

# **Role of Civil Society in Achieving Health for All**

## **India Country Study**

August 2016

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## 1. Background

The 4 year action research project initiated by Peoples Health Movement (PHM) with support from IDRC. The project incorporates two major objectives/components:

- A formative evaluation of PHM's five main programs: the Global Health Watch (GHW), the International People's Health University (IPHU), the 'Health for All campaign' (HFAC), the 'Democratizing Global Health Governance focusing on watching the WHO (WHO-watch), and the movement building at country level.
- Empirical research into civil society engagement in working towards Health for All.

It aims to document (and support) the People's Health Movement (PHM) and other Civil Society Organisations (CSOs) in their activities that promote 'Health For All' (HFA), while locating health in an understanding that embraces the structural and social determinants. A major portion of the research at the country level is located in 6 countries: Brazil, India, South Africa, Italy, Colombia and the DR Congo. While the study is designed to focus on PHM, its scope also includes a range of other CSOs that are not necessarily part of PHM but that actively promote or support the cause of HFA. In addition there is a global component of the study directed at researching PHM's global programs and other aspects of PHM's work directed at 'movement building'. Thus the study aims to generate knowledge about how social movements and CSOs are influencing health systems and the social and structural determinants of health and building a larger and stronger people's movement for Health for All at both national and global levels.

The term 'Health for All (HFA) movement' is used to refer in aggregate to represent various civil society organisations and networks who are trying to achieve Health for All including for decent health care for all and for social conditions which support good health, as part of PHM or independently. To understand engagement of CSOs in HFA movement in different country settings, country study teams were tasked with studying CSO contributions on: (1) campaigns and advocacy; (2) movement building; (3) knowledge generation, dissemination and use; (4) capacity building; and (5) engagement with global health governance; towards promoting 'Health for All' in the specific country.

This report presents the country study for India.

## 2. Methodology

### 1. India Research Team

In accordance with the expectation of the involvement of the India PHM country circle in supervising, conducting and participating in the research for India, an India Research Team was convened. The group comprised JSA members who expressed an interest in undertaking the responsibility of . The JSA members of the India Research Group were:

- Amit Sengupta
- Susana Barria
- Vandana Prasad
- Ganapathy Murugan
- Indranil Mukhopadhyay
- Joe Varghese
- Raman VR
- Deepa Venkatachalam
- Sarojini N.B.

The India Research Team was assisted by Rohan Mathews in conducting the literature review and by Kajal Bhardwaj in the research and in writing of this report.

The India Research Team convened three meetings at the beginning of the research to adapt the global research to the situation in India. In these meetings, the following decisions were taken:

- a. **Formative Research (as opposed to action research):** The research conducted in India would not be action research but would be formative research instead given the timeline for the research, the limited human and financial resources and the unique nature of the PHM in India.
- b. **Case Studies and Processes:** The data collection for the research would focus on case studies and processes
- c. **JSA and non-JSA Groups:** Given the nature of the health movement in India, the interviews would be conducted with JSA and non-JSA groups. Non-JSA groups would include those that are formally members of the JSA as well but would be interviewed on their work outside of the JSA.
- d. **Selection of non-JSA groups for the research:** Across the 5 main themes of the research, the India Research team first identified as many key networks, groups and organisations as possible working in the area. The long list is at Annex 3. Based on their own experience and knowledge, a short list was prepared and the groups identified were further categorised based on their area of expertise. Five of these were selected for in-depth interviews across all the areas of research while the rest would be interviewed only in select areas of research. To account for bias and lack of knowledge, a call was put out on the JSA list serve for the submission of experiences in the different areas of research. Based on the submissions, the short list was modified to include additional groups in the list of interviewees. The final list along with the areas that they were interviewed on is below.

	Campaigns	Movement building	Training/ capacity building	Knowledge generation & dissemination	Engagement to Global Health Governance
Jan Swasthya Abhiyan (JSA)					
Right to Food Campaign					
Medico-Friends Circle (MFC)					
All India Democratic Women's Association					
Delhi Network of Positive People (DNP+)					
SAMA – Resource Group for Women and Health					
Peoples Health Resource Network (PHRN)					
Action Northeast Trust (ANT)					
Jan Swasthya Sahyog (JSS)					
Breastfeeding Promotion Network of India (BPNI)					
Third World Network (TWN)					
Society for Community Health Awareness Research and Action (SOCHARA)					
JSA Chhattisgarh					

- e. **Adaptation of Global Data Collection Protocols and Consent form:** With the inclusion of the non-JSA groups, the protocols prepared by the global research team were adapted for the India research and a consent form was drafted for interviewees. The Final Protocols used in India are at **Annex 1**. The Consent Form is at **Annex 2**.
- e. **Ethics Committee Approval: The research proposal, the final protocols and the consent form were** submitted to the Ethics Committee of the Peoples Health Resource Network (PHRN) for review and approval. The Ethics Committee gave its approval to the research in April 2015.
- f. **Literature Review:** Before commencing the interviews the research team commissioned a literature review to analyse the secondary literature on the health movement in India. The Literature Review is presented in Section 3 of the report.

## ***2. Data Collection***

Interviews were conducted by members of the India Research Team between May 2015 and March 2016. Interviews were recorded through hand notes and voice recordings that were destroyed after the writing of the report. Interviewers also provided assessments and key points emerging from the interviews to inform the analysis in the report

## ***3. The Report***

The Report was written as a joint effort by the India Research Team. Each area of the research in the report is preceded with a thematic explanation written by various members of the research team.

### 3. Social Movements and Health for All: Review of Literature

**Editor's Note:** As the literature review progressed it became apparent that there is insufficient secondary literature on the health movement in India particularly after 2000. As a result the India Research Team determined that the review would cover as much literature as possible about the health movement but there would be a focus on movement building studies. The Literature review is presented in two parts, one focusing on the dynamics of movement building in general, and the second dealing with the movement for health in India.

#### 3.1 Part I: Approaches to Movement Building

##### 3.1.1 Introduction:

Pursuing a trail of literature analysing civil society activities under the broad theme of 'Health for all', at first, appears to be a fairly straightforward task. 'Health for all', as a term, carries with it an assumption that health is not restricted to merely 'healthcare' and activities focused on improving quality, access and coverage. An overall assessment of the health system as a whole, which consists of both concerns of healthcare as well as determinants of health (for example, access to safe drinking water, right to food, conditions of living) is an initial starting point. The range of challenges these two aspects pose constitute the background within which civil society activities emerge, in fact, it is the social character of health that constitutes the basis of any collective action, because mere personal healthcare would not require any such collective mobilisation of human and social resources<sup>1</sup>. The mandate under which the paper is conceived requires addressing civil society action within this broad category of 'health for all' [henceforth, HFA].

Deriving analytical categories of discussion is the first task. Unravelling civil society as a category, especially when assessing collective action under a HFA theme, becomes central to this task. This review seeks to identify different features of civil society action, as well as multiple layers through which this action identifies challenges and addresses them. This, in turn, requires invoking the state as a category, identifying the character of state intervention on HFA, whilst recognising the state as an evolving category. Recognising the state and civil society as categories interfacing over socio-economic challenges under HFA means introducing social reality as a component. Quite often confined to a 'clay like' existence, social reality appears to be moulded by contending forces both within and outside the state. Therefore, these three categories emerge, interlinked and interdependent, forming the 'underbelly', the 'core' as well as the 'epidermis' of this study. During the course of the review of focused literature, the analysis surrounding these categories will emerge. Situating these categories in a theoretical framework is limiting when dealing with a review of this form, where the focus is within a particular subject. Hence, identifying these three categories, almost as *a priori* categories, existing, tangible and intuitively recognizable becomes necessary. But, the theoretical unravelling will take place through actual assessments made in the literature.

##### 3.1.2 Social Movements in India

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<sup>1</sup> Phadke, A. and A. Shukla (1999), Health Movement in India, *Health Action*, Vol. 12, No. 12.

Movement studies as a discipline owes its origins to a variety of influences, from disciplines such as sociology, history and political science. Earlier, historical moments of mobilisation focused on a grand narrative, weaving together diverse demands into one collective movement, for example, the 'class struggle' of the Russian revolution. The content of a movement was quite often homogenous, as was the mobilisation that defined the movement. Subsequently, the emergence of heterogeneity of struggles, such as the ecology-based movements or the gender movements or those relating to racial equality, all of these appeared to fragment the marquee of collective mobilisations. This fragmentation, in itself, was accompanied by a more vocal citizenry that used several means to meet their demands, diversifying methods of 'mobilisation' as well as the scale of mobilisation. Movements or mobilisations now meant either individuals inspiring a collective endeavour, or organisations outside the traditional institutional structure guiding mobilisation or events leading to collective action. This transition meant that the forms of movements, the content and methods of action all required a unique discipline geared towards constructing a theoretical connection between these 'individuals, events, organisations and moments' that led to social movements.

What are the key questions that any social movement analysis must aspire to address? Della Porta and Diani attempt to outline these questions. First, what are the origins of social movements, and whether they can be explained as expressions of conflict? In other words, what is the "relationship between structural change and transformations"<sup>2</sup> and how do social movements operate within this relationship. Second, what are the specific 'cultural representations' that emerge and what role do they have in defining collective action. What are the determining factors that see "social actors come to develop a sense of commonality and to identify with the same 'collective we'?"<sup>3</sup> Third, how do these values, sense of commonality, actually translate into collective action and "What are the roles of identities and symbols, emotions, organizations, and networks, in explaining the start and persistence of collective action?"<sup>4</sup> And, how do organisational forms emerge to strengthen and achieve outcomes embarked upon. Finally, while movements contain a certain individual character, the context within which they operate presents certain challenges as well as definitive influences on the direction movements take. This is necessary to situate movements within existing political arenas, and also important in understanding 'tactics' and 'strategies' in continuing to remain relevant.

While considerable literatures on social movement studies exist outside India, the discipline in India has taken root through several studies attempting to resolve theoretical lacunae in disciplines such as sociology and political science. Instances are outlined below. Ghanshyam Shah, in his seminal review of literature on social movements<sup>5</sup>, attempts to fill a lacuna in political studies in India. He contends that there is limited focus among political scientists on the subject owing to three issues: first, questions relating to the aspirations and demands, articulation of problems and modus operandi in asserting demands outside institutional structures has never been the focus of political science in India. Second, the focus among political scientists has largely been on public administration and the study of formal institutional aspects of the state. This owes its origins to the function of the discipline within the colonial tradition, where issues relating to efficiency of administration took precedence over any deep analytical insight. Finally, in the context of post-independence (post world war) social science, the dominance of the liberal approach as well as the structural functional approach, the focus was largely on harmony and equilibrium as opposed to conflict and change. This disciplinary constraint defined a focus on strengthening 'institutional efficiency' paradigms

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<sup>2</sup>Della Porta, Donatella and Maria Diani (eds.), (2006), *Social Movements: An Introduction*, Oxford: Blackwell, pp. 5

<sup>3</sup> Ibid., 5

<sup>4</sup> Ibid., 6

<sup>5</sup> Shah, G. (1990), *Social Movements in India: A Review of Literature*, New Delhi: Sage



focused on internal regeneration of institutions through public intervention through formal political channels.

Shah seeks to present an outlook that attempts to identify movements in a distinctly 'movement' realm, utilising traditional theorisation in political theory and social sciences. In terms of definitions, Shah showcases a collection of contradictory or ambivalent definitions surrounding social movements. For example, in many cases movement is interchangeably used with organisation or union, while in other cases it is seen as a historical trend or tendency which includes several actors. In many cases, the mere issuing of press statements appears to be sufficient to categorise an action as a movement<sup>6</sup>. There is no doubt that the usage of 'movement' as a term is different for scholars as it is for activists. Shah writes,

*"It is fashionable for political leaders and social reformers to call their activities, which are essentially confined to lobbying or advocacy, as 'movements' even though their activities are restricted to forming organisations with less than a dozen members"*<sup>7</sup>.

Using Paul Wilkinson's definition, Shah outlines key points of contestation within movement definitions. The definition is as follows:

*"A social movement is a deliberate collective endeavour to promote change in any direction and by any means, not excluding violence, illegality, revolution or withdrawal into 'utopian' community"*<sup>8</sup>.

The understanding of what constitutes 'deliberate' action ensures a first level axis of inquiry. Wilkinson's definition continues,

*"A social movement must evince a minimal degree of organization, though this may range from a loose, informal or partial level of organization to the highly institutionalised and bureaucratised movement and the corporate group"*<sup>9</sup>.

The nature of organisation is essential to concretely undertake 'deliberate action', and presents another axis of inquiry. In addition, while the influences of unconscious Social movements are thus clearly different from historical movements, tendencies or trends. It is important to note, however, that such tendencies and trends, and the influence of the unconscious or irrational factors in human behaviour, may be of crucial importance in illuminating the problems of interpreting and explaining social movement. "A social movements' commitment to change and the raison d'être of its organisation are founded upon the conscious volition, normative commitment to the movements' aims or beliefs, and active participation on the part of the followers or members."<sup>10</sup> The relationship between movements and the context, the creation of values and self-identification mechanisms, and eventually the commitment of actors to a 'deliberate action' provide another crucial axis of inquiry. These axes, as outlined in the definition by Wilkinson loosely correspond to the questions raised by Della Porta and Diani on social movement analysis.

When referring to deliberate action within the context of social change and transformation, we need to look at studies that attempt to locate movements within broader social friction and conflict emerging. In India, some other theorists contend that mass movements are constantly

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<sup>6</sup> Ibid., pp. 16

<sup>7</sup> Shah, G. (ed.) (2002), *Social Movements and the State: Readings in Indian Government and Politics-4*, New Delhi: Sage

<sup>8</sup> Shah (1990), pp. 16

<sup>9</sup> Ibid., pp. 16-17

<sup>10</sup> Ibid, pp. 17

diluted by the presence of hierarchal structures in our society, leading to a very docile, obedient and fatalist subordinate class<sup>11</sup>. Others assert, countering this claim that a vast tradition of struggle from below exists in pre and post-independent India. Many see the scale of movements in post-independence India as a result of conflict occurring between modernity and tradition, wherein a 'transplanted' parliamentary democracy in the face of no 'tradition of voluntary effort' leads to a skewed and ambivalent legitimacy of political authority. Kothari, an exponent of this view, contends that 'direct action' is inevitable in the Indian context, as the existing political institutions are unable to satisfy the aspirations of the people. In fact, Kothari expands that "the ineffectiveness of known channels of communication, the alienation and atomization of the individual, the tendency towards regimentation and the continuous state of conflict between the rulers and the ruled -- all these make the ideal of self-government more and more remote and render parliamentary government an unstable form of political organisation<sup>12</sup>. However, inherent in Kothari's analysis is a focus on formal government and the processes that surround it. This changes in the 1970s and 1980s, and Kothari re-frames his perspective on institutional frustration and the need for protest directed at institutions, noting that "democracy in India has become a playground for growing corruption, criminalization, repression and intimidation of large masses of the people. The role of the state in 'social transformation' has been undermined"<sup>13</sup> and hence, a renewed assertion of peoples struggles, made more urgent with a shift towards neoliberal globalisation.

This re-framing of institutional frustration corresponds with the growth of what are termed as 'new social movements', which are seen to 'talk of humanity' and not categories of humans, focus more issues of identity, and are supposed to exist in a post-modern world -- moving away from hegemony of homogenous categories common to the modern world. However, Shah contests the 'newness' that these movements present, arguing that questions of identity are historical and not a new phenomenon<sup>14</sup>. Further, are these movements focused merely on demands that are non-economic or are there any economic demands being made, and finally, the self-reflexive social categories that are embedded in these movements are the driving force as opposed to political motives focused on changing existing institutional framework to meet these economic demands. This interestingly begins to resemble Ambedkar's characterisation of 'class enclosed in caste'<sup>15</sup>. One can extrapolate from here and seek to delve deeper, addressing this institutional frustration defining the context of emerging social movements. The question can be framed as, do these movements represent an underlying inability of the existing institutional structure to ensure a transformation of regressive and hierarchal social structures, resulting in multiple ruptures, within and outside the political arena, spilling into the realm of social movements.

While this spill-over cannot be denied, there is significant disagreement over how to characterise movements in such a context of institutional frustration. Dhanagre<sup>16</sup> and many Marxist scholars (including Andre Gunder Frank and Fuentes<sup>17</sup>) contend that movements need to be categorised into political and social, wherein one addresses key political questions within an overall claim to state power, while the other using social power contends for greater autonomy. The second is embedded in existing social hierarchies, while the first can potentially embark on a task of emancipation enshrined in modern institutions within a liberal democracy

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<sup>11</sup> Ibid, pp. 23

<sup>12</sup> Kothari, R. (1960), Direct Action: A Pattern of Political Behaviour, *Quest*, 24, Jan-Mar

<sup>13</sup> Kothari, R. (1986), Masses, Classes and the State, *Economic and Political Weekly*, vol. 21, no. 5

<sup>14</sup> Shah (1990)

<sup>15</sup> Ambedkar, B. R. (1916), *Castes in India: Their mechanism genesis and development*, Jullundur, India: Bheem Patrika Publications.

<sup>16</sup> Dhanagare, D. (1983), *Peasant Movements in India 1920-1950*, Delhi: Oxford University Press

<sup>17</sup> Frank, Andre Gunder and Fuentes, Marta (1987), Nine Theses on Social Movements, *Economic and Political Weekly*, Vol. 32, No. 35

or a socialist future. In fact, social movements, in their exercise of social power and interest in social justice are seen to 'depoliticise' the social realm. This is refuted by Shah, who sees it as a mere glossing over of 'political processes' in totality and the complex relationships underlying it<sup>18</sup>. In fact, M.S.A. Rao, in his seminal volume<sup>19</sup> on social movements includes the 'naxalite movement' (a movement for systemic revolution) as well as the backward caste movement for higher status in India. Oommen<sup>20</sup> refers to the sociological approach in India, which looks at collective action as a response to crises which occurs in society, and based on the existing type of society and structure of deprivations, a variety of movements, merge, crystallise and fade away. Using Durkheim's analysis, collective action is seen as a possible response to crisis within society, where society is "strained by a continuous struggle between forces of disintegration (rapid differentiation) and forces of integration (new and renewed commitment to shared beliefs)"<sup>21</sup>. Therefore, when referring to the context of movements, and the linkages with political and social structures, the narrative of institutional frustration is accurate, but, it cannot be seen as a sole factor, instead, factors such as disjunction between adopted formal institutional structures and persisting social structures of hierarchy and exploitation, or, contending trends within social forces to newly articulate new emancipatory futures, all are crucial to understand the vast terrain of social movements. However, the complexity of the political situation and the persistence of an electoral democracy mean that social movements in India, while requiring separate study cannot be delinked from a study of political processes.

When looking at social movements as an empirical category, the nature of 'deliberate action' needs to be unpacked. Expanding on 'deliberate action', one contends two actors, the *individual* who stands committed to a *collective*. This translation of individual capacities into a collective form leads one to recognise the importance of some form of organisation. When looking at organisational forms, one is actually referring to forms of collective action, in which case the definition needs to break into categories of self-definition as well as external definition. It is clear that analytical clarity is always contingent on the lens from which one views the movement, whether it is within institutions or outside institutions.

Self-definition of movements cannot be side-lined merely on grounds of myopic inaccuracy, as many claim. A movement, of course, aspires to be a 'movement', and it is the normative commitment, the ideological breadth and conscious acceptance of this that underlie the potential of an aspiration of being a 'movement', and, yet in most cases, this is not a final rule or definitive in any sense and subject to challenge. In defining this 'deliberate action', Shah uses the following, "non-institutionalised legal or extra-legal collective political actions which strive to influence civil and political society for social and political change"<sup>22</sup>. Institutionalised action refers to those that are within the confines of the existing institutional structure and include petitions, advocacy, lobbying, voting and fighting legal cases in courts. However, sometimes these institutionalised forms are used by movements as tactics, but, the core focus of Shah's work is on 'illegal public protest', which includes resistance against dominance and oppression, as well as positive action towards building or reconstituting the existing institutional framework. The key aspects that emerge are collectives (not individuals) confronting (modus operandi) authority (objectives). Further, examples of non-institutionalised collective action could be protest, agitation, strike, Satyagraha, hartals, gheraos or even riots. However, the 'illegality' of some action cannot be confined to existing legal structures as the protesting actors could hold an alternate definition of what is legal. In fact, in many cases, even if intentions are not specified, movements are strictly involved in a political process, and their contentions have

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<sup>18</sup> Shah, G. (1990), pp. 20

<sup>19</sup> Rao, M.S.A. (1978), *Social Movements in India: Vol. 1*, Delhi: Manohar

<sup>20</sup> Oommen, T.K. (ed.)(2010), Introduction in *Social Movements II: Concerns of Equity and Security*, Delhi: Oxford University Press, pp. 2

<sup>21</sup> Ibid., pp. 3

<sup>22</sup> Shah, G. (2004), *Social Movements in India: A Review of Literature*, New Delhi: Sage

implications for the existing political structures. Of course, the domain of influence varies; yet, their contentions on existing legal structures and mode of protest involve some claim to transforming the system. In fact, the choice of ‘illegal public protest’, which Shah seeks to study contains within it an implicit understanding that the actors are in no-way laying claim to state power, and hence, participation in a movement does not explicitly hold any political ambitions, and yet, its influence within the scope of mass politics cannot be denied. The complexity of political processes retains its relevance in defining social movements, and no attempt is made to isolate organisational form or any other feature of ‘deliberate action’ from the context prevailing.

<b>Typology of Social Movements- Ghanshyam Shah (1990)</b>
Reform: Under this objective, the focus is not on changing the political system, but to attempt to bring about changes in the parts of system, facilitating greater efficiency, responsiveness and workability.
Revolt: the objective is to challenge political authority aimed at overthrowing the government
Rebellion: here the objective is an attack on existing authority without any intention of seizing state power
Revolution: This is an organised attempt at changing the political order as well as the social order.

Oommen examines movements, further, by attempting to generate typologies that address the core questions brought forth by Della Porta and Shah. There is the life-cycle approach, which traces the career of movement, where key questions are how did movements get institutionalised as conventional structure? What are the characteristics of participants and their motivations? This straddles the axes of values and commitment to movements, and the emerging organisational forms. Using Durkheim’s analysis, mentioned earlier, Oommen shows that Durkheim derives three kinds of collective action: Routine, when shared beliefs outstrip stress imposed by differentiation<sup>23</sup>, Anomic, when differentiation outstrips shared belief<sup>24</sup>, and Restorative, which mediates between routine and anomic collective action. This framework allows us to study “segments of population which are newly emerging and/or displaced by differentiation engaged in collective actions”<sup>25</sup>. Weber, as Oommen illustrates, sees “collective action as the outgrowth of commitment to certain systems of belief”<sup>26</sup>. Collective action, under this framework, is reliant on the shared beliefs of the group, and organisations crystallise to mediate between the beliefs of actors and group interests establish themselves. In Weber’s view, “groups commit themselves to collective definitions of the world and themselves and the definitions, in turn, incorporate goals, entail standards of behaviour and include justification of the power of authorities”<sup>27</sup>. And, this leads to Weber’s famous characterisation of ‘charismatic leaders’, who can attract followers, and includes the routinisation of ‘charisma’ under a framework of shared beliefs. However, while Durkheimian structural differentiation and Weberian rationality in ‘shared beliefs’ worked towards displacing traditional collectivism with modern individualism, they could not account for modern collectivism, which was largely theorised by Marx, applying class analysis<sup>28</sup>, where the mode of collective action was embedded in a move from a ‘class in itself’ to a ‘class for itself’.

Responses to this lineage of sociological analysis include the rational choice framework, where “participants in movements are not swayed by sentiments, emotions or ideologies, but

<sup>23</sup> Differentiation refers to the tendency, as theorised by Durkheim, of society to differentiate into organs or self-sufficient entities of organisation

<sup>24</sup> Shared belief refers to the undifferentiated entity with a tendency towards integration

<sup>25</sup> Oommen (2010), pp. 3

<sup>26</sup> Ibid, pp. 4

<sup>27</sup> Ibid, pp. 4

<sup>28</sup> Marx, K. (1898), *The eighteenth Brumaire of Louis Bonaparte*, New York: International Pub. Co.

collective action is understood in terms of the logic of costs and benefits as well as opportunities of resource mobilisation". This forms the organisational analysis of movements, looking at different ways in which movements address their own requirements while attempting to achieve the goals they set for themselves. New Social Movements analysis moved away from this approach, looking at the 'social background of participants' , while steering clear of any overarching ideology, working with post-class categories such as feminist, youth, peace, environmental, national, ethnic etc. New identities are continuously being forged, mobilisation styles are characterised by non-violence and civil disobedience, interrogate traditional legitimate institutions and tend to be diffuse, decentralised and segmented. It may appear to be largely based on building a new paradigm of social organisation, and yet, the scope of activity is not pan-society, but, more fragmented. And, yet when looking at these movements, the analysis requires engagements with key features of these movements, distinguishing between outbursts and movements, wherein an elementary collective action (protests, mobs) "acquires organisation and form, a body of customs and traditions, established leadership, an ensuring division of labour, social rules and social values, in short- a culture, a social organisation, and a new scheme of life, it becomes a social movement"<sup>29</sup>.

Oommen's own analysis of movements takes on a typology where he categories them into ideological, organisational and charismatic, as defined by the central guiding tendency within the movement. The underlying assumption is that when strain exists in social relations, either of these, ideology, organisational form or leadership emerge to deal with this strain. And, irrespective of which one emerges, eventually, the other aspects will come together for it to be a social movement. But, one of these will acquire primacy, and sustain a relationship of cooperation and conflict which will define the regeneration of social energy. It is obvious that none of these defining aspects can work in isolation. Inherent to all of this is recognition that movements represent an impulse towards change or transformation.

This is distinct from typologies utilised by other authors, such as Mukherji<sup>30</sup> who define movements in terms of the quality of change as accumulative, alterative or transformative. The first refers to changes within systems, while the latter two refer to mobilisation geared towards change from outside the system. Rao<sup>31</sup> sees three levels of structural changes and on that basis three types of social movements, reformist- working towards partial changes in the value system, transformative- aimed at effecting middle level changes, and revolutionary- radical change in the social and cultural system.

However, when referring to the forms that movements take, in terms of collectivities that form or the nature of goals pursued through an organisational form, Oommen's analysis is valuable and unique within movement studies in India. He refers to group formation within movements based on the following:

- Biological and spatial- gender, race, age, regional/local groups (more or less stable- as in people will always be part of some biological unit/identity as well as some space)
- Civil- workers, peasants, students, professionals (amenable to change owing to being a product of socialization/enculturation processes)
- Primordial- linguistic, religious caste groups (attributes are slow to change owing to being ascriptive and internalised)
- Rationale- fixed flexible continuum- given the relative fixed-flexible continuum, the possibility of crystallization of collective conscience

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<sup>29</sup> Oommen (2010), pp. 7

<sup>30</sup> Mukherji, P. (1977), Social Movement and Social Change: To a Conceptual Clarification and Theoretical Framework, *Sociological Bulletin*, Vol. 26, No. 1

<sup>31</sup> Rao (1978)

And, the goals these collectivities pursue are either instrumental where they are oriented towards redistribution of resources and power, or symbolic, wherein they refer to a redefinition of status and privilege. Therefore, any study of movements will need to see the intricate “intertwining between the nature of attributes of a collective, the prospects of mobilisation and the shaping of its consciousness”<sup>32</sup>

In addressing questions of collective will and the notion of values underlying movements, it is important to place this issue within the context of how movements emerge and the manner in which they evolve. In many cases, a new need is felt to address deprivations of various types. These, quite often, emerge in undefined or unstructured situations, wherein movements gradually attempt to identify what it is directed against and what it hopes to combat or eliminate. In this process, the movement utilises several motifs, values, which began to give shape to the movement and also influence the commitment of the individuals engaged with the movement. Using a structural functional approach, Oommen attempts to trace the history of movements as structurally constructed. Movements are seen as “conscious efforts on the part to mitigate deprivation and secure justice” and “mobilisation and institutionalisation are crucial to movements”. It is important to recognise that ‘institutionalisation’ here, is not taken in a negative light, but, represents a transition from a nascent collective action to a more concerted and organised action, in fact, representing the movement as an idea concretely playing itself out. The level of commitment is guided by the level of structural similarity and whether it is enough to build collective commitment<sup>33</sup>. The consciousness that a movement form builds defines the process of institutionalising commitment, for example, ascriptive entities find it easier to achieve this task. While in civil collectivities, the individual and groups are made aware of the conditions, beyond mere appearances. A latent dissatisfaction is crucial. In institutionalising movements, the “extent of gap between expectations and satisfactions is crucial. If strains are accepted as facts of life there is no possibility of challenging the status quo”<sup>34</sup>.

In looking at institutional forms that movements take, one must recognise that movements can be seen as ‘fluid states’ while institutions are ‘solid states’, and a process-based link exists between the two. In fact, movements targeting institutions are also posing an alternative institutional structure, and in many cases “movement provide institutions with the possibility of re-legitimation”<sup>35</sup> [Oommen 25]. In fact, the institutional mechanism provided make sure that mere aspirations don’t remain so, and “institutions are instruments of movements to translate ideology into programme, theory into praxis, without which they remain shells without substance”. In fact, a more concrete organisational form is important to fulfilling the goals of a movement, and it is important to see processes of mobilisation and institutionalisation as two dimensions of a movement.

Below is reproduced is a table<sup>36</sup> by Oommen defining characteristics of the Different Aspects of a Movement at Two Phases:

Aspects of a Movement	Mobilisational Phase	Institutionalisation Phase
Ideology	Very important, emphasis on mass appeal, centres on issues of deprivation, stress on collective participation	Not so significant, emphasis on translating movement ideology into specific programmes, stress on implementation
Organization	Embryonic and rudimentary,	Crystallised and complex,

<sup>32</sup> Oommen (2010), pp. 16

<sup>33</sup> Ibid, pp. 20

<sup>34</sup> Ibid, pp. 23

<sup>35</sup> Ibid, pp. 25

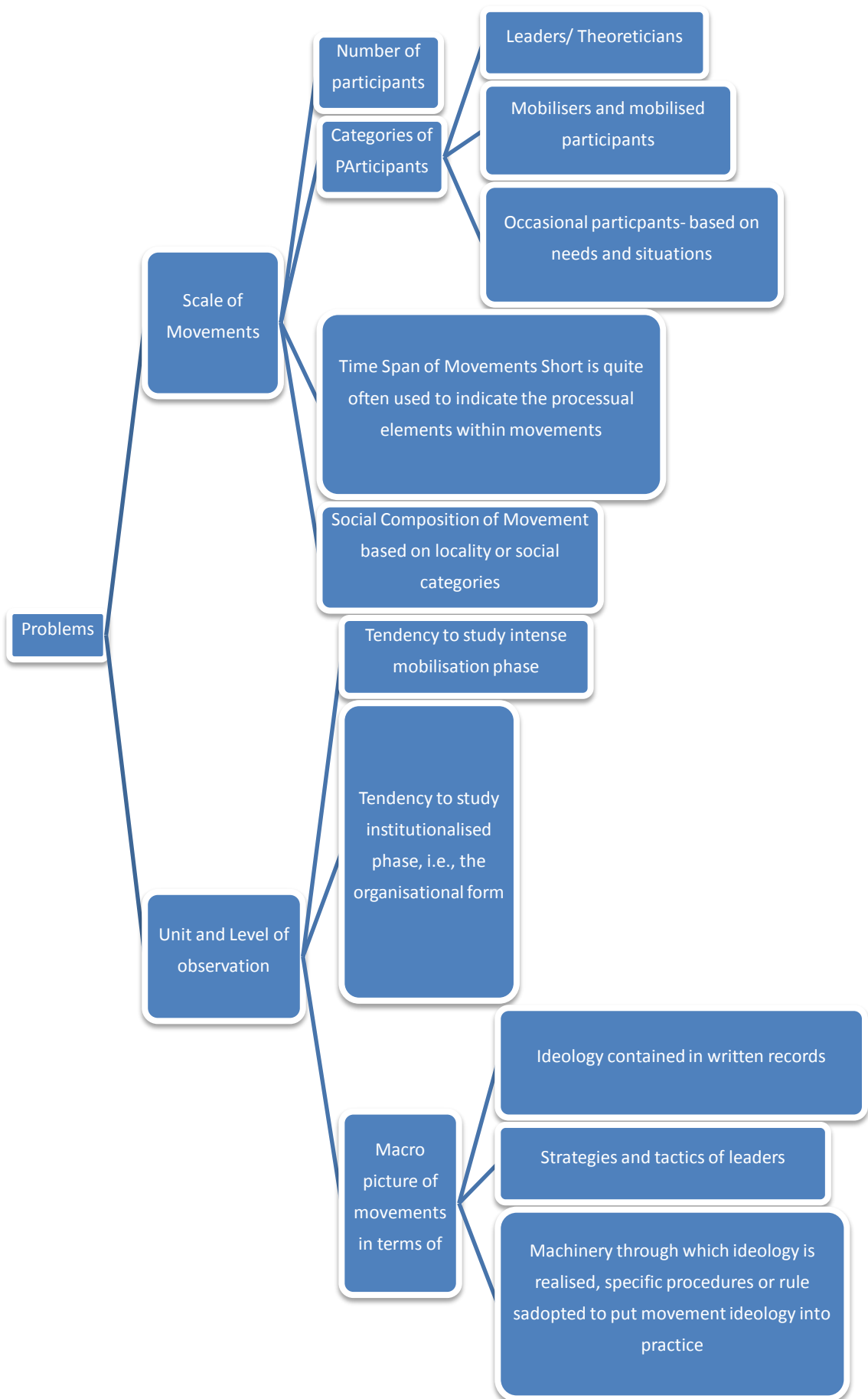
<sup>36</sup> Ibid, pp. 27

	leader-follower relationship emphatic. Stress on the movement functioning as a propaganda vehicle, emphasis on martyrdom.	leader-follower relationship replaced by 'professional-client' relations, operate as interest groups, stress on administration of justice.
Strategy and Tactics	Stress on collective actions (agitations, strikes, gheraos, satyagrahas, demonstrations etc.); emphasis on propaganda and communication of ideology to sensitize participants of their rights	Interest articulation (bargaining, submission of memoranda, petition, lobbying for legislation), emphasizes the 'here and now' goal, namely, welfare of participants/social change.
Leadership	Professional revolutionary (typical roles; prophet, charismatic hero, demagogue)	Institutional entrepreneur (typical roles: manager, bureaucrat, bargainer, legalist).
Membership	Inclusive, expansive, undefined	Exclusive and defined, clearer boundary demarcation

Below is a chart identifying key methodological issues in studying movements based on Oommen's analysis<sup>37</sup>

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<sup>37</sup> Ibid, 28-34





### 3.1.3 Organisation Studies

At this point, it is important to introduce some discussion on organisational studies and its contribution/relationship with movement studies. Organizational studies as a discipline is currently in a state of flux. There are varying opinions on the direction it must take, and the possible paradigms that must be taken as necessary conditions. The failure to find commensurability in paradigms is a major concern for the discipline in its current phase. The paradigmatic choices are fundamentally governed, in this case, by the need of the current order of organizations. There is a prevalence of structured bureaucratic organizations, resembling the Weberian notion of calculable rational action. The voices of the current order speak for a rational, reasoned approach to understanding organizations. Pfeffer<sup>38</sup> furthers this view, speaking of the study of organizations as 'paradigmatically not well developed', and explicitly speaking of a need of scientific progress, "which requires some level of consensus, as well as for its likely ability to compete successfully with adjacent social sciences such as economics in the contest for resources." While looking at movements studies, it appears that no connection between the fields seemed possible since organisation studies concentrated on instrumental, organised behaviour while movement studies focused on spontaneous unorganised and unstructured phenomena. The breakthrough took place when movement scholars "reframed the view of protest and reform activities from one of irrational behaviour- a flailing out against an unjust universe- to one involving instrumental action"<sup>39</sup>, which meant that greater focus on mechanisms of mobilisation and opportunities to redress wrongs gained priority. Several strains within organisation theory developed which attempt to assess movements. They are listed below:

- **Resource Mobilisation perspective:** using organisation studies, this perspective works on the principle that if movements are to be sustained, they require a clear form of organisation which includes leadership, administrative structure, incentives for participation and a means for generating resources <sup>40</sup>.
- **Political Process perspective:** Here the focus is on political environment, and how political opportunities and constraints facilitate and structure collective action. In fact, whether in a pre-existing form or as a contingency emerging during the course of mobilisation, utilising political process environments to generate social capital critical for the flourishing of a movement is an instance of this perspective<sup>41</sup>.
- **Organizational Ecology perspective:** This focuses on material resource environment of organisations, and how organisations survive in within their resource constraints. The "emphasis shifted to organizational survival, rather than efficiency or effectiveness, with analysts expressing scepticism regarding any straightforward linkage between performance and persistence<sup>42</sup>.

