

# COLLECTIVE ACTION TO CHALLENGE POWER AND ADDRESS HEALTH CHALLENGES AND INEQUITIES IN MUMBAI, INDIA

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## BACKGROUND

Mahila Milan, “Women Together” in Hindi, are a women’s collective in slums and slum relocation colonies, who work with resident communities, their political representatives and municipal officials to manage credit and savings activities. Mahila Milan was created in 1986 when hundreds of women who lived on Mumbai’s pavements organised to successfully prevent the demolitions of their homes. Their aim is to provide a space for women to take on important decision-making roles and be recognised for their contributions towards improving their communities.

Prior to the ARISE programme, Mahila Milan already functioned in an organised manner with its women’s savings network, and were looking at issues of water, sanitation and housing. Mahila Milan’s work on health was minimal, and the majority of their interventions were on savings activities. During the COVID-19 pandemic in 2020, SPARC and Mahila Milan started working with a focus on health drivers and systems, including the healthcare professionals. In the beginning, Mahila Milan had not considered using surveys as a method for research and action. However, over time, using the learning-by-doing process with SPARC, Mahila Milan realised the relevance of doing surveys to gather data, collectivise and initiate action on health and wellbeing. They were able to distil their findings into small data points with discussion groups in communities, to ensure the survey provided an accurate representation of community views and needs.

## CONTEXT

SPARC first realised the challenge of TB at ARISE action sites when they were distributing food support during COVID-19 lockdowns. The connection between TB and poor nutrition was already known to SPARC and Mahila Milan. It had been as documented since the 1980s that community support can make substantial contributions to people’s ability to follow the treatment regimen religiously as well as helping in developing feelings of well-being and support that assists in the recovery process.

When SPARC and the Mahila Milan began working with families, including people with Tuberculosis, the sole purpose was to identify if the families needed nutritional assistance over and beyond what the state provided. The process would involve constant interaction with the family, throughout the period of treatment where they would be supported with the nutritional assistance. The interactions would prove instrumental in understanding the multitude of challenges that the families face, much of which is poorly understood when looking at the issue in a clinical sense.



## KEY MESSAGES

- The work of the Society for the Promotion of Area Resource Centers (SPARC), together with partner Mahila Milan, has strengthened quality and equity in health services in the marginalised areas in India where they operate.
- Mahila Milan have a new awareness of both health vulnerabilities, and the systems that influence these. SPARC has equipped them with the tools to interact and negotiate with the health system and community to understand vulnerabilities and then direct health services to where they are needed most.
- An example of this is in relation to TB where SPARC supported Mahila Milan and communities through a Community Based Participatory Research (CBPR) methodology to actively locate affected and vulnerable families, support stakeholders to understand their vulnerabilities and to seek support for those most vulnerable within the network.
- Health was historically often seen as a private issue within the informal settlements, an issue that seldom garnered interest for collective action.
- By working with SPARC, Mahila Milan initiated a stream of work focussed on health and wellbeing which considers wellbeing as a collective experience, thus opening the door to enhance the power of the collective, challenge power and demand action from the governance actors to address their health and wellbeing challenges.

## THE STORY OF CHANGE

The most prominent trigger for this work and focus on TB and primary healthcare with Mahila Milan was the COVID-19 pandemic in March 2020 which laid bare the fact that epidemics and health issues not only affect everyone but also further relegate the vulnerable populations to the brink of marginalities.



At every stage, the work streams were carried out based on the feedback and response SPARC encountered from their work with communities, such as with selecting the most suitable research method to begin with. The initial plan was to facilitate Focus Group Discussions (FGDs) to find the pressing health issues of the community and then develop a health and wellbeing survey accordingly. However, SPARC realised that residents ended up discussing individual challenges rather than communal challenges in the FGDs so decided to begin with a data gathering health and wellbeing survey first, and to use the survey data to conduct FGDs for improved understanding and to decide on accountability-seeking actions with the community.

When distributing rations to families living with TB, long term relationships were established between the families and Mahila Milan, which allowed for Mahila Milan to learn more about their lives. This can support future initiatives to address the intersecting challenges that the families faced.

While SPARC did encounter dismissive behaviour from officials in the health system initially, sustained interaction and engagement helped to develop relationships with them. Eventually, when SPARC told them about their process of identifying families for providing ration support, they did share the list of patients and their address details on an agreement that their names and their support be kept confidential.

## KEY MESSAGES CONTINUED

- While the Mahila Milan groups existed before ARISE, the SPARC work has seen a shift in behaviour and awareness of community members, Mahila Milan and healthcare professionals to consider health as a collective issue.
- Challenging power through collective action to address health challenges and inequities is therefore a novel approach for Mahila Milan and the community members with whom they work.

## BUILDING ON STRONG FOUNDATIONS

Mahila Milan were able to use their existing network and skills in negotiating with political and municipal officials. The existing relationships of the Mahila Milan with resident communities were also a significant contributing factor to community members trusting in the process and engaging with researchers, without which, the ARISE work may not have been so fruitful. SPARC researchers developed the research structure with the Mahila Milan.

ARISE was the first health focussed research project that SPARC, together with Mahila Milan, were part of. The shift in approach to incorporate health and its social determinants into their work was largely driven by ARISE and SPARC's interest in working on health, however, the advent of the COVID-19 pandemic was also a contributing factor that justified this shift.



