

Civil Society Engagement in Health Research

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22nd October 2008

1. Introduction

The Community Health Cell which a group of us initiated in 1984 and where I was based for 25 years, started with the premise of building and strengthening a community health movement in India working a lot with NGOs and field groups. The founding group earlier held faculty positions in the department of Community Health in a leading medical college in South India. Over the years working linkages were built with a number of NGO's, federations and networks. Over the years as our understanding of underlying health determinants deepened we became actively involved in the evolving Peoples' Health Movement where the engagement both with social movements and with the state increased. Since 2006 we are also trying to foster a Public Health Movement in public health education. In 2008 on the occasion of the silver jubilee of CHC, the Centre for Public Health and Equity was established by SOCHARA to take forward the health policy and research work, along with continued support to earlier work in an advisory capacity.

With our academic background, since the 1980s in our new civil society base we continued teaching research and practice of Community Health but with a clear focus on contributing consciously to social change processes. Some of the studies that we were involved with include:

- As conveners of the Medico Friend Circle we supported community based studies after the Bhopal industrial disaster taking the findings back to people.
- A study of the social relevance and community orientation of undergraduate medical education using multiple methods was conducted and followed up with the State Health University, government and some educational institutions over the years.
- We undertook the golden jubilee evaluation of one of the large voluntary sector health networks with 2500 health institutions spread across India. As part of the Policy Delphi study of future trends was done in 1991-92. A questionnaire and field visits to a 2020 sample of 400 institutions were done by trained investigators. Follow up discussion meeting were held with 13 sub-groups among the membership and with regional groupings. The Association changed its name and Constitution with a greater focus on community based work.
- A health policy analysis of policy process and implementation factors was undertaken as a doctoral study using the National TB program as a case study. This fed into our subsequent work with state governments in Karnataka, Orissa, Madhya Pradesh, and Chhattisgarh and with the federal government through the

National Rural Health Mission which was launched in 2005. This also led to a twin pronged approach of strengthening the PHM and engaging with the WHO.

- We have supported environmental health studies through a loose network that emerged around 2001. Team members continue to work in this area.
- Other international studies that we collaborated with included a study by WEMOS in the Netherlands on global public private initiatives in health. Currently we are the Asian hub for a study on “Revitalizing Health for All – Learning from Comprehensive Primary Health Care”. This study is funded by the Teasdale Corti project with the co-principle applicants being in the Universities of Ottawa and the Western Cape. It has a strong PHM presence of persons from the PHM Research Circle.

All the studies were done based in the non-state civil society sector which offered a lot of freedom. Links have always been maintained with government, academic institutions, NGOs and a number of individuals. What we consciously did not get into was publishing in mainstream journals by and large (though there have been some publications). We published reports for circulation locally where decisions and action were required. We have also introduced local language publications.

As mentioned earlier as an understanding of the underlying determinants of health and determinants of inequalities in health deepened we become actively involved in the first, People’s Health Assembly in Savar, Bangladesh, as an alternative to the World Health Assembly which was open only to state representation. The first PHA had around 1400 participants from 75 countries and adopted the Peoples’ Health Charter (see www.phmovement.org). The Charter has spontaneously translated into around 50 languages including Braille and is also taught in some postgraduate public health schools. We subsequently were deeply involved in the People’s Health Movement globally, nationally and at state level, hosting the global PHM secretariat from 2003-2006.

Within India we are currently involved in a large scale pilot testing of community monitoring of the health system with a network of organizations with active support and institutional legitimacy and mechanism provided by the National Rural Health Mission of the Ministry of Health, Government of India, from 1999-2002 through the task force on health and family welfare setup by the commissioned stretches which helped shape our recommendations.

2. Enablers and barriers to civil society engagement in health research.

- Visionary, progressive, leadership in the civil service and the political establishment (which in our case in India is a democratic system) has provided very valuable policy space for health research by civil society and its follow up. When there is mutual trust and respect and time and effort are made on both sides a positive synergy has developed. This enabling environment can be consciously built by groups who have an equity oriented, inclusive approach.
- However the sustainability of these arrangements can be fragile and short term. Lobbies, and competing interests are always present. In environmental health research this has led to court cases, setting up of counter expertise and other

attempts to influence the policy process. However all of this is positive as it leads to a larger public debate.

- If researchers see themselves only in their professional capacities as knowledge producers then the studies get limited to publications, bookshelves and do not influence policy and political processes. Skills within the research teams or organizations for participatory, inter-disciplinary work, communication and engagement are required,
- An evolving system of engaged researcher's interacting and working with policy makers, practitioners and civil society changes the knowledge production and utilization process. Information and communication technology when coupled with oral group communication at community level has been very much more positive in bringing about change in knowledge, attitudes and practice.
- Status quo factors which sometimes include professional associations, research councils particularly from a biomedical background, and other procedures that may be bureaucratic are often barriers to the progress of engagement. Different strategies have been attempted to overcome this and the pathways of change could in themselves be an area of study.
- Funding institutions and mechanisms can play a significant role in broadening the focus of health research to research for health, development and equity.
- National health research policies could provide a framework through which institutional strengthening for research for health could occur in a manner that can include civil society actors.
- Development of institutional capacity and human resources in research for health need to be prioritized with a time frame. This effort should be focused both on the public sector and civil society- developing strong public-public partnerships.
- Privatization of health /medical research with a strong focus on clinical trails is draining trained human resources with research capacity. Attractive salary packages, perks and working conditions and the absence of a social perspective is resulting in a significant imbalance.
- Social –cultural and economic factors privilege status and a life style whereby the brightest and best are drawn into international bodies and business/industry in health research. An internal and external brain drain among researchers is more active and present than that among health practitioners where the brain drain from lower income countries and populations is also significant. The focus of health research also gets skewed.
- Peer pressure and aspirations play an important role in career choices by young researchers.
- The provision of funds, mechanisms for professional support and legitimacy as well as institutional mechanisms to strengthen capacity and ability for sustained work by civil society based researcher will bring in fresh perspectives from community based work.
- While qualitative research, inter-disciplinary and trans-disciplinary research, participatory action research and ethical issues in research are gaining ground – they are still relatively marginal. This needs to be reversed and balanced by pro-active policy measures. Involving civil society research into the research main

stream and the policy discourse also needs to be legitimized and mainstreamed while maintaining autonomy and creativity.

3. Message for Bamako.

a) Decisions and strategies should be encouraged by global and national policy making bodies to recognize, legitimize and establish concrete mechanism to involve civil society research /researchers to participate in research and policy process.

b) Developing institutional capacity to manage research and to strengthen human resources for research for health, development and equity in civil society should be given greater priority with earmarked funding.

These steps would help to further enhance both understanding and action to address the underlying determinants of health and the determinants of health inequality in our inter-connected world.