

## NATIONAL CONFERENCE ON HEALTH INEQUITIES IN INDIA: TRANSFORMATIVE RESEARCH FOR ACTION



January 8-11, 2018

Achutha Menon Centre for Health Science Studies,  
Sree Chitra Tirunal Institute for Medical Sciences and Technology,  
Trivandrum, Kerala

## Background and objectives

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'The National Conference on Health Inequities in India: Transformative Research for Action' (AMCCON 2018) took place from 8<sup>th</sup> to 11<sup>th</sup> January 2018. The conference was the 2018 edition of the annual public health conference series hosted by Achutha Menon Centre for Health Science Studies, Trivandrum, Kerala, India.

AMCCON 2018 conference aimed at

1. Disseminating the findings of a 3-year research project on titled, 'Closing the gap: health equity research initiative in India,' undertaken by Achutha Menon Centre for Health Science Studies
2. Finalizing the agenda for health equity research that has evolved over the duration of the project
3. Creating a platform for researchers, academicians and policy makers to effectively engage with each other on issues related to health inequity
4. Identifying key research areas and priority questions, for health inequity research in India and serve as a platform for discussion on transformational research that can contribute towards effectively addressing the persistent health inequities in India

The conference was attended by about 175 participants, of which more than a hundred were students. There were six plenary sessions, one panel discussions explicitly focusing on Kerala and one non-paper presentation session. A wide range of issues around health inequity was covered in these sessions, including:

- Structural drivers of health inequities
- Health issues and challenges of 'socially constructed' vulnerable groups
- Studies on the health of Adivasis and tribal communities from different parts of India
- Policy interventions for health equity
- Role of social movements and civil society organizations in addressing health inequity

Apart from these, 12 parallel sessions were conducted on different themes as well. These presentations were organized mainly for AMCHS students and young public health researchers to showcase their work. Students got an opportunity to share their work with senior professionals in the field and get their feedback regarding their study methodology and future directions. On day three, a small group of researchers and academicians had a closed-door discussion on the future agenda of health equity research in India, and to identify the priority topics for future research. The research agenda was shared with the broader audience during the concluding session of AMCCON- 18 on 11 January 2018.

The present report summarises the proceedings of the plenary sessions. Abstracts of papers presented in the parallel sessions are available online at [https://drive.google.com/open?id=1\\_pokRJ5Uph0g5sW2Hf64VCtXraCqgvY](https://drive.google.com/open?id=1_pokRJ5Uph0g5sW2Hf64VCtXraCqgvY)

## Inaugural session

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### Welcome address

Dr. Sundari Ravindran, Professor, Achutha Menon Centre for Health Science Studies welcomed all the delegates and briefly explained the background and objectives of the conference. This conference is held at a time when the world is marked by levels of economic inequalities unprecedented in more than a century. One of the most adverse consequences of such inequalities is health inequities, which result in avoidable deaths and disability and affect both the present and future generations.

This conference is organized as part of a four-year initiative, titled 'Closing the gap- health equity research initiative in India', led by AMCHSS, since 2014. Numerous activities were conducted as part of this research, including the creation of synthesis of evidence, conducting capacity building workshops and webinars, creating a web portal, and identifying priority issues for future research.

During the three days of the Conference, participants were to be exposed to some of the key health equity challenges, and to the efforts to address these challenges in different contexts. The conference aimed to contribute to the evidence on health inequity in India, help in forming new alliances, identifying research priorities, and put health equity on the research and policy agenda. The field of transformative research will bring in a paradigm shift in health equity research and pave the way for a change.

### Inaugural address

Mr. Vijayanand, former Chief Secretary, Government of Kerala gave the inaugural address. We live in the most unequal and iniquitous period in human history. He stated that poverty and inequality are empirical concepts. Equity, however, is a moral concept, linked to the concept of social justice. The 73<sup>rd</sup> and 74<sup>th</sup> amendments to the Indian Constitution reflect it. The Indian Constitution has taken into consideration the historical inequities about certain disadvantaged sections of the society, particularly Scheduled Castes and Scheduled Tribes. Now there is a need to add gender, people with disabilities and other marginalized groups to the list of disadvantaged.

Health inequity represents gaps in health that are unfair and unjust and are remediable and avoidable. Efforts to ensure equity in health have not been successful. The conventional method has been top-down, focusing on infrastructure, human resources, medicines and

other facilities. However, there is a need to understand and address the social determinants of health, such as the issues of water, sanitation, nutrition, skill, livelihood, and housing.