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<sup>38</sup>Pfeffer, J. (1993), Barriers to the Advance of organizational science: paradigm development as a dependent variable, *Academy of Management, Review*, 18(4), pp. 599-620.

<sup>39</sup>Davis, G. F. Et. Al (eds.) (2005), *Social movements and Organization Theory*. New York, N.Y: Cambridge University Press, pp. 6

<sup>40</sup> Ibid, pp. 6

<sup>41</sup> Ibid, pp. 7

<sup>42</sup> Ibid, pp. 7-8

- **Resource dependence and Conflict theory:** A challenge to the rationality based perspectives, focusing on power as a determinant, arguing for attention towards the political implications of asymmetric relations, and how “organisation is fundamentally a structure of dominance and exploitation”<sup>43</sup>.
- **Neo-institutional Theory:** This directs attention to cultural and normative frameworks in giving rise to and sustaining organisations. Here, the organisation is assessed in terms of their ‘social fitness’, ‘performance legitimacy’ and ‘accountability’.

If one were to assess the framework where movement studies and organisation studies intersect, it is through replacing organisations or movements within a field where the organisation is a fundamental unit of analysis, looking at three classes of actors, dominants, challengers and governance units referring to those organisational units that exercise field level power and authority<sup>44</sup>. This organisational field operates within a wider social environment which includes, non-participants influencing the organisational field, authority and power structures across society and formal institutions that create a web of constraints and opportunities governing the organizational field.

There is a challenge to this organisational field approach within organisation studies. Movements appear to be relevant within the post-modern paradigm, because of a constant flow of meanings and varied social settings that retranslate meanings and the language of development. Olivier de Sardan<sup>45</sup>, in his study of NGOs in rural Africa speaks of how there are specific meanings attached to particular development interventions, and how they are quite often far away from the intended meanings. These meanings define a system of local knowledge/truth that is constantly in a relationship with power and the ‘rules of right’. NGOs refer to specific organizations that are constantly engaging with power in the channels of authority that are placed, and through the meanings they derive within the social milieu. Gergen<sup>46</sup> defines power ‘as the capacity to achieve specified ends’, and places two components within this capacity, first, the criteria for the achievement of power, second, the range of activities that must be coordinated to achieve these ends. There is a need for agreement, and therefore he concludes, “Power is inherently a matter of social interdependence, and it is achieved through the social coordination of actions around specified definitions.” The interesting extension to this argument lies in the fact that this sense of coordination creates a meaning within the organization, but in the bargain, erecting ‘a barrier between it and adjoining communities of signification’. Therefore, power is seen as self-destructive within an organization of complete coordination, and this is where the challenge to the positivistic organizational studies is located, a challenge that specifies that an organization as such cannot be fragmented into particular chains of action and reaction, and super ordination and subordination, instead there needs to be an endeavour to move to an understanding of the need for an open organization, i.e. an organization that does not self destruct on the basis of its sense of coordination.

### 3.1.4 Non governmental organizations (NGOs)

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<sup>43</sup> Ibid, pp. 8

<sup>44</sup> Ibid, pp. 17

<sup>45</sup> Olivier de Sardan, J.P. (2004), *Anthropology and development: Understanding contemporary social change*. London: Zed Books

<sup>46</sup> Gergen, Kenneth J. , *Organization Theory in the Postmodern Era* in Michael Reed and Michael Hughes (eds) *Rethinking Organization: New Directions in Organization Theory and Analysis*, London: Sage, (1992), pp. 207-26.

While the review of social movements in India includes a focus on organisational forms, and many movements take on specific organisational structures, it is crucial to distinguish the specific type from the content. The prevalence of a particular organisational form and its interface with social concerns leads one to assess NGOs.

The late 20th century saw the growth of a specific organizational type, the 'non-governmental organization' or NGO, a term that encompasses a variety of organizational structures. It is impossible to formulate exact organizational narratives for all of the different kinds of NGOs; however, it is sufficient for the time-being to see them as specific interventions within a specific locale that have variable aims, either individually decided or externally dictated, but mostly specified within a large realm of collective action. These units of collective action owe their origin to the 1970s and 80s, when development agenda was dictated by state-defined policy, with specific international agencies also available that chose to intervene and supplement these policy resolutions. However, by the 1980s the spectre of structural adjustment began to overwhelm many economies, leading to reduced public expenditure. It is here that NGOs significantly began to transform the development discourse, with their ability to produce units of collective action at a smaller scale, and their ability to garner networks of information that facilitated the structurally-obsessed large development agencies and banks. There was a widening belief that market interventions would allow greater progress and possible equity in the long-run. 'A new policy agenda' was on the cards, 'heterogeneous set of policies based on a faith in two basic values- neoliberal economics and liberal democratic theory.'

The current space of NGO activity works on a specific discourse of knowledge, one that uses ideals of participation, empowerment and the 'micro' perspective to change the lives of people. This knowledge enacts a play of images that reacts with specific images of the locale of intervention. When we speak of images we refer to 'structures of meaning through which social actors interpret the actions, or inactions, of others, and hence decide what form of relationship with them (they) should take.' These actions and reactions create layers of relationships, which are embedded within larger social images that constitute a language. A language that emphasizes the need for bottom-up development, but mostly interestingly working on a top-down framework. This very language also transforms the activity within the organization and the levels of relationships that are created. The subordinate nature of the recipient of development is one aspect of this whole framework, the other being the very model of functioning that creates this process of subordination.

A very important point of contention within these organizations is the level of political action within these networks. The relationship with the state and the notaries of power within the area of intervention reveals the level of political action that the NGO undertakes as an organization. There is a move in many organizations to depoliticize their efforts. There is a move towards seeing them as tools of anti-politics machinery that works on specific realms of volunteerism, non-profit and as a third sector that is independent from the state and the market. However, "If politics is taken to refer to power-structured relationships maintained by techniques of control, as it is by these radical critics, then politics is not confined to institutions but pervades every aspect of life."<sup>47</sup> 'Anti-politics' is an obscuring of this relationship. It is a denial of the political potential of NGOs.

There is a tendency to present NGOs as welfare mechanisms that are used to deliver specific and loaded objectives to specific populations. This refers to the focus on technical solutions for people-centric problems, and the reductionism, wherein the people are seen as mere recipients of aid and welfare, so that they may link up with the larger bandwagon of development. This also brings into question the relationship of these NGOs with the state machinery, and how in

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<sup>47</sup>Ferguson, J. (1990). *The anti-politics machine: "development," depoliticization, and bureaucratic power in Lesotho*. Cambridge [England: Cambridge University Press.

certain cases they facilitate state operations, while in other matters they allow for an alternative or a challenge to state activities, letting the population be alienated or separated from state-directed poverty-alleviation strategies. There is a move towards a counter-structure at times, and this move quite often is dictated by external agencies that have the ability to bargain for NGO activities, within the larger macro-economic arena of development banks and dependent governments.

However, this is not a gross generalization. It is just one aspect within the topic of NGOs, and needs to be recognized. NGOs, in fact, are a large influence on state policy with their alternative models and policy studies. The micro and macro coordinate in a specific relationship that works on a lot of giving and taking on both sides. Another aspect of the relationship between NGOs and the state lies in their transformation of the political structures within the geographical area of their activity. The competition to develop a certain population and provide services creates specific relationships, and requires the power-brokers in the region to re-assess their priorities and those of their political clientele.

## **3.2 Part II: The Movement for Health in India**

### **3.2.1 Public Health and the State in India**

The narrative of public health in India remains one of neglect and inadequacy. India's colonial inheritance included a limited health infrastructure with a skewed distribution, yet, internationally and nationally there remained a momentum across the world recognising the urgency to address health of its citizens<sup>48</sup>. The early evidence acknowledging health as a matter of concern in colonial India was regarding the health of British soldiers in India. In fact, this concern is evidence that the colonial state reluctantly and in a very ad-hoc manner moved from primarily concerning themselves with the health of British residents, dealing with public health concerns of the 'natives' and the threat of epidemic<sup>49</sup>. Therefore, the orientation towards health, as a matter of public intervention was skewed in favour of a small elite, and the health of the larger public remained an insignificant matter left to traditional and private means. It may be noted that this inadequate attention was concealed by an overwhelming coincidence of modern medicine, where it has been argued that the colonial legacy ensured access to the new developments focused on curing deadly diseases.

The nationalist movement did recognise health, especially disease and death, as a major factor defining the poverty and squalor in India. The nationalist elites, with the National Planning Committee in the 1930s recognising poverty and its deep relation to ill-health formed the initial thrust. By the 1940s, there emerged, within the National Planning Committee (NPC) that "the root cause of disease, debility, low vitality and short span of life is to be found in the poverty – almost destitution – of the people"<sup>50</sup>The NPC saw great potential in an army of health workers, imbued with an almost 'missionary spirit'<sup>51</sup>. They elaborated state led social insurance schemes focused on providing a national health cover to citizens, inspired by the welfare schemes in continental Europe<sup>52</sup>. However, fundamental towards providing a concrete framework for health in India was the Bhore committee, which submitted its report in 1946. Consisting of a variety of members of the Indian Civil Service and international consultants, the committee acknowledged that social, economic and environmental factors contribute to sickness, as well as linking improved economic development to better health outcomes<sup>53</sup>. With a scathing critique of the colonial intervention in health, rigorous study of existing health systems in the west, the committee broke away from the colonial legacy by stating that "the comprehensive conception of what a community health service should undertake has led to the development of modern health administration, in which the State makes itself responsible for the establishment and maintenance of the different organisations required for providing the community with health protection"<sup>54</sup>. Significant in its formulation, the Bhore committee ensconced in the debates within the National Planning committee meant that at the point of independence there was

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<sup>48</sup> Amrith, S. (2007), Political Culture of Health in India: A historical perspective, *Economic and Political Weekly*, Vol. 42, No. 2

<sup>49</sup> Amrith S. (2009), Health in India since independence, BWPI Working Paper 79, Manchester: The Brooks World Poverty Institute, p. 6

<sup>50</sup> NPC (1947): Population: Report of the Sub-Committee, chair: Radhakamal Mukherjee, K T Shah (ed), Bombay: Vohra and Co, pp. 17-19

<sup>51</sup> *ibid*, p. 42

<sup>52</sup> NPC (1947): National Health: Report of the Sub-Committee, chair: S S Sokhey, K T Shah (ed), National Planning Committee, Bombay: Vohra and Co, Bombay.

<sup>53</sup> Amrith, S. (2007), Political Culture of Health in India: A historical perspective, *Economic and Political Weekly*, Vol. 42, No. 2

<sup>54</sup> Government of India (1946), *Health Survey and Development (Bhore) Committee Report*, Volume-2, Delhi: Publications Division

evidently enough public discourse surrounding health systems, and more importantly, a recognition of the central role of the state in achieving better health outcomes for its citizens.

Subsequently, several factors collided to force health to retreat to the background. First, the new nation with an underdeveloped productive sector, required intense focus on a modernization drive that eventually meant planning as a process lay greater emphasis on industry. Second, the range of territorial disputes directed a major section of the resources as well as attention towards matters of national defence. Third, as evident in the constituent assembly debates, resources required to operationalise the Bhole committee recommendations were apparently far beyond existing resources, which led to a renewed attention at expanding the productive sphere and further neglect of overall health objectives<sup>55</sup>.

In this context, the focus on health took on a very disease eradication approach, and was plagued by an overall centralised state apparatus. For example, the malaria eradication drive that began in the 1950s required extensive external support, relied on an army of practitioners, was completely supply driven, and relied on the 'centrality' of the state. Amrith argues that apart from a fairly successful eradication rate what came out most starkly in the anti-malaria program and subsequent intervention such as IUCD towards population control was "a militarised, disciplinary narrative that presented malaria eradication as an assertion of the state's power, its technology and its sovereignty. The emphasis, tapping into the emphasis on personal and national discipline in the debates of the 1930s, was on centralisation and obedience to authority; public health as responsibility of the citizen. The malaria eradication programme found ritual expression in a way that underscored the state's presence in the lives of its citizens"<sup>56</sup>.

What emerges from this brief narrative is a realisation that health as a state priority relied on a purely centralised, problem-solving mechanism, ignoring health services. Further, the social, economic and environmental determinants of health, as spelt out in the NPC and the Bhole committee, were overshadowed by a focus on dealing with immediate problems in a context of limited resources. In fact, in the 1960s the National Tuberculosis Institute in Bangalore spelt out the price of neglecting local health services, and in a report of the WHO in 1963<sup>57</sup>, the much avowed claim of 'ignorance of the poor' was dismissed, instead stating that "the problem lay deeper, and lay in the lack of confidence that many Indians' prior experience with the public health services had engendered in them"<sup>58</sup>. This meant, both an overt reliance on private health providers, and further paved the way for significant intervention from non-state actors.

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<sup>55</sup> Amrith, S. (2007), Political Culture of Health in India: A historical perspective, *Economic and Political Weekly*, Vol. 42, No. 2, pp. 117

<sup>56</sup> Amrith, S. (2007), Political Culture of Health in India: A historical perspective, *Economic and Political Weekly*, Vol. 42, No. 2, pp. 118

<sup>57</sup> WHO (1963). Stig Andersen, 'Assignment Report', SEA/TB/49, WHO Print Archives, WHO Library, Geneva.

<sup>58</sup> Amrith S. (2009), Health in India since independence, BWPI Working Paper 79, Manchester: The Brooks World Poverty Institute, p. 16

### 3.2.2 Civil Society Initiatives in Health

Manoj Sharma and Gayatri Bhatia<sup>59</sup> outline what they term the 'Voluntary Community Health Movement in India'. They begin by first identifying the challenge of understanding the voluntary sector owing to the "wide gamut of difference in terms of organisational sizes, legal status, sources of funding, fields of activity, and working philosophies"<sup>60</sup>. Additionally, the lack of documentation is seen as reason for their limited visibility in the available literature, with many organisations not possessing written documents outlining their mission statements or reports that record their activities. The authors see this as a deterrent for these organisations to plan effectively, and characterise it as a missing 'feedback loop'.

In identifying key categories of voluntary health initiatives in India, the authors provide a context where two major groups, the Gandhians and the Christian missionaries pioneered voluntary work in health. Of course, the Gandhian movement did not see health as an isolated phenomenon, instead focusing on overall development. With the three wars in the two decades of the 1960s and the 1970s, and concurrently a reduction in foreign aid meant that several home-grown initiatives emerged that sought to meet the needs of poor, especially with regards to improved health outcomes. The spirit of voluntarism at that juncture did not wholly rely on a medical worldview, instead grew out of a social and political phenomenon where young, recently graduated doctors wanted 'to change the world'. In this light, the authors mention three such initiatives in community health, first, those that focused on 'alternative appropriate technology' such as the Comprehensive Rural Health Project (CRHP) at Jamkhed (Maharashtra), the Integrated Rural Health Project at Pachod (Maharashtra), and the Child in Need institute at 24 Parganas (West Bengal). The other group is termed as 'coordinating, networking and coalition building organisations' which included the Voluntary Health Associated of India (VHAI), Catholic Hospital Association of India (CHAI) and the Christian Medical Association of India (CMAI). And, the third group had groups involved in 'lobbying, issue raising, and advocacy' such as Medico Friends Circle (MFC), Kerala Shashtra Sahitya Parishad (KSSP), All India Drug Action Network (AIDAN), All Indian People's Science Network (AIPSN) and Lok Swasthya Parampara Samvardhan Samiti (LSPSS).

Sharma and Bhatia elaborate further on the strengths of the voluntary sector in health in India. They identify, for example, their campaigning in adverse situations and becoming leading voices in the public discourse, especially, in the case of the Bhopal disaster (industrial genocide in Bhopal caused by a toxic leak from a Union Carbide factory that killed about 3,000 people in 1984) and justice to the victims as well as a pro-people drug policy. Second, some remarkable results achieved by the sector in many areas where the government has not been able to intervene. For example the "Lok Biradari Prakalp -- an organization working with a tribal community of Madia Gonds in Hemalkasa in the district of Gadchiroli (Maharashtra) -- had achieved an infant mortality rate of less than 50 per 1000, in 1990, which was almost half as compared to national figures"<sup>61</sup>. Third, with the influence of liberation theology, social activist and rural development as guiding principles has ensured that these initiatives rely "on accepting that people have the potential, focusing on the reality of experiences rather than mere knowledge, respecting the views of the community, and working from the mutually shared ground rather than imposing theoretical ideas onto the community"<sup>62</sup>. Their focus on participatory training and research, like the case of VHAI, according to Bhatia, show promising results through a personalised approach and non-bureaucratic structure with flexible

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<sup>59</sup> Sharma, M. And Gayatri Bhatia (1996), The Voluntary Community Health Movement in India: A Strengths, Weaknesses, Opportunities, And Threats (SWOT) Analysis, *Journal of Community Health*, Vol. 21, No. 6

<sup>60</sup> Ibid, p. 454

<sup>61</sup> Ibid

<sup>62</sup> Ibid, 458

operations which make them more acceptable options as opposed to the state in many instances.

When outlining weaknesses, the authors feel an inherent dependence on external assistance is a significant barrier, where many of these agencies function under donor-driven agendas. And, conversely, the authors feel that those organisations that work in smaller setups with motivated selfless staff have limited resources, and are unable to support their activities, quite often. Further, they feel that a lack of coordination among these organisations leads to misallocation of resources and in many cases “duplication of efforts”. In outlining one major lacuna, at the time, the authors felt that many of these organisations failed to generate epidemiological data about the communities they work with, lacking any baseline data to compare and evaluate results and outcomes of their work. Other features the authors highlight include “crises driven management, lack of professional and systematic approach, and highly exploitative structure arising out of ‘tight manning’ and limited resources”<sup>63</sup>.

While the opportunities the authors refer to may have been addressed in subsequent years, some of them merit mention here, like the need to acknowledge those communities that are traditionally ignored such as disabled, especially in rural areas. Finally, the authors refer to threats, and contend that lack of monitoring and self-reflection may lead to what they term as “superstructure without grassroots”, where alienation from the people one works with slowly sets in. Further, the inflow of professionals in the field is also seen negatively, with many of these individuals possessing different ideologies, knowledge bases and motivations, distinct from the earlier generation who pioneered this movement.

The example of the CRHP in Jamkhed has been widely documented -- it was also the subject of a chapter in an edited volume by the WHO titled *Health by the People*. Founders of CRHP, Mabelle and Rajanikant Arole decide to move away from a traditional curative-oriented hospital system<sup>64</sup>. They were instrumental in the formation of the Community Rural Health Project (CRHP) in Jamkhed, Maharashtra. Established in 1970, CRHP continues work with the local communities through groups including a farmers group, a mahila mandal (women’s group) and adolescent girls groups. Their work ranges from income generation activities to education, hospital and referral services and rehabilitation for disabilities, but primary focus is on working with women. However the Jamkhed program, while internationally acclaimed, remains essentially a micro program with inadequate evidence of how such initiatives can be scaled up. The Jamkhed project has resolutely resisted the temptation to scale up. In fact, the present reach of the project is lower than in the 1990s.<sup>65</sup>

A slightly different case is that Karunaa Trust which started work in the B.R. Hills of Karnataka stae, with the Soliga tribes. A key aspect of its action has been a sense that a mere focus on health in itself is inadequate. Instead, approaching the problem through the concerns of literacy and education provided significant traction in establishing work in the area<sup>66</sup>. Karuna Trust’s success led the Karnataka government to issue a formal policy on public-private partnerships in 2000 and the model has been upscaled and Karuna Trust runs 26 centres in all the districts of the state of Karnataka and nine more in the north-eastern state of Arunachal Pradesh, covering a population of approximately 1.2 million people. The initiative has been a subject of considerable debate within the country. The Trust sees itself as building “models”, and does not

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<sup>63</sup> Ibid, p. 460

<sup>64</sup> Arole, M. and R. Arole (1975) in K.W. Newell (ed.), *Health by the People*, Geneva: World Health Organization, p. 70

<sup>65</sup> Sengupta A (2012), Creating, reclaiming, defending Non-commercialised alternatives in the health sector in Asia, p 207, in McDonald and Ruiters (Eds.) *Alternatives to privatisation*, Routledge, New York, 2012

<sup>66</sup> Bose, A. (2006), Empowering Soliga Tribes: ‘Sudarshan’ Model of Karnataka, *Economic and Political Weekly*, Vol. 41, No. 7



see the initiative as an alternative to the state taking the responsibility in managing and maintaining the public health care system. Its experience in managing the Primary Health Centres indicates that success is variable and depends crucially on strong support from the local public health department<sup>67</sup>. However the model of outsourcing the running of PHCs has been critiqued as another form of privatisation of healthcare services.

Another trend in civil society action is that of secondary and tertiary care based hospitals, such as the Voluntary Health Services<sup>68</sup> Chennai setup by Dr. Sanjivi, or the Jan Swasthya Sahyog (JSS)<sup>69</sup>, setup by All India Institute of Medical Sciences (AIIMS) educated doctors in Chhattisgarh. The primary aim of these actions is to provide direct health services to those unable to access primary and secondary healthcare. The main focus is on service delivery. In the case of JSS, community level training is also part of their activities. The Shaheed hospital<sup>70</sup> in Dalli Rajahara is another instance of a community hospital, which was created by a trade union, the Chhattisgarh Mukti Morcha (CMM), in the 1980s. Similar instances are the 'People's Hospital' in Nellore, setup by activists close to the Communist party of India – Marxist (CPI (M)) or the Shramik Krishak Maitri Swasthya Kendra (Worker-Peasant Friendship Hospital) led by Punyabrata Goon in West Bengal<sup>71</sup>.

The Shaheed hospital case reveals an example of a movement generating resources towards meeting the healthcare needs of its members. This originated when a member of the union died at childbirth, which meant the CMM took upon it the burden of ensuring a holistic improvement of the lives of its members. Punyabrata Goon, who was part of the initial group of doctors writes, "What led Chhattisgarh Mines Shramik Sangh (CMSS) to take up the creative work of constructing a hospital? To answer this question, one has to understand CMSS policy of "Sangharsh and Nirman (struggle and creation)"<sup>72</sup>. The Shaheed hospital was formed by the contributions of the workers. Most of the doctors came from the revolutionary students movement in West Bengal, and apart from their health related responsibilities, they also involved themselves in peoples education, where "during the campaigns in colonies and villages, during interactions of indoor or outdoor patients with doctors or health workers, posters, poster exhibitions, slides, magic shows, wall magazines, and health related booklets of 'Lok Swasthya Shiksha Mala (public health education series)' were used"<sup>73</sup>.

### 3.2.3 Campaign and Alliance Building

#### Jan Swasthay Abhian – a network of networks

Over the last decade several groups have come together, with the sole focus of making health a matter of public debate. This means they have focused on the right to healthcare as a concrete demand. The Jan Swasthya Abhiyan (Indian Chapter of the People's Health Movement), established in 2000, is an umbrella organisation of diverse groups across the country that stand by the declaration that "We reaffirm our inalienable right to and demand for comprehensive health care that includes food security; sustainable livelihood options including secure employment opportunities; access to housing, drinking water and sanitation; and appropriate medical care for all; in sum – the right to Health For All, Now!"<sup>74</sup> The thrust of the JSA is to

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<sup>67</sup> Sengupta A (2012) p 208

<sup>68</sup> <http://www.thehindu.com/mag/2003/12/28/stories/2003122800240400.htm>

<sup>69</sup> Venkatraman, A. et al (2009), Jewel of a Social Service, Student British Medical Journal, 11 November

<sup>70</sup> <http://sanhati.com/excerpted/3938/>

<sup>71</sup> <http://www.tehelka.com/doctoring-a-revolution-2/>

<sup>72</sup> <http://sanhati.com/excerpted/3938/>

<sup>73</sup> ibid

<sup>74</sup> Indian People's Health Charter

reinvigorate the public debate on HFA, combating a technocratic approach which now includes a shift towards greater private intervention in healthcare provision and consequent retreat of the state.

John and Legge in a piece outlining the history of the Peoples Health Movement<sup>75</sup>, refer to the Jan Swasthya Abhiyan. The authors comment on the strong participation from the women's movement, science movement and national alliance of peoples movements, adding that "the growing dalit and environmental movements and trade unions participate sporadically". When referring to positives in the movement, they see the strength in "its diversity, its experience and the willingness of its members to work together". Further, they feel that this plurality or diversity can be both strength and a weakness, especially noting the value non-health and non-medical networks with clear political positions bring to coalition, and, yet recognising that "it is the health groups who maintain continuity and momentum of JSA's work".

Campbell and others in an article titled, *Heeding the push from below: how do social movements persuade the rich to listen to the poor?*<sup>76</sup>, look at the Jan Swasthya Abhiyan and its different approaches, arguing that JSA follows a 'social determinant' approach, which argues that poverty, privatization and gender inequality also determine health, as well as providing a critique of capitalism and its endemic link to worsening "health inequalities". However, they specially refer to JSA's contribution to the National Rural Health Mission, which included "lobbying to reduce the allegedly pro-privatisation slant of the NRHM, creating spaces for community monitoring of the programme and setting up a parallel independent monitoring system called People's Rural Health Watch to enable those receiving care through the NRHM to monitor the mission's failings and demand improved services"<sup>77</sup>. However, one challenge the authors note is the fact that many constituents of JSA debate the merit of working with the government. The NRHM experience saw some constituents express their reluctance sensing that working with the government could relax their critical stance.

Further, the role of the constitutive National Health Assembly held in Kolkata in 2000 needs highlight, which aimed at reminding the government of its health pledges, and by joining JSA, "small and medium sized groups across India working on local issues could amplify their message, increasing their access to media, expert advice, and government attention"<sup>78</sup>.

When referring to its legitimacy, Campbell et al show that the coalition uses its membership among well known activists and politically prominent members, as well as well known doctors and academics. Further, using this position JSA has been able to build a linkage between activists and poor people at the grassroots with middle class activists and eminent personalities, which led to vital support for the 2003 Right to Health Care Campaign (RTHC) by the National Human Rights Commission (NHRC). In this campaign, JSA used its immense network to hold public tribunals, whose findings were then shared at a national level hearing in front of key government ministers and officials. Therefore, JSA represents a broad alliance, where diverse interests converge towards a common goal.

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<sup>75</sup> John, P.C. and David G. Legge (2011), *The People's Health Movement: health for all, now!* in Löfgren, H., Leeuw, E. J. J., & Leahy, M. (2011). *Democratizing health: Consumer groups in the policy process*. Cheltenham, UK: Edward Elgar.

<sup>76</sup> Campbell, Catherine and Cornish, Flora and Gibbs, Andrew and Scott, Kerry (2010) *Heeding the push from below: how do social movements persuade the rich to listen to the poor?* *Journal of Health psychology*, 15 (7)

<sup>77</sup> Ibid, p. 19

<sup>78</sup> Ibid, p. 20

### **Feminist movements and the health sector**

The contentious issue of building connections with policy platforms, contributing to policy spaces and demanding state action needs more interrogation. Dianne Bush<sup>79</sup>, in a paper comparing social movements in the United States and India working on domestic abuse, highlights the challenge these movements face, wherein they not only refer to a 'problem', but in doing so challenge the very separation of 'spheres' which is implicit to the approach of a so-called 'gender neutral' state structure<sup>80</sup>.

Several women, mainly urban middle-class and professionals, began organising autonomous women's organisations (AWO's), which Bush sees as analogous to the women's liberation movement in the United States. This new wave included a rejection of the older social-welfare organisations that worked among women. There was a focus on direct action and militancy, and, yet, worked in concert with party-related Women's groups. Among these groups, a collective began publishing a feminist magazine *Manushi* in 1979, which "detailed accounts of dowry beatings and murders, cataloguing police indifference and malfeasance". In May 1979, the burning of Tarvindar Kaur sparked the formation of new grassroots organisations, bringing together women from different strains of the women's movement. With a greater awareness of similar cases; similar groups came together in Bombay to form the Forum Against Oppression in 1981. Subsequent protests over the next few years led to the Delhi Police setting up an Anti-Dowry Cell, which was renamed the Crimes against Women Cell. Bush makes a significant point, where she sees the relevance of establishing such criminal justice measures as important and yet raises the argument that "the sex-gender system encoded in both the ideology and organisational structure of the state may be able to absorb women's movement demands by providing special protection for women in the context of the criminal justice and/or mental health system. Her assessment is that achieving 'protection' from the state does not ensure the original stated goal of women's freedom, and denigrates the idea of a woman as a free citizen. Hence, mere legislative recognition or legal protection cannot be seen as a criterion for success. Therefore, in her own estimate, rigorously interrogating 'success' in social movement organisations needs to include a wide gamut of relations, and cannot be seen in isolated realms of policy or legislative decision, instead focusing on wider social problems.

Padma Prakash in a paper titled, 'Women's Health Movement in India'<sup>81</sup> attempts to identify key historical moments in the attempt to address the concerns of women within the healthcare system as well as women as actors in a society embedded in deep patriarchal relations. She presents the women's health movement (further referred to as WHM), as a 'patchwork' quilt with several strains. Using a chronological methodology as well as thematic segregation she outlines key moments in the WHM in India. She acknowledges the influence of the feminist movements in the United States, and how it "created a body of knowledge and practices that is a feminist understanding of the body and mind, a critical perspective on the science of medicine and of its practice. This provided an impetus for the emergence of a coalition of women health workers, dissatisfied women health consumers, academics, activists of the anti-war movements, community activists and others"<sup>82</sup>. She accepts that there existed a tradition of maternal healthcare and a pro-abortion attitude of the state in post-independent India, which meant that the women's movement did not have to contend with two core issues that formed the basis of the women's health movement in the United States, and yet, several issues existed, especially, the deteriorating condition of women and alarming sex ratios. A starting point was the medico-

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<sup>79</sup> Bush, D.M. (1992), Women's Movements and State Policy Reform Aimed at Domestic Violence against Women: A Comparison of the Consequences of Movement Mobilization in the U.S. and India, *Gender and Society*, Vol. 6, No. 4

<sup>80</sup> *ibid*, p. 588

<sup>81</sup> Prakash, Padma (2005), 'Women's Health Movement in India: A Historical Perspective' unpublished Paper presented in 10th International Women and Health Meet

<sup>82</sup> *Ibid*.

friends circle annual meet at Anand, Gujarat in 1983, under the theme of 'Bias against women in the health care system'. Prakash contends that this meeting saw a first where members of the medical establishment were able to build a 'dialogic' relationship with the feminist movement in India.

