Swasti also conducted a baseline survey among Panchayat members, other community stakeholders and PLHIV to understand their level of awareness about HIV-related stigma as well as their attitudes and perceptions toward PLHIV. They found high levels of misconceptions about HIV, yet a strong willingness to take action against stigma and discrimination.

Project highlights

- This was the first programme in India to target and engage the Gram Panchayat (GP) system in HIV-related stigma reduction efforts in rural communities.
- Panchayat members and community leaders took on the role of ‘Stigma Busters’.
- The project succeeded in creating a sustainable space and time within the existing GP platforms for discussion between Panchayat members and people living with HIV.
- While the key focus on transformation was GP members, the project also build a cadre of community members to monitor action and to support GP members to perform their role.
- The District AIDS Prevention and Control Unit and the District Administration expressed interest in replicating the model in other Panchayats.

RESPONDENTS CATEGORY

<table>
<thead>
<tr>
<th>NO. OF RESPONDENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grama Panchayat members and staff</td>
</tr>
<tr>
<td>Other key stakeholders (health service providers, teachers, AWW, police, PDS, local leaders)</td>
</tr>
<tr>
<td>People living with HIV</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

Skill transformation

The project team aimed to institutionalize capacities to deal with stigma and discrimination within communities including the local Panchayat and service infrastructure. This would ensure a steady and sustained pool of active members during and beyond the study period. A sensitization training workshop was conducted separately for Panchayat members and other stakeholders. A total of 44 individuals across five villages participated, engaging in discussions on the facts around HIV and AIDS, forms of stigma, facilitators and actors who stigmatize, manifestations of stigma and discrimination and the roles and responsibilities of community leaders to reduce stigma against PLHIV. Additionally, 14 PLHIV were trained in leadership skills and 12 community members trained to be ‘Stigma Busters’, which included the use of a community monitoring mechanism to report stigma against PLHIV.

Swasti found that what triggers the participation of the Panchayat in a community issue is “pride, visibility and benefits to their electorate”.

Ensuring collective decision making and meaningful roles

The project team fostered the co-creation and joint implementation of a plan of action against stigma and discrimination. The Panchayat played the leadership role while giving other stakeholders meaningful roles to play, such as setting the agenda, allocating resources and active participation in implementation. The existing fora of the Gram Panchayat such as members’ meetings and Gram Sabha (village meetings) were used for planning, implementing and monitoring the initiative.

Taking action

The Gram Panchayat members, in collaboration with other stakeholders, Swasti and community youth, conducted a stigma reduction campaign in each of the five villages. Panchayat members passed a formal resolution against stigma and discrimination directed at PLHIV, which was painted on walls in the five villages. They formally endorsed the current stigma reduction initiative and engaged the media to publicize their efforts. These activities served to sensitize people about HIV and stigma, while creating an enabling environment for PLHIV.

Key outcomes

Pre- and post-surveys with Panchayat members (N=22) and other community leaders (N=30) suggest improvements in knowledge, awareness and attitudes. For example, knowledge of the four modes of HIV transmission among Panchayat members increased from 14% to 57%. There was a similar level of improvement among the other stakeholders. Although high at baseline, awareness of stigma in both groups rose after the intervention. Additionally, there were substantial reductions in blaming different groups for spreading HIV (Figure 2).

Lessons learned

• Panchayat members have great influence in the community and can be excellent role models for fostering reductions in stigma. However, strategic guidance and implementation support will enable GP to move faster from intent to sustainable action.
• It is essential to have a transparent framework of engagement with GP, clarifying the intention of supporting GP and its subsidiaries to become successful entities, as this will foster trust between Panchayat members and a facilitating organization such as Swasti.
• To work effectively with PRIs, implementing organizations and researchers should remain neutral and should not intervene in PRI internal affairs.
• Due to self-stigma, PLHIV may not take a leadership role at the onset, highlighting the importance of empowering individuals while working with community structures.
• Holding regular discussions on the issue in Panchayat platforms is important for sustaining interest in the long term.

Figure 2: Changes in perceptions around the spread of HIV