There is a need for participatory planning for health, which is multi-level, polycentric and deconstructs the concept of health at the community level. A recent study showed that significant inequities still exist in Kerala, especially with respect to the tribal population. He pointed out that the voice and choice of these communities have been suppressed. The process of 'othering' by health workers and other staff, and the trust deficit, among others, have contributed to poor health outcomes. Other factors include the advent of modern medicine ignoring traditional medicine and new forest regulations. All these interrelated factors need to be addressed to attain health equity.

The way forward to address health inequity among the tribal population in Kerala are:

- Build social capital
- Organise self-help groups
- Engaging the community continuously
- Health literacy to enable informed choice
- Participatory health analysis
- Focus on sustainable development goals

There is a need to go beyond conventional quantitative research to understand health inequities and their determinants. Anthropological studies and participatory qualitative studies would be more relevant. Active and effective dissemination of research conducted about community health has to be widely disseminated using formal as well as informal communication methods. We need to achieve equity as it is an intrinsic human right and a foundational value. Inclusion and social justice should be the hallmark of development.

### **Presidential address**

Professor V. Raman Kutty, Head of the Department, Achutha Menon Centre for Health Science Studies delivered the Presidential address.

Health inequity has attracted global attention of academicians, policy makers, and activists for a long time. While the field of biomedicine has seen unprecedented advances in the last 40-50 years and has brought about great benefits to humankind in general, such as increased life expectancy and improved quality of life, it has left behind great numbers of people who lack access to resources to be healthy, and access to healthcare. There is a need to look beyond the technology and biology to causes that are deeply embedded in our society, national and international factors. Differences in access, cost of healthcare, quality of care and health outcomes cut across many axes. Most of these differences can be attributed to gender, socioeconomic class, urban-rural difference, and caste. A study conducted at AMCHSS found stark gender differences in access and practice of diabetic care

in Kerala. Women were found to have poor process indicators and outcome indicators for diabetes. Another study from the Centre found that migration to another country leads to unhealthy lifestyle and contribute to early onset diabetes. The current study on equity has found significant issues concerning tribal health.

Equity is a real challenge faced by the country and documenting inequity is the first step in addressing them. However, it is the policy makers who tweak the policy to address inequity and hoped that this conference would facilitate exchanges between researchers and policy makers. He urged the students to make use of the conference to interact and learn from their peers and experts.

### **Keynote address- Dr. Jaime Breilh, University of Andina Simon Bolivar, Quito, Ecuador**

We live in an era of concentrated opulence and technology in certain regions and certain groups, and of ever-worsening poverty and ill health for the vast majority. There was an urgent need for transformative research on the social determination of the health gap, understanding the social determination of health by using critical epidemiology, and reframing the 'health gap' theory.

He urged the audience to reflect on why there is a need for transformative research to focus on health gaps in societies, and how the social determination paradigm helps to transform functionalist public health into emancipatory collective health.

Wellness and optimal life in a healthy society presuppose the 4 "S's" of life, which are structurally denied today to a large group of people. These are:

1. A sustainable economy for the reproduction of human beings
2. A sovereign libertarian identity and culture
3. Solidary politics and agency for equitable relations
4. Integral human and natural bio-security for a healthy society-nature metabolism, and modes of living

However, these S's get systematically destroyed and submitted to private accumulation and concentration of wealth, and that in turn has resulted in dispossession and opportunistic exploitation of disasters, pandemics, and fear.

This situation cannot be just described as a gap between the wealthy and the poor, or between the empowered and the vulnerable. To call the disparity which exists between the well-off and the wealthy corporations versus the backward, less developed communities as

a 'gap' is flawed. These are socially created by powerful forces, for example, large-scale food and agriculture industries. The water drainage issue in Plachimada, Kerala, by the Coca-Cola Company is an example of the deliberate depletion of resources essential for good health. It is found that the maximum annual production of Coco-Cola occurs when the groundwater levels are lowest. Usually, the company withdraws from communities only after destroying their natural water source, and it then sets up production in new areas. Coca-Cola owns almost 400 brands in approximately 200 countries. It currently faces multiple accusations for dehydrating communities, drying farmers' wells and destroying local agriculture due to their constant search for water sources to supply their industrial plants. This kind of extreme concentration is clearly a destructive process with obvious health hazards. Conscious efforts can also reverse this dangerous situation. In Ecuador, of how work carried out through the Simon Bolivar University has helped to reduce the use of chemical pesticides for agriculture and reduce water extraction over a period.