Subsequently, the entry point for the movement was the prevalence of a 'pregnancy test' which consisted of a synthetic hormonal preparation containing estrogens and progesterone, which had already been banned in many countries owing to accumulated evidence against it. EP Forte was a product of this variety manufactured in India. On March 8, 1982, a campaign was launched to seek a ban on the manufacture and marketing of the drug, which resulted in the Drug Control Authority issuing a ban on the combination of drugs. This was met with a challenge by the drug companies, and following an extensive period of litigation and public hearings, eventually the drug was banned. The intervention in checking technological and pharmacological dangers within the medical establishment appears to be a major aspect of the early women's health movement in India. Prakash outlines some of the key reasons for the enthusiasm around this movement for banning the drug, first, it associated with a vibrant drug consumer movement which was its peak, which meant resources were available to build a case, second, the women's groups had gathered around dowry deaths and rapes and this momentum allowed for these movements to come together, third, there was a realisation that if the problem would not be met at this stage, it would largely effect those women in far-flung areas who did not have access to any alternative health care system.

Since the 1970s a test had gained popularity which could check abnormalities of fetuses, however, this was being misused to determine the sex of the child. In the context of declining sex ratios, based on the census in 1981, the 1980s saw a landmark campaign against sex-determination tests. The campaign was launched, initially against the bold advertisements in the dailies by clinics offering sex-determination and selective abortion. Saheli in Delhi, Sabala in Calcutta, Women's Centre in Bombay as well as some of the pioneering women's studies centres organised a protest against such advertising. It was realised, soon, that legislative action was needed to regulate use of these new technologies, and the Forum Against Sex Determination and Sex Pre-selection Techniques was launched in Mumbai, which included feminist activists, health activists, sensitive lawyers, social scientists and a newly emerging layer of progressive and sensitive journalists<sup>83</sup>. The Maharashtra government eventually became the first state to pass legislation banning the use of sex-selective techniques, followed by a nationwide legislation banning such tests in 1993.

Another important component of the WHM Prakash focuses on, is the organisation of women health workers, which included a variety of nurses' organisations. A major problem, though, with these organisations was that most of them were located in government run institutions and excluded membership of the vast variety of nursing professionals engaged in private hospitals and nursing homes. There have been agitations for uniforms for nursing officials, and in most cases these organisations have been acting as trade unions. Recently, more focus has gone into organising para-health workers such as *Anganwadi* workers (women workers in state run child feeding schemes) and community health workers known as ASHA, to ensure that they are provided with decent wages and working conditions. Owing to the temporary and casual nature of their employment, their precarious employment position, not only violates their rights as workers but threatens their contribution to a very crucial component of the healthcare infrastructure in India.

Further, while looking at non-allopathic alternatives to healthcare, in October 1987, a national consultation was held to discuss women's health issues, and a member of the Geneva Women's Health collective presented on the possibilities of non-allopathic alternatives. Following

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<sup>83</sup> Ibid.

discussions, several groups realised the preponderance of these diverse alternatives. It was felt that this knowledge needed to be documented. In the course of this, a small group, “Action Research on Alternative Medicines and Women’s Health was formed that brought together a number of field based organisations, and others to collect, collate, test and document information on traditional medicine under ‘Shodhini’. The result was a unique compilation and a network of graded self-help groups”<sup>84</sup>. There was an emphasis on articulating women’s experiences of health and illness over an experts opinion, recognising that an expert can only cure when the whole perception of the illness is understood, underlying the basis for a “feminist approach to health and healing”. Similar practices included MASUM setup near Pune which created feminist health centres in Saswad and village based health centres known as Sadaphuli Kendras in 1995.

While Prakash accepts that WHM remains amorphous with several cross-cutting agendas, there is no doubt that campaigns on women’s health issues sustain themselves through these diverse agendas, and the generation of vast literature and knowledge on bringing alternative perspectives on health care and determinants of health of women has been a significant contribution of the Women’s Health Movement.

### **3.2.4 Health Planning and Information**

While the focus of the review has been on HFA through initiatives working with communities or within the political realm, the healthcare system in India has evolved over the last many decades. This includes an elaborate organisational structure with expanded healthcare facilities. Civil society has intervened, working with governments and outside governments by actively participating in the overall healthcare system.

Under the realm of health planning, the district is seen as the microcosm, where policy and implementation interface. In such a situation, adequate training and capacity building among different constituents of the health apparatus becomes urgent. This includes both government and civil society, wherein the latter may be actively involved in district health committees, hospital management and community health programs. The Public Health Research Network (PHRN) is crucial in building capacity in this direction, through its distance training program that is meant to build capacities oriented towards decentralised health planning, as well as reaching out to motivated health workers to enhance their capacities<sup>85</sup>. PHRN’s activities include providing technical assistance to health workers, sharing public health technical resources with managers at district and block levels, engaging as well as providing technical resources with civil society to enhance their participation in public health as well as creating spaces of interface between public authorities and civil society, and building networks to enhance favourable public health outcomes. These programs have seen participation from government in ensuring fast track programs, which have been an encouraging sign. PHRN, as a distance program has meant increased networks for engagement with the government towards the end of decentralised planning, and still, while there has been enthusiasm to participate in these programs, further motivation to pursue projects is lacking owing to no formal accreditation.

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<sup>84</sup> Ibid.

<sup>85</sup> Kalita, A., S. Zaidi, V. Prasad, V.R. Raman (2009), Empowering health personnel for decentralized health planning in India: The Public Health Resource Network, Human Resources for Health, No. 7:57

### 3.2.5 Healthcare and Allied Services

Community Health Insurance (CHI), alternatively known as micro-insurance, as Devadasan<sup>86</sup> and others write, aims to provide healthcare to poorest as well as protecting them against indebtedness and poverty. They highlight major challenges faced by CHI, which include, first, they are short-lived and fail to meet their intended goals, secondly, they enrol small populations “thus limiting the extent to which there can be pooling and resource transfers”, third, they have excluded the poorest in communities owing to a flat premium rate which is quite unaffordable for many of the poorest families.

The authors, in a survey of over 20 CHI initiatives, identify key features: first, most of these initiatives are based in rural or semi-urban areas, which “ranges from tribal populations (ACCORD, Karuna Trust, RAHA), dalits (Navsarjan Trust), farmers (MGIMS, Yeshasvini, Buldhana, VHS), women from self help groups (BAIF, DHAN) and poor self-employed women (SEWA)”, second, the size of the target population varies from a few thousands to 25 lakhs, third, quite a few of them use existing community based organisations to initiate the CHI programs, while some use existing self-help groups and in others existing unions or cooperative movements are crucial to their functioning. In fact, in many cases, these community organisations have been helpful as a platform to promote health insurance and provide a strong organisational mechanism to take forward CHI initiatives. Further, the authors acknowledged the sense of community ownership in CHI programs, where most of the responsible functionaries who collect premium, select individuals, monitor fraud and conduct other tasks are from the community or from the voluntary organisation concerned. This has the added benefit of lowering costs; however, a limitation in this model is that quite often the lack of techno-managerial expertise leads to adverse selection, information asymmetry where the sick are most likely to enrol in such programs.

The authors identify some key aspects that ensure success: first, a credible and effective community organisation, which is “absolutely necessary as it is the foundation on which health insurance can be built”, second, ensuring low premiums, third, offering comprehensive benefit packages with minimal exclusions, fourth, having a credible insurer, normally the community organisation or NGO concerned, and finally, reducing paper work which normally acts as detriment to poor people joining who are anyways plagued by paper work in all other departments of the bureaucracy. They, of course, locate these aspects within a public discourse, recognising the need to limit the exclusions as improved health outcomes lead to better overall life prospects. While concluding, the authors feel, that while CHI is a small initiative in the wide scope of health interventions in India, there is immense scope to expand coverage through cooperative and trade union organisations, and ensuring a wider section of the poor are able to access low-cost healthcare.

#### **Mental Health**

Assessing the role of NGOs in Mental Health, Vikram Patel and Mathew Varghese<sup>87</sup> highlight the salient features of an NGO intervention in mental illness, even in the face of limited resources. These include their ability to work in partnerships, collaborating with other agencies and individuals unlike the government where hierarchies prevail and “collaborations may be perceived as a threat to the practice” [Patel et al. 2003:149]. Further, the authors see the proximity to the community as an advantage in terms of assessing changing needs and perceptions, and their services “may be attached with much less stigma than formal psychiatric

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<sup>86</sup> Devadasan, N., Kent Ranson, Wim Van Damme and Bart Criel (2004), Community Health Insurance in India: An Overview, *Economic and Political Weekly*, Vol. 39, No. 28

<sup>87</sup> Patel, V. And M. Varghese (2004), NGOs and Mental Health: Search for Synergy in S.P. Agarwal (ed.) *Mental Health: An Indian Perspective 1946-2003*(pp: 145-51), New Delhi: Directorate General of Health Services

services, and may thus attract a much wider range of clients". [Patel et al. 2003: 150]. Further, their non-profit nature, according to the authors, contributes a transparency as well as funding contingencies require constant performance and meeting deadlines. However, the authors feel along with these advantages, some limitations can be identified, such as the problem of sustainability wherein the same funding mechanism means possible resource constraints at unavoidable junctures hindering operations. Further, this funding concern means lesser stability of employment for the staff. In fact, the authors see a high turnover in NGO staff. In addition, donor focus on particular disease prevention programs could mean dilution of mental health focus of many NGOs, as is seen with the inclusion of HIV/AIDS as a core priority among many NGOs, which "may broaden the scope of MHNNGOs by enabling an integration of existing priorities with new ones, there is equally a need not to allow the focus on mental health to be diluted to the point that it become irrelevant"<sup>88</sup>. Other concerns raised by the authors include the lack of accountability among NGOs, with several allegations of misuse of funds and limited coverage and scope of their operations. The authors contend that while NGOs serve an innovative role in providing models for mental health programs for the public sector emulate and collaborate with, "they cannot meet the needs of the under-served and underprivileged sectors of our population... that responsibility, was, is and must rest principally with the public health sector"[Patel et. Al 2004: 151].

### **Palliative Care**

Another major challenge in developing countries is building a strong infrastructure of palliative care (PC) and Long Term Care for the chronically ill, founded on contextual socio-economic and cultural factors and accessibility to those most in need of it. Suresh Kumar<sup>89</sup> looks at a model in Kerala known as the Neighbourhood Network in Palliative Care (NNPC). This initiative focuses on developing capacities within communities to ensure palliative and long term care to its members, through a network of trained volunteers, and over time this network has been successful in replacing the dominance of the doctor-led model. The paper distinguishes between two forms of community participation, first, where it entails using resources available in the community such money etc. and volunteers fit into designated roles, second, it serves the purpose of empowering the communities, including them in processes of planning and monitoring the process as well as inducing ownership of the initiative. NNPC is an attempt at the latter, where people who can spare 2 hours a week are trained and then form groups of 10-15 volunteers, after which the focus is on identifying the problems of the chronically ill in the area and organising appropriate interventions. OF course, support is provided by trained doctors and nurses. The aim is not to replace active medical care, but "to supplement the efforts of trained doctors and nurses in psychosocial and spiritual support by trained volunteers in the community"<sup>90</sup> The essential challenge that this initiative addresses is the realm beyond medical care, where solutions to social and psychological issues arising out of chronic illness can be explored within the community itself. The NNPC has grown to ensure locally generated funds, and the author contends this theme of community participation is beginning to gain more traction with "the partnership of the state with civil society is now seen by many as a means through which a raft of societal and political ills can be addressed"<sup>91</sup>. Further, recognising the diversity within a community, and discarding any notions of one single homogenous category of a community becomes essential, and in fact, Kumar notes that "the extent of participation of people from the poor and middle class strata of the society has been one of the main characteristics of the NNPC program" [Kumar 2007:626].

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<sup>88</sup> Ibid, p. 150

<sup>89</sup> Kumar, Suresh K. (2007), Kerala, India: A Regional Community-Based Palliative Care Model, *Journal of Pain and Symptom Management*, Vol. 33, No.5

<sup>90</sup> Ibid, p. 625

<sup>91</sup> Ibid, p. 626

## 4 Role of Civil Society in Achieving Health for All: Analysis of Primary Research

The literature review in the previous section highlights some of the history of the health movement in India particularly in the context of movement studies. The empirical investigation into some of the questions thrown up by the literature review took place through key interviews of JSA and non-JSA respondents into various aspects of movement building.

### 4.1 Movement Building

The purpose of this inquiry is to assemble an historical overview of the recent developments of the 'Health for All' movement in India; to explore the drivers, constraints and dynamics which have characterized the development of the HFA movement, having regard to the context of place and time; and to review, evaluate and learn from the different strategies used by different social movements and CSOs, including, importantly, the Jan SwasthyaAbhiyan (JSA), to facilitate movement building.

In order to understand various aspects of movement building some key research questions were identified. In addressing questions of collective will and the notion of values underlying movements, it is important to place this issue within the context of how movements emerge and the manner in which they evolve. In many cases, a new need is felt to address deprivations of various types. These, quite often, emerge in undefined or unstructured situations, wherein movements gradually attempt to identify what it is directed against and what it hopes to combat or eliminate. In this process, the movement utilises several motifs, values, which began to give shape to the movement and also influence the commitment of the individuals engaged with the movement. It is important in this context to understand the factors which led to the development of JSA (and other movements) and reflect upon the implicit and explicit program logic for setting up the same. There is an attempt here to identify the principles based on which constituents of JSA has come together.

Though movements are seen as 'fluid states', they are often linked with institutions which are in the 'solid state', through processes. It is argued that institutions are instruments of movements to translate ideology into programme, theory into praxis, without which they remain shells without substance<sup>92</sup>. In fact, a more concrete organisational form is important to fulfilling the goals of a movement, and it is important to see processes of mobilisation and institutionalisation as two dimensions of a movement. In this context it is important to understand the governance structures of JSA and review its effectiveness in attractive activists, mobilizing resources; identify the enablers and barriers as these are crucial in sustenance of any movement.

When looking at organisational forms, one is actually referring to forms of collective actions that are within the confines of the existing institutional structure and include petitions, advocacy, lobbying, voting and fighting legal cases in courts. However, sometimes these institutionalised forms are used by movements as tactics, but, the core focuses on resistance against dominance and oppression, as well as positive action towards building or reconstituting the existing institutional framework. The key aspects that emerge are collectives (not individuals) confronting (modus operandi) authority (objectives). Further, examples of collective action could be demonstrations, meeting with politicians, policy influencers, media, social media,

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<sup>92</sup> Oommen 2000



education/awareness (e.g. community mobilizing, popular education). The forms of political protests and deliberate actions actually define the social movements and needs to be studied in the larger political context.

Alliance building, developing partnerships, collaborating with various movements and organisations is a crucial element in taking the Health for All agenda to larger masses. In this context it is important that we study JSA's approach in identifying potential partners and bringing together other Civil Society Organisations (CSOs) chosen for collaboration. An attempt has been made to study the successes and failures in partnerships to understand how campaigns and movements can work collectively, what are processes involved in collective agenda setting etc. It is important to see JSA in connection with the PHM global how each one shape the other. For instance, the role regional forums play in the links between JSA and global PHM and its other CSO allies, activities and campaigns would influence the agenda of both the country circle and the international forums. It is also crucial to study the governance structures globally, and understand how do these enhance or impede work at the country circle level.

Another crucial aspect of the study is to consolidate the learnings till now from JSA's work and identify emerging challenges, especially in the context of changing global and national economic and political landscape including neoliberalism, new government and funding. We would also attempt to reflect upon the role of peoples' conferences like the World Social Forum and the Women's Conferences or other similar movement building events and bringing people together. It is crucial that they are evaluated and successes and failures are understood and improved strategies are adopted in the convening of such conferences.

#### **4.1.1 JSA and Movement Building**

##### **History of the JSA**

The history of the Jan Swasthya Abhiyan, according to the JSA respondents, pre-dates the first People's Health Assembly (PHA) in Dhaka, the formative assembly which led to the establishment of the PHM.

"JSA in India has a different history which is much older, and informs the reasons behind the mobilisation towards Savar. After independence, the Bhole report thought of primary health-care, through health centers, in 1946. This affected the whole sub-region, as it was before independence. It was very close to the Alma Ata perspective, which is therefore an endorsement, not an inspiration. The only difference is that the Bhole Report was government focussed, while Alma Ata is more grounded in civil society." [Respondent 3]

After independence the government pushed for healthcare but with an urban bias and without a focus on marginalised sections. NGOs started experimenting in reaching out to areas which were not covered by government efforts. This came to be known as the Community Health Movement. According to Respondent 3, four major networks were created in 1970s, the Voluntary Health Association of India (VHAI), the Christian Health Association of India (CHAI), Medico Friends Circle (MFC) and the Christian Medical Association of India (CMAI). These networks started working together on different aspects of primary healthcare – either through direct provision of services (CHAI and CMAI) or through advocacy and knowledge creation and dissemination (VHAI and MFC). The Alma Alta Declaration for HFA in 1978 and the global discourse around it energized this movement as several efforts at promoting healthcare, by both government and civil society, felt legitimized. The WHO's formulation of a model Essential Drug List in 1977 was an important landmark, which inspired the creation of the All India Drug Action Network. Key health activists brought the community health groups together from across South Asia created the Asian Community Health Action Network (ACHAN), headquartered in India. These according to Respondent 3, are the six health networks that would contribute later

to the formation of the JSA. In 1984, the Community Health Cell (CHC) and this transformed into the Society for Community Health Awareness, Research and Action (SOCHARA), with an aim to bring medical groups and social movement and broader movements together.

During the 1990s, there was a realization that globalisation and economic policy were changing the whole philosophy behind primary healthcare and a larger coalition took shape which included the All India Peoples Science Network, the feminist movement and groups working on livelihood issues. This larger coalition (still informal) helped health groups to understand that in looking at health policy, an understanding of the economic and political scenario was central. The Independent Commission on Health in India report issued by VHAI, but which was a collective report by civil society included a chapter on human resources development that concludes that there was a need for a movement to push these policies.

Simultaneously in 1988, the WHO started a process to gather inputs on health sector reforms and pushed for the creation of an international group of NGOs. In 1999, the news about a proposed Peoples Health Assembly (PHA) in Dhaka started to spread (particularly through Zafarullah Chaudhury's visits to India and his interactions with several groups) and there was a decision to join the PHA mobilisation rather than create a network under the aegis of the WHO. This mobilisation really led to the subsequent formalisation of the JSA.

"The decision to set up the JSA was taken in December 2000. Till then there was not adequate commitment to even having a continued platform. We started this as an event and decided to make it a platform and that decision happened in December 2000. The origins of this December 2000 event which is the National Health Assembly went back 18 months before that when Zafarullah Choudhury approached some of us and said that we are holding an international health assembly in Dhaka and would you like to participate." [Respondent 1]

According to the JSA respondents the key idea around the pre-PHA mobilisation was to mount a large national campaign on health. This resounded with several of the individuals, networks and groups working on health. At a preliminary meeting of 20-30 activists in Chennai at the Madras Institute of Development Studies in 1999 the idea for a huge national health assembly (to be held in Kolkata just prior to the People's Health Assembly in Dhaka in December 2000) was born as was the idea of a massive national health campaign. There was no donor funding, and as yet and no organisational structure to carry out proposed activities. A decision was taken to invite all groups and individuals who would have an interest in the campaign to participate and also in the proposed national Assembly in Kolkata.

"We recognized that there were different formations or groupings or networks of NGOs existing like the faith based organizations which were the catholic hospitals, the Christian Medical Associations and Ramakrishna Mission and then there were people like the National Alliance for People's Movement which we thought was important. Then trade union organizations we had identified a few, then all the women's organizations we started organizing. Then there were some choices to be made as to why some were included and some were not, but sometimes the choices were self made like we did approach the youth organizations and the women's organizations, we approached the DYFI (Democratic Youth Federation of India) and the (All India Democratic Women's Association) but the latter responded much more enthusiastically and participated in every event subsequent to that, so in some sense it became more self chosen and the initial group formed." [Respondent 1]

Five popular booklets on health were put together in the process. JSA respondents highlighted the process of researching and writing the booklets as key to consensus building. The Peoples Health Charter which is the India specific health charter and has little formal connection to the international charter was the other document identified as critical to the process of setting up the JSA. [For more details see section on Knowledge Generation].

Thus activities organised in the run up to the National Health Assembly and then the PHA witnessed the coming together of various networks that had never before worked together. For the actual mobilization, something more than the booklets and the charter was required. To this end, activists and groups were asked if they could hold assemblies at the district and state level and many of these assemblies did take place. Various organizations joined these assemblies bringing their respective flags and banners. For the travel to the national assembly, all participants were asked to pay for their own travel but this itself turned into a significant mobilisation as the travel was coordinated.

"What we did was we coordinated and asked people to book 3 months earlier on a given date on the same train. So 1000 people booked on 4 trains; we were able to book 200 seats, 150 seats; we had explored the possibility of hiring buses or trains, we had nowhere near the money needed, so we just made sleeper class and sitting class bookings for these teams and everybody piled in. It became very spontaneous. When the team was travelling I think from Trivandrum to Ernakulum in the Gauhati Express or something, wherever stations it stopped, if it stopped in Vishakapatnam or if it stopped in Vijaywada local district assemblies would have been completed and the people would come to the train, one or two people from the local assembly would get on, the other people would give us breakfast or lunch and the railway station platform would be converted into a celebratory issue and also into a protest atmosphere, slogans would ring out and we would go. So in fact we were able to get 1000, 1500 people to this conference without any expenditure involved. I think this strategy of having a number of local events which then streamed into, people finished their local event and joined the mainstream and joining the mainstream was literally going up to the mainstream on the train and get on. So I think that idiom worked." [Respondent 1]

The National Health Assembly thus convened in Kolkata with activists and groups from around the country whose solidarity had solidified over the year and a half of organising that had preceded it. From Kolkata, 300 activists who could self fund (it cost each participant about 3,000 Indian Rs., roughly 75 USD, and no external support was available) and had passports (many activists got their passports for the first time to attend the PHA!) travelled in 4 buses from Kolkata to Dhaka. The PHA itself was the first time several individuals and groups in India looked beyond the country to what was happening internationally. After the PHA, when the activists returned, there were several rounds of discussions about how to institutionalize the platform created at the National Health Assembly, how to sustain the movement beyond mega events as well as a very different dialogue on how issues would be taken up and protests and activities organised. The period till December 2000 is considered by Respondent 1 to be one of broad based mobilization. (See **Annexure 3** for a detailed overview of the formative process of JSA till 2000, retrieved from archives held by the current JSA Sectt.)

Between 2000 and 2005, apart from the establishment of governance structures and functioning of the JSA (see below), three key activities solidified the role and involvement of the JSA at the national and at the State levels. In 2001, the second national health policy was issued with the government asking for comments which many in the health movement felt required a collective response under the JSA banner. The critique of the draft health policy was the first letter written to the health ministry in the name of JSA. Between 2002 and 2003, the National Human Rights Commission had one staff who was a health resource person. This person had also attended the National Health Assembly in Kolkata and the collaboration between NHRC and JSA resulted in state, regional and national level people's hearings on right to health. In 2004, prior to the national elections, JSA started engaging with the 12 national political parties through a policy brief on health while the State level circles also started their own campaigns.

"In 2005 the game changed considerably." [Respondent 1]

After a strong period of solidarity and consensus building, the period between 2005 - 2010 is considered by Respondent 1 to be one where ideological differences within the JSA led to

significant schisms in the movement. These differences were brought on by the election of a national government that had a strong involvement from the Left and that had proactively reached out to and secured the support of several CSOs. The launching of the National Rural Health Mission (NRHM) by the government was considered to be an outcome of this relationship between the government and the CSOs and within the JSA resulted in very strong positions being taken by groups on whether or not to participate in this government programme and in government committees that were being set up and more importantly what form should such participation take. The 2nd health assembly convened in 2006 in Bhopal was, as a result, "rather dramatic." An action plan prepared after a long process and considerable negotiation could not ultimately be followed up with very concrete actions.

"We did not handle coordination or participation in working with the government very well. We were rather good at working against government but we did not know what to do with ourselves when we were working with them. I think what divided us was on the issue of how do you look at the ASHA(government accredited community health workers) movement, how do you look at the Janini Suraksha Yojana (Safe Motherhood Plan), is it co-opting women or is it expanding facilities service. Is NRHM to be labelled as privatization or is NRHM anti-privatization or is NRHM a confused terrain in between. It wasn't participation or non-participation, it was how we took part because those who could participate participated, those who by inclination or by influence could not participate, did not. Even those who participated could have widely different understandings on what the Asha is, is she a link worker, activist or service provider. From one end of extreme positions to moderate positions of opposition. I think that was a period of great tension." [Respondent 1]

In 2009, by winning a re-election, the national government that had initially worked with the CSOs was now challenging the very programmes that had been introduced by it, including key government figures denouncing the NRHM as a failure. This period also saw an increasing hold of neo-liberalism in government discourse. This was particularly evident with the release of the draft of the 12<sup>th</sup> five year plan in 2012 which was strongly critiqued by JSA in what came to be called the green booklet ("Dangerous Drift in Health Policy") and the process of the critique of this draft was considered by one respondent to be a "huge unifier" and "almost as influential as the people's health assembly booklets of 2000." The process led to considerable mobilisation of the JSA and there was in a sense a return to activism.

Reflecting on the reasons for the formation of JSA, one respondent felt that the immediate reason was the entire process leading up to the National Health Assembly led to a realisation across the various networks and groups the knowledge and resources required in ensuring HFAdoes not reside within one group and what was needed was a mix of resources and activists. The people working on health went from the "health wallah"(those whose main activity is health activism) to a broad forum that includes peoples movements, trade unions, youth movements, women's organizations and so on which provides a significant amount of technical analysis and resource inputs from people who think alike. According to another respondent, it was the core issue of the crisis of public health that combined with the increasing importance of the language of health rights violations and the growing understanding of the multiple facets of healthcare including the private sector, social determinants of health, access to medicines and womens health rights that precipitated the forming of the country circle.

#### **4.1.2 Membership and Outreach**

In terms of the membership of the JSA, according to Respondent 3, it has been mostly collectives and platforms that have been targeted as opposed to individuals or small NGOs. *"This approach ensures that no one group can take over the network or movement and allows for greater accountability while also helping in governance."* However individual NGOs are encouraged to

join at the State level. Respondent 2 noted that the JSA is built as a broad based social coalition with a common minimum platform and while groups working on specific issues may become part of JSA (HIV, tobacco control), these do not become the main focus of JSA's activities. Respondent 1 stated that the peoples' health charter did form a basis for membership but not necessarily in any direct way and often people join JSA because of more recent campaigns or activities.

JSA outreach takes many forms including through organisational contacts, events, campaigns and individual outreach to name a few. One respondent highlighted the individual nature of outreach where people involved reach out to others that they think can potentially be interested. E-groups were highlighted as an important method of outreach but also "because the old form of it still is there, so at seminars, conferences people who come in and get news from them and hear of JSA's work."

There were very few instances of people or groups leaving the JSA according to the respondents; mostly they tend to become dormant. Some because of a lack of follow up from JSA and others because they have their own priorities or because they feel a specific issue has not been taken up that should be. Inclusiveness was highlighted by one respondent as necessary for keeping JSA members engaged and noted that in some states or situations the leadership has not been participatory or inclusive and "if a single group is dominating in a state, than it might lead to people dropping out." Serious cases that may arise in such situations are taken up at the national level. Asked if the number of groups outside the JSA had some reflection on JSA, one respondent 3 noted, "the sign of success is not the number, but being able to change the discourse and perspective from the market to public health." Similarly another respondent noted that this should not be seen as a problem and there was a need to respect those who do not want to join as well who may be hesitant to join because they do not want to be seen as part of the organised left which in some States appears to be the case.

The attraction of JSA lies in the platform it provides for health rights. According to Respondent 3, for some it is the sense of belonging to a larger group. According to another, member-organizations have three main reasons for joining the JSA i.e. because it enhances their own ability to contribute to change, it provides peer recognition of the work and the desire to show solidarity. Members remain engaged with JSA because it engages actively with the burning issues of the health sector and because organizational strategy is based upon many organizations coming together and at any time some will be very active. The discussion on this aspect of movement building threw up some interesting reflections on JSA which would be interesting for further analysis and reflection within JSA.

"JSA is not a people's movement, it's a movement of health for all activists. It is not a grassroots process that started from the bottom up. The national JSA came up before the states, states came up before the districts. JSA is a movement of the instrumental consumer NGOs as providers or health professionals not as communities organisations. In some states, community organisations might be involved, or are even members, but the lead comes from the health activists / professional organisations. It is people inspired, but not people lead. The process is democratic from that perspective (of being made of health activists / professionals organisations), but not democratic if taken from a real people's democracy sense." [Respondent 3]

On the other hand for another respondent, JSA is very much a network of different grassroots organisations.

"Initially it was always only the 'health wallah', but we have a forum of people, we have people from the Alliance of People's Movement, we have trade unions, we have youth movements, women's organizations, so it becomes more general and does not stay confined to doctors and the health sector. That was the most exciting thing. For JSA members who

come from their own movements, they were very conscious that whatever mass mobilization they need to do they could do on their own but they liked this forum because it gives them a whole lot of technical analysis and resource inputs from people who think alike." [Respondent 1]

[Note: In an interesting aside, one of the respondents referred to a sort of "core group" that has stayed steady through even the tumultuous periods that JSA has faced. If there is indeed a n identifiable core group, the dynamics of this group and their comfort with each other may explain why JSA managed to stay together despite some serious schisms forming within it. This may be an area that requires more exploration as for the future of JSA, with younger or newer people coming in, reliance on a core group would not be sufficient to deal with conflicts and heated internal debates]

#### **4.1.3 Governance**

"India is a federation, and JSA is one JSA and 16 State JSAs, which is also unique."  
[Respondent 3]

As one respondent rightly predicted, the answer to the question of the governance structures of JSA would depend on the person answering. According to one respondent, there is a loose and flexible framework that is effective. This allows for many to participate in the current state level circles and the current coordinating committee at national level. There can be situations where a State circle is not sufficiently inclusive in which case that circle does not develop and remains limited in reach.

"There is no formula to solve this. We need to keep on trying to make JSA as inclusive as possible, while remaining focused. "It is a continuous process of democratisation."  
[Respondent 2]

According to another respondent, there are both formal and informal governance structures. For instance, in taking up an issue as JSA, sometimes one person may write to everyone on the matter and there is natural consensus on taking it up. The basis of the JSA remains consensus. The formal structure comprises the National Coordinating Committee (NCC) and a secretariat. The secretariat meets and takes a call and JSA-NCC is the co-ordinating group. Initially the NCC was meant to be a representative group of organisations and in 2000 every group that was part of JSA sent two representatives. As State circles came up the NCC evolved into the coordinating body of the State circles through the State convenors. JSA members by and large became members of their respective State circles and few retained direct representation at the NCC and were instead directly represented at the State level. There are at least two meetings in a year with one at the larger level convening all members. Usually a three month notice period is given and some degree of mobilisation takes place to get as many members to be present as possible in what is usually a two-day programme. The secretariat meets at least three times a year. For the approval of new members, the process is formal and is taken up by the national secretariat and the application is passed on to the NCC where membership is approved if two members recommend it and if there are no strong or serious objections. One respondent pointed to the email group as the place where many positions are evolved. Working groups are also created and documentation is used to support this process.

"I don't know whether you should base it as a movement or as an institution. This is the institutional format of the movement. The institutional format for the government or for corporates is different. This is an institution in the general sense of the rules of the game, and organizations are players of the game." [Respondent 1]

At the state level, the decision making process was described as "bewildering" where the formal consensus is still that they need a network of organizational representatives and activate functions in most states. With varied outputs from the States, one Respondent felt that national coordination was essential to encourage and motivate and provide the technical competence and inputs required on a wide number of areas. Active national coordination is needed for more effective state level action. On whether there was a sense that there was less activity at the national level than the States, another respondent noted that while some state circles are indeed very active, significant activities (such as the ongoing process with the National Human Rights Commission) start as national level processes and get implemented at the state level.

#### **4.1.4 Ideology**

The question of whether an ideological position is important and whether JSA had a clear ideology saw three different answers from the JSA respondents.

