Person-centred programmes

Opening up spaces for transgender communities in India


Pehchan was the name given to a five-year HIV programme (2010-2015) that was implemented in 18 Indian states. It was managed through Alliance India along with a consortium of six organisations and was funded by the Global Fund to fight AIDS, Tuberculosis and Malaria. The programme was designed to complement the government’s HIV/AIDS response which focused on providing ‘Targeted Interventions’ for key populations. The objectives of Pehchan included the scale up and expansion of HIV prevention services for men who have sex with men, transgender, and Hijra communities; building the capacity of over 200 community-based organisations (CBOs); and creating an enabling environment and encouraging healthy behaviours.

Pehchan was implemented through two packages of combination prevention services including biomedical, behavioural and structural interventions. The first was a development package for newer CBOs aiming to build their organisational capacity and provide basic services to encourage healthy behaviours in each of the three target communities. The second strengthening package was for existing CBOs to go beyond the basic HIV prevention services defined in the National AIDS Control Programme and provide more comprehensive services tailored to the communities.

* Hijra are individuals belonging to a distinct socio-religious group, who may identify as female transgender, woman or neither man nor woman. Hijra live together in close-knit communities, grouped around a number of religious mythologies in temples, organised hierarchically in the form of a guru-chela (teacher-pupil) relationship.
What are person-centred programmes?

In recent years, there has been increasing momentum to create more person-centred approaches to deliver HIV and health services. While there are many ways of defining person-centred approaches, they are all founded on common principles such as empowering and informing beneficiaries to enable them to participate in joint decision making; tailoring services to suit their context; respecting their preferences; and adapting and linking services to ensure that all their needs (physical, emotional and psychological) are met over their life course.

The International HIV/AIDS Alliance (The Alliance) believes that many of the community-led programmes around the world especially those designed to reach key populations have been following a person-centred approach. The Alliance is undertaking rapid case studies in different contexts to see if this proposition is true and also to provide practical examples of what person-centred HIV programmes look like. The emphasis is on learning from the experiences and perspectives of the beneficiaries of these programmes.

Pehchan’s achievements

The Pehchan programme had significant achievements, including:

- Supported 201 CBOs, of which 90 were new;
- Reached 434,400 men who have sex with men, transgender and Hijra people, of whom 78% received HIV prevention services for the first time;
- Supported 223,792 men who have sex with men, transgender and Hijra people to access HIV counselling and testing.

“First and foremost, Pehchan was community systems strengthening, not just of organisations but also individuals. A truly community-led project. The implementers were also beneficiaries.” Abhina, National Programme Manager

“Earlier I used to look down and walk but after I got associated with Pehchan, I held up my head high and walked. I got my Pehchan from Pehchan in the truest sense.” Deepika
To what extent did Pehchan follow a person-centred approach to meet the needs of transgender people and those from the Hijra community?

Pehchan was designed to provide services for men who have sex with men, transgender and Hijra communities. This case study focuses specifically on members of the transgender and Hijra communities to learn more from their experiences of Pehchan.

The programme was implemented by a consortium of organisations led by India HIV/AIDS Alliance. In March 2018, beneficiaries and people who had worked on Pehchan were interviewed to discuss their perspectives on the programme. Two focus group discussions were held involving one Hijra and 13 transgender people and four interviews were conducted with key informants who had been involved in managing and implementing Pehchan.

The study was not an evaluation of the programme but specifically considered whether the Pehchan programme adopted a person-centred approach. The discussions were structured to review the extent to which beneficiaries felt the Pehchan programme met their needs, not just as members of the transgender and Hijra community but as individuals. The interviews examined whether the programme had responded and adapted to their context and changing needs—including through linking to other services beyond HIV. Most importantly, the interviews also aimed to find out if and how Pehchan built trust among a highly stigmatised community and made the beneficiaries feel respected and empowered.

Below are the main findings of the study, along with some of the participants’ contributions to the focus group discussions.

Supporting a sense of identity and dignity

Many of the beneficiaries talked about their own uncertainty about their identity; they had often felt alone; some were unsure of their identity; and most felt unable to express their identity. Through their involvement in the programme, the beneficiaries developed a greater sense of dignity and were empowered to be more comfortable with themselves. For many of them it was their first opportunity to explore their identity and express themselves openly. These themes of identity and empowerment recurred throughout the discussions.

“When I got to know about Pehchan, I realized that we also have certain rights. It gave me a lot of strength.” Fiza

“I used to think some people are good and some are bad. Over here I learnt that everyone is equal.” Akanksha

“Whatever I wished to do, I used to come here and do it. I fulfilled all my dreams here. At home I lived under many restrictions. But here I got complete freedom.” Arshi
Building trust and offering inspiration

It was clear from the focus group discussions that many of the *Pehchan* staff were dynamic individuals who won the trust and friendship of beneficiaries.

“Everyone felt a connection with [Deepak] ... Because of him I am working here.” Arshita

Beneficiaries repeatedly highlighted the role that two of the programme managers played in mentoring them and creating a positive environment for the programme as a whole.

“She was the heart of *Pehchan*; the first person that I met there. We all used to follow her and abide by what she said. If she is there we used to feel very free. Like, we wanted guidance from someone elderly; but our parents were not allowing. If we wanted to dance, or act feminine then she used to help us and guide us. She taught us how to behave rationally.” Arshita

These key individuals were able to link with other members of their community to build the scale and reach of the programme. Even remote and hidden communities were involved in this way. The project was not limited to urban areas: outreach workers also visited small remote villages. Other people were given support over the phone.

Developing safe and social spaces

Most of the focus group participants were drawn into *Pehchan* in search of a safe space where they could socialise, express themselves and meet others with similar life experiences. Few of them were looking for any form of medical support. By organising social events such as Hijra Habba, *Pehchan* particularly succeeded in empowering the beneficiaries to express and share their identity.

“After being a part of *Pehchan*, I came across many others (sisters) who were like me. There are many different degrees like mine. I realized that I am not the only one like this. I used to feel very good, interacting with other people like me.” Bobby

“After joining *Pehchan*, I can do things I couldn’t otherwise do. At home, I cannot wear lipstick or bangles, so I used to come here and fulfil my desires.” Kishan Kumar

Integrating and linking services and making them accessible

While people did not necessarily first visit *Pehchan* for health reasons, the programme offered a comprehensive package of services including HIV services. Many people accessed services for HIV, sexually transmitted infections (STIs) and some sought referrals for Sex Reassignment Surgery (SRS) as a result of their involvement in the programme.

“I used to feel shy buying condoms from outside. But when we got condoms from *Pehchan* I felt very good. We even got knowledge about HIV and STIs: about which I had no knowledge of earlier.” Maahi

For some services that the programme could not provide, such as antiretroviral treatment (ART), *Pehchan* staff referred beneficiaries to state run facilities. In other cases, where services were not integrated, *Pehchan* took a proactive role in sensitising staff at related health facilities to ensure that beneficiaries felt safe and able to access the services that they needed.

National Programme Officer, Rohit, explained that when they received reports of discrimination or stigma at a health facility, project staff or the community advisory board intervened with advocacy and further sensitisation.

“I went to the hospital. They shooed me away. They told me why do you do such dirty work even though you are a man? ... After that I went along with the people from Basera [a *Pehchan* supported CBO]. Then they treated me properly and took care of me.” Kajal

“The advocacy provided by the *Pehchan* staff was good. The doctors, counsellors and the ICTC [Integrated Counselling and testing Centre] used to give us first priority no matter what time we went there. That was the kind of bond they shared with *Pehchan*. They used to tell their staff to cater to us as we have come from *Pehchan*.” Sneha

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Providing comprehensive peer counselling

During the programme Pehchan offered a range of counselling services: pre-test, post-test, risk assessment, risk reduction, high risk behaviour, STI related and general sexuality related.

“After being counselled I got to know the difference between gender, sex and sexuality. Then I realized that I am a transgender. I actually got an identity from Pehchan.” Sneha

Kajal talked about a friend who was living in a Hijra community. Hearing that she was being mistreated by other members of the community, the Pehchan counsellor spoke to individual members of the group to teach them about HIV: “earlier when they got to know that she is HIV positive they isolated her, there was discrimination but after the counselling there was a positive shift in their attitude towards her. Now they consider her as a part of their family.” Kajal.

Offering crisis and legal support

Many of the participants turned to Pehchan at a time of crisis, in particular when they were struggling to deal with authorities such as the police, law courts or hospital staff.

When Deepika was gang raped on her way to college she felt unable to tell anyone. It was only when someone introduced her to a CBO supported by Pehchan that she was able to speak out. “They took action on it. They filed the report in the police station. And they got the rapists arrested.” Deepika

Seema was caught up in a dispute with her (Hijra) community and was struggling to understand how to deal with it. “I contacted Rizwan at 2am. He took me to his office and then to his home. He fed me. The very next day he got me an affidavit drafted.” Seema

Engaging family, friends and community

Many of the participants felt driven to Pehchan because their family and friends did not understand or accept their identity. To bridge this divide, the programme began to engage with these family and friends in different ways.

“This was in a crisis as he got hit from his family. He took help from the community members of Basera … The Crisis Response team helped him and took him to the hospital and got him treated. They took him back to his family and counselled him and his family. They then mediated between them and made his family understand.” Kajal, speaking of a friend

Creating life opportunities

The focus group participants spoke repeatedly about the practical challenges they face in their daily lives, including finding somewhere to live and getting safe work.

“I presumed that only a male or a female can get a job … When I got associated with Pehchan … then I got to know that people like us can also work and do a job.” Deepika

“When Pehchan was there, educational classes were given. Half of the people learnt to read and write their names and a little bit of Hindi. Many people wanted to learn English as well. Due to the end of the project, many people have left studying and those who wanted to learn English could not do so.” Kajal
Moving on from *Pehchan*

Deepak, a *Pehchan* State Coordinator, outlined some of the problems facing the transgender community during his interview:

“If I am a transgender, I may be a sex worker, injecting drug user or maybe I require PrEP or ART, but all these services are not provided by any one organisation in India. I have to take all the services from the local government hospital and that is very difficult … there is so much stigma and discrimination. In hospital I have to act like a male or female, I cannot show them that I am a transgender because they have a fixed mindset about transgender… It's really complicated for us.”

This case study highlights good practice that could be replicated in future programmes. In addition, the beneficiaries and key informants had suggestions to improve future programming for these communities. Many spoke of the need to engage with the families and communities surrounding the beneficiaries themselves. There were also calls for specific interventions including more crisis support, a 24-hour phoneline and temporary shelters for people evicted by their families.

Many people involved in the implementation of *Pehchan* were themselves members of the men who have sex with men, transgender and Hijra communities and beneficiaries of the programme. A great deal of training and investment went into building their capacity, and as Abhina, *Pehchan* National Programme Manager said, “the programme may die but these individuals will continue to lead.”

However, many individuals were left without work once the programme ended and it was felt that more needed to be done to mobilise resources and put in place structures to sustain the CBOs that had scaled up due to *Pehchan*. In addition, people raised concerns that stigma in the wider society still prevented members of the Hijra and transgender communities accessing work.

While the participants in the focus groups and interviews had many different ideas on what should be included in future programmes, there was one area in which they were all united – their desire to see a new programme similar to *Pehchan*:

“I would love it if *Pehchan* came back. It gave a lot of people identity and a reason to live.” *Arshita*

“I got everything from *Pehchan*. Now that *Pehchan* is not there, nothing is there. I wish a big and similar project to *Pehchan* could be launched for the transgender, Hijra and MSM community.” *Kajal*