'The concept of 'progressive neo-productivism'- the theory that 'there is a good extractivism (of the kind indulged in by Coca-Cola) which pays for social expenditures and jobs and

progress, propagates a myth. Is it the small family producers who protect the water and ecosystems and avoid waste? Alternatively, is it the affluent who introduce chemicals into the environment, monopolize land, water, seeds, apply dangerous high-tech products for expanding profit? Who is sustainable? Who is sovereign? Who is bio-secure? Who is solidary (a term used to describe living in solidarity) Who works better for health?

The neoliberal global rule of corporations is capable of influencing and undermining the sovereignty of states, penetrating into global organizations and significantly influencing global health governance. Financial control is a necessary condition for sovereignty. Corporations control even



international organizations. The Bill and Melinda Gates Foundation has financially supported the World Health Organization. One can well imagine the implications of this.

In the BRICS countries, the neoliberal diet -- high energy food and drinks- and the newer ways of food production and distribution due to the new policy developments, have resulted in a higher prevalence of diabetes. WHO has put forth the risk factors for diabetes in its Global report on diabetes. This way of looking at diabetes identifies certain factors but does not look at the processes that underlie these. There is a need to uncover the underlying processes than to look at the superficial or the 'tip of the iceberg' factors, to examine the social determination of health inequities.

Social-determination is a concept that is different from social determinants – the latter uses more linear, static and reductionist thinking. In critical epidemiology one talks of social determination – which makes explicit that an active process is underway, which creates inequities. To conduct a critical inquiry, just criticising the data on inequality or criticising the social or cultural conditions are not enough. Critical epidemiology entails questioning the material basis and epistemological/cultural basis in an integrated way. It questions the material (objective) and cultural (subjective) fundamentals of society. Critical epidemiology developed in Latin America and is a multidimensional concept which uses an emancipatory perspective and talks about the transformation of power relations. For research to be transformative, researchers needed to locate themselves as active participants in unmasking the social-determination of health inequities, as well as in demonstrating alternatives to the status-quo.

## **Panel discussion: Kerala- Going the last mile, addressing pockets of health inequity**

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### **The health of the elderly**

Following the demographic transition, health of the elderly is a complex emerging problem in Kerala. Dr. Praveen Pai spoke about some initiatives undertaken for the health and well-being of the elderly in Kerala state. Aging in Kerala is associated with the burden of illnesses among elderly and high out of pocket expenditure on healthcare. However, beyond the obvious health issues, there were issues of social exclusion. It was important for policies to find ways to integrate older people into the society so that they can be a part of the community and live with dignity.

Initiatives for the aged in Kerala have evolved by networking and convergence with different stakeholders, including the community, NGOs and the Government of Kerala. The Government of Kerala, under its social security mission, has come up with the 'Vayomithram' (friends of elderly) programme, which focuses on preventive and palliative care for the aged. As part of the National Health Mission, NCD clinics have been initiated. The Department of Social Justice has initiated a new programme called 'Sayamprabha' to

offer day care facilities for the elderly. Under this programme, an array of services including opportunities for social interaction, Yoga and meditation training, counseling, medical check-ups, physiotherapy and healthy meals are provided to senior citizens.

There have also been civil society initiatives in selected panchayats and blocks of Ernakulam district, focusing on creating age-friendly communities and cities. Dr. Pai is associated with one such organization, known as MAGICS. The organization aims to create an age-friendly atmosphere for the aged and to foster principles of social inclusion. It focuses on:

- Housing- in collaboration with Confederation of Real Estate Developers' Association of India (CREDAI) and other associations, there are specific initiatives to make housing more aged friendly. Particular attention is given to prevent accidents, by providing railings, and adjusting the heights of toilets and showers and so on.
- Transportation- to provide aged friendly public transportation, discussions are in progress with Kochi Metro. There is another initiative called 'senior taxi,' where training is provided to drivers to deal with special needs of aged commuters.
- Better social interaction- To facilitate social networking and to improve social life of the aged, many programmes are organized such as New Year party, and computer classes. These programs aim to give seniors platforms for social interaction so that seniors are not confined to their homes. There have been specific initiatives to make public places more accessible to aged citizens.
- Emergency response system- an emergency response system has been put in place for elderly who live alone. Using a community- run helpline, the elderly could reach out to volunteers for any help.
- Healthcare- there have been telemedicine initiatives in selected places in Kerala. Treatment camps are arranged for addressing old age conditions such as diabetic retinopathy.

### **Migrant Health in Kerala**

Dr. Ajith Kumar spoke about in-migration into Kerala and migrant-health issues. Interstate migration is wide-spread in Kerala, and as per the statistics, there are about 2.5 million migrants from other states of India. Children from 14 Indian states are found in schools in Ernakulam district alone, which shows the magnitude and diversity of migrant population in Kerala. Since the majority of the migrant population in Kerala are in the age group of 20- 34 years, they bridge the significant gap in Kerala's young workforce, resulting from international migration of Keralites. A majority of the migrant population are employed in skilled and semi-skilled labor. They are a vulnerable group due to various cultural,

socioeconomic, linguistic factors as well as the lack of entitlements and legal protection from states of origin.

There is a great deal of difference between Kerala and the states of origin, with regard to socioeconomic indicators and health indicators, at the same time, health care costs are found to be higher in Kerala compared to those states. In states such as Orissa, Gujarat, and West Bengal, communicable diseases constitute a significant challenge to their health systems while in Kerala, the higher burden of NCDs poses the key challenge. The healthcare needs of the migrant population are therefore different and often challenging. The inconvenient hospital timings, language barriers and lack of insurance coverage reduces their access to health care services. Dependence on private sector health facilities adds to their financial burden. Studies on migrant workers in Kerala have reported that migrant communities are prevented from accessing public distribution systems and *anganwadis* (day care centers for children).

There are some state-level initiatives for migrant population. An insurance scheme in the pipeline has a specific focus on migrants. The state has initiated a Migrant Suraksha project mainly to address HIV infection among migrants. Another programme aims to improve sanitation facilities for them. The primary challenge while planning interventions for migrants has been the lack of adequate data regarding migrant communities.

Public health care system should be responsive to the needs of the migrant population. There is a need for more policy-oriented research on internal migration. Issues of migrants should be integrated into development strategies at the state, district and local levels. The health sector in the state has started responding to the emerging needs, but it has to go a long way to take-on the influx of migrants from other states of India.

### **Persons living with disabilities**

Dr. Asheel defined disability in the context of equity, which captures impairments and activity limitations. He also highlighted the need to have an intersectional perspective, which factors-in other co-existing vulnerabilities, alongside disability.

According to a survey conducted by the Department of Social Justice, there are close to 800,000 people with disability in Kerala. Moreover, among them, more than 150,000 are illiterate, about 46% of them due to intellectual disability. The Government of Kerala initiated a Comprehensive plan for differently abled, using a life- course approach called 'Anuyathra.' The project adopts a rights-based lifecycle approach to disability management, from primordial prevention to organizing sustainable rehabilitation programmes for the disabled. Primordial and primary prevention of disabilities will be ensured through awareness creation regarding pre-natal determinants of disability. Secondary and tertiary prevention will include early identification through screening; and disability management,

including rehabilitation and palliative care services. As per this approach, tailor-made strategies would be adopted to deal with each category of disability. Special anganwadis for the needs of children with mental disabilities and developmental delays would be set up in districts. The pilot project has already been started in Kozhikode, which provides custom-made wheelchairs and computers to persons with physical disabilities.

The most critical challenge in dealing with disability and providing individualized care plans is the convergence of many departments, such as health, education and social justice.

### **Persons living with psychosocial disabilities and mental health conditions**

In India, suicides are the leading cause of death among adolescents aged between 15 years to 19 years. India has been called the world's most depressed nation. Kerala is one of top three states with a high rate of suicide (24.3%). Young suicides are on the rise; the recent National Mental Health Survey shows a prevalence of 11.4% in Kerala, which is relatively high. The data also shows that higher prevalence of depression and suicide in urban metros compared to no metro/rural areas. Kerala also has a high consumption of alcohol.

The key challenges in mental health care are:

- lack of exhaustive data on prevalence, most are from regional surveys
- Higher levels of stigma, for patients and healthcare professionals
- Allocation of funds- not streamlined
- Availability and accessibility of services not assessed, reasons for low availability and access not examined
- Affordability of care
- Out of pocket expenditure 1000-1500Rs/month
- Poor insurance coverage
- Disability schemes present but have limitations
- The 'treatment gap' is very high, estimated to reach about 76 – 85%
- Care and long-term issues, reduced life expectancy- loud silence on end of life care issues of mentally ill

*Mehac* is a model of long-term mental health care in the community initiated by Dr. Chitra. The *Mehac* model incorporates palliative care principles to provide quality care to the mentally ill. It goes beyond the medical aspects and looks into the physical, social, and the economic issues. *Mehac* believes in community participation and gets volunteers from the community. *Mehac* also provides home- care services. It promotes a public health approach, by focusing on overall well-being and stability of the person and not just on symptom control. *Mehac* conducts its activities in collaboration with local Panchayats, PHCs, and NGOs in the area