"It is important to have a broad church. A small group of strongly ideologically people does not allow the group to grow and attract broader public participation. It is important that documents are inclusive of these different positions too. There are four kinds of captures of movements: the first is ideological capture which creates; the second is iconic capture where a few inspirational figures become the only thinking leaders; the third is elite capture where a few academics or activists do not accommodate people still developing their positions and finally there is the single organisation capture where a large NGO through the weight of funds becomes predominant. It is necessary to guard against all these forms of capture."  
[Respondent 3]

"Many of people involved subscribe to an anti-neoliberal ideology, but the words will not be used prominently in the documents; nor is this a pre-condition for joining and working together. This ideology is reflected in the charter and it is only organisations that are comfortable that would join. It will attract people too. It is an underlying political ideology. Having an explicit ideology would not be a good idea for such a broad platform, as people who do not have a clear position or have an ambiguous attitude, or would be interested to join programs but not join such ideology would be put off. But a broad direction is also important, through the various documents (charter, booklets, manifesto). In the health sector, intuitive activists might not be comfortable with an explicit ideology."  
[Respondent 2]

"The people's health charter and the booklets are the commonality. The adoption of that people's health charter brought together a lot of positions. The people's health charter does take a position on globalization and neo-liberalism, so clearly for somebody who thinks that neo-liberal policy is the way to go, privatization of healthcare remains a goal in itself, public services have to be privatised, you will not be allowed. So when a new membership is considered especially when those who sometimes have externally funded agencies, you would look at what their positions have been vis-à-vis this debate. It is not ideologically neutral. The other is the secular issue. An organization could be communal but have a correct position on health care but it could not get into the JSA, not in any way that I can understand it. This was a critical issue in 2000 and it was an important demarcation that we made at that time. There are greater risks in not having an ideology rather than in having one. The greater risk is that the JSA today represents something, people refer to it, they may not invite it formally, but they know they listen to it and at some point its influence is vastly under-rated. Without the ideology, the credibility will be lost. There are risks of being victimised with such a clear ideology but these are risks that those who are part of JSA have agreed to take."  
[Respondent 1]

#### **4.1.5 Strategies**

In terms of strategies used by JSA, the respondents confirmed that a wide variety of strategies are employed including assemblies, mass gatherings, manifestos and manifesto analysis, people's watch of government policies, people's dialogues/tribunals, producing publications, organising and hosting IPHUs and other fellowships. According to Respondent 3, this is how JSA acts as "the countervailing movement." Networking and alliance building is also an important part of the JSA's work. One respondent noted that JSA also uses judicial and quasi-judicial forums such as the NHRC and Public Interest Litigations. According to another, the most important tool used by JSA is that of issuing policy briefs or activist notes, noting that this has the most pervading influence.

#### **4.1.6 Collaborations and Partnerships**

According to one respondent, collaborations and partnerships for the JSA can be categorised into three types:

- People who are seen as potential members who could join JSA
- Organisations that are like minded and work together with JSA but their primary focus is on issues other than health (right to food, womens' movement). In such cases events are often organised together and JSA will contribute to these movements but not lead them. Even within this JSA has a range of relationships. With some there is a close coordination and both JSA and the partner organisation see each other as a space to learn from and build solidarity. In the case of others the involvement may be quite low
- Forums set up by the government or development agencies, in which JSA is present, but not leading the platform. In these situations particularly, it is not the Charter or the ideology that guides JSA's involvement. Some of these may be for promoting privatisation for instance but for JSA this is a terrain of contestation and policy influence. "Within this space JSA members coordinate among each other, and expose policies that could be harmful. representation is sometimes in the name of JSA itself, such as the national human rights committee and pricing committee."

According to one respondent, there is more experience at the State level than at the national level in terms of collaborations. State level JSAs interact with other networks and with the government and some have consistent collaborations with other movements.

"With a campaign working on the right to food, JSA organised a convention on malnutrition and food security with participation from across the state and by experts and government officials. A range of demands was developed to reduce malnutrition in the state. Meetings were held with government officials and with Members of the legislative Assembly (MLAs) who were sensitised on social sector budgets, focusing on health, foodsecurity and child nutrition. This collaboration is now over 10 years old and is a natural alliance for the JSA." [Respondent 3]

Choose collaborations with other organisations is also based on complementary expertise. One respondent gave the example of an institute which provides the institutional framework, physical space and legitimacy while JSA has mobilization capacity. Another example is of collaboration with a movement that focusses on the urban poor while JSA's focus has been on the rural poor thus working in a complementary way even in terms of the base. Collaborations in the form of peoples conferences also take place but the importance of there being direction in such conference was expressed by one respondent who noted that one particularly large, international peoples gathering in India, "became a jamboree" and that "mega events like these make sense only if they are a rallying point on a road map of mobilization and they are followed up by specific initiatives."



According to the JSA respondents there are differing views of the JSA externally. While service based NGOS find JSA too radical as it keeps fighting with the government, trade unions see JSA as an important alliance to raise certain issues. Semi-government and academic institutions tend to take JSA seriously. According to one respondent, "other CSOs look at JSA as having a consistent leftist view, being adverse to privatisation."

#### 4.1.7 Resource Mobilisation

All JSA respondents agreed that resource mobilisation was a concern and that JSA relied heavily on voluntarism. Most resources are generated in kind and through informal contributions, volunteer time and use of existing offices. From time to time, JSA has also received funds for specific activities or for support to the secretariat. such as WHO support for work on social determinants. Largely the organization is self financed and this is considered to be a historical approach given that in the mobilisation for the national Health Assembly there was no central proposal and no central receipt of funds. People were asked to use their own resources to come to the meeting and contribute their bit to the total meeting expense. This according to one respondent, remains the guiding principle. If there is a specific project that JSA undertakes, one of the members will receive the funds and there is strict documentation. Some JSA members have provided infrastructural support, hosting the secretariat for instance. Mass organisations who are part of JSA contribute very small amounts as they have no fund raising or project activity while others who have some form of resources contribute more. Financing by members is based on their capacity. While there are occasional attempts at creating a buffer or raising funds, this seldom takes shape and in many respects the JSA respondents felt the approach to resources was fine.

"There is a large base of contributory support and occasional institutional funds. After 15 years, we are still going so it must be sustainable enough. It is not a good idea to be completely dependent on institutional funding, but there are disadvantages also to be completely dependent on contributions, especially for travelling - it becomes a constraint. But there is no visible alternative and this works for now. We have discussed organisational contributions on an annual basis, but it has not worked. It works for events, not for regular expenses." [Respondent 2]

#### 4.1.8 Enablers and Barriers to Movement Building

"There is a continuous tension between the individual agenda of specific organisations and the collective agenda and it is only when the collective agenda is strong enough - this becomes an enabler." [Respondent 3]

"Pitches should not be too shrill, emotional or passionate pitches-which can become tiring for those who are actually working to match this and for marginal supporters who will always be the majority, it pushes them away. It appeals to the converted but a growing network needs to primarily appeal to those on its fringes and bring them in." [Respondent 1]

While reflecting on factors that enable movement building, one respondent felt that JSA is strongest when there is a common activity or campaign in the states. Noting that the 2000 PHA was the biggest enabler, he gave the example of the right to health care campaign in 2003-04, which he felt energised the JSA across the country through the collection of testimonies and organising public hearings. From the interviews, a few key enablers in movement building emerged including:

- Continuously updating strategies in keeping with newly emerging situations;
- Ensuring maximum inclusiveness and continuous outreach;
- Good quality, updated analysis, which addresses concerns that people are facing.
- Need to be constantly in touch with the network members which required a very competent and acceptable nodal network.
- Place for network members to display their individual/organization identity without undermining the group solidarity.

- Activities where many can participate contribute, some in a major way, some in a minor way.
- Strategies of financing, both the node and other key constituents.
- A good proportion of the membership should come from individuals organizations who do not depend on this work for their incomes- but have the time to contribute to this work.

For one respondent the various discussion, debates and even extreme differences on some issues within the JSA are necessary for movement building.

"There are things that unite us and there are things that divide us but the things that divide us also organizationally maybe acting as a unifying issue because many of us love a good argument and to have an opportunity to argue about it is very useful. And for a lot of people out there observing both sides of the argument is the most educative part of it all. If there was agreement there would not be as much clarity as there is clarity that emerges from the dialogue." [Respondent 1]

#### **4.1.9 JSA and PHM Global**

##### **a. Contribution of PHM Global to local circle building**

JSA respondents had differing views on the contribution of PHM global to JSA. One respondent commented on the solidarity that global actions can inspire.

"It contributes to the larger spirit of the enterprise. knowing that something similar is happening in the rest of the world, north and south, in terms of resistance, is encouraging. These are difficult times in the face of shifts happening at global level. It emboldens us and this is the most important contribution of PHM global. Global PHM is also an alternate to the bleak scenario of global governance. Coming out with GHW is an important global event, though dissemination should be much more." [Respondent 1]

The respondent also noted that as an if one sees PHM as the most important (alternative) global health institution, it is important that its governance reflects the responsibility that has come to its shoulder, but does not know enough about it. institution taken to mean an organisation with a framework, which can be more or less formal, or more or less bureaucratic (then it becomes an issue).

According to one respondent the expectation that people involved in the global work would bring it back to the local circle has not been met. Another respondent felt that although there are JSA people active at the global level, this is more as individuals than as JSA. According to this respondent, global initiatives are not fundamental to the way JSA decides its agendas but this is also linked to the nature of the country circle and the state level processes which themselves are quite independent.

"From the perspective of states and members of the coordination committee, the interaction is infrequent and not very intensive. If there is an important activity, then there is much more interest from everyone in JSA and more involvement. WHO Watch and GHW, there is some contribution from some people, but its limited to experts. Attempts have been made, but the impact is not there. I cannot think of any global campaign that had a significant impact on JSA. Signing on letters is happening. but the opinions will vary a lot depending on who is asked the question. PHM exchange does keep us aware of what is happening though." [Respondent 2]

One respondent similarly noted that JSA has its own identity and leadership and is not dependant on PHM for either. While some people from JSA are involved with PHM Global, this is seen as sufficient for JSA's engagement. However, much deeper engagement is required but this is dependent on human interactions, and opportunities for this at a global level are very limited in PHM.

"For example during the PHA in Cape Town I was able to connect with a number of activists from other countries and get a sense of their work. But since then there have been no occasions to deepen the connection." [Respondent 5]

Another respondent noted the difficulty inherent in global movements as grounded activism makes sense from local to state and from state to national, as the target is the State. But at the international level, the target becomes much more difficult to identify, as well as the ways of intervention.

One JSA respondent suggested that PHM also needs to look at global health diplomacy - i.e. health as part of external affairs policy. "This new phenomenon needs to be understood, how does it contribute to achieve US and other powerful countries' strategic objectives."

#### **b. Regional Forums**

The question of regional forums saw some skepticism with respondents noting that this seemed unlikely to work at the South Asia level. One respondent pointed out that PHM members in the region do meet at various south or south-east asian conferences and should use those opportunities for PHM meetings or discussions.

#### **c. PHM Global Governance, links to local circles and the question of membership**

On the link between PHM global and local circles, one respondent noted that there were regional representatives but that there was no mechanism to evaluate the role that representatives are playing in bringing groups together, for movement building. Pointing out the global coordination takes a lot of effort, he noted that if regional representatives were not effective, the focus of the work will naturally be only on the global level. An idea for country contact persons has apparently also not progressed. In terms of membership, one respondent noted that there isn't membership of PHM global, but to a country circle and in places where there is no country circle, the regional representative has a key role to play in creating initial linkages and allowing for activities to take place. Advisory council members would be good people to play this role in new countries.

"PHM has a dialectics and there is a need to decide if this is a movement or an international NGO. if a movement, no need of registration. in JSA, members are there, but not as individuals, as organisations. but each country has to decide, as size of the country might play in this."

Another noted that the model for PHM is a federative model and the major limitation of a global federation is the difficulty in having face-to-face meetings. The second problem is that people involved in activism are very busy and involved in local activities. As a result it is people with more time and mobility that end up being part of the global governance structures.

"This creates a relatively small circle of people who have know each other well, have created trust among them. There is also the question of people being interested but not able to spare the time. As PHM we are rarely able to take up intensive joint campaigns at the global level, except for the PHA." [Respondent 2]

One respondent noted not being very optimistic about the global processes saying that, "governance should be linked to what we want to do." According to this respondent the work of PHM Global has not contributed to mobilisation and movement expansion and for this to happen a new structure would be required.

"The Right to Health Campaign that a few of us had envisaged never took off. now further diluted into the health for all campaign. not sure what is happening to it." [Respondent 3]

Another respondent noted that there is a case for organisational membership and that individuals who are not sponsored by organisations should not hold key positions, though they should be involved. The respondent felt that organisational clarity on processes to define positions, how much distance from common positions can be taken is required and the democratic model must be fundamental to PHM. Speaking of JSA, they noted that JSA is not registered (non-incorporated) which allows for a plural identity, avoids capture and allows for participation and diversity

#### **4.1.10 Strategies for the Future**

One respondent laid out in details some of the strategies for the future of JSA and noted that the most important challenge is of organizing a much wider public understanding of health policy and undertaking mobilization on four parallel tracks:

"In the first and most important track is to point out the denial of health care and give voice to the suffering and impoverishment that results from the current organization of care. In the second track we recognise that pointing out to failures of public health services is used to further privatise it or attack workers in public services and their terms of employment. We therefore have to increase understandings of why public health systems fail and what must be done to improve its functioning. In this track therefore we need to work with government and with organizations of health sector employees for more investment in public health and for improved delivery of public health services.

In third track we need to work on monitoring and demanding improvements in publicly funded insurance schemes. Though we do not believe they are a solution- there is considerable expectation in the public mind, and considerable propaganda that posits access to private health care as a right and as need. But by ensuring that families do not get ripped off, and that the flaws in their policy and management get exposed- public understanding of this would improve.

In the fourth track we need to work for better regulation of private sector, and more ethical private practice. Here we need small ethical providers and not for profit organizations as our allies- and also need to alert them to the implications of corporate control." [Respondent 1]

Commenting on the shifting global and national economic and political landscape the respondent highlighted three areas of concern:

"A shift from insurance as it is now practiced to outsourcing entire populations to corporate entities. An effort to open up primary care to corporate control. Failing which, and in parallel, starve public systems of funds, while blaming them for the poor performance by themselves highlighting all the gaps." [Respondent 1]

## **4.2 Campaigns**

The Jan Swasthya Abhiyan, established in 2000, is an umbrella organisation of diverse groups across the country that stand by the declaration that “We reaffirm our inalienable right to and demand for comprehensive health care that includes food security; sustainable livelihood options including secure employment opportunities; access to housing, drinking water and sanitation; and appropriate medical care for all; in sum – the right to Health For All, Now!” The thrust of the JSA is to reinvigorate the public debate on HFA, combating a technocratic approach which now includes a shift towards greater private intervention in healthcare provision and consequent retreat of the state. Progress towards HFA is driven by more effective campaigning which depends on building a stronger global movement and both in turn depend on stronger networking (local, vertical, global and inter-sectoral). Stronger networking and campaign collaboration include first, building relationships and collaboration with existing community organisations and networks and secondly with researchers, officials and practitioners.

Attempt has been made here to identify key campaigns including those which are ongoing and identify different strategies used. We would like to study the historical and political context through which these campaigns have emerged. It is also crucial for us to understand the key actors involved in the process. Jan Swasthya Abhiyan (JSA), for instance in one of its key campaigns for the 2003 Right to Health Care Campaign (RTHC) by the National Human Rights Commission (NHRC) JSA has been able to build a linkage between activists and poor people at the grassroots with middle class activists and eminent personalities, which led to vital support. In this campaign, JSA used its immense network to hold public tribunals, whose findings were then shared at a national level hearing in front of key government ministers and officials. Therefore, JSA represents a broad alliance, where diverse interests converge towards a common goal.

Long terms sustenance of any campaign depends on the ability to mobilise human and physical resources- here the attempt is to identify various strategies adopted by different campaigns in this regard. The other crucial aspect of campaign is to generate the knowledge that feeds into the campaign, articulates the position clearly and help the activists understand the nuances of the issue and brings various constituencies together. For instance, PHM produces the Global Health Watch which explains the political economy analysis and its applications in practice. Our objective is to assess the extent to which GHW is used by activists and also identify various strategies adopted by campaigns in reaching out to larger population.

The other important objective of the study is to have insights on the strategies used by campaigns to identify the selected issue(s), mobilize participation, build coalitions, select the strategic actions, sustain participation, enhance skills/capacities for activists involved in the campaign, and evaluate its outcome. Attempt here is to learn from other successful campaigns about these critical aspects of campaign building. However, the understanding is to see these in light of the overall political context, the constituents of the campaign, external factors and internal dynamics.

There is a lot of learning opportunity for the JSA in particular and PHM in general from various campaigns about the barriers and enablers faced by them and identify activities that have been adopted by various campaigns to maximize enablers and minimize barriers. It is also important in this context to understand the various forms of collective actions and strategies used by the campaigns to achieve their demand. Collective actions could be in the forms of demonstrations, petitions, lobbying with politicians and policy influencers, media, social media, education/awareness for mobilizing communities and spreading popular education. It is crucial why certain strategies are used against others.

Discourses around campaign demands are evolving over time, often being shaped by the overall changes in socio-political contest and also in reaction to developments in policies and programs. In the current political context in the country, where there is an upsurge of one kind of political formulation which has general disregard for civil society, it is imperative that tactics and strategies adopted by campaigns also appraise the reality. Another crucial objective is to understand from other movements and campaigns how they see the Health for All movement and JSA in particular. In its endeavor to bring together various groups, mass organisations, networks for Health for All, to understand from other campaigns the complexities, contradictions involved in the partnerships and how they were resolved, how decisions are taken when there are divergence of opinion.

#### **4.2.1 Campaign Case Studies**

Interviews with JSA and non-JSA respondents revealed a long and rich history of health related campaigns. As these campaigns highlight both the diversity and impact of the efforts of CSO in India they are **presented as case studies at Annex IV**

#### **4.2.2 Resource Mobilization**

The interviews highlighted varied approaches to resource mobilisation. Some groups reject project-based funding and do not rely on extensive or concerted fund raising. One interviewee highlighted a "friends and neighbours policy" stating that they never believed in funding per se and have used all opportunities, and a partnership approach to reach the needs of campaigns. Resources are mobilized mainly through personal commitment, small fund raising, individual donations, contributions towards travel expenses, etc. Others have adopted strict funding policies which are documented. One respondent noted the importance of funders who trust in the vision and implementation of those they are funding, do not attach strings to the manner in which funding is spent, let them remain independent and do not desire any visibility in the campaign. Another highlighted the flexibility shown by funders who allowed funds originally given for another project to be re-purposed for a particular campaign once the importance of the campaign was explained to them.

"For events also we don't accept funds from funding organisations, but contributions from individuals and participating organisations, in the form of money or payment of any bills. The campaign is not registered, we have a bank account, our accounts are put up on the website and audited." [Respondent 11]

"We never believed in funding per se. Ours was never funded by a particular source, we never had a project that was like that. We always used all the opportunities, and a partnership approach to reach the needs of these campaigns. Even now, if you see, our regional workshops were done solely with donations from a range of local partners. Each organization gave five thousand or six thousand and the workshops were conducted. I would like to call it a '*friends and neighbors policy*' for fund raising because it's a collective." [Respondent 8]

"In the first meeting we had of JSA, we passed a box around and everyone pulled out from their pocket whatever money they had. We feel, there has to be that sort of a contribution in every campaign." [Respondent 8]

Most respondents highlighted their dependence on voluntarism and sharing of resources. One respondent noted that their campaign was hosted by a partner organisation for a nominal rent that did not change even when the organisation moved to a more expensive office. Another noted that their secretariat is run by often a fresh graduate who is willing to work at a low

salary and that lot of people contribute their time in guiding the secretariat, organizing and mobilizing, creating the knowledge base, doing research. Another respondent reported that human resources were mobilised by mobilising organisations who were involved in the campaign.

### **4.2.3 Knowledge Resources**

Campaigns rely on multiple sources for knowledge that both inform the campaigns and that emerge from them. One respondent reported using studies as well as cultural media (skits, slogans, songs) and generating and disseminating knowledge based on "doing rather than from others/theory." Another respondent noted the importance of generating campaign materials during the initial phases of the campaign including primers, questionnaires and research tools. Most of these were generated using secondary sources and the government's own data simplifying them to understand what is happening.

"From the beginning we had a small research base. Often small pilot research studies are done and then questionnaires are put up on the website, organisations are encouraged to conduct similar studies in their own settings and the findings are used to shape campaign demands one is making on various programs as well as disseminating as part of the campaign." [Respondent 11]

Another noted that the kind of knowledge required changes during the course of the campaign.

"First was access to government documents to understand what the government was doing. For this we relied on existing literature and consulted colleagues from JSA at the national level. Then there was a different kind of knowledge needed, on the actual status of the services, which required creating knowledge, which was done through the surveys. Also, it was important to create a narrative on the experience with the private health system, which again was an important knowledge to foreground. This was gathered through interactions with health workers, and in the public meetings that were organised in the districts and at the state level too. The village meetings that activists organised for the campaign, and as part of their own usual activities with the communities, and with community leaders. Local groups also interacted with the local elected representatives." [Respondent 12]

One respondent highlighted an example where even the government requested and relied on knowledge generated by their campaign. On receiving the request for detailed information from the government, the campaign was able to get together a detailed report, using secondary data and primary research of individual members, going to the extent of indicating what kind of resources were required for implementing the policy change the campaign was working towards. The report generated as a result of the field research of the campaign was used not only by the government but by others as well. The importance of disseminating the research was also highlighted.

"Our research tools and reports were put up on web and used by many people and organisations. All these were done using voluntary resources. Field research is often done by students and grassroots organisations' volunteers. Research is sometimes not led by members of the campaign, but from institutions but the findings were extensively used by campaign." [Respondent 11]



#### 4.2.4 Campaign Strategies

Respondents identified several strategies that are used in campaigning and nearly all reported relying on a mix of strategies. While some called their strategies "opportunistic" and based on the situation, others had more planned approaches to the use of strategies. According to one respondent, documenting strategies is critical and they write a lot in support of their activities. Some noted the evolution of their campaign strategies particularly with the growth of both mainstream media and social media.

"Multiple strategies were used in the campaigns ranging from street action, protests, research, fact finding, legal action, policy advocacy, public hearings about the violations that had ensued, endorsed letters and memorandums, press conferences, etc." [Respondent 4]

"Strategies were often opportunistic based on what is appropriate for a situation and the issue- what issues could be fought at the ground, where we need judicial intervention etc or both level. For instance using the courts, can be seen as a strategy. Advocacy on various themes with Government, Parliamentarians, Planning Commission etc. was taken up based on the opportunities where you are able to fund a space and what works at that moment. There was a constant focus on doing mass mobilization, even if advocacy happening simultaneously, with varying success." [Respondent 11]

"Nothing new, usual campaign tools were used. Try one based on the aim and an evaluation of the impact it will have, and if it does not work, try another tool. An important part of this was to have a constant monitoring of what was coming in the news also." [Respondent 12]

"We tend to use five clear strategies in all our campaigns: a) Direct Actions; b) Media strategies; c) Legislative Advocacy; d) Legal Action and e) International advocacy. Each of these strategies plays a vital role in our advocacy efforts." [Respondent 13]

From the interviews, the key strategies highlighted included:

##### **a. Internal Strategies**

One respondent highlighted the importance of internal strategies to handle campaigns noting that their approach is to always have one or two people in the team who are totally committed towards specific issues. While the team discusses and understand the issues, there is a core team dedicated to the campaign. Another strategy is of critical engagement or a holistic approach which approaches issues from all angles. For one respondent for instance, campaign on health posit it both as a right and a responsibility not just as an individualistic right. Another example is of addressing and acknowledging problems or that come up in programmes that were demanded by a campaign. Another continued their campaign as a watchdog once their demand for a particular legislation was met to ensure its proper implementation.

##### **b. Direct Actions (Rallies, letters)**

Nearly all respondents use some form of direct action including post card campaigns, street protests, letters, etc. Research, fact finding and public hearings were also listed by some respondents. Mobilisation is a key strategy for some campaigns. According to one respondent, yatras (road shows) are used to mobilise people. Yatras combine multiple local issues not and don't just focus on central campaign demands; they will also join others' mobilisations which is "critical to building solidarity.

"Local groups use small meetings in the villages and that's where it begins. The approach to mobilisation differs a lot from state to state. For last 5-6 months 5 states have had yatras, where people go from one district to the other in a group. In one state, the yatra was not only about our specific campaign but also raised issues being raised by other groups; issues of land acquisition for instance and our role was to bring together various groups. In another state, the yatras were specific to our issues. In yet another state, our specific issues are subsumed within larger campaigns on grievance redressal and transparency." [Respondent 11]

**c. Media Strategies**

Several respondents noted the importance of media strategies and engagements. Some have specific media strategies while other don't. Those that do noted that work with media requires constant and dedicated work. Mainstream media attention was the focus of strategies for many respondents. One respondent noted that mainstream media attention could be fickle giving examples of both successes and failures. One successful instance resulted in 6-7 episodes on a national mainstream news channel. On the other hand the same respondent noted that the response of the media to rallies and mobilisations has been weak.

"We call them for each dharna but our activities never get reported. We are not sure how big the gathering has to be to draw attention." [Respondent 11]

According to some respondents, the use of social media is of growing importance. One respondent noted that social media gave their campaigns international reach and allowed international activists to express solidarity through various internet platforms. Another however, admitted to having difficulty in using these platforms effectively.

"However, on social media we have not been very effective, that has come up in our reviews as something we have to build on. In social media you need to be completely engaged and need people who understands everything otherwise it is very easy to goof up. We are yet to find a right team who can be constantly engaged but at the same time don't need any one to monitor and filtering. Though the campaign has lot of grassroots organisations, who may not be too active on social media, but this is necessary for wider audience and the middle class attention." [Respondent 11]

One respondent felt that targeting local media and FM channels is as important as targeting national media. The work of one group in one of the states was highlighted were through dedicated media advocacy a cadre of local journalists has been created who understand the issues and are reporting on it in district papers.

**d. Litigation as a strategy**

While some of the respondents use litigation occasionally, for some engagement with the legal system is central to some of their campaigns. One campaign relies heavily on Supreme Court oversight and reports from states on the implementation of the campaign's key demands. Another respondent engages with the legal system in a somewhat different manner. As a group challenging unwarranted patents on medicines, this group in collaboration with lawyers and scientists challenge patents based on the provisions of the relevant Indian law. These are described in greater detail in the Campaign case studies.

**e. Creative/unexpected strategies**

A few respondents highlighted their use of creative strategies. One respondent employed the use of sting operations or using decoys to unearth illegal practices by medical practitioners.

These strategies are backed up by research and advocacy. Another respondent functioning in an urban area uses the tactic of flash rallies without police permission. The respondent noted the attempt to restrict areas where rallies can be held minimising their impact and accordingly hold peaceful rallies in unusual locations. This can lead to detentions but the respondent felt this was a more effective advocacy strategy. Another respondent related the example of creating a student army of volunteers and activists.

"One of the leaders in our campaign coordinates a group of students. These students are trained to talk to Parliamentarians. While the campaign met 100 MPs and these students met another 100. They carried a simple handout with 2-3 messages written and would report progress on their Facebook page when they come back after meeting MPs. It can be a powerful tool if someone can be engaged constantly. Some of them joined in the secretariat, later become researchers and continue to work on these issues." [Respondent 11]

#### **4.2.5 Enablers and Barriers**

In discussing barriers faced in campaigns, the lack of a driving will was considered a key factor by one respondent who described an urban healthcare campaign that was set up with multiple meetings but with the groups involved also involved in several other issues, this campaign did not have the "driving force" required to make it a success even though the need for an urban focussed campaign is great.

Pressure from the "other side" was another key barrier. The extent of opposition faced at times has extended to cases filed against the organisation and its staff by companies whose products the campaign centred on. In the face of such pressure, groups have relied on support from the highest levels of the organisation but also in the support and solidarity of other groups. On legal matters for instance, one respondent identified the support received from public interest legal aid groups and lawyers- One respondent reported constant pressure and spoke of being visited by the companies they were challenging at least 3 times in a year.

Disagreements within different segments of a movement were also identified as potential barriers. According to one respondent, there is no such thing as a movement, there are always multiple movements within a movement. As a result not all of them will have the same stand or position on a particular campaign or at least on what the campaign demands should be. A campaign relating to hormonal and injectable contraceptives for instance saw disagreements between those who wanted a blanket ban on such forms of contraception and those who were arguing for greater access to contraceptives that women can control.

"Women can avail of injectable contraceptives without the husbands or in-laws finding out. On the other hand the widespread availability of this contraceptive could dilute efforts to challenge the basic social and economic conditions that produce women's powerlessness. Moreover, the drug's side effects can never justify its use. This debate persisted through the campaign." [Respondent 4]

Some respondents pointed out the emergence of much stronger opponents in the current global health context i.e. "big pharma" and "big philanthropy." According to one respondent the rhetoric created by international processes such as the SDGs also create barriers as they often

do not reflect ground realities and tend to pre-set national agendas on health which grassroots movements struggle to convey actual needs on the ground.

"Not fitting the traditional mould of an NGO and being a movement can become a barrier as often these movements are not invited to committees or when they are, they are disliked for taking strong positions." [Respondent 14]

Barriers can also be specific to certain circumstances or situations. One respondent outlined the following barriers faced at the local level in one state:

a) Vernacular media is very pro-state government. The initial study of the proposal was seen as very objective, did not have rhetoric, allowed them to feel that they were being neutral when writing about it. Also health was seen as not being a controversial area (like displacement, coal). Privatisation of the social sector has received a good response after that also, education for instance.

b) Trade unions in the health sector were mostly pro-government. We gave them information they did not have and showed that they were going to be directly impacted. They were initially in denial, but then also started raising questions. They never came to be visible in our activities, but did raise the same issues in their own forums which was also very effective as the same critique was coming from different fronts.

c) This state government is not friendly to dissent, but this did not become a barrier so much as the social sector is not controversial. Though the police was very visibly present at the public events

d) By 4 or 5 months, energy was coming down and wearing off and there was a danger of popular mobilisation getting thinner. It is difficult to sustain an intense campaign over such a long period. if the privatisation project had not been stalled, there would have been a need for a strategy to address this and mobilise people again (afresh)." [Respondent 12]

Reflecting on what enables campaigns, according to one respondent, "early victories are important to sustain campaigns." One JSA respondent felt that having a history of campaigning and advocacy by all the groups, having untied funds available, ownership of the campaign by local groups and that the local organisations bought into the campaign and owned it, JSA nationally supporting it and using their own time and contacts to give visibility nationally was important.

One respondent reflected on the differences between campaigns that were successful and those that weren't and noted that the successful ones had "popular support" and because they could "communicate the issue in a way that would garner public support" and that "there was far more consensus on the [successful] campaign."

"What worked is ultimately persistence, what works is persistence, what works is to be hands on and understand all the aspects of the act and implementation I mean you have to study, you cannot be superficial about it and also you have to technical. We are basically nontechnical people dealing with doctors so always likely to face challenges - for that I believe you have to work with others, you have to bring on as many people as possible and all kinds of resources, you know, you must have to make friends in media, you must have lawyers to help you, you must have doctors with you, you must have to be able to dialogue." [Respondent 14]

#### **4.2.6 Organisation of Campaigns**

In terms of organisation, one respondent stated that the campaign is decentralised, organic and not planned in terms of budget and infrastructure. Another, however, reported a detailed organisational structure at the heart of their campaign. This includes a steering committee and a secretariat. The secretariat has an advisory group for day-to-day functioning while the steering committee takes major decisions between conventions. The convention is the general body where decisions are taken setting the direction for the campaign. The resolutions of the convention reflect positions on larger issues as well as priorities for action which the steering committee is supposed to implement. More recently sub-committees have been introduced as part of the steering committee.

"We had a meeting recently where we discussed the steering committee in itself become heavy with around 50-60 members. Getting all these people together is a challenge because each one of us are leaders of a campaign. So we are trying out a number of sub-committee, which can take independent decisions so long its within the framework of the convention. If it's a new issue that the campaign has not discussed before, we would ideally take this up at the convention." [Respondent 11]

In terms of infrastructure, this particular campaign is dependent primarily on its website. According to the respondent a lot of effort goes into sending monthly updates to a mailing list comprising of 3000 plus people and one set of volunteers is dedicated only to this work. The campaign relies heavily on volunteers and particularly on students to volunteer their time and effort.

Another respondent highlighted the role of partnerships in their campaigns and stated that networking is one of their foundational principles. The respondent also noted that partners may not all be at the same level but will contribute within their understanding and capacity, which is pro-people, pro-equity and pro-social justice.

#### **4.2.7 Reflections on changes, good and bad**

For one respondent the growth the media, including the internet and social media has been a positive change in recent times enabling campaigns and helping in sharing information. According to one respondent, some positive changes include the introduction of the NRHM and though there have been gaps in the programme it was described as a positive experience. The increasing involvement by the government of NGOs and community groups in the implementation of social welfare and health programmes was also considered by one respondent to be a positive development. The persistence and expansion of campaigns relating to tobacco and women's health were also identified as positive factors.

"Our engagement with one state government during 1999-2005 was extremely positive. There was a lot of mutual trust. They put us into some implementation committees also. The whole group has travelled all the districts in the state. The experience range from policy articulation to some levels of implementation. Despite the changes in governments, there are many positive sides and the improvement in the health indicators also tells us that." [Respondent 8]

One respondent felt that the coming up of disease based patient groups had great potential for future activism. Another also highlighted that the importance now placed on increasing connections with wider issues as a positive development.

"There is now a focus on connecting with wider issues and this is a major change in the campaign; jal-jungle-issues, trade and agriculture, women's issues. There have been critiques within the campaign that we have not been able to successfully raising these issues or formed

larger alliances with say farmers' groups, though some dialogue has happened." [Respondent 11]

For one respondent there has been a noticeable decrease in community level or the local level engagement. This is of particular concern given that neo-liberalism is deepening over the years with negligible variations.

"In the early days the interaction was much closer. Now people are happy with computer activism. Which has changed the dynamics totally. We become distant from the self, abstract, and be even disconnected from certain realities. We depend on various vacant reports, etc. The engagement with raw reality as we call it has declined in my opinion. What was being attempted was a counter culture and an attempt to strengthen communities and civil society. I would say, civil societies and communities are relatively weak in the context of the change." [Respondent 8]

The respondent noted that they now focussed on community health learning programmes in an attempt to expand their reach to communities. Increased gender based violence against girls, children and women was also highlighted as worrying with the respondent commenting that perhaps there were certain social and economic forces that are beyond the current capabilities of the various groups and movements

Nearly all respondents pointed to the recent change in the Indian government as a matter of concern. One respondent highlighted the attack on foreign funded NGOs as part of this change. But there are larger impacts as well on what "you can say and what can't, there is a general threat on NGOs how to deal with those threats." Another respondent felt that feels that the current context of the new government makes a difference to their campaign(s) because of heavy 'vested interests' referring to examples of amendments in progressive laws that have been proposed that would weaken them. According to one respondent, the change in government is also leading to a change in the issues being raised in their campaigns and there is a greater shift to work on civil liberties with clamp downs on free speech and increasing detentions and arrests.

#### **4.2.8 Association with the health movement/JSA**

One respondent gave the example of a successful collaboration between their campaign and JSA in highlighting issues of malnutrition among children.

"Issue of malnutrition is one where both the campaigns have been associated and as a result a comprehensive understanding of the whole issue has been developed. JSA has not seen malnutrition as only a health problem and correspondingly we have not seen it only as a food problem. This has also happened because some individuals are associated with both the campaigns." {Respondent 11]

One respondent who is formally a part of JSA admitted not being very active but this was because of the effort and human resources involved which as a "a mass organization depending on voluntary effort" they did not have. [The respondent felt that the discourse in the JSA is strongly controlled by health rights NGO activists but it was unclear if this was an observation or a criticism.] According to another respondent, health was always an important issue but it's increasingly become important particularly given the greater push on insurance based models and called on JSA to put forward alternative models and narratives to counter this.

#### 4.2.9 Challenges for the future

One respondent felt the need for campaigns in general to move away from “event management.”

"I think we need to move away from event management to actual jointly sitting, reflecting, and sharing. There is a need for strong mutual trust among partners. I think, the time for actual deep reflection is not so much nowadays. We may find some of the discussions superficial also. It's my perception. I think there is a lack of deeper discussion. We are not sharing enough."  
[Respondent 8]

Another felt that challenges arise from the lack of documentation of the successes and failures of campaigns as well as of processes. It was noted that this was necessary to allow for proper reflection. In this regard it was also noted that researchers not directly connected to campaigns or movements also had to take greater interest in this work.

One respondent highlighted the challenge in making these issues “middle class issues.” The respondent also noted that they are often accused of "holding the country back." It was felt that this was a challenge for movements across the country. The respondent also felt one of the key challenges for the future was the relationship with the government.

“How do we partner with the State when the State is pretending to be social welfarist at the same time promoting crony capitalism? But then these are opportunities. With the [current government] it's more clearer now, both the State and the campaign don't want to engage with each other. The focus has shifted from entitlements to larger social change. Once you get into access to resources and ownership you are raising larger production relations issues. There are some who feel that entitlements are just palliative and we need to move on but others feel that these are opportunities we need pick up and take them forward. One has to strike a balance. It's a matter of continuous debate and unresolved.” [Respondent 11]

### ***4.3 Civil society led knowledge generation, dissemination and use for Health for All in India***

Knowledge when appropriately used can be a powerful transformative tool for the HFA. There are multiple ways through which civil society engage in the production and use of knowledge towards HFA. To understand this further, it is essential to know the process of how the civil society identify and analyse gaps in knowledge and utilise it towards HFA. A significant consequence of this process is better informed civil society which is not only able to negotiate its power relationships with policy elites, but also able to effectively engage in movement building. However, it is reliant upon how effective they are in utilising their knowledge. Therefore, understanding of the pathways through which knowledge is generated and utilized by the civil society is an essential component of this research. We discuss here broad input process pathways of civil society engagements that lead to knowledge generation and utilization.

#### **Creating knowledge through engagement and research**

Civil society organizations and movements use multiple means to generate collective wisdom through the mobilization of knowledge. Collaborative enquiry, especially the participatory forms of enquiry is often a key to civil society's approach that leads to practical and authentic knowledge generation. The democratic social engagements of civil society often seek to understand the world by trying to change it. By thinking, acting and learning collaboratively with community that they work with, CSOs reclaim the vast knowledgebase of the marginalised communities. Such process of knowledge creation is an essential component of the very nature of the civil society engagement in the change process as they try to integrate knowledge produced into planning and decision-making.

While such participatory and experiential ways are dominating the core of knowledge creation of civil society sector, there are also significant body of knowledge created through established means of formal research. Such initiatives are carried out by sympathetic 'activists communities' within the academia as well as selected resource organizations within the civil society movements. Unlike the usual academia research which are created mostly to merely occupy space within peer-reviewed journals, these researches are different in their very intent. Therefore, they are extensively used for advocacy and action.

#### **Using knowledge to evoke critical thinking**

Building perspectives on human rights involve sharing the knowledge for winning the hearts and minds of masses on the side of health and human rights. One of the key processes of knowledge dissemination is through the idea of promotion of critical thinking. Critical thinking can be used to challenge the structural injustices related to cultural, economic, political and social factors that come in the way of HFA. The process of perspective building varies from knowledge dissemination through mass education to targeted dissemination of ideas and messages to specific stakeholders. Considering the low priority that 'health' occupied in the Indian political sphere, large scale mobilization was essential to raise the public consciousness on their health rights.

Wider social acceptance of health rights is an essential pre-condition for the realization of HFA. Successes of such initiatives are realized only when the civil society initiated dialogues are relevant to people's daily lives and show them the glimpse of the world without injustice and structural violence. The mass contact programmes began by the science movements are good examples of such initiatives. The 'kalajaths' as they are widely known, communicates the social



and scientific messages through traditional as well as modern art forms, such as songs, street theatre and poster exhibitions.

There are also vast body of health and health rights related information developed and used by civil society organization which is in the form of booklets and campaign materials. These materials are specially designed to mobilise communities for HFA campaigns. The contents of such materials are often developed through consultative processes and written for popular reading and understanding. Mainstreaming the key political and technical arguments is the core idea behind such materials. The several booklets created by JSA for the People's Health Assemblies in Kolkata and Bhopal are examples of such materials. They were translated into local languages and were used extensively by grassroots activists in the run up towards assemblies.

### **Networking for co-creation and sharing of knowledge**

Networking by CSOs is a key strategy to transfer knowledge beyond individual organizational boundaries. By doing so they are able to find new partners and transcend the potential vulnerabilities that arise when challenging the powerful vested interests. The networks for knowledge sharing may be formed around thematic areas or geographical regions. However, they are relatively small circles, with similarity of views and interests. For instances All India Drug Action Network (AIDAN) is one of oldest national networks in the area of rational use of medicines in India and consisted of organizations and activists working in the field.

Networks facilitate shared space for exchange, learning and development. In fact, the culture of sharing of knowledge and other resources is the core of the existence of such networks. However, how they organise locally, regionally and nationally have profound influence on effectiveness of their capacity as knowledge sharing platforms

#### **4.3.1 Knowledge Generation and the JSA**

A major driver of the year and half long process in India before the first National Health Assembly in Kolkata and the first Peoples Health Assembly in Dhaka was what came to be known as the magic of the 'five booklets'. These five booklets (on Globalisation and Health, Health Systems, Child Health, Women and Health and Confronting Commercialization), written in a popular style formed the bedrock of the massive mobilisational campaign in 1999 and 2000.

The process of writing these booklets was embedded in the participatory spirit of the 1999-2000 campaign. To build a common understanding of the programme content for the pre-PHA campaign, the founding meeting for the campaign authorized a team to collect resource inputs in the form of theme papers. 30 base-papers were collected from over 30 resource persons. Then a small group worked intensively to edit and transform these base-papers into four simple popular booklets. A hundred xerox copies of these booklets in draft form were brought to the next national preparatory workshop. Here over 100 delegates from at least 9 organizations went through all the four booklets, in small groups, while rapporteurs noted down their suggestions. The group then incorporated these suggestions, and the text, which was complex in places, was made readable by an illustrated, 'conversational' presentation. A fifth book was also finalized, albeit with a more limited discussion. In English 4000 sets of these five books were printed and sold. Many times this number were printed and sold in the form of translations in Hindi, Kannada, Tamil, Telugu, Oriya, Bengali and Malayalam and in adapted versions in other languages like Marathi and Gujarati. The sale of the five books was in itself a campaign and nearly 25,000 sets, all languages included, were sold.

The five books represented a shared understanding of the critique of existing policies as also our recommendations for change and the possibilities for peoples' initiatives. It was published not in the names of individual authors or organizations but collectively by the entire group and thus became a binding force in itself.

A similar process, albeit much less participatory led to the publication of 7 popular booklets prior to the Second National Health Assembly in 2007.

JSA also regularly produces booklets on issues around which campaigns are ongoing or on issues in which it thinks it is useful to intervene. Generally the booklets are collaboratively written and not identified by authors. Attempt is made to keep the language as easily accessible as possible for JSA activists and lay readers. Given the diversity in language, all JSA booklets are written and first published in English and then translated into Indian languages.

Most booklets produced by the JSA are funded through local resources, which are through amounts pledged by JSA affiliated organisations. Almost all are linked to campaigns and are seen as important for setting positions on issues and as contributing to campaign related mobilisation.

The participatory process of the development of the 5 initial booklets has never been duplicated, at that scale however. Which JSA developing a more organised institutional structure, somehow the participatory process of the 1999-2000 have not been subsequently captured to the same extent. Neither have subsequent booklets had the same range of readership and achieved the same popularity as the five original booklets.

Respondents when asked about their knowledge about the PHM's Global Health Watch (GHW) publications and their utility, generally had positive comments. Respondents were aware of the GHW and most claimed to have used it for advocacy. They also said that it had a limited reach because of it being available in English and because the contents were not directed at local activists.

"PHM evolved different programs, and people from different places join them. They were created for different constituencies. GHW [is] for academicians and evidence gatherers. (JSA respondent 2)

It was recognised that the use value would increase if 'readers' on important issues could be created in local languages. As one JSA respondent said:

"I use GHW extensively and it is extraordinarily useful. It has the evidence I want to use and am able to quote from it in my advocacy and research work. I want both what GHW is now, and make it available to activists in different forms. Peoples movements have to promote changes in discourse at macro and academic level and GHW caters to this need".

The need to disseminate the contents of GHW more extensively was also articulated.

"Global PHM is also an alternate to the bleak scenario of global governance. The coming out of GHW is an important global event, though dissemination should be much more". (JSA respondent 1)

It was also articulated that local (JSA) involvement in developing GHW is limited to experts and not from a bulk of JSA's constituency.

"GHW, there is some contribution from some people, but limited to experts". (JSA respondent 3)

### 4.3.2 Knowledge Generation by non-JSA groups

"On the links between TB and nutrition for example there just wasn't much evidence. But we published evidence in PLOS and were then able to successfully campaign in Chhattisgarh for the provision of food for TB patients. We did operational research with action including on what the food should be and how it should be delivered. We worked with other research groups." [Respondent 6]

Knowledge generation was considered by some respondents to be critical to strengthening and substantiating their capacity building and advocacy efforts and have played a key role in changing perceptions and perspectives on health. The development of information resources, publications and dissemination is an integral part of the initiatives of several groups. Wide dissemination of knowledge has also been effective in outreach to groups at different levels and across several states and districts. According to one respondent, generation of knowledge takes place through research and fact finding on a specific area or issue being assessed or examined.

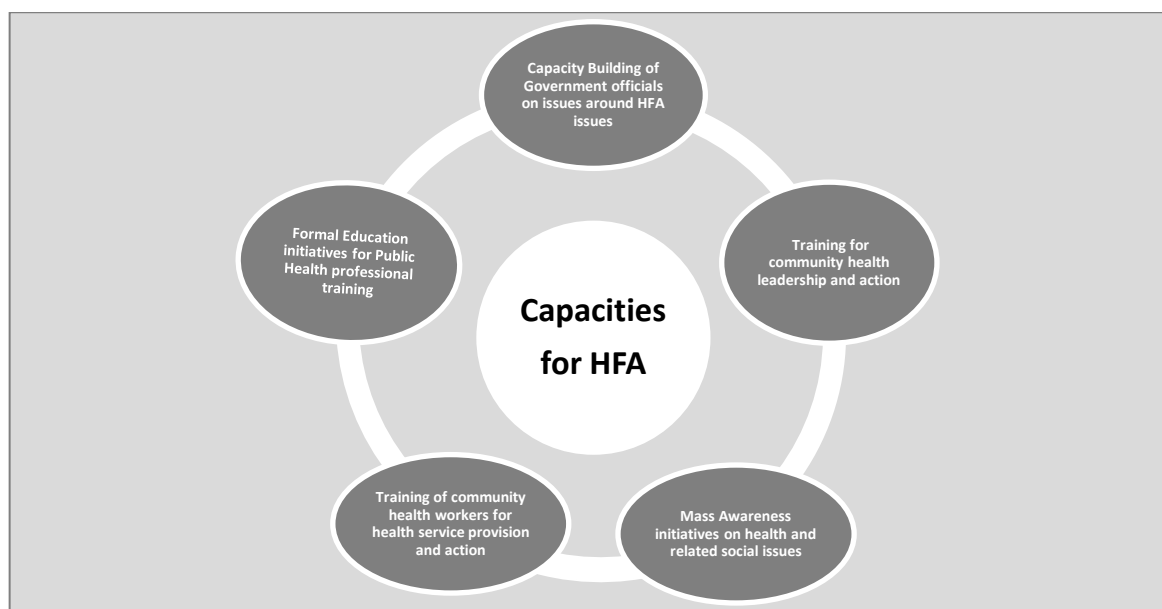
"For example, along with other groups, we undertook a fact-finding on the deaths that took place following sterilizations in one state. The fact finding provided important information and documentation of what had transpired and contributed to the campaign against such violations, policy level advocacy as well as towards justice for those who experienced morbidities or for the families of those who died. The fact finding generated this knowledge within a short duration as was required in such a situation to mobilize a campaign on this issue." [Respondent 4]

In several areas, knowledge generation has strengthened campaigns and advocacy on the issues. For instance the research by one women's organisation on the impact of the two-child norm on women in one particular State provided critical insights about the violations taking place and provided the evidence for building a campaign against coercive population policies. More recently, a study by the same group on population perspectives in school curriculum generated knowledge and insights that will enable expansion and nuanced understanding of the discourse and campaign against population control and related issues.

Ensuring that the knowledge created is accessible on respondent has developed simple, informative and effective material such as pamphlets, brochures, booklets, posters. Writing articles, academic papers and research reports is also considered an important part of knowledge dissemination and over the years these publications have reached several organisations, institutions and individuals across the country and globally. Dissemination also highlights challenges posed by different language and though translations can be challenging it is considered important as "in general, access to knowledge resources is limited by it unavailability in local languages."

#### **4.4 Civil society led training and capacity building for Health for All in India**

A quick review of available resources gives a diverse picture of training and capacity building initiatives for HFA in India, by different HFA movement constituents. Mainly, it seems that such capacity building initiatives that contributes to health for all could be classified into four types of initiatives by civil society initiatives, namely, (1) Mass political awareness and social mobilisation on health related issues (2) formal public health training and education initiatives (3) skill development for community level health care provision (4) Training for community level health leadership and action (5) Training for Government. Given the size and scale of India, needless to say that none of these interventions could cater for HFA across India, but they contributed specifically to local areas with larger knowledge impact for the country as such. Figure 1 gives a quick glance on the types of capacity building initiatives for HFA.



**Figure 1. Types of Capacity Building initiatives contributing to HFA in India**

#### **Mass political awareness and social mobilisation on health and related issues**

If we look at the history of people's initiatives for health in India, before and after the inception of Jan Swasthya Abhiyan (JSA- the India chapter of global Peoples Health Movement) one can clearly see that the capacity building had a major component of mass awareness and mobilisation around various health and related issues. A range of activities could be found of this nature, while we look at the available resources. While trying to list these, there is a possibility that we would have missed out some important initiatives under this category, due to the fact that documentation around many such initiatives are either not available in public domain, or they are not prepared. However, since many of the organisations who led such initiatives are either directly part of, or closely aligned to, the JSA or its larger network of organisations, we were able to produce a reasonable picture of such initiatives. Such public awareness and mobilisation largely cover issues such as community health, rational drug use, local health planning, women's health, health/ health care rights, health and related policies and so on. In most of these cases, it appears that the training/ awareness needs were identified based on the campaign or programme requirements, and few of them had structured curriculum planning. Most of these trainings or mass awareness initiatives seem to have been organised through a cascade of volunteers in a campaign approach. Key outcomes of these

trainings have been the enhancement in public understanding on various issues around health policies and programmes, and around the social determinants of their successes.

### **Formal public health training and education initiatives**

In the Indian Public Health Scenario, given the large scale of requirements, contributions from the Civil Society initiatives seem to have been very significant. Outcomes of these initiatives were that these initiatives increased the availability of health professionals of various streams. Christian missionary organisations seem to be the strongest contributors to this stream, who has set up institutions for formal medical and public health educations across the country. Several important medical as well as public health institutions in India are from this group. In the recent history more non-Christian civil society initiatives have joined the list, also widening the horizon of formal capacity building towards HFA. Indirect contributions of several civil society initiatives are also an important component to be mentioned here, wherein the experiences/ understandings of such civil society players or organisations influenced the curriculum development for such formal programmes.

### **Skill development of community health workers for health service provision and awareness**

In this category we have looked mainly at various community health worker programmes of small to large scale coverage. Here too, India has a rich experience of shaping the discourse globally, and most of such training programmes were structured around the perspectives of Comprehensive Primary Health Care and Health for All school of thought. These interventions served the populations, prominently in difficult or medically underserved areas, to have basic health awareness and a set of first level curative care services- which could be seen as one of the first steps towards health for all. Interestingly, most of these programme initiatives were initiated and led by committed medical professionals, hence the focus was around provision of health services and related health education. It is also to be noted that most of these initiatives, except a few, are standalone health programmes, without much direct linkages with the public health systems for primary health care institutions. While it is a known fact that most of these programmes have successfully addressed the health problems that the localities were primarily facing and in educating communities on those issues, we don't have enough evidence to establish the contributions of many of these programmes towards strengthening public health systems in the locality, or in mobilising the communities for action around health rights.

### **Training for community level health leadership and action**

In this category we have looked at many organisations that identified and built capacities of individuals and equipped them to lead community level health initiatives and action. As we understand, such programmes largely gave exposure to these individuals to the world of health rights, to the ideas and opinions on people's health and public health, various initiatives that influenced the health of populations and communities and the politics of health and health programmes. There are capacity building initiatives that equipped and empowered NGOs too, to take up and to lead programmes on community health. It seems that most of such initiatives are mostly initiated and driven by organisations that are part of the people's health movement directly or indirectly, although some of the fellowship programmes of some other organisations would have influenced this too. Off late, some of the civil society organisations were able to effectively use some of the civil society spaces provided by state run health initiatives too.

### **Capacity Building of Government Health Officials**

Here we are looking at capacity building of the officials of public health systems, by civil society organisations, towards orienting them or equipping them for leading health programmes. in

some instances, the civil society groups seems to have influenced the government(s) for putting its staff into such trainings; some programme spaces opened up as part of the national health programmes would have opened up spaces for some of the civil society groups too, to advocate for and to implement training initiatives for the government officials. Here, we are able to see structured training curriculum, training material and some reports and publications too.

### Examples for various types of civil society led capacity building initiatives for HFA in India

Table 1 presents a quick list of names of key organizations contributed to specific types of capacity building and examples of their interventions. Here, it is to be noted that this list does not cover awareness and capacity building initiatives specific to control or management of any specific diseases, though some of them may have significance for HFA movement.

**Table 1. Capacity building relevant to HFA in India: at a glance**

Type of Capacity Building initiative	Organizations that led these initiatives	Examples of specific interventions	Key contributions to HFA
<b>Mass Awareness initiatives on health, and related social issues and on people's rights</b>	<ul style="list-style-type: none"> <li>Voluntary Health Association of India</li> </ul>	Various booklets on community health issues and action through member networks	Awareness on various health issues, health programmes. Wide outreach
	<ul style="list-style-type: none"> <li>Locost, AIDAN, VHAI</li> </ul>	Mass education on knowledge on rational drug use	Critical knowledge on drugs imparted. Limited outreach but instrumental in recent actions around drug control
	<ul style="list-style-type: none"> <li>Peoples Science Movements (such as Kerala Shastra SahityaParishad, Tamil Nadu Science Forum, Pondichery Science Forum and Bharat Gyan Vigyan Samiti)</li> </ul>	Mass training programme through booklets on various health issues, local level health planning initiatives	Opened up public debate on health policy issues and facilitated local health planning
	<ul style="list-style-type: none"> <li>Women Organisations such as All India Democratic Womens Association</li> </ul>	Mass training through education programme on women's health and rights	Developed AIDWA's inter-organisational understanding on health issues, and shaped their health interventions
	<ul style="list-style-type: none"> <li>Religious Missionary Groups such as Catholic Health Association, Rama Krishna Mission Ashram</li> </ul>	Training through Diocesan centres and other programss (CHAI)/ community health programs (RK Mission)	Spread health awareness in local communities.
	<ul style="list-style-type: none"> <li>Peoples Polyclinic, Nellore</li> </ul>	Orientation of medical doctors and communities on people's health issues	Influenced a section of young medical doctors to work for health for all
	<ul style="list-style-type: none"> <li>Shahid Hospital, DalliRajhara, Chhattisgarh</li> </ul>	Mass training on community health and health rights issues; training of young doctors on community health	Built mine workers awareness on health and shaped their local action

Type of Capacity Building initiative	Organizations that led these initiatives	Examples of specific interventions	Key contributions to HFA
	<ul style="list-style-type: none"> <li>SathiCehat/ Cehat, Maharashtra.</li> </ul>	Educating people on health care and health rights issues through innovative material	Built awareness on health entitlements, patient rights, health safety and other important areas, and facilitated action
	<ul style="list-style-type: none"> <li>KisanMazdoor Shakti Sangathan, Rajasthan</li> </ul>	Educating and mobilising people on various health related rights	Built awareness on health and related rights of citizens and developed action
	<ul style="list-style-type: none"> <li>Jan Swasthya Abhiyan</li> </ul>	Mass awareness initiatives by constituent organizations using the booklets prepared on various health issues in different local languages	Built foundation for the mass movement for health for all
<b>Formal Education initiatives for Medical/ Nursing/ Public Health professional training</b>	<ul style="list-style-type: none"> <li>Christian Medical Association / Emmanuel Hospitals Association</li> </ul>	Medical, Nursing and Paramedical Institutions across country	Helped addressing the workforce challenges, especially for rural areas
	<ul style="list-style-type: none"> <li>Catholic Missions, Catholic Health Association of India</li> </ul>	Medical, Nursing and Paramedical Institutions across country	Helped addressing the workforce challenges, especially for rural areas
	<ul style="list-style-type: none"> <li>Public Health Resource Network</li> </ul>	PG Diploma in District Health Planning in partnership with IGNOU	Contributed in building capacities of health workforce and civil society actors on various aspects of district health planning
	<ul style="list-style-type: none"> <li>SOCHARA??</li> </ul>	School of Public Health Education and Action (SoPHEA)- collaboration with RGHSU, Karnataka, in partnership with several organisations	Catalysed an HFA oriented MPH programme
	<ul style="list-style-type: none"> <li>IPH Bengaluru</li> </ul>	PHD and MPH programmes in public health in coordination with ITM Antwerp; distance learning programmes in India	Contributed building public health capacities on various aspects
	<ul style="list-style-type: none"> <li>Public Health Foundation of India?</li> </ul>	Future faculty selection and their public health training and posting them back in IIPHS; programs such as certificate courses, collaborative formal education programs on public health; IIPH Gandhinagar as University	Built a large number of training workforce for the public health discipline
	<ul style="list-style-type: none"> <li>IHMR</li> </ul>	PG Diploma in Health/ Hospital Management & Masters in Public Health	Contributed in the production of health management workforce

Type of Capacity Building initiative	Organizations that led these initiatives	Examples of specific interventions	Key contributions to HFA
	<ul style="list-style-type: none"> <li>Ford Foundation International Fellowship Programme??</li> </ul>	Fellowships for students for higher studies in various streams including public health	contributed experts public health and related areas from needy communities and locations
	<ul style="list-style-type: none"> <li>Tata Institute of Social Sciences</li> </ul>	Masters and PhD level programs in health/hospital management, public health and related sectors	Contributed in the production of public health/ health management workforce
<b>Skill development for community level health care provision and CHW programs</b>	<ul style="list-style-type: none"> <li>CRHP, Jamkhed</li> </ul>	CHW training under the Comprehensive Rural Health Project	Created a model for community centred rural health programme in India
	<ul style="list-style-type: none"> <li>SEARCH, Gadchiroli</li> </ul>	'Arogyadoot' CHW training for neonatal survival	Built a model for indigenous community based neonatal survival programme
	<ul style="list-style-type: none"> <li>RUHSA, Vellore</li> </ul>	Training of CHWs and local communities	Built a model CHW programme, based on the social responsibilities of a medical college community
	<ul style="list-style-type: none"> <li>RAHA, Pathalgaon</li> </ul>	Training of Rural Health Nurses and building of a community based health financing programme	Learnings for running rural health centres; also lessons for managing local health financing models
	<ul style="list-style-type: none"> <li>FRCH, Parinchay</li> </ul>	Training of CHWs and rural populations	Understanding on how communities can look after their own health issues
	<ul style="list-style-type: none"> <li>THI, Sittlingi</li> </ul>	Tribal Health Workers initiative	Knowledge on how to impart critical care skills to communities, including for basic surgical interventions
	<ul style="list-style-type: none"> <li>VGKK, BR Hills</li> </ul>	Tribal area health workers initiatives	Understanding on how indigenous communities can look after their own health needs
	<ul style="list-style-type: none"> <li>FRLHT, Bengaluru</li> </ul>	Traditional Health Practitioners training	Knowledge on use of local knowledge traditions for HFA
	<ul style="list-style-type: none"> <li>ArogiyaIyakkam (TNSF), Tamil Nadu</li> </ul>	Training of CHWs and Health Committees	Knowledge on preparing CHWs in large scale, working with local health committees and local bodies
	<ul style="list-style-type: none"> <li>All India Peoples Science Network</li> </ul>	Peoples Campaign for Health - Training of CHWs and Health Committees in several	Knowledge on preparing CHWs in large scale, working with local health committees and local



Type of Capacity Building initiative	Organizations that led these initiatives	Examples of specific interventions	Key contributions to HFA
		states	bodies
	<ul style="list-style-type: none"> <li>Shivgarh Project, UP</li> </ul>	Training of Community level health workers on neonatal survival	Built a model for community based neonatal survival programme
	<ul style="list-style-type: none"> <li>Gyan Vigyan Samiti, Uttar Pradesh &amp; Uttara Khand</li> </ul>	Multisectoral Approach to Health- Training of CHWs, Health Committees, PRIs and health officials	Knowledge on preparing CHWs in large scale, working with local health committees and local bodies, and in setting up systems for district health management
	<ul style="list-style-type: none"> <li>Prem Jyoti Hospital, Sahebganj</li> </ul>	Training of Tribal area health workers	Understanding on how indigenous communities can look after their own health needs
	<ul style="list-style-type: none"> <li>SEWA Rural, Gujarat</li> </ul>	Training of community health workers	Understanding on how women's initiatives can look after local health needs
	<ul style="list-style-type: none"> <li>JSS, Ganiyari</li> </ul>	Training of community health workers and educators	Knowledge for running community based health and nutrition programmes; also on innovative referral systems
	<ul style="list-style-type: none"> <li>CARE India?</li> </ul>	Change Agents for Health and Nutrition as part of RACHNA and INHP	Knowledge on community based nutrition and health interventions in coordination with public health systems
	<ul style="list-style-type: none"> <li>State Health Resource Centre, Chhattisgarh??</li> </ul>	Mitanin Programme, Training of hamlet level female health workers, womens health committees, Cascade of CHW trainers and programme managers	Knowledge on training and managing large scale CHW programme and women's committee initiatives on behalf of public health systems
<b>Training for community health leadership and action</b>	<ul style="list-style-type: none"> <li>SOCHARA, Bengaluru</li> </ul>	Community Health Fellowships and Community Health Learning Programme; IPHU course on researching HFA	Knowledge on developing people's leadership for HFA
	<ul style="list-style-type: none"> <li>PRAYAS, Chittorgarh</li> </ul>	IPHU course	Prepared leaders for HFA movement
	<ul style="list-style-type: none"> <li>SathiCehat, Pune</li> </ul>	Training of PRI members and NGO leaders	Knowledge on including health into the agenda of action of the local bodies
	<ul style="list-style-type: none"> <li>PHRN, New Delhi</li> </ul>	Training of community health fellows	Knowledge on developing skills on local social workers to engage with public health

Type of Capacity Building initiative	Organizations that led these initiatives	Examples of specific interventions	Key contributions to HFA
			systems for joint health action
	<ul style="list-style-type: none"> <li>IHM, Pachod</li> </ul>	Training programme for adolescent health workers and peer educators	Knowledge for running community based adolescent health programmes
	<ul style="list-style-type: none"> <li>Institute for Development Action, The Ant, Rowmari</li> </ul>	Training of NGO leaders	Knowledge for catalysing action on local specific health issues
	<ul style="list-style-type: none"> <li>Sahaj, Baroda</li> </ul>	Training of urban women from vulnerable urban populations	Knowledge on developing indigenous women leadership from urban vulnerable populations
	<ul style="list-style-type: none"> <li>Ekjut, Chakradharpur</li> </ul>	Training of women leaders and women's groups	Knowledge on how to equip local communities for understanding and analysing local health problems and in solving them
	<ul style="list-style-type: none"> <li>The Hunger Project</li> </ul>	Training of women leaders of local self-governments	Knowledge on building capacities of local body leaders on health
	<ul style="list-style-type: none"> <li>Urban Health Resource Centre, Indore</li> </ul>	Training and organisation of women groups in urban slums	Knowledge on how to equip urban slum populations for understanding and analysing local health problems and in solving them
	<ul style="list-style-type: none"> <li>SHRC, Chhattisgarh?</li> </ul>	Training community representatives to facilitate Panchayat action for health and for Community nutrition programme	Understanding on how to build multisector action for health, through local animators coordinating between communities and state systems
	<ul style="list-style-type: none"> <li>PRADAN, New Delhi</li> </ul>	Initiated livelihood programmes and to act upon issues that improves life	Learning on how to catalyse health action through livelihood initiatives
	<ul style="list-style-type: none"> <li>Health Watch</li> </ul>	Capacity Building of NGOs in reviewing health programs and services	Learning on building community capacities for keeping alert on health and health services
	<ul style="list-style-type: none"> <li>CHARM, Bihar</li> </ul>	Training of community health leaders	Knowledge on organising local health action
	<ul style="list-style-type: none"> <li>Advisory Group on Community Action, and associated groups</li> </ul>	Community Based Monitoring and Planning programme in different states - capacity building on community led health monitoring and planning under National Health Mission mainly in states	Learning on building community capacities for monitoring health and health services and planning for betterment of the same, in coordination with public health systems

Type of Capacity Building initiative	Organizations that led these initiatives	Examples of specific interventions	Key contributions to HFA
		such as Maharashtra, TN, Rajasthan, Gujarat and Karnataka	
<b>Capacity Building of Government Health Officials</b>	• VHAI, New Delhi	Training of government officials on various health issues	Learnings on how to build capacities of health systems actors on various HFA priorities, also developing amongst them a community centred understanding on these issues.
	• Delhi Society for Promotion of Rational Use of Drugs	Capacity Building on rational drug policy and management	
	• PHRN, New Delhi	Fast track capacity building of health department officials in district health planning	
	• CHSJ, New Delhi	Training of health officials on various issues	
	• SathiCehat, Pune	Training of health officials and Panchayati Raj Institution Leaders	
	• Chetna, Ahmedabad	Training of Health Officials as part of the Reproductive Child Health projects	
	• SahajBRC		
	• Gyan Vigyan Samiti Uttar Pradesh	Training of health officials and Panchayati Raj Institution leaders on local health planning	
	• KSSP, Kerala	Training of Health officials in local health planning	
	• IPH, Bengaluru	Training of state and district level officials in decentralised health planning and action	
• PHFI, New Delhi?	Regular training of health officials from various states on public health management,		

Based on this overview we have developed specific case studies on the examples of capacity building initiatives that contributed to HFA in India. The analysis focused on full documentation of and comparison between how training needs, curriculum and pedagogy are developed by JSA and other CSOs; with the intent of linking certain approaches, curriculum content and pedagogy (learning styles) to sustained and more effective activism amongst participants in such training.

#### 4.4.1 JSA and the IPHUs in India

[Editor's Note: The interviews with JSA respondents focussed on the IPHUs conducted in India.]

#### Curriculum, Pedagogy and Recruitment

For the curriculum of the IPHU (Bangalore) in India, the first step involved examining IPHUs that had taken place previously in other countries. Based on this, a core set of topics was identified and shared an advisory group within JSA which comprised key JSA member organisations with expertise in capacity building who then anchored the process. The advisory group evaluated the usefulness and appropriateness of these topics in Indian context. Specific topics were then added such as gender and communal issues which were brought in because of the work of some groups in one Indian state that had witnessed serious communal riots. While the curriculum was developed following these steps, there was also sufficient space for issues raised by the participants. The curriculum was supplemented with additional reading materials, evening discussions, etc.; discussions were not limited to substantive issues alone the use of the media, particularly social media was also part of the discussions.

The pedagogy was done by activists, not academicians, was discussion based and focused on group work. "A conscious decision and commitment to democratization and participation drove the pedagogy." The JSA members involved were committed to "pedagogical innovation" and while each resource person was free to use any method they wanted, there was an overall understanding that informed their sessions. Resource persons were encouraged to stay for at least a day or two to encourage multiple forms of interactions and not just classroom interactions. Each evening there was a feedback session on content and methodology that led to changes to the program, almost on a daily basis and even new sessions introduced.

"IPHU in Bangalore was one of the best capacity building experience has been part of, flexibility, ability to learn, exciting, vibrant. improving not sure. But post-course follow up was the real issue - not sure who should have anchored it, and maybe lack of clarity on a specific framework for this led to gap and missed potential" [Respondent 7]

However, one respondent who participated as a resource person did not share an entirely positive view of the IPHU in India.

"Experience was not good. Felt 'bitter' about the process not being 'home grown' and grounded in JSA and had a sense that it was being organised by some international PHM activists. The pedagogy and content was unsatisfactory -- for example nutrition was not part of the course. Do not know where and how these were decided upon. Appeared a 'top down' process." [Respondent 5]

Recruitment for the IPHU was largely done through local JSA chapters while PHM chapters in the region were encouraged to nominate persons for the IPHU. A few applications were received from abroad (one from Germany, one from Africa). The local JSA chapters were encouraged to consider some criteria in selecting participants i.e. former involvement with JSA and commitment to remain involved. This was left to the local chapters to interpret and implement.

## **Evaluation**

Active evaluation was adopted for the IPHU in the form of daily feedback. Participants' representatives were elected on the first day who would sit with resource persons every day just after the sessions to provide feedback. Other participants could also join these sessions. After this, student representatives, resource persons and the core group would meet to make required changes to the program and include it in the following days' sessions. Formal feedback forms were also provided and filled. However, the core group of organisers did not meet for an evaluation after the IPHU and although there were plans for long term follow up with the participants, it is unclear whether this took place.

## **Impact on participants and on JSA**

In terms of the impact of the IPHU on JSA, former participants are not necessarily formally involved in JSA now but according to one respondent they are to make contributions and noted that in several States former participants are called on by the state level JSAs. In the case of Tamil Nadu, the State circle was strengthened as a result of the IPHU while it led to the creation of a network in Madhya Pradesh.

"IPHU introduced a new perspective on things that was rights based. Also brought the perspective that there are other people involved in the same struggle. IPHU lays the foundation for networking or alliance building in the future. A key element for this to happen, is that there needs to be JSA activities." [Respondent 7]

Another respondent largely agreed with this assessment but did feel that the links between the IPHU and PHM needed work.

"The IPHU provides space for access to knowledge and dissemination for participants from different countries and regions. IPHU has reached out to new people and groups and build capacities of young and new activists. However, currently this knowledge has been limited to the participants who are part of the IPHU. Processes for wider dissemination of the knowledge/information have to be streamlined. Further, the linkages between IPHU participants and the PHM needs to be strengthened." [Respondent 4]

Agreeing with this another respondent stated that the IPHU participants would contribute as much as JSA wants them to contribute. Once the course is complete, it is up to local chapters to involve participants and give them opportunities. The example of one of the first IPHUs was given where there was active follow up and the respondent was still in touch with 7-8 of the participants. Keeping the e-group running with updates was considered important for this. Another positive example was where a campaign was actually conceived of within an IPHU and went on to become an actual project of PHM (revitalisation of comprehensive primary health care). An annual meeting of the alumni from the training (which is an example from another organisation involved in training) was also suggested for the IPHU where current and past students get linked to meet the responsibility of continuing mentoring and investing time in the participants.

### **Ongoing training, internships**

While the overall positive aspects of IPHU in terms of giving skills, perspective and enthusiasm are important, it requires consolidation through internships and apprenticeships. According to one respondent, informal frameworks are essential to consolidate learnings in formal spaces. Mentorship is an informal, but crucial part of training work.

"It is extremely critical that a space is created for active engagement with role models and seniors, so that confusions and doubts can be addressed. This does not need to be based on a clear learner-teacher relationship (and hierarchy), but on a discussion of what one did in a particular situation and having a place to go back to from a perspective of sharing tools more than sharing solutions." [Respondent 7]

### **What works, what doesn't**

In determining what makes capacity building sessions successful, the importance of the preparation put in by the organisers was highlighted.

"When resource persons have not spoken to each other before the training, when the organisers don't have a clear understanding of the kind of participants this leads to problems. As long as trainings are clear on their objectives and objectives are linked with

methodology, it's not about the material, language, jargon, interactions. Getting clear information in advance gives one an idea of the preparation that has to go into it." [Respondent 7]

The role of a charismatic leader was also highlighted as interactions with role models can be inspiring for young people. In this regard, the space for personal stories is important. Another key area is the balance between theory and experience and how much of each should be included in a session.

"There is no answer to this, but the debate is healthy and required. Different groups will come up with different formulae, but the fact that both are given equal legitimacy and therefore importance has been in several IPHUs. It is important that participants leave not only with inspiration, but also with concepts, frameworks and the right readings." [Respondent 7]

## 4.4.2 Non-JSA Groups and Capacity Building

### Training Initiatives

Interviews with non-JSA respondents highlighted the diversity of capacity building initiatives being undertaken by civil society in India. These initiatives could be at the national level or the village level and could address health broadly or focus on specific issues. Three case studies of these training initiative are at Annex [ ].

### Curriculum, Pedagogy and Recruitment

Respondents approach curriculum, pedagogy and recruitment from different perspectives. While some have a standard approach, one respondent noted that their approach differed based on the training requirement. The example of work done with a government run health programme which with its announcement led to a sudden and immediate requirement of large scale training and capacity building highlighted the importance of being able to adapt trainings to specific circumstances. In this case, the government staff required systematic technical and management related inputs for being effective in the health sector. Their professional and planning skills also needed to be updated to effectively plan and manage district health systems and it was in this context that a contextualized comprehensive programme of capacity building on public health was conceptualized.

"The central task was designing, production and dissemination of learning material on public health written with a specific focus on the challenges of district health planning and district health management. A series of 18 books were produced in English and Hindi and more than 20000copies have been disseminated. Our editorial advisory committee comprises a number of resource persons on public health who have combined working with government to strengthen public health systems with advocacy for better health policies. The drafting process has included national and state level consultations with both experts and district level officers. The material is also allowed to constantly evolve from one edition to the other based on feedback and further elaboration." [Respondent 5]

A structured learning programmes has been constructed around these materials and modules which includes a) self-study modules, which is accompanied by b) interactive workshops (contact programmes) and which is interspersed with c) mentored field activity. Activities under the courses were supported by competent resource persons working with the respondent while quality control was done a well known and well respected government health resource centre.

For the training programmes conducted by another respondent, a national consultation is held to put the curriculum together. They also try and get feedback from the fellows who go through the training. The ability to change curriculum is one reason given by the respondent for not being affiliated to any university. At present, as and when new issues come up they are included in the curriculum.

"For example, when there were farmers' deaths in a particular area, we had one of our faculty members as part of the local group which led an investigation into the incident. He went to the place and stayed there to visit farmers. That's why some people call it a university without walls. We are not only learning from the text but also from the context. Context is the living reality of people who are the social majority." [Respondent 8]

The respondent also noted that a lot of feedback on issues comes through their website and newsletter. A major initiative in providing materials that people can access and books that are probably not available in any library has been the setting up of community health in which is making gray literature and older publications available through the internet. The respondent

referred to their strategies as being non-formal and stated that this was what keeps them, "alive and dynamic."

Recruitment for the training programmes of this respondent is done through advertisements on the internet and word of mouth but not through newspapers due to the lack of resources. There is a specific selection procedure where applicants write their statement of purpose, shortlisted candidates go through an interview and are selected based on 10 criteria assessed by three independent people who conduct the interview. Reference checks are also conducted and the whole process is documented.

"The weakness is that, since we don't take any fees or participant contribution, it makes it vulnerable. Donors can't keep supporting us forever. We are presently at that stage asking what to do next." [Respondent 8]

For one respondent whose work is more strongly linked to healthcare services, their clinical experience of running a hospital as well as community based medical centres forms the basis of their curriculum. The observation of outcomes, processes, behaviours and discussions with state health officials who ask for help on technical issues informs their capacity building. For instance, their work on animal bites was initiated after a series of deaths happened and the group started to realize there was a silent rabies epidemic happening and the system was totally ill equipped to handle it. The pedagogy is largely guided by the fact that they are themselves practitioners in a challenging context and they know the key gaps and training requirements as well as have the technical expertise. The respondent highlighted the effectiveness of audio-visual materials (especially videos) saying that "a picture is worth a1000 words but videos are worth more than a 1000 pictures." The quality of the film is very important and this can be done cheaply in real time without hiring too many people. "For example a video on how to administer anti-snake venom." The main thing according to this respondent is effectiveness, not so much the cost. The main concern in their approach to capacity building lies in learning by doing. In terms of post training follow up, an interactive voice recording system, posting questions online and getting answers are the main methods employed for on-going learning. Recruitment for the trainings is opportunistic and done through word of mouth or if demanded by the government then through their selection.

One respondent detailed the multiple ways in which they identify training needs including (i) on issues related to ongoing campaigns or policy advocacy towards building a wider understanding and to mobilize around ongoing campaigns or for inputting into policy/programme/law conducted with organizations/networks, JSA partners, policy makers; (ii) by organisations that articulate their needs for training on gender, health rights, ARTs, GBV or on any other specific issues. The need for trainings on health related programmes, policies and their analysis; building capacities in research on issues of women, etc; (iii) by health system/healthcare providers with regard to skills, knowledge regarding young people's sexual and reproductive health and rights, gender based violence etc. Based on the training needs, the profile of participants and the objectives of the training, curriculum and pedagogy is adapted. The training methodology has also evolved over time. Previously, the respondent would carry out multiple trainings over a period of 2-3 years for a specific organization or group. Here the training was conceptualized in a manner that provided the basis for application by the participating organization in their respective work/areas. Emerging from this experience, further areas for training were identified and conducted. Given the nature and length/duration of these training, their numbers were limited. In more recent years, the trainings are carried out for diverse groups/participants with a wider outreach and usually span 1- 3 days. The trainings also facilitate application of the information either as individual organizations or also collectively towards future monitoring, policy advocacy and campaigns.



"We have developed a range of training curriculum, methods and tools over the years on health rights. Usually, trainings are preceded by a situational/needs analysis through discussions with prospective participants, peer organizations, key informants, to ascertain and enable planning of the trainings. Based on the situational/needs analysis, the curriculum and pedagogy are developed/adapted for respective training. Such assessments may also be done "virtually" by dissemination of formats for the assessment of needs or expectations from the training." [Respondent 4]

For this respondent, selection of participants is generally decided by the organizations/institutions whom they represent. Participation in trainings is invited from organizations based on the theme/objectives. These would be organizations that have been part of ongoing campaigns, partners of JSA, organizations working on women's health and rights issues, gender based violence, young people's sexual and reproductive health and rights. Where trainings on research or advocacy may benefit certain kinds of participants, the criteria is mentioned in the invitations. Pre workshop formats are also developed and used for the process of selection where necessary.

### **Evaluation**

For one respondent, there have been eight external evaluations in the past 13 years. The programmes are also evaluated by the participants and internal evaluations are also conducted within the team. The respondent has established a council as well as a school of public health as an initiative. The council has annual meetings where the curriculum is evaluated and approved. There have always been advisory committees as well, the members of which change every three years in order to keep things democratic. There is now a scientific and ethics review committee as well. According to the respondent, "these are institutional mechanisms that strengthen the process. These also help us get a lot of mainstream people on to the body of the organization. So there is a mutual influence. They raise questions to us and we raise questions to them. They get to know a lot too."

One respondent said that their evaluations were formal but not quantitative and are carried out by external people. For the trainings themselves, there are pre and post assessments. Another respondent detailed the following ways in which they carry out the evaluations:

- Feedback provided by the participants immediately after the conclusion of the training – regarding different aspects of the training (verbal / written)
- Feedback from / review by resource persons / facilitators of the training.
- Evaluation of the outcomes / application of the skills and knowledge by the organizations through discussions with them or with community representatives.
- Skills and knowledge gained by health care providers may be evaluated through discussions / interviews with those who are received the care / response.

### **Impact on participants and on health movement**

"Many of our fellows work at community level, some go into academia, several are coming back to us for periods of time. I think they maintain the perspective, overall value, and the ideas that people are central, the whole question of autonomy, democracy, rights. They are very strong as we intended. They take it much beyond. They are very dynamic guys." [Respondent 8]

Several respondents saw a positive impact of their capacity building initiatives on the health movement. One respondent gave several examples of participants and fellows who are now part of JSA or other health groups but also noted that there needs to be proper documentation of this impact. Another respondent believes that appropriate and responsive public health services are imperative for the health and well-being of people and that in strengthening public health

services and making them more pro-poor, there is a need for both advocacy and alertness, as also for creative and innovative thinking.

"We are constantly in pursuit seeking new knowledge and perspectives as much as questioning the existing ones. We seek to deeply engage with public health practitioners on the frontline of action and the community and seek to facilitate and enable them with core knowledge and competencies that will add value and strength to both their advocacy work and their partnerships in implementation and research. Our capacity building programmes are being run to strengthen the capacities of field level civil society organisations and in the process build a team of professional and dedicated practitioners with the perspectives and skills to contribute to pro-poor community development work throughout the rest of their careers." [Respondent 5]

One respondent, however, viewed their work primarily as improving skills and as skill based training with little link to the health movement or to campaigns and felt there was "no direct connection between campaign and capacity building."

### **Ongoing training, internships**

Several respondents provide ongoing training through internships and fellowships. In the case of one respondent, physicians spend between six months to a year with them to learn skills. They have now formed a network of rural physicians. Another respondent views its internship programme as a continuous effort to provide a practical exposure to the students from various fields and institutions. The organization builds their capacities through their involvement in its ongoing activities and helps them to develop an understanding on various social, health and nutrition related issues. Another respondent suggested that some sort of creation of a network or alliances or collective retreats was necessary to keep up the engagement as often a lot of fellowships start but stop or die out.

### ***What works, what doesn't***

Reflecting on training and capacity building programmes generally, one respondent noted that the old fashioned, hierarchical and top-down approach does not work nor do programmes aimed at creating role models as these do not help anyone. Another noted that bad trainings are often because of the resource persons who do not have the right methods, are not competent in role plays and group discussions and have a serious lack of skills.

One respondent has developed a module on 'good training'/capacity building which talks of how to design a good training programme. Their trainings are usually linked with campaigns unless it involves training government personnel. Trainings should not be used to raise resources. Good trainings according to another respondent should result in attitudinal change and this depends on the richness of the experience of the trainers.

Another respondent noted that a lot of young people are very enthusiastic and committed so much rests on a good training programme. However, financial constraints were a big concern for this respondent who stated that "to have team members who would work on a relatively low salary for a long period of time, to have a sustainable team, is an issue." He argued for a working model that provided training teams with adequate living wages and adequate social security.

## **4.5 Global Health Governance**

In recent decades, issues under the purview of global health have moved far beyond the physical spread of diseases<sup>93</sup>. Since the early 1980s, the global architecture of governance, trade and economics has come to be informed by globalisation, and consequently national decision making and national policies are often subject to global influences. This is true in the health sector as well, and the advent of globalisation marks a shift in institutions and structures that govern health at a global level.

It is possible to identify four major developments in the last three decades that have had a profound impact on the structures and processes of global health governance. The first is the emergence of the World Bank as a major player in the arena of health governance in the 1980s. Second, the growing importance of global trade in international relations, and its impact on health in different situations across countries, has led to a major role for the World Trade Organisation (WTO) and regional and bilateral trade agreements in global health. Third, private foundations (such as the Bill and Melinda Gates Foundation) entering through public private partnerships and other avenues, have become big players in global health issues. The fourth development is the demise of the World Health Organisation as the premier organisation in the area of global health governance. While all the four are somehow linked, each has arisen in specific contexts that are analysed below.

A new family of global initiatives that have a major impact on global health governance are Global Public Private Initiatives (GPPIs). In the past two decades several hundred such initiatives have been launched, with over 100 in the health sector alone. The genesis of these GPPIs is fairly recent, dating back to the 1990s. GPPIs came to be developed based on an understanding that multilateral co-operation in the present globalised world could no longer adhere to the older principle of multilateralism that primarily involved nation states. Global partnerships were, thus, imbued with a new meaning, that involved not just nation states, but also other entities, including, prominently, business organisations such as pharmaceutical companies that work through the medium of the market. These new partnerships were further promoted by philanthropic foundations, largely located in the United States, such as the Bill and Melinda Gates Foundation. Partnerships with the private sector and civil society are thus held up as the way to achieve what governments and the United Nations cannot manage alone.

GPPIs need to be viewed in the context of an attempt to address the obvious failure of the market to deliver services and goods where most required, i.e. to the income and resource poor, while at the same time staying within the boundaries of neoliberal economic policies. They address what neoliberal economists describe as "market failures", but at the same time do not question the fundamental faith in the ability of the market to regulate the global flow of goods and services.

The WHO faces three key challenges, related to its capacity, legitimacy and resources. Its legitimacy has been seriously compromised because of its inability to secure compliance of its own decisions, which are reflected in the various resolutions passed at the World Health Assembly. Developed countries which contribute the major share of finances for the functioning of the WHO have today a cynical disregard for the ability of the WHO to shape the global governance of health. They see the member state-driven process in the WHO (where each country has one vote) as a hindrance to their attempts to shape global health governance, and

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<sup>93</sup> **For a more detailed exposition on this issue see: Sengupta A, Global governance of health: a minefield of contradictions and sectional interests, Indian Journal of Medical Ethics, Vol 8, No 2 (2011)**

prefer to rely on institutions such as the World Bank and the WTO, where they can exercise their clout with greater ease.

As with many other UN organisations, the WHO's core funding has remained static because of a virtual freeze in the contributions of member states. Its budget amounts to a tiny fraction of the health spending of high-income member states. In addition, a large proportion of the WHO's expenditure (about 80%) comes in the form of conditional, extra-budgetary funds that are earmarked for specific projects by contributing countries.

Global governance of health is shaped by multiple agencies and by multiple interest groups. Civil society engagement with global governance for health, in any systematic manner, is fairly new in India. Earlier limited to engagement with the WHO, the changing landscape of global governance for health has prompted greater civil society interest in engaging (and often challenging) different actors that influence health outcomes. Prominent among civil society groups in India that engage in global health issues are Indian counterparts of iNGOs such as MSF, Third World Network (TWN) and Oxfam. Activism around access to treatment by HIV groups has also prompted actions challenging trade agreements, especially in the context of intellectual property related issues. This has been of particular relevance in the context of India's generic industry being viewed as the key supplier of low cost generic medicines to poor patients across the world. The access campaign has, in the last decade and half, grown tremendously with the association of positive peoples' networks such as the Delhi Network of Positive People (DNP+) and of lawyers' organizations such as Lawyers' Collective.

#### **4.5.1 Local Knowledge of Global Issues**

For respondents engaged at the international level, the local implications of global decisions hold a lot of importance. According to one respondent, links between the global and local take place through the structure of their network. The international network has country offices responsible for the region as well and through various tools provides vital information that can be used at the local level as well as the global. Data for 56 countries for instance is available online on the implementation of a core demand of their campaign. The international network holds regional trainings and country representatives are provided with the information and tools for using the information at the local level to hold governments accountable.

Another respondent highlighting the importance of this connection, notes that the WHO itself has regional and national meetings that inform the discussions in its global structures. This is a way to connect those discourses.

"It is important, as the local informs the global, and the global informs the local. Our work is a two way traffic. For instance, access to medicines is a local issue, but it is important to bring it into the global level. On the other hand, anti-microbial resistance came up as a global issue, though it is felt at the local level too. We have to create the linkages between the discourses at these different levels." [Respondent 9]

A JSA respondent noted the importance of strengthening the connection between global health governance and national or sub national level work. Though there is some understanding of the debates on health at the international level including through the PHM exchange, a more regular process that feeds into the country level discussions of the JSA is required.

The importance of linking local CS in particular to global health governance was highlighted through examples where local groups held government accountable for international commitments. Thus in one case where the government was planning to repeal very strong laws

enacted under an international treaty on baby foods, it was local organisations that campaigned to prevent the repealing of the laws.

#### 4.5.2 Engagement of national governments

The importance of engaging national governments on global processes was underscored by all respondents. According to one respondent, governments are often not prepared well before they leave for WHO meetings, or other global fora and sharing language before the delegation leaves is useful. Strategically, this respondent noted that they choose participants to the WHA based on if people know delegates and will be able to have access to them as the impact on the WHA is through delegates' interventions.

"It has happened to us that the country delegation reads our submission verbatim at the meeting and our submission becomes part of the country position at the global level. In February or March, we have some intelligence on the delegation that will be going and entry points for dialogue. In the case of India, the position taken at WHO is not very dynamic and tend to stick to the position decided before leaving from the capital. Frustration comes when the delegation is back and there is no action or follow up. The WHO Resolutions are not very relevant at the national level, it is important to evaluate carefully where one wants to put energy. In many ways, the bureaucracy is unpredictable." [Respondent 10]

Similarly another respondent noted that developing countries in particular have a capacity problem at the global level and they welcome the support and inputs of organisations. In addition, there is a convergence of concerns on certain issues, that allows CSOs and governments to work together. They pointed out that this actually makes that these countries not hostile at the local level and opens the space to engage in policy discussions and advocacy.

"For instance, we did this on access to medicines in India. India has a position against TRIPS+ at the global level, and we followed it up at the national level, by showing what the negative impacts of agreeing to TRIPS+ provisions in trade agreements would be." [Respondent 9]

However, the respondent also pointed out the problems in holding governments accountable for their positions in international fora. While the WHO comes under the Health Ministry, the issue of AMR may come under the Ministry of Chemicals. In such cases it is difficult to refer back to positions taken at the WHO. Also, for instance in India, the Cabinet does not give clearance for positions to be taken at WHO (while it does with regard to WTO for instance). "So in practice, holding countries accountable for what they say in global fora can be difficult."

#### 4.5.3 On WHO Watch

The views on the WHO Watch differed based on whether respondents were within or associated with JSA and respondents who come across WHO Watch in their international work. According to the latter, "the analysis provided through the WHO Watch is important. It is always good to have a team from PHM at the WHA, as for us, PHM is an ally." According to another respondent, WHO Watch is an important initiative as it has a monitoring function for local civil society and monitoring of discussions and discourses in WHO's governing bodies. However, the respondent also pointed out two limitations:

"Its engagement is limited in time. WHO Watch engages with issues from a few weeks (or a couple of months) before the meetings and during the meetings. The role of country circles needs to be strengthened in the sense that at the end of this engagement and as an outcome of this effort, there should be views and perspectives that are fed back into the circles, as PHM's views. The critical time for this is that in between the EB and the WHA. There should be pilot countries where active engagement takes place between the EB and the WHA, based on the outcomes of the engagement in the EB. This means that the messages that emanate from the commentary, statements, etc should be converted into a position after the EB. And this position should be conveyed to government - through mobilisation, campaigns, advocacy

- towards influencing a country's position at the WHA. In addition, WHO Watch only engages during governing body meetings, but important discussions also happen at other times. Instead of choosing meetings to watch, PHM should choose 2 or 3 issues and follow them in the different forums / meetings where they come up, and all the way to the ground. For instance, in July there will be a meeting in Geneva on the involvement of non-state actors and while PHM did very good work on this issue in May, it should continue that work and follow it through in other forums as well.

The other limitation is that WHO Watch needs to also have positive campaigning for changes that safeguard public health at the global level. For instance, campaign for an increase in assessed contributions, or against PPPs in health. It is important for PHM to put an agenda on the table too. For instance, the UNGA is a legitimate space for global health governance too, and there are Resolutions on Global Health and Foreign Policy every year. PHM should draft a Resolution and push it there, see it through." [Respondent 9]

For one JSA respondent, while the WHO Watch process seems and has been useful to influence dialogues at the WHO level based on the critiques / inputs from national organizations and networks, "it may gain from more streamlined processes that feed into the international process and also feed back into national advocacy processes. For example, we provided feedback on notes circulated by PHM on the issues to be discussed at the WHO or World Health Assembly. However, on what ensued and what changes took place – positive or negative –it would be useful communication at the national level."

According to one JSA respondent the engagement with international processes is very important because "countries are not islands." Noting that there are different pathways of engagement for individuals and groups with a movement at the global level, they admitted that they had been unable to find a pathway of connection with global policy dialogue. On the WHO Watch, the JSA respondent stated that they knew very little about it, had little time to get directly involved and had the impression that WHO Watch can engage certain kind of constituents – viz. academics.

"Activists have limited time choose to volunteers in areas where they feel most motivated to work in. Sustained engagement with global work needs some funding support for people to engage. When people choose voluntary work they choose work that is more 'organic'. If people are to be engaged in global work then specific demands have to be placed on them -- won't happen by itself as natural course for activists is to work on local issues that they closely identify with." [Respondent 5]

Another JSA respondent reported having heard of the WHO Watch but not really knowing what it did.

"On the WHO Watch, there is not enough corresponding effort at dissemination and engagement. When the national committee meets, there should be information shared, maybe a poster to explain it. We need more understanding on the linkages between WHO and national issues. There is reasonably good job being done on this with regard of medicines, but not that good in other areas. There is also a need to champion and reflect on the space that is accessed through the WHO so that there is a greater sense of ownership - we must show how CSO are fighting against the corporate capture of WHO and the meaningfulness of the victories in this area." [Respondent 1]

### **Linking the Watch to country level activism**

According to one respondent, the information generated through the Watch can simply be brought back to JSA and workshops or seminars can be organised to discuss it.

"Currently there are lots of emails exchanges, information is there. What is needed is a space to discuss it, so that people that are here and have an interest can express it and a process can be developed. A kind of national internal JSA dialogue after the EB and towards the WHA." [Respondent 10]

The respondent did admit that though they work closely with JSA they tend to bring global issues back to the national government but not the JSA. The discussion with JSA is limited to national policies. They also noted that they have never heard a government official use a WHA resolution as a reference point and so national organisations also do not use these as tools of advocacy.

Another respondent notes that the watching has been successful in step 1, which is creating information on global debates on health and discourses on global health governance. Step 2 needs to be to engage country circles with this information, and step 3 will be to have a proactive agenda, on a span of 3 to 4 years like pushing a Resolution at the UNGA, for instance. The respondent suggested that the outcomes of the Watch should be discussed at the steering council and communicated to the secretariat for implementation and dissemination to the country circles.

The importance of PHM creating alliances with other international groups was also pointed out.

"Alliances with other CSOs/networks could be on the issues of public financing, with Tax Justice Network, with Jubilee South, with Global Union Federations, such as Public Services International. It could also be on private sector influence, with organisations such as Corporate Europe Observatory, Corporate Accountability International." [Respondent 9]

### **Identifying Weaknesses and Improving the Watch**

Among the weaknesses of the Watch noted by the respondents was the gap in funding and human resources. Another was in terms of lobbying where the Watch brings in several people to Geneva but their use in lobbying is limited.

"WHO Watch should better use the existing contacts in Geneva to facilitate introduction of watchers and have targeted lobbying efforts. The work load per person in the Watch appears to be too much. Note-taking should be lightened as it sucks out the energy out of Watchers. The skype channel allows people to see what is happening. With the webcast now, notes can be less comprehensive and only new and controversial points need to be taken down while the reports of national activities can be cut out." [Respondent 9]

More generally, some respondents noted general weaknesses in the response of the international community including what was referred to as "stakeholder-isation and-self silence" due to funding influence.

### **4.5.5 Lessons from other international processes**

The respondents gave some examples of their work with other global processes. One spoke of involvement in the reporting work on the Convention on Rights of the Child and the preparation of alternative country reports. Another noted that there are several global fora where the health component could be followed, such as BRICS, SDGs, UNHCR, G20/G8 and the UNGA. The respondent noted that the engagement does not require physical presence and "Watching" these events could mean to look at the documents, have an analysis and publicise it. The respondent pointed out that there are already internal resources and PHM does not need to



reinvent the wheel or take it all these up on its own. "But the secretariat has to reach out, push key resource people to take a stand and write on it."

## Annexes

### ***Annex 1. Final Protocols – IDRC Project – India Study***

The Protocols and suggested questions under each theme are below:

#### **1. Campaign**

1. Identify key campaigns. This may include not so successful campaigns or different strategies from other campaigns.
2. What was the historical and political context of the campaign and how did the campaign start?
3. Who was/is involved?
4. How were resources, (human and material) mobilized for the campaigning?
5. What knowledge was accessed for the campaigning, and how? How was the knowledge accessed?
6. What strategies did the campaign use to identify the selected issue(s), mobilize participation, build coalitions, select the strategic actions, sustain participation, enhance skills/capacities for activists involved in the campaign, evaluate its outcomes?
7. What were enablers to campaigning, barriers to campaigning, activities to maximize enablers and minimize barriers?
8. What strategies did the campaigns use to achieve its demands? E.g.: demonstrations, petitions, lobbying (meeting with politicians, policy influencers), media, social media, education/awareness (e.g. community mobilizing, popular education); Why do you use certain strategies and not others?
9. What has changed (if anything) in the discourse around the campaign demands?
10. What has changed (if anything) in actual policies/programs?
11. How did changes in the political context (if applicable) affect changes in the strategies used by the campaign, and its messaging and policy/program influence?
12. Which other campaigns and movements do you think have been significant and why?
13. What lessons could be drawn from these?
14. Are you associated with the health movement? How do you see the association?
15. How do they see the future of their movement in coming decade or so? What strategies are emerging or do you see emerging to deal with the changing scenario.
16. Who are your partners and allies? What were the complexities, contradictions involved in the partnerships and how they were resolved? How were decisions taken?
17. How is the campaign organized including budget, infrastructure etc. for the campaign?

#### ***Notes on Protocol for Theme 1:***

Interview prompts may include the following suggested questions:

- How organizations approached campaigns
- Besides own campaigns, key informants can be asked about their opinions and perceptions of other campaigns
- For JSA case study, multiple campaigns can be the focus
- Specific enquiry into JSA role in right to food
- The overall theme and thrust must be “Health for all”
- Expert interview to focus on analytical information in addition to narrative/factual

information

- For those case studies with focus on all themes, the movement building questions can be asked in the beginning followed by detailed questions on campaigns
- Permission for publication of the information should be sought from all informants.

The following additional points can be kept in mind while deciding interviewing

1. Questions should be asked in the present tense to encourage responses on ongoing campaigns
2. The informants should be asked to identify key campaigns and then focus on one that they would think most suitable for the in-depth interview. However, at the later stage references may be drawn from other campaigns.
3. Informants should be encouraged to refer to not so successful campaigns or changed strategies from other campaigns
4. Focus on narratives including what helped and what hindered in the campaign identified for in-depth interview.
5. Informants should be asked for illustrations for each response.
6. Informants should be encouraged to be reflective and focus on what strategies specifically have they found that were not useful as well as if they would have done certain things differently and why.
7. As informants can be selective and forget factual information or perhaps not offer it in the interview, the interviews should not be the only source of information for the case study.
8. For Jan Swathya Abhiyan (JSA)/Peoples Health Movement (PHM), we would not restrict the questions to one campaign - there would be multiple campaigns: for instance Right to Health; Malnutrition, Medicines. Three or four persons would be interviewed for each of these campaigns.
9. Two campaigns for the Right to Food: Public Distribution System (PDS) and the working group for children under 6.
10. There should be focus on analytical components during interviews, whereas background work has to be done beforehand. There should be documents to support the case study.

## **2. Movement Building**

### ***Protocol for JSA (PHM) interviewees***

#### **1. History of PHM country circle (\*):**

- a. When did the PHM circle start and who were the activists early on?
- b. What precipitated the circle development and what initial strategies/activities (etc.) did they undertake?
- c. What was the implicit or explicit program logic of circle building?
- d. Does PHM target specific individuals/groups, or use a 'big tent' approach (anyone who agrees with the Charter and its principles, more or less)?
- e. How do people hear about PHM? Why are people attracted to PHM? Why do some people leave PHM?

#### **2. Structure**

f. What are the governance structures in country circles (decision making)? How effective are these in attracting people to become active?

g. Does PHM have a committed political ideology (e.g. anti-neoliberalism)? Can it be defined? What are the benefits/risks of having an explicit political ideology?

h. How are resources mobilized for circle building?

i. What are enablers to PHM circle building, barriers, activities to maximize enablers and minimize barriers?

j. What strategies does the PHM use to achieve its goals? E.g.: demonstrations, petitions, lobbying (meeting with politicians, policy influencers), media, social media, education/awareness (e.g. community mobilizing, popular education)

### 3. Collaboration and partnerships and linkages – national and international PHM and other CSOs:

a. How are other Civil Society Organisations (CSOs) chosen for PHM collaboration? How are they approached?

b. How do different social movements with which PHM engages agree on campaigns, strategies and analyses? What are some of the successes in doing so, or failures (and why)?

c. How are PHM and its campaigning and circle building activities regarded by other activist CSOs? (\*) – ADAPT 4 to include here for others

### 4. PHM country circles and PHM global:

a. How do global PHM activities contribute to circle building in countries?

b. What role do regional forums play in the links between local (country circles) and global (PHM and its other CSO allies, activities and campaigns)?

c. What are the governance structures globally, and how do these enhance or impede work at the country circle level?

d. What are the strengths/weaknesses of changing PHM governance to a model of membership vs. non-membership, incorporation vs. non-incorporation?

### 5. Strategies for the future

a. What challenges do you see emerging and what learnings from your work till now will you employ towards these new challenges?

b. Specifically identify challenges related to shifts in the shift in global and national economic and political landscape including (a) neoliberalism (b) new government (c) funding

### 6. Reflections on Movement Building

a. What brings people together?

b. Specifically please reflect on the role of peoples conferences like the World Social Forum and the Womens Conferences or other similar movement building events. Were these successful? Why, why not? What should change in the convening of such conferences?

### **(\*)Notes on Protocol for Theme 2 for JSA interviewees:**

- Questions under points 2-4 may be addressed in a group interview involving several PHM active members; the questions could also be emailed to active members (individually) as a sort of survey to have them answer to their best ability, although interviews would probably elicit richer responses.

- For JSA organisations, questions should be altered to reflect the fact that JSA is a network and not an organization so questions for JSA interviewees should include:
  - Reflections on the dynamics in assembling the networks
  - Organizational approaches that keep the network together or create barriers
  - What is the incentive for an organisation to be part of JSA
  - Why are there so many organisations outside – how do JSA members interact with them
  - What sustains JSA as a network
  - JSA seldom has nationally co-ordinated activities as there are primarily state actors. How do they see the links to national level work.

***Protocol for non-JSA interviewees***

1. History of your organization/movement:

- a. When did your organization/movement start and who were the activists early on?
- b. What precipitated the development of your organization/movement and what initial strategies/activities (etc.) did they undertake?
- c. What was the implicit or explicit program logic of organization/movement building?
- d. Does your organization/movement specific individuals/groups, or use a 'big tent' approach (anyone who agrees with the Charter and its principles, more or less)?
- e. How do people hear about your organization/movement? Why are people attracted to your organization/movement? Why do some people leave your organization/movement?

2. Structure, systems, processes, resources, membership, decision making, leadership sustainability

- a. What are the governance structures in your organization/movement (decision making)? How effective are these in attracting people to become active with your organization/movement?
- b. Is your organization/movement national, local, regional? Are you a grassroots organization/movement?
- c. Does your organization/movement have a committed political ideology (e.g. anti-neoliberalism)? Can it be defined? What are the benefits/risks of having an explicit political ideology?
- d. Which are different ideologies that motivated your movement and how do you deal with different ideologies?
- e. How are resources mobilized for your organization/movement?
- f. What are enablers to the building or development of your organization/movement, barriers, activities to maximize enablers and minimize barriers?
- g. What strategies does your organization/movement use to achieve its goals? E.g.: demonstrations, petitions, lobbying (meeting with politicians, policy influencers), media, social media, education/awareness (e.g. community mobilizing, popular education)
- h. Do you face barriers in sustaining leadership within your organization/movement? Do you have strategies aimed at leadership sustainability? Please describe including what has worked and what has not worked?
- i. How do you resolve conflicts within your movement? Please provide illustrations of particularly difficult conflicts that have arisen and how they were resolved or not resolved.

3. Collaboration and partnerships and linkages:

- a. How are other CSOs chosen for collaboration with your organization/movement? How are they approached?
- b. How do different social movements with which organization/movement engages agree on campaigns, strategies and analyses? What are some of the successes in doing so, or failures (and why)?
- c. How is organization/movement and its campaigning and development activities regarded by other activist CSOs? (\*)

#### 4. Strategies for the future

- a. What challenges do you see emerging and what learnings from your work till now will you employ towards these new challenges?
- b. Specifically identify challenges related to shifts in the shift in global and national economic and political landscape including (a) neoliberalism (b) new government (c) funding

#### 5. Reflections on Movement Building

- a. What brings people together?
- b. Specifically please reflect on the role of peoples conferences like the World Social Forum and the Womens Conferences or other similar movement building events. Were these successful? Why, why not? What should change in the convening of such conferences?

#### ***Notes on Protocol for non-JSA interviewees for theme 2:***

- In theme two we are looking at the movement as a whole keeping in mind the distinction between campaigns and movements.
- For those whom we are interviewing for all the five components we would start with movement building. We start with historical questions, organisational questions and then operational issues.
- If the informants provide or indicate that individuals are key to movement building then this should be captured.
- Informants should be encouraged to reflect on the processes of social movements coming together
- Interviews should attempt to capture the difference between campaigns and movements and encourage informants to reflect on this as well.

### **3. Knowledge Generation and Dissemination**

1. Which CSO knowledge products/ forms/ media have been most useful in country circle/movement building, how and why?
2. How do you generate, disseminate or feed knowledge into your campaigns? What has been the key learning and the key challenges in this regard?
3. What different languages do you use? How do you simplify technical, policy language for knowledge dissemination? What forms of dissemination do you use: literature, film, theater, songs, media, posters, stickers, journals, annual diaries, calendars)
4. Do you use the internet/social media? What social media campaigns do you find useful and not useful? What do you think of “internet activists or activism?” Is it or can it be useful?
5. For JSA interviewees: Have you found the booklets useful? What suggestions do you have for continuing or not the process of creating or simplifying the booklets and the information in them?
6. Which PHM knowledge products have been most useful in country circle/movement building, how and why?

7. Specific to Global Health Watch (GHW):
  - a. Is global knowledge/politics important in your work? How do you access this and how do you push it through your channels/networks? Do you use the Global Health Watch in this regard?
  - b. Have there been events (such as launches or other organised efforts) to publicise the GHW?
  - c. How important or useful is GHW to you in your local/country campaigning and movement building? (why or why not?)
8. For all CSO and PHM knowledge products:
  - a. What are the strengths and weaknesses of existing resources for Health For All (HFA) movement building and campaigning?
  - b. How can the effectiveness and reach of these resources be improved?
9. Knowledge practices and products:
  - a. How do global PHM activities contribute to knowledge access, generation and dissemination in countries?
  - b. What are the international linkages between country circles, their campaigns and knowledge needs and PHM global knowledge generation and dissemination? How can these be aligned better?

#### ***Notes on Protocol for Theme 3***

- For the Global Health Watch there are two levels of questions. One relates to the report itself and the second is disseminating it wider (translations, trans-creations). The second set of questions relates to outreach. For those informants familiar with Global Health Watch, interviews should stress on aspects of outreach and how they do this.

#### **4. Capacity Building and Training**

1. How are training needs identified, curriculum assembled and pedagogy developed (what principles guide educational planning within the training/capacity building program)?
2. Do you evaluate your training/capacity building? How? What have been successful methods of evaluating trainings?
3. How are the recruitment and selection processes for participants handled?
4. How do such programs affect the activist/career choices of participants, and how do they influence participants' future engagements with PHM or other HFA movements?
5. How can we enhance the impact of training/capacity building courses (preparations, structure, content, dealing with language, enhancing relevancy, etc.)?
6. To what extent have these courses contribute to the strengthening of the PHM or other CSOs/movements at the country level?
7. Do you use informal methods of capacity building? Do you have systems of formal or informal internships? Do you find these useful in building capacity or commitment?
8. What sort of trainings have you attended that you did not find useful and why? (Material, language, jargon, interaction).
9. What trainings and capacity building sessions/methods of other organisations/movements have you found useful?
10. In your experience of your own training and capacity building and that of others, what has worked what has not?

#### ***Notes on Protocol for Theme 4***

- The idea for the questions in this theme should be to address the issue of training with a critical look at methodology.

- In terms of the IPHU Indian experience, it will be documented through the India based interviews of those involved in organizing it. It may be noted that the Global Research will capture the experiences of the IPHU participants including those who participated in the Indian IPHUs.

## **5. Policy dialogue**

1. How important is it to build local knowledge about the kinds of issues being debated at the global level? Do you think that there is a disconnect between global health governance issues and your own work nationally or at the state level? How can global issues be connected to local issues. (For those who are familiar with WHO Watch) How useful is WHO Watch for this purpose?
2. How important is it to engage national governments in dialogue around the national positions taken in international fora? (For those who are familiar with WHO Watch) How useful is WHO Watch for this purpose?
3. How important is civil society advocacy in influencing global health governance? (For those who are familiar with WHO Watch) How useful is WHO Watch for this purpose?
4. What is the role of PHM global and PHM country circles in following this watching and feeding it into political mobilisation at the country level?
5. What is the potential use of information generated through Global Health Governance watching for country level activism, campaigning, movement building, including new policy dialogues and alliances with other 'watching' and HFA activist CSOs?
6. What are the barriers to the full realisation of this potential; including gaps in the watching, weaknesses in the documentation and analysis, and weaknesses in dissemination and communication (including linguistic exclusion)?
7. How could the logistics of the watch be undertaken more efficiently?
8. Are you involved in any other international processes (such as CEDAW or Convention on the Rights of the Child or other UN bodies reporting efforts or in MDG/SDG processes) from the country? Are these efforts effective and useful? How can similar efforts be made in the health field?

### ***Notes on Protocol for Theme 5***

- The questions above include general questions about international, processes and institutions (such as CEDAW).
- However, we are also looking for specific case studies, expert/ organisations and this should be kept in mind while speaking to informants.



***Annex 2. Consent Form***

**Title of Research Project: The contribution of civil society organizations towards achieving ‘health for all’.**

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences.

I understand that there will be a sound recording of the interview only for the purposes of collating and writing the research report, that the sound recording will be accessed only by the interviewee and the PHM researchers writing the final report and that the sound recording will be destroyed on or before 30 September 2015.

Participant’s name.....

Participant’s signature.....

Witness.....

Date.....

### ***Annex 3. The PHA Process***

#### **The Objectives**

The Peoples' Health Assembly aims to draw public attention to the adverse impact of the policies of globalization on the health of people worldwide, especially on the health of the poor.

The Peoples' Health Assembly aims to focus public attention on the passing of the year 2000 without the fulfillment of the 'Health for All by 2000 AD' pledge. This commitment needs to be renewed. Health and equitable development needs to be reestablished as priorities in local, national, international policy-making, with primary health care on the strategy for achieving these priorities.

In the Indian context, globalization's thrust to privatization and retreat of the state has exacerbated the trends to commercialize medical care. Irrational, unethical and exploitative medical practices are flourishing. The Peoples' Health Assembly expresses the need to confront such commercialization.

In the Indian context, top down, bureaucratic, fragmented techno-centric approaches to health care have created considerable wastage of scarce resources and failed to deliver health. The Peoples Health Assembly seeks to emphasize the urgent need to promote decentralization of health care and build up integrated, comprehensive and participatory approaches to health care that places *Peoples Health in Peoples Hands*.

The Peoples' Health Assembly seeks to network all those interested in promoting peoples' health. It seeks to unleash a wide variety of people's initiatives that would help the poor and the marginalized to organize and provide some relief to their immediate predicament as well as contribute to building long-term and sustainable solutions to health problems.

#### **Inspiring the India Campaign**

Among the countries participating at the Peoples' Health Assembly at Dhaka, India has seen one of the most extensive pre-conference campaign activities. This has a history. India has an excellent tradition of progressive academic scholarship. This scholarship has laid bare the class and gender bias of health policies. It has exposed the problems of a technocratic approach that sees health as being given by a benevolent state and a benevolent medical profession to people who are seen as passive beneficiaries. India has also seen a large number of innovative models of community health care. These models have provided rich insights into community health care they have established the fact that 'Health for All' is not only desirable - it is possible as well.

The challenge that the PHA process in India set itself was to extend this understanding beyond select intellectual and NGO circles and make it part of the public consciousness. Without such widespread public understanding of the reason for the crisis in health care as well as the nature of the alternatives needed and possible one cannot succeed in placing 'Health for All' in the political agenda of the nation.

The India campaign of the PHA also understands that the vast majority of the country who are poor and who bear the brunt of the crisis in health care, have also their perceptions of what is needed for their health. Moreover they have rich experience in daily coping with the crisis. Efforts by a growing health industry to shape peoples' wants to suit the market needs of capital cannot succeed beyond a point. People can articulate what they need better if they are provided the space and organisation for doing so. The challenge however is to synergize the efforts of voluntary organizations and health

action groups with them and their organizations such that their voices are heard and their needs gain priority.

## Organizational Approach

To achieve this organizational goal of 'taking health care issues to the streets', the PHA process in India adopted a number of strategies:

- **Involving New Networks and strengthening existing ones:** A number of organizations and national networks who share a common understanding on globalization and have a considerable presence in the villages, but who were hitherto not involved in health care issues joined in the campaign. For example, the BGVS networks has a large team of literacy workers, but their health work was confined to only 20 districts across the country and that too in a very limited way. By getting involved in the PHA process, they could build up an understanding on health issues and strengthen the forces working for alternative health care policies. The BGVS is by no means a new network but its large-scale involvement in health issues is certainly a new and welcome development. This could be said about other networks also. For example the NAPM, which has been active in livelihood issues and on peoples' control over natural resources, enters with this campaign into the national scene as an advocate for alternative health care policies. This strengthens the alliance building up against globalization and its adverse impact on the health of people. For networks like the FORCES, which have always been active on child health issues, this campaign has provided it an opportunity to strengthen and extend their existing structure and outreach.
- **Networking Networks:** The other major dimension of the PHA organization was the mutual support and reinforcement that bringing together of the networks provided. Thus some of the organizations like CEHAT or CHC acted as resource groups to strengthen and deepen the district and village level mobilization of field based groups. In other states, AIPSN or MFC activists or VHAI state units provided critical resource inputs.
- **Resource Sharing:** Other than in program content, financial and infrastructure resources were also extensively shared. Thus in most states and often in the districts, some organization which had a training infrastructure supported both boarding and lodging expenses for the entire training programme, or at least a considerable part of the expenses. Others contributed to publicity activities and still others provided the capital to print the booklets. In the Tamilnadu campaign for example, TASSOS (related to CHAI) provided training infrastructure, VHA of TN provided support for *Dear Doctor* letters and contributed to the state convention, FEDCOT printed the posters and TNSF undertook most of the block level enquiries.

Without such extensive sharing of financial resources, in almost all states and at the national level, the programme in such an extensive manner would have been inconceivable. The entire cost of the PHA process had it been done in a full-fledged project would have cost a minimum of Rs. 25 million. Even if peoples' mobilization met over 85 percent of the costs incurred, the critical 15 percent that goes into centralized expenses at state and national level was impossible but for this sharing of financial resources.

Beyond, knowledge, skills and finances there were other shared dimensions too. New partners brought new confidence and new optimism. Groups working in the field or in isolation experienced the warmth of peer recognition of their work from others working for the same cause. Public recognition of their work has also enhanced.

And most important *Networking Networks* also brought forth new ideas and possibilities for future action.

- **Combining advocacy with community action:** One major dimension of the PHA organizational process was the linkage between advocacy/agitation for policy changes and voluntary/NGO work amongst communities including work in health care delivery. Though some organizations like the VHAI, CEHAT or FORCES have always had a synergy, for many others it was a policy decision to build up one or other dimension of their work. Thus organizations like CHAI, CMAI and Ramakrishna Mission have been over 40 years active in provision of health care services though seldom involved in advocacy work on such a large scale. Others who had functioned as resource groups active in policy concerns forged alliances with large field-action based groups.

By providing space for such synergy, the number of networks involved and therefore the outreach and the credibility of the entire process could be enhanced.

- **Autonomy, Flexibility and Coordination:** One other key understanding of the PHA organization was to safeguard and guarantee autonomy of individual organizations even while ensuring coordination. Coordination committees (made of organizations) and working groups (made up of members sponsored by the organizations) were set up in national, state and the district levels. These coordination committees planned for some coordinated or joint activities at that level and whichever organizations joined in and were active at that level could identify themselves publicly as the organizer at that level. Thus in each state the set of organizations that made the state coordination committee was quite different from that which made the national committee or the district coordination committee. This allowed for over 1000 organizations (that we have information of) to be listed as participants at either block or district or state level! This approach allows for an organization which is making a more extensive contribution to be seen publicly at so many more places and it ensures the distinct identity of each organization, especially the smaller groups. Nor was coordination insisted on. All organizations were welcomed and encouraged to take independent activities.

The other dimension of autonomy was that all national coordination committee decisions were in effect viewed as guidelines by states. Even 'quotas' set for funds or coordinated events left room for individual states or organizations to opt out or do it differently if so desired. The result has been a wide panorama of activities and vastly different levels of participation.

It is difficult in this short note to do justice to all these variations. Given below is only a brief overview of processes that were largely common - cutting across most states.

### **Activities - seen as processes**

#### **Building a common understanding**

After Dr. Zafrullah Choudhury had approached a number of sections of the AIPSN & BGVS leaders about the PHA, a national consultation of all potential partners - largely those already in touch with the Dhaka process - was organized in Chennai. Subsequent to this, the National Coordination Committee and the National Working Group was formed and it met subsequently at Bangalore in March 4th&5th, in Hyderabad on April 6th and 7th, at Delhi in August and at Kolakata on November 4th and the 5th.

To build a common understanding of the programme content, the Chennai meet authorized a team to collect resource inputs in the form of theme papers. By March end, 30 base-papers were collected from over 30 resource persons. Then a small group worked intensively to edit and transform these base-papers into four simple popular booklets. A hundred xerox copies of these booklets in draft form were brought to the national preparatory workshop at Hyderabad. Here over 100 delegates from at least 9 organizations went through all the four booklets, in small groups, while rapporteurs noted down their suggestions. The group then incorporated these suggestions, and the text, which was complex in places, was made readable by an illustrated, 'conversational' presentation. The four books were printed in last week of May. A fifth book on Confronting Commercialization was also finalized, albeit with a more limited discussion, and that too was printed by June end. In English 4000 sets of these five books were printed and sold. Many times this number have been printed and sold in the form of translations (and that proved to be an equally daunting task) in Hindi, Kannada, Tamil, Telugu, Oriya, Bengali and Malayalam and in adapted versions in other languages like Marathi and Gujarati.

The five books represent developed for the campaign represented a shared understanding of the critique of existing policies as also our recommendations for change and the possibilities for peoples' initiatives. It was published not in the names of individual authors or organizations but collectively by the entire group and thus became a binding force in themselves.

Establishing the commonality of understanding in a more succinct way was also the people's health charter. First mooted in Hyderabad workshop then worked up by a sub-committee and circulated to the states, discussed in state conventions, and finally at the national convention, the charter helped a closer understanding emerge amongst the partners.

Together the five books and the charter have become the central instruments through which the public understanding of the crisis in health care is sought to be built up.

### **The District Level Process**

The programme has reached out approximately to 250 districts of the country. Though there are wide differences in what happened in various districts, the most common process at the district level was as follows:

1. A district resource group and a block resource group in each block was built up through a district level preparatory workshop. The five-book set and a model questionnaire served as the training material.
2. The block resource group conducted a dialogue (or participatory, rapid appraisal) with people in about 30 villages. They also visited the local PHC and subcentres and talked to the personnel there. In conducting this dialogue, they were assisted by an interview schedule/questionnaire prepared by the district team, based on state level guidelines for the same.
3. Based on the enquiry/dialogue, a local health charter was prepared. This charter places immediate demands that the local administration can meet and also charts out the follow up actions that can be done by people themselves. The charter is placed before the block convention.
4. The block level conventions were followed by a district convention. The charter was given to the administration as well as adopted at the convention. In many districts, block and district conventions were held together. The district report was then used as an input to a public awareness campaign. It was also placed before the state convention.

## **Public Awareness Campaign**

The public awareness campaign took different forms in each district. In all states, the number of people involved in workshops, seminars, peoples' dialogue, surveys and conventions was the main form of building up public awareness.

The sale of the five books was in itself a campaign and nearly 25,000 sets, all languages included, have been sold. (That is worth about Rs. 250,000 !)

Poster campaigns also played a major role. The *kalajathas* - traveling street theatre - took the message to 23 districts in TN, 5 in AP, 14 in Karnataka and almost all districts of West Bengal, Kerala and Tripura. Kalajathas were also planned in some other states.

Rallies and Processions also contributed- especially the rallies in Delhi (1200 people) and Chennai (3000 people) and of course at Calcutta (over 30,000 people being mobilized).

Media coverage received was weak, partly because of our inexperience in handling media and also because of media's own preferences for news. Of course in almost all states, the news was given prominent and repeated space in local papers and in the regional pages of the national newspapers.

One interesting aspect of the campaign in many states was to reach out to the medical profession. Dear Doctor letters were sent on the PHA and these letters called for some immediate reforms within the profession. The campaign also involved few respected and concerned health professionals in most district and state levels. Though their numbers were few they played very important roles as resource persons and in lending a wider credibility to the proceedings.

The Peoples' Health Trains are another unique highlight of this process. Not only are they media events, they are an occasion for the over 2000 delegates to interact informally over 2 days of traveling together to the national convention.

The culmination of the public awareness campaign is in the National Health Assembly.

## **The National Health Assembly**

This is a unique event and was a challenge to draw up a programme for such an assembly.

To do justice to the mobilization that had taken place and to catch the public imagination it had to be massive - over 2000 delegates are participating. But it also had to be participatory and allow for sharing a wide variety of experiences and concerns - from village level health workers to senior medical professionals and sociologists. The assembly needs to review work done as well as plan for the future. It had to be educative (what did we learn new is one question participants ask) and as a conference productive (what was the outcome?). And most importantly, the conference had to be designed by consensus amongst the 18 NCC organizations and itself was to become a consensus building process.

## **Beyond the Calcutta & Dhaka Assemblies**

Understanding the PHA process is essential to plan for our future actions. We also need to take stock of what have been the limitations. Was there adequate dialogue between all the 18 organizations or were some not enabled to contribute optimally? Was the quality of the district level processes adequate? Has adequate understanding been built amongst many new sections, which have joined in? Could we have involved more health professionals in this process and so on?

Learning from the experience of working for the PHA process a consensus is emerging around the Post-Dhaka programme. The three essential processes that would go into a successful post Dhaka programme are:

1. An organizational form, which retains this mix of coordination and autonomy and allows for frequent consultation and mutual support.
2. Advocacy for policy changes (immediate as well as long term) based on a set of well defined objectives.
3. A few well-chosen coordinated programmes that would catalyze a wide number of peoples' initiatives, that would extend the outreach of the PHA network and thereby enlarge the forces working for alternatives. If our programmes also help people cope with the health crisis that would lends credibility to our efforts for policy changes.

In the final analysis, we will have to concede that the entire PHA process, massive as it has been, has only helped us to come together and engage with the problem. Unless we are able to sustain these processes for a few more years at least, we cannot hope to make an adequate impact! Placing health care on the political agenda requires far more than a year's campaign!

## **State Activities**

In Kerala, Tamilnadu, Andhra, Karnataka, Maharashtra, Madhya Pradesh, Chattisgarh, Orissa, West Bengal, Assam, Tripura, Bihar, Uttar Pradesh, Himachal, Haryana, Rajasthan, Delhi and Gujarat, the PHA campaign at the state level has been led by a broad based coalition of 15 to 40 NGOs and People's Organizations.

The 5 PHA books have been translated/transcreated by the respective states into Malayalam, Tamil, Telugu, Kannada, Oriya, Bengali and Hindi. 2000-5000 copies of these books have been printed and sold by these states. The Karnataka Directorate of Health Services have asked for the 1 set of English books to be given to all Medical officers in all the PHCs and the a possibility of getting the Kannada books to all the ANMs is being worked out. Maharashtra has prepared a set of 5 books (though not a translation) based on the 5 NCC PHA books. Based on these books, all these 18 states conducted their State Preparatory Workshops. In most of the states, this was followed by the formation of broad based District Coordination Committee in 15-30 districts and then district and block level workshops.

Most of these states have also organized Block, Village and PHC Level Enquiries followed by Block/District Conventions. Apart from these common activities, most states have also independently organized a number of state level campaigns. The highlights of these special activities are given below:

**Kerala:** A series of lecture classes in all the 1000 panchayats (local self government units comprising village clusters) were organized. Arogyakootams - Meetings with activists, people, medical professions and administrators organized at the district and block level. A round of Kalajathas

(moving caravan of cultural activists) covering the entire state has been organized. State convention held on November 15<sup>th</sup>. 124 delegates will travel by Ernakulam Patna Express to the NHA.

**Tamilnadu:** The SCC has 32 State Level Organizations. The campaign covered about 160 blocks in 23 districts. Based on the enquiries and the overall perspectives of the PHA, District Health Charters have been prepared and adopted in several district conventions.

15,000 Dear Doctor Letters were printed and sent to doctors across the state – apart from explaining the PHA process, the letters urge doctors to fight against feticide, commissions system and to follow rational prescription procedures. Five Kala Jatha teams were trained which then covered 23 districts between November 12<sup>th</sup> and 25<sup>th</sup>. Nov 14<sup>th</sup> was celebrated as Girl Child Day (with emphasis on preventing Feticide). 3 posters – on Female Feticide, on Impact of Globalization on Health and on the Commercialization of Health Care – were designed and 2500 copies of each was printed. They were released all over the state on Nov. 14<sup>th</sup>. The State Convention was held on November 26<sup>th</sup> with about 1000 delegates. This was followed by a rally and a public meeting with about 3000 people. A Policy Dialogue has been planned after Dhaka. 160 delegates will travel by Ernakulam Patna Express to the NHA.

**Andhra Pradesh:** 30 posters have been designed and 1000 sets printed. The campaign covers 500 villages in 18 districts. Of these in 12 districts the campaign has been more intensive covering all the mandals. Two districts have organized Kala Jatha programmes. The State Convention was organized on Nov 12<sup>th</sup>. About 140 delegates will travel to the NHA by the Ernakulam Patna Express.

**Karnataka:** The SCC has 19 Organizations. The campaign reached out to about 50 blocks in 15 districts. A preliminary Kala Jatha was organized followed by a training workshop and Kala Jatha programmes in 10 districts. A Policy Dialogue was organized on Nov 11<sup>th</sup>. The State Convention was held at Davangire on the 26<sup>th</sup> and 27<sup>th</sup> of November with about 500 delegates participating. 5 Kalajatha teams performed at the convention. 156 delegates will travel to the NHA on Coromandel Express.

**Maharashtra:** Health Dialogues organized in 50 Talukas. A 15 point criteria was used to evaluate the government health system in 16 districts and in Urban slums in Mumbai and Pune. Nov 1<sup>st</sup> to 14<sup>th</sup> was celebrated as People's Health Fortnight. 6 posters were designed and printed. *Dear Doctor* letters have been sent to doctors asking them not to give injections and saline. In one case, 3000 adivasis put their thumb impressions after the letter was read out and explained. A PHA Jatha was organized in 15 villages in Nashik District. On August 1<sup>st</sup>, a 6 km long *Arogya Dindi* (Health Procession) was taken out in Pune. The State Convention was held on the 18<sup>th</sup> and 19<sup>th</sup> of Nov. 78 tickets have been booked on Ahmedabad-Hohrah Express. Important magazines/weeklies related to various movements have started publishing articles on PHA. Starting August, a series of fortnightly articles in District and Regional Marathi Newspapers have been published.

An interesting experience of the campaign in Maharashtra was a rally on 18<sup>th</sup> September in Kolhapur district. 400 people shouting slogans took out a procession and met the Medical officers and the BDO. They raised a number of issues about malpractices in local Rural Hospital. After a stormy debate, the officials agreed that all doctors in the Rural Hospital would henceforth reside there, be available 8 hours every day besides their weekly 24-hour emergency duty, and that no illegal charging of patients would take place in the future. A proposal for people's monitoring of health services was also accepted - it was agreed that, people would maintain a publicly displayed calendar in some villages with the dates of the ANM/MPW's advance programmes. If the health functionary did not report, s/he would be marked absent by the people and this issue would be raised with the PHC. It was also agreed that a meeting would take place every two months between the health



authorities and the people's representatives. This would form a mechanism for ongoing feedback and 'people's supervision'.

**Gujarat:** Campaign reached out to almost all the districts. The state convention held on the 11<sup>th</sup> and 12<sup>th</sup> of Nov at Baroda with more than 500 people attending. Along with the convention, a policy dialogue was also held. 84 delegates have booked their tickets to the NHA.

**Madhya Pradesh:** Block enquiries completed in about 20-25 blocks. 3 posters have been printed. A Kala Jatha team has been trained and is touring the state. On 23<sup>rd</sup> Nov, a Health dialogue was organized in Badwani. The State convention was organized on 25<sup>th</sup> Nov in Bhopal. 70 delegates will travel by Shipra Express to Calcutta for the NHA.

**Chattisgarh:** The campaign has reached out to 8 districts. A Chattisgarh Health Status Report has been planned. 24 delegates will attend the NHA by the Ahmedabad Howrah Express.

**Orissa:** SCC has 22 organizations. Campaign reach - 125 blocks in 15 districts. District Conventions held in 12 districts. The State Convention and the district conventions in the remaining districts will be held after the NHA. 50,000 posters on the PHA have been published. Lyrics for an Audio Cassette on the PHA has been composed and the recording has been planned. 2 Rallies have been organized in Cuttack and Bhubaneswar and a document outlining case studies and work done by NGOs is being published. Reception to the People's Health Trains is being organized all along the way - at Behrampur, Cuttack, Bhubaneswar, etc. The Local and National Press has been invited for this. A policy dialogue on Disaster Management is being organized. 100 delegates will come to the NHA.

**Tripura:** The SCC has more than 18 organizations. All blocks in all the districts have been covered. The State workshop had 300 people from all the sub-divisions. The Tripura committee also hosted the Indo Bangladesh Kala Jatha which covered all the blocks in Tripura and now has moved to Bangladesh. After 7 days performance in Tripura, the teams moved to Bangladesh. There they are performing for 7 days before finally coming to the International Assembly on 3<sup>rd</sup> Dec. The State convention has been planned for the 26<sup>th</sup> and 27<sup>th</sup> of November. 70 Delegates are coming for the NHA.

**Assam:** 2 state workshops have been held. There are about 15 organizations in the SCC. They have planned intensive programme in 5 districts and in others are holding a meeting. 70 delegates are coming on Kanchenjunga express to the NHA. The planned state convention on Nov 12<sup>th</sup> has been delayed.

**West Bengal:** SCC has 75 organizations! The entire state team has been very active in organizing the NHA and the Public Meeting and Rally. A total of 100 blocks are being covered as part of the campaign. Block and district level enquiries and conventions have been completed. In South Bengal due to floods, this process has been affected. Kalajathas programmes are being held in various districts. The State Convention has not been planned separately – it is possible to organize it along with the NHA. 300 delegates will be attending the NHA.

**Bihar:** SCC has 18 organizations. The programme is on in about 140 blocks in 35 districts. District conventions have been conducted in 20 districts and Block conventions in 100 blocks. In each block 5 villages have been covered. 4 posters have been printed. 12<sup>th</sup> September celebrated as *Health for All-Now!* Day. (On this day in 1978, the Alma Ata Declaration was passed). As part of the

celebrations, 7 districts had seminars and 2 districts organized cycle rallies. A State Level Seminar was also organized on this day, in which prominent doctors and media persons participated. The State convention was held on 19<sup>th</sup> Nov at Patna and a policy dialogue on 18<sup>th</sup> Nov. Kala Jathas and Cycle Rallies have been planned in 9 districts. 190 delegates will come to the NHA.

**Uttar Pradesh:** 22 Districts covered. 6 zonal workshops and block enquiries completed. State convention has been planned for 26<sup>th</sup> and 27<sup>th</sup> Nov. They have booked 50 seats and 100 delegates are coming for the NHA on the Kalka Howrah boarding at Kanpur.

**Delhi:** SCC has about 50 organizations. An intensive signature campaign mobilized people on a set of local demands linked to larger demands of the Health Charter. With each signature, Re. 1 was collected. Six Health Melas were organized on the Health Policy, Population Policy and Reproductive Health, Violence of Women, Food Security, Economic and Health Security, and Child Health. A Phad (Street Drama) team was trained and scripts prepared. A rally was organized on 15<sup>th</sup> Nov in which 1200 people from various bastis participated. The procession was planned as a carnival ending in a public meeting. DD Metro is covering the rally. 67 people have been confirmed for the NHA and 9 for Dhaka. A big send off is being organized at the time of boarding of the train to Calcutta.

**Haryana:** SCC has 9 organizations. State Convention was held on 1<sup>st</sup> Nov. The campaign has covered 9 districts. In 5 districts, workshops and block enquiries in 3-5 villages (large ones) each have been conducted. Special seminars on Health for All organized in 5 districts. Policy Dialogue on Feticide will be held after Dhaka. 56 Delegates for NHA booked.

**Rajasthan:** SCC has 10 Organizations. In 8 districts out of the 14 planned, the district conventions have been held. The State Convention is on the 27<sup>th</sup> Nov. 72 tickets have been booked on the Jodhpur Howrah.

**Himachal Pradesh:** SCC has 11 Organizations. The campaign was organized in 51 blocks in 9 districts. Kalajatha teams covered all the districts. 4 pamphlets on the PHA Process, Continuing Education, Status of Health Services and on the RCH programme were printed. The sale of the PHA books (both English and Hindi) has been very brisk. The state convention is on 26<sup>th</sup> and 27<sup>th</sup> Nov. 72 tickets have been booked on the Kalka Howrah for the NHA.

## **Annex 4. Campaign Examples**

### **Campaigns by JSA (National and/or State level)**

#### **Campaign Example 1: Wielding the 'Right to Health' approach<sup>94</sup>**

Since its formation during the National Health Assembly and People's Health Assembly mobilisations in 2000, the perspective of PHM-India (Jan Swasthya Abhiyan) has been to oppose the weakening of public health systems, to make health systems accountable and effective, to counter commercialization of health care, and to ensure access to health care for all within a broader 'Right to health' framework. Although not always adopting an explicit 'Right to health' terminology, a wide range of activities have been carried out by PHM-India associated groups in various states, towards demanding the right to health care, as well as working for the right to various determinants of health. Here certain major campaign activities carried out by PHM-India and its constituent organisations in a broadly 'Right to health / health care' framework are outlined as an example of how the Right to health approach might be effectively used in a country context.

The stage was set for a Health rights campaign to emerge in India based on stagnation in funding for public health systems and consequent deterioration in public health services from the early 1990s onwards, accompanied by massive unregulated growth of the private medical sector – making even basic health services increasingly inaccessible for common people. A social response to the lack of access to quality health care had been developing through articulation of various health policy critiques in the voluntary sector during the 1980s and 1990s, contributing to the large scale mobilisation and formation of PHM-India (Jan Swasthya Abhiyan) in the year 2000 as a coordinated response to the health sector crisis.

It was on the basis of these preceding efforts that the Indian ***Right to Health Care (RTHC) campaign*** was carried out in 2003-04. The RTHC campaign was an important initial phase of mobilisation, when stagnation and decline of the public health system in India had reached a crisis point, and it was necessary to highlight large scale denial of services. This campaign included documentation of large number of cases of denial of health care, organisation of a national public consultation with presentation of testimonies of denial of health care to the chairperson of the National Human Rights Commission, participatory surveys of rural public health facilities, local 'Jan Sunwais' (public hearings) in some states, regional public hearings in all regions of the country followed by a national public hearing on Health rights, the last two organised in collaboration with the National Human Rights Commission. While this campaign was focused on demanding provision of quality public health services as a right, the PHM-India network has simultaneously been actively involved in the nationwide ***'Right to food campaign'*** since its inception in 2002 (see box), considering food security and nutrition to be key determinants of Health.

In mid-2004, significant political changes began to emerge on the horizon with the impending national elections in India. Prior to the elections, PHM-India organised a national dialogue with various political parties, placing key health policy issues on their agenda and published a policy brief 'Make Health care a Fundamental Right! Subsequently, due to a combination of factors focused on the change of government at the national level, the situation regarding the public health system in India was somewhat modified. A 'National Rural Health Mission' (NRHM) was launched by the Union government in 2005, which has proposed increased public health financing as well as strengthening of rural public health facilities. In this situation, PHM-India's health rights activities entered a new phase, attempting to shape NRHM in a pro-people manner while trying to assess to what extent the proposed improvements were actually being implemented, in form of conducting a ***'People's Rural Health Watch'*** in seven northern states

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<sup>94</sup> A different version of this campaign case study was carried in Global Health watch 3, Zed Books, London, 2011

during 2006-08. This 'watch' was viewed as a way of taking forward the 'Right to Health' process; given the objectives of the NRHM to improve rural health services, PRHW was conceived as an activity to assess whether or not the healthcare infrastructure was being strengthened in a pro-people direction, and to assess whether or not people were getting health services with the introduction and implementation of the Mission. This was done by collecting primary information through two rounds of surveys, as well as looking at relevant policy documents, and preparing state level and national reports based on this information.

In parallel to this, advocacy was carried out by certain PHM-India associated activists to give institutional and regular form to health rights processes within the NRHM framework. Carrying this forward, and based on coordination by the NRHM Advisory Group for Community Action, from 2007 onwards an innovative process of '**Community based monitoring of health services**' (CBM) has been developed; in the pilot phase during mid-2007 to early 2009 this was implemented in 35 districts of 9 states. PHM-India member organisations have anchored this activity in certain states. This activity which continues and in some states has expanded beyond the pilot phase, is built into the public health system framework and is supported by public funds, and involves regular participatory monitoring of health rights by community members and civil society organisations. Although this is a broad, publicly organised and funded activity, groups and individuals associated with PHM-India continue to play a key facilitating role in this process in certain states.

This accountability process is led by networked civil society organisations from block to state levels, with the following key features:

- **Community awareness and activation about health entitlements** has been generated by village meetings, display of health rights posters, expansion and strengthening of Village health committees (VHCs), and training of VHC members.
- **Multi-stakeholder community monitoring committees** have been formed at Primary Health Centre (PHC), Block and District levels including community members, NGO / CBO representatives, elected political representatives and public health staff.
- **VHC and other committee members periodically collect information about health service delivery** using objective semi-quantitative tools, and rate these through publicly displayed **report cards**, each service being rated as 'good', 'partly satisfactory' or 'bad'. This data is collected at both village level (concerning outreach services) and health facility level.
- **Public hearings with mass participation are organised** at PHC, Block and District levels, where report cards and cases of denial of health care are presented, and public health officials need to respond regarding remedial actions.
- **Periodic state level events** enable dialogue between civil society monitoring committee members and the state health department, seeking resolution of critical, unresolved and systemic issues, and help reinforce government support for the CBM process.

As an example of this process, one may consider the western state of Maharashtra where CBM is being implemented in over 500 villages spread over 23 blocks in five districts of the state. A network of fifteen civil society groups including mass organisations, mostly associated with PHM-Maharashtra, have developed this activity to enable people to claim their rights related to rural public health services. Four rounds of data collection and report card preparation at various levels have been organised and over 180 public hearings have been organised so far in the state. Presentation of objective, community based evidence, persistent pressure for improvement through periodic mass public hearings, and systematic follow up of demands from village to state levels have led to a wide range of improvements in public health services within a few years of implementing this approach.

In Maharashtra, three rounds of community based collection of information were organised between mid-2008 and end-2009. Over these one and half years, the *overall proportion of village level health services rated 'good' by communities increased from 48% to 66% while services rated as 'bad' have declined from 25% to 14%*. Community based data showed that overall PHC services rated as 'good' improved from 42% in the first round to 74% in the third round.

This has been accompanied by significant increase in utilisation of PHC services, as people have started shifting from dominant private providers to improved public facilities. In Thane district of Maharashtra, during the period 2007-8 to 2009-10, OPD, inpatient and delivery related utilisation of Primary health centres in CBM areas increased by 34%, 73% and 101% respectively; this was *one and half to twice as high* compared to the average utilisation increases for PHCs in the district as a whole. Corresponding to this, a wide range of qualitative improvements have also been documented: in most CBM areas, attendance by field staff and doctors has increased, illegal charging by providers has been checked, functionality of PHCs and sub-centres has gone up and provider behaviour has improved.

Similar processes of community based accountability have been developed in other states where CBM has been implemented with a strong rights based perspective. In Tamil Nadu, CBM processes have been facilitated in 446 panchayats (village councils) in 6 districts, with two rounds of data collection so far. There has been a strong emphasis on community based health planning, with each plan consisting of commitments made by both local health care providers and the village community. Major effort has been invested to ensure active involvement of the Health system at various levels, to help institutionalise the process. In Rajasthan, CBM was implemented during 2007 to 2010 in 445 villages belonging to 5 districts of the state, where major improvements in rating of village level services were documented during the period of community based monitoring. Overall, the community based monitoring approach has shown definite potential to empower people to demand their health rights, and based on public accountability processes has induced significant improvements in delivery of public health services; however this accountability process needs to be assertively socially promoted to ensure that it continues to be accepted by the public health system, while it retains its critical edge.

To conclude, the journey of health rights-oriented campaigns in India over a decade has moved from broad civil society mobilization and network building (People's health assembly process in 2000) to public highlighting of denial of health rights in collaboration with the national human rights body (Right to health care campaign in 2003-04). Advocacy with political parties on the eve of national elections, demanding that Health care be made a fundamental right (2004) played a role in subsequent reshaping of health policy. With the advent of NRHM as an official initiative to strengthen rural health services, efforts shifted to accountability oriented community based surveys of health rights (People's rural health watch in 2006-08) and further regular community based information collection and accountability processes for health rights developed within the public health system framework (Community based monitoring of health services, 2007 onwards). In India the rights based approach to health has often been used in an implicit rather than explicit form, and it has been wielded in a flexible and evolving manner, contextualized and supported by complementary approaches. Such broader understanding has ensured that health rights have been effectively promoted in the evolving context, as part of a wider socio-political process.

In 2015-16 a fresh process was initiated with the National Human Rights Commission for organizing countrywide public hearings on the denial of the right to health. This time around the intent was to also include the private sector. The NHRC however had reservations about inclusion of the private sector, arguing that their mandate did not extend to the private sector. JSA argued that the private sector needs inclusion while documenting denial of rights especially given outsourcing of tertiary care services to the private sector through public funded health

care delivery mechanisms. However the NHRC agreed only to broad presentations on the role of the private sector in denying health rights and did not wish to examine specific cases.

The program with NHRC was conceived as a nationwide program that would culminate in five regional public hearings. A very successful hearing for the Western region, attended by over a 1,000 people was organized in Mumbai in early 2016. However, for internal reasons, NHRC has not proceeded with the collaboration in other regions of the country.

### **Campaign Example 2: Access to healthcare with JSA**

We have worked on the global campaign on access to health care with JSA since the Savar meeting of PHM in 2000. Subsequent to that, especially at the national level but also at the global level, we resorted to multiple methods and one was the JSA campaign. The other one was the process of engagement with people who are engaged with the system, the National rural Health Mission (NRHM) in particular. That was also to strengthen the health system by bringing health systems reforms. We helped to evolve the integrated health policy in one State. This was through discussion with a lot of academic campaigns in that State and we also held a number of meetings. A lot of papers were translated into the local state language. We put them into some newsletters we have. We also had a series of workshops on primary healthcare. I am talking about 2003-04. Then along with the global campaign for access to health care the process continued through the engagement. Not everything that we tried in terms of strategies worked. We set up something to focus on urban healthcare at the district level. This probably was the first time in the country that there was a district related campaign. All the others were state level units. We had several meeting during 2001 to 2003. But because of involvement in other issues, and the lack of a driving will, it wasn't really taken care of. If you ask me now, I would say that initiative is not active. If you ask what's the need, I would say as a campaign focussed on an urban area there is a huge need but this just died out

### **Campaign Example 3: Opposing Privatisation of Diagnostics**

JSA ran a campaign against privatisation of diagnostic services in public facilities in the central Indian state of Chhattisgarh. The campaign started in 2012 with the publication of a Request for Proposals by the state government to outsource diagnostics in 379 government health centres and hospitals. looked at the proposal in great details and critiques the rational of the proposal itself. had a media outreach strategy, had a press brief and contacted the media. campaign meetings started.

As the state level JSA, we were at the core of the campaign and we worked with health NGOs, grassroots tribal and community organisations working on anti-displacement issues, farmers unions. We also reached out to the government health workers unions. Initially the health workers did not believe that this could be happening but then they understood that it was going to affect them. They started asking in their departments and then realised what was going on. They then started talking to the press too. JSA had a meeting and called all these various organisations. The campaign was organised by districts, each took district responsibilities to go meet with the collector and raise the issues. Out of 26 districts, around 16 were covered. We also met the Governor.

A lot of the gaps we identified were addressed in a new draft which was published in 13 January 2013. But the process still went forward and the next stage of campaigning was necessary. So a decision was made to bring it to the national level. We brought it to the national press. At the same time, it was important to broaden the knowledge based and pamphlets were prepared in local languages so that the vernacular media could also carry the information. A State level large event was organised, with a dharna (rally) and a press conference. This was extensively covered by the local press and the national press. JSA colleagues nationally were also contacted and

asked to write editorials, in journals, etc. At the same period, the NRHM team had gone to Bihar and criticised a similar system.

Despite this the government did not budge. In March and April, a signature campaign was carried out in order to get endorsements from the public to stop the privatisation of lab services. We also had sit-ins in public places. We went to smaller towns, to the facilities as well. The doctors did not know what was happening and collecting signatures also allowed us to raise awareness among health workers.

In the meantime the bidding process and these were only in urban areas and not in remote areas. But the government discourse was that it was to allow better facilities in remote areas as the urban areas did not need additional resources. The government changed the bidding requirements making it compulsory to bid for remote areas if an entity was bidding for urban areas. This was widely published in press, through JSA networks as well. JSA organisations are active in rural areas. We felt that it was important to reach out to urban middle classes too, as they are important to influence policy making. We also used the list of hospitals that were going to be privatised. We decided to build evidence on the status of labs in facilities that were going to be outsourced. We had an existing network with the staff of one government programme and through this we made a survey of the status of the labs.

We also held a silent march in the city using a cloth with signatures to put pressure to government to take action on the demands. We made it visually attractive and it was extensively covered by the media. The final nail in the coffin was the rejection of the proposal of the State government to the national programme. Although the state government could have done this without central funding, this effectively stalled the proposal.

#### **Campaigns Example 4: Environmental Issues (JSA Karnataka)**

We have been quite active on environmental issues. We have realized the need for environment protection long time back. Starting with the Bhopal disaster, which was actually an industrial disaster. It led us to whole lot of other issues such as problems of pesticide use, etc. Some of our team member are doing full time work on environmental issues much before the present climate change debate started. After the Bhopal disaster, we got involved with something called Harihar Polyfiber. We worked on pesticide usage issue, then the issue of radioactive sands in Kerala, we supported that also this is from the 80's. At the world social forum and all the JSA meetings, in Mumbai when we were organizing it, we had workshops on environmental issues. It has adverse effects on everybody's health and our position in this is to hold the larger corporations accountable. We have had court cases filed against us. When we were involved with a pesticide related campaign, there was a report called the '*Killing Fields of Warangal*'. It was an investigative study by a then team member of ours. The pesticide companies-they have an alliance-actually took us to court. They also sent their representatives to meet our team members when the rest of us had gone for fact finding related to the Endosulphan issue in Kerala. They put a fair amount of pressure on us but we just ignored it. Our executive committee was very supportive on this as well as the legal aid organisations we reached out to for assistance. Even now, these companies visit us around three times a year.

#### **Campaigns by Broad Platforms, including by non-JSA formations**

##### **Campaign Example 5: Right to Food**

The first set of major issues that were raised through the Right to Food campaign were around universalisation of school mid-day-meal and ICDS, based on the orders of the Supreme Court. Up

to 2008 the main focus of the campaign was on entitlement based schemes i.e. implementation of SC orders on the ground, making guidelines, doing policy advocacy, mobilisation for budgets for the scheme etc. Post that other issues became quite prominent, for instance access to resources and livelihood and how these are related to the right to food because many constituents were working on these issues. That was also the time when Singur Nandigram became prominent and questions of resources and livelihoods were being raised. In 2009 when UPA II came to power, they proposed passing of a bill on the right to food. Post 2009 a greater focus on issues related to livelihoods and agriculture, though there were critiques that we are unable to do enough on that.

The campaign came in to being based on the initial orders of a Supreme Court case which led to a landmark judgment on universalisation of school meals in 2001. The orders were not being implemented on the ground even though these were SC orders. Many organisations were working towards getting these schemes implemented on the ground. So the initial focus of the campaign was to ensure the implementation school mid-day meal and the ICDS. Although there were orders related to the Public Distribution System and Pensions, these were not being universalized. In 2004 school mid day meals were universalized. ICDS universalization took till 2008.

The World Social Forum 2004 in Mumbai and the Asian social forum were instrumental in bringing lots of civil society people together. In both of these there were sessions related to food. It was realized that lots of people/organisations had interest in issues related to food who could come together on this issue while working on their respective constituencies. Before that there was an informal support group who were involved in the case and organizing the work related to the case and informing others about the developments, but WSF brought together the other networks in to the campaign.

In the first National Convention in Bhopal in 2004, the first steering committee was formed. the idea was that the steering committee would have one or two members from 14 national networks plus members of original support group. The secretariat was then set up. Over time two kinds of memberships evolved within the Steering Committee - the national networks and people from states. Strategies were often opportunistic based on the what is appropriate for a situation and the issue- what issues could be fought at the ground, where we need judicial intervention etc or both level. For instance using SC, can be seen as a strategy. Advocacy on various themes with Government, Parliamentarians, Planning Commission etc. was taken up based on the opportunities where you are able to find a space and what works at that moment. There was a constant focus on doing mass mobilization, even if advocacy happening simultaneously, with varying success.

The issues have changed depending on the context. The Food Security Act was part of the charter but not something that came from campaign. It was the government proposing it and making it an issue that meant that we had to engage with it. Through this process, there was a two yearlong churning that happened within the campaign on what is food security, what are the issues that have to be taken up. Had it not been part of their Manifesto of parties, at that point our campaign wouldn't have taken it up.

Since the issue of maternity entitlement coming through the discussion on childhood malnutrition is picking up, lots of women's groups are joining our campaign. We have always consciously felt that the women's groups and Trade Unions are the main constituencies that need to be linked of the campaign. Similarly when we take up agricultural issues, we have to reach farmers' group and ally with them more. With this there have been successes and failures on how much we have been able to build the coalition. But the issue itself determines which alliances to be build. Since the campaign in itself is in the form of coalition, the issue of forging coalitions outside doesn't occur. For instance, the work on malnutrition stayed within the



campaign even though it was not just our campaign involved. We saw a meaning in being located within the larger group and co-location of food and health and making the links while talking about child nutrition. The issue of tea garden workers in West Bengal is another one. In West Bengal the group that was active within our campaign was a trade union. They managed to build the coalition between independent trade unions and our campaign. We do see the state government responding, recognizing that there are issues of hunger and malnutrition related to the closure of tea gardens and those worker's entitlements. At other times, our campaign has supported but not led campaigns like the one on genetically modified food we worked on mobilisation or the one related to trade issues, we worked with groups who took the lead on that.

In terms of actual policies and programs, if we take the long term view a lot has changed. We didn't have cooked meals, we started with 6lakh Anganwadi Centres, we have 14 lakh now; we had people within government not accepting malnutrition as an issue. We don't claim all that is because of our campaign but in making malnutrition an issue, keeping it alive in media and public discourse, not letting the view that malnutrition no more exists dominate, and bringing forth everything that needs to be done and developing an alternative perspective that it's not about a single medical intervention or a product but a holistic intervention that is required. If there were no campaign, things like 'plumpy nut' would have been implemented much faster. Given the strong lobbies behind these, sometimes it feels like a losing battle, but we have definitely resisted speedy implementation. If the campaign had not taken up the issue of targeting PDS and not got a stay from the SC on the 36%, and not asked for a review of the whole identification issue, things would have been worse. Now the official poverty line is around 22%, the PDS would have been closed. State level political factors played some role along with a small role for our campaign for continuously putting out resistance.

### **Campaign Example 6: Campaign against Long-acting Hormonal Contraceptives**

India has historically been pushing for population control/stabilisation and hence targeting women towards controlling their fertility. The Indian government has long been trying to introduce long acting, invasive, hazardous hormonal contraceptives, such as the injectables (Net-en and Depo-Provera) and sub-dermal implants (Norplant) that are likely to cause irreversible damage to women's and their progeny's health. The serious side effects of Net-en and Depo-Provera are well documented, which include "menstrual disorders, cessation of the monthly cycle or irregular bleeding, general weakness, migraine headaches, and severe abdominal cramps. Depo can also lead to cancer of the breast and uterus, weight loss, loss of libido, heavy and prolonged menstrual bleedings and at times complete amenorrhoea. Moreover, studies have shown that injectable contraceptives like Depo-Provera can also lead to osteoporosis." This is bound to have further more serious implications for the health of poor women who suffer from low bone density due to poor nutritional status.

Women's groups, health groups and human rights groups throughout the country have been carrying out a campaign to oppose the introduction of these injectables and implants given the potential for abuse, non-completion of mandatory trials and the lack of accountability of pharmaceutical agencies. In the mid seventies, the Indian Council of Medical Research (ICMR) was conducting clinical trials of these injectable contraceptives. In 1975, ICMR discontinued the Depo-Provera trials, but the drug itself was not banned. There was no licensing policy and hence the drug could not be imported from other countries. A renowned gynaecologist and former Chairperson of Indian Association of fertility and sterility, filed a case against the Drug Controller of India and the Union of India for being refused a license to import the drug, which was opposed by a women's organisation and a health network. They argued that the use of the drug in India's Family Planning Programme could be disastrous for women's health. Following this, importing the drug or using it on women was prohibited.

ICMR initiated the Phase IV (Programme Introduction) trial in 1983-84, in both urban and rural centres to with a view to introduce injectable contraceptives in the National Family Welfare Programme. A rural health centre in Patancheru, a village close to Hyderabad in Andhra Pradesh, was one of the centers where this study was conducted. In April 1985, some members of a women's group in Hyderabad, learnt of Net-en trials taking place in Patancheru. Women from the poorest class were recruited for the trials. They were not informed of either its side effects or contraindications. When the group intervened and explained the side effects and long-term implications of the drug to the women, only 5 out of 50 women remained for the trials. Subsequently, women's groups filed a writ petition in the Supreme Court against the Union of India, ICMR, Drug Controller of India (DCI) and others, asking for a stay order on the Net-En clinical trials in India. However, the government's admission at the close of the case in 2000, that mass use of Depo-Provera in the FP programme was not advisable, was a clear indication that there were potential risks associated with the injectable and that there was a need for closer monitoring and follow up.

Following the public attention on unethical trials in Patancheru, Depo-Provera was placed at the backstage while clinical trials on Norplant, a hormonal implant, was set in motion. A brief study of the women who have undergone Norplant trials in Baroda, conducted by the Forum for Women's Health, revealed the unethical and unscientific way the trials were conducted. The issue of informed consent, checking women for contraindications, follow up care and counselling was completely ignored. Women's groups in Delhi, Mumbai and other cities protested against the introduction of Norplant. All these groups took an active role in the campaign and met regularly to discuss strategies of the campaign, compile information on these contraceptive methods and send information to other groups to involve them in the campaign. They submitted a memorandum to the Health Minister demanding the exclusion of Norplant from the National Family Welfare Programme.

They also made a joint representation to the Ministry of Health concerning their opposition to the government's plan to introduce injectables and implants. At this juncture, women's groups realized that the contentious issue of hormonal contraceptives need to be addressed comprehensively, as USFDA finally approved the use of Depo as a contraceptive method in 1992 after repeated requests by the manufacturing company Upjohn, and the DCGI approved its use by private practitioners in 1993 in India. Subsequently the Indian Government had also planned to approve the entry of Depo-Provera in the Family Welfare Programme without conducting the mandatory Phase 3 trials. Upjohn, the American multinational company, thus gained access to one of the largest markets for contraceptives without following the mandatory requirements.

Women's groups, health groups and human rights groups throughout the country opposed the introduction of this injectable given the potential for abuse, non-completion of mandatory trials and the lack of accountability of pharmaceutical agencies. Conclusion from analysis of major studies from all over the world have compelled a call for a complete ban on injectable contraceptives, and particularly its introduction in the public (National Family Welfare Programme) sphere, because of the health hazards it poses. They also strongly protested against the government's approval of a Post Marketing Surveillance to be carried out simultaneously by the pharmaceutical company Upjohn.

In 1994, a women's group and a group working on HIV and other individuals filed a case in the Supreme Court against Depo-Provera, asking to include it in the list of banned drugs. In the course of preparing the petition, substantial data and medical research work was studied with help from doctors who were supportive of the campaign. After much lobbying and pressure from women's and health groups, the Drug Technical Advisory Board (DTAB), on the direction of the Supreme Court, passed a recommendation stating that Depo-Provera is not recommended for inclusion in the Family Welfare Programme.

Right from the experience in Patancheru in Andhra Pradesh in 1985, women's groups have monitored the violations of 'informed consent' while administering contraceptives during clinical trials and research. "Unveiled Reality – A Study on Women's Experiences with Depo-Provera, an injectable contraceptive" conducted by us revealed that women in Delhi were administered injectable contraceptives in a public hospital without informed consent. Vital information regarding the safety and adverse effects of the contraceptive were withheld from women, thereby depriving them of the right to make an informed choice.

In 2004, in a series of public hearings on the Right to Health initiated jointly by the National Human Rights Commission (NHRC) and Jan Swasthya Abhiyan (JSA), testimonies of women's experiences with Depo-Provera were collected and presented by Sama before the NHRC and health officials from different states. The NHRC panel was surprised that a public health establishment was administering Depo-Provera and subsequently has demanded an explanation from the officials for the same.

In 2004, we along with other groups strongly opposed initiatives to "expand choices of contraception" by the introduction of injectables organised by a National level NGO in collaboration with Government of India, UNFPA and Packard Foundation through Population Foundation of India. Many health and women's groups across the country submitted a Memorandum to the Health Minister against this move. In 2007-08 the MOHFW once again began initiating processes for introduction of Net En and Cycloprovera in the public health system. But women's and health groups met with key authorities which eventually resulted in their non-introduction. However, even as recently as 2015-16, news reports stated that the government was planning to introduce injectable contraceptive, Depo Provera in the public health system.

Multiple strategies were used in the campaigns ranging from street action, protests, research, fact finding, legal action, policy advocacy, public hearings about the violations that had ensued, endorsed letters and memorandums, press conferences, etc. The campaigns were able to ensure that the introduction of hazardous contraceptives were not introduced in the public health system and for a long time were also not available in the private sector. The campaigns flagged substantive opposition to the popular perspectives of population control by targeting women, particularly marginalised women for use of long acting, hazardous contraceptives.

The campaign and movement faced several predicaments. Questions about whether to go for a blanket rejection of all hormonal contraceptives or only those, which do not grant user control to women were raised. The concern was also regarding provision of safe and effective contraceptives to those demanding contraceptives. Contraceptives like injectables and implants are perceived by some as the only way poor and powerless women can have control over their lives (the contraceptive is an injectable, so neither husbands nor in laws would come to know of the contraceptive method and they can escape pregnancy). The widespread availability of Depo can dilute efforts to challenge the basic social and economic conditions that produce women's powerlessness. Moreover, the drug's side effects can never justify its use. The current global health context is also pushed / influenced by big pharma, big philanthropy which are pushing for long acting contraceptives in countries such as India. Global discourse such as FP 2020, the SDGs etc. are once again referring to "basket of choices" of contraception, regardless of the side effects that Depo has been known to have. The women's and health movements continue to be extremely polarised on the issue.

### **Campaign Example 7: Patent Oppositions**

India, as the 'pharmacy to the developing world' for its ability to produce and export life-saving affordable generic medicines, is a key country of focus for many of the treatment access activities. Safeguarding and strengthening policies that protect India's production and export of

generic medicines, whether campaigning against unwarranted patents or harmful provisions in trade agreements, is vital in ensuring that in developing countries across the world continue to have access to affordable generic medicines. India being the pharmacy of the world provides as much as 80% of the lifesaving HIV related anti retro viral supplied globally and without these life-saving, affordable medicines, it would have been impossible to scale up treatment to the levels seen today.

In 2005 when India's patent law was amended, key provisions allowing public interest groups to file patent oppositions and grounds like Section 3(d) which prohibits ever greening were included in the law. Having campaigned for the inclusion of TRIPS flexibilities in the Indian law, we then took it upon ourselves to also make full use of these flexibilities. We have filed successful patent oppositions for Tenofovir (TD), Tenofovir Disoproxil Fumarate (TDF), Lopinavir, Lopinavir/Ritonavir (soft gel), Ritonavir, Efavirenz and Valganciclovir. The success of these patent oppositions means that generic competition in these drugs can continue. Details are as follows:

#### Patent Oppositions filed

Sl No.	Drug	Application / Patent No.	Application Status
1)	Valganciclovir	Patent Number: 207232	Pending
2)	Fosamprenavir	Patent Number - 240930	Pending
3)	Abacavir Hemisulphate	Patent Number - 212734	Pending
4)	Ritonavir	IN/PCT/2001/00018/MUM	Patent Application Rejected
5)	Lopinavir	IN/PCT/2002/1243/MUM	Patent Application Rejected
6)	Tenofovir Disoproxil	2076/DEL/1997	Patent Application Rejected
7)	Tenofovir Fumarate	896/DEL/2002	Pending
8)	Tenofovir Disoproxil Fumarate	2256/DEL/2009	Patent application pending
9)	Tenofovir Disoproxil Fumarate	1135/DEL/2007	Patent Application Rejected
10)	Raltegravir	4187/DELNP/2007	Pending
11)	Efavirenz (Patent Number: 195367	IN/PCT/2000/553/MUM	Post grant opposition rejected

We have also recently filed a pre-grant opposition to the sofosbuvir patent application in India. Hepatitis C is a significant public health issue for low- and middle-income countries, which are home to 90% of the 185 million people infected worldwide. The disease is curable, but high drug prices make treatment inaccessible, leaving people at risk for liver cancer or liver failure. We filed an opposition to pharmaceutical transnational Gilead's patent application on Sofosbuvir, a crucial Hepatitis C antiviral a crucial medicine for Hepatitis C for lack of novelty, inventive step and efficacy. We used multiple strategies as part of the legal challenges including media outreach and rallies. For example, following the opposition filed in Delhi patent office, we also held a demonstration in front of the office of Union Ministry of Health and Family Welfare, demanding that the government should ensure that oral drugs to treat Hepatitis C are made available to patients.

#### **Campaign Example 8: EU-India FTA**

EU-India FTA negotiations began in 2007. We have been campaigning against the demands of the EU in these FTA negotiations as they go far beyond what is required by the TRIPS Agreement and will undermine the TRIPS flexibilities in the Indian law. In 2009 and 2010 even in the face of police crackdowns, we demonstrated in front of the Commerce Ministry in Delhi. As a result the Commerce Ministry and Health Ministry started consulting us and other civil society groups on the text being proposed by the EU. In collaboration with legal experts we submitted an analysis of the EU text and submitted to the Indian government.

It is easier to mobilize and motivate people when they are educated and trained on the issue that touches them and their loved ones. Since most of the issues are technical and many new peers comes in everyday, there is a constant need to educate, train and refresh the people about the implications of Bilateral trade agreements, EU India FTA, patents, etc. There is a need for an ongoing treatment literacy campaign which will allow people to understand these issues and how they relate to the treatment people are taking every day. We do this through our outreach workers on a daily basis in the DIC (drop-in-center) and hospitals and we are creating a mass of people who understands at least the basics of EU India FTA, what it entails, its implications, what is a patent, how it can create a monopoly and other issues.

We also spread information and awareness through our monthly community meeting. In each monthly meeting we expect 30-40 participants. The monthly community mobilization meeting serves as the back bone of all our activities since our inception. The meetings serve as a platform to interact with members of our community to help share information related with treatment & access to treatment. The participants gain knowledge on their treatment and related issues from the meetings. At these monthly meetings issues related to IP, teaching basics of patents, impact of trade agreements, update on trade negotiations in the country, update on legal cases on patents, update on activities by regional and international partners is also provided. We believe integrating the IP discourse into the understanding of treatment is the only sustainable way to build community capacity to understand and advocate on these issues. Thereafter they disseminate to their peers in their respective locality and become treatment educators and advocates of issues related with HIV treatment. This helps in an increased knowledge level of the PLHIV on all issues related with treatment of HIV and AIDS and also sense of belongingness, oneness and brotherhood. Our staff and Outreach workers have been using these meetings as a source of motivating people, mobilizing more people for advocacy on IP barriers and FTAs.

### **Community Mobilization since 2010 against India-EU FTA**

Year 2010: In 2010 we organized a peaceful rally for the fourth time in the year during which some of our members were beaten and charged with batons by the local police and were also arrested but later on release without any charges. The police brutality was quite evident from the recorded video clipping of this rally. The news of the police brutality and arrest of our members were flashed and highlighted in all the leading e-listserves, which angered, encouraged and motivated many activist around the world, who are working on issues related to access to treatment.

Year 2011: We organized 3000+ people living with HIV and health activist from across India and a representative from Cambodia, Indonesia, Thailand and Nepal had peacefully rally/march from Ramilila Maidan to Jantar Mantar, Delhi, India on the 2<sup>nd</sup> March, 2011 in protest against EU-India FTA. Right after the rally, there was a Press Conference at Foreign Correspondents Club, with our allies including the former UN Health Rapporteur, a representative from a cancer group and representatives from other countries who came for the rally. The next day along with activists from Asia we met with various Indian official and UN to raise the community concern on harmful provision included in EU-India FTA.

Year 2012: Representatives from our government were meeting the EC at the EU- India Summit starting on 10 February 2012. It was expected that key decisions on the shape of the agreement would be taken at this Summit. We had raised concerns about several provisions within the draft agreement that would have serious negative implications for access to medicines and public health. As the negotiations progressed, certain damaging provisions have been removed - patent term extensions, for example. However the enforcement and investment provisions within the draft agreement are still a matter for serious concern as, unchanged, they will have significant negative implications for access to affordable medicines in India and throughout the developing world

As the EU-India Summit kicked off in Delhi, we delivered black coffins to the office of the Delegation of the EU at the swish Golf Links Enclave and the EU official was asked to sign the receipt for their delivery. The motive was to highlight the deaths of people living with HIV/AIDS across regions who are reliant on production of Indian generic pharmaceutical that will be trammled due to India-EU FTA. After that over 2000 people living with HVI who we mobilised along with other networks across the country, marched alongside farmers in protest of the EU-India FTA.

We have also regularly conducted trainings on FTAs, Intellectual Property Rights in 2010, 2011, 2012 and 2013. The training provides a platform for participants on ways and opportunities of advocacy related to bilateral trade agreements. The workshops are designed for the community leaders and activists.