## CBPR

The CBRP methodology, which was central to ARISE, ensured a continual process of learning by doing, sensitivity to context and focus on the needs of the community, which led to the focus on TB coming to light. By using the CBPR research methodology, SPARC were better equipped to stay attuned to the health and wellbeing needs and priorities of the urban marginalised groups that they were working with. Actively listening to their voices led SPARC to have a more 'learning-on-the-go' approach which allowed them the space to change directions, adapt, and reorient as and when needed to address the pressing issues of the community. Besides, this also enabled SPARC to understand and highlight that health and wellbeing is not an individual/private problem of the household, but a public issue and one that is dependent on structural determinants of health.

SPARC's approach to promote working on health as a collective was to first seek out existing collective action processes that SPARC could anchor their work to. Mahila Milan already functioned in an organised manner with its women's savings network, and had started looking at issues of water, sanitation, and housing. ARISE through SPARC therefore targeted this and proposed the focus of health to be brought in as an area for collective action. This was a

new terrain for Mahila Milan to explore. This approach was important for SPARC because it allowed them the opportunity to gauge if this use of pre-existing community networks as anchors for incorporating health systems delivery works in practice. Learning from this can then support their wider efforts to contribute to improving health equity in cities.

## SURVEYS

In terms of technical skills, prior to ARISE, Mahila Milan were unable to carry out surveys related to health and wellbeing. ARISE providing the training for Mahila Milan to learn these skills, they have opened the potential for Mahila Milan to use this methodology in the future, even once ARISE funding is no longer there.

## DEVELOPMENT OF WORK ON TB AND HEALTH

Following awareness raising work delivered by SPARC, Mahila Milan now take into consideration several socioeconomic markers (such as the age of the TB patient, number of children in the family, if any single/widowed women in the family, and number of earning members) to decide which families affected by TB are to be given ration supplies. This approach has led SPARC and Mahila Milan to imagine health and nutrition in tandem with other structural markers of vulnerabilities and risks, including the social determinants of health. After these socioeconomic markers of the TB patients in the community are discussed in detail, Mahila Milan brings these cases to their Committee, the Committee then goes to the area to inspect the household for another round of verification and considers the patient's current medical status.

Work through Mahila Milan with communities has let to TB patients being more forthcoming with information and sharing this with Mahila Milan. In the initial days of working on TB, they were met with a lot of resistance and the communities would ward them off. Over time, after seeing what Mahila Milan has been able to do in their work on tuberculosis (TB), the communities began trusting them more.

The healthcare professionals, who were originally reluctant to share relevant TB information with Mahila Milan, are now forthcoming with this data so Mahila Milan can help support these families through their network. Health professionals can also now work out more accurately which families to provide support to.

## CHALLENGES

Challenges arose with initial resistance from communities and Mahila Milan. Both were apprehensive about whether a largely community-led non-research organisation like SPARC could actually take up this project and benefit them. There was also initial resistance from governance actors, at the

beginning stages of SPARC's work on TB, when Mahila Milan approached health systems for data on TB patients, SPARC were met with a lot of reluctance and were turned down by them.

The contribution of the ARISE Responsive Fund to support a community health camp where community members could access care and screening is important to consider. The camps gave further impetus to the knowledge and understanding of the extent of health issues among poor communities, which will go a long way to support their claims and demands for the improvement of primary public health care for the vulnerable.

## REFLECTIONS

ARISE was the primary contributor to the inclusion of health work into Mahila Milan's work portfolio. The CBPR approach that SPARC adopted through ARISE allowed them to imagine a larger sphere which encapsulates the larger embedment of health improvement work within the collective action framework of the grassroots. Encompassed within are smaller spheres each representing the micro actions that emerge from the data shown up by the research methods used, such as the health and wellbeing survey. This helped SPARC produce more intended data outputs; seek knowledge from varied sources such as community interactions, training and reflexivity sessions, surveys, and so on; and learn from each activity and navigate through them. Additionally, CBPR facilitated the participation of the impacted people in the research and the production of knowledge for action to address challenges emerging from the research.

The SPARC-Mahila Milan work exemplifies that communities that are already organised on collective challenges and are financially supported for their work can perhaps be more receptive to taking up work around health systems improvement. The existing connections with the community through Mahila Milan were key to harnessing this power of collective action.

## FURTHER RESOURCES

- SPARC (2023) Tuberculosis and community care: SPARC – Mahila Milan's experience and plans for future, ARISE Consortium <https://www.ariseconsortium.org/tuberculosis-and-community-care-sparc-mahila-milans-experience-and-plans-for-future/>
- Iyer A. (2023) Reflections from health camps in the relocation colonies of Ahmedabad, India, ARISE Consortium <https://www.ariseconsortium.org/reflections-from-health-camps-in-the-relocation-colonies-of-ahmedabad-india/>
- Hawkins K. and Rao V. (2002) Building health alliances to improve TB outcomes in Mumbai, ARISE Consortium <https://www.ariseconsortium.org/building-health-alliances-to-improve-tb-outcomes-in-mumbai/>
- SPARC (2023) Health and wellbeing surveys: Experience and learning, ARISE Consortium <https://www.ariseconsortium.org/health-and-wellbeing-surveys-experience-and-learning/>
- SPARC (2023) Video: Exploring the community-involved TB support program in Mumbai, India, ARISE Consortium <https://www.ariseconsortium.org/learn-more-archive/video-exploring-the-community-involved-tb-support-program-in-mumbai-india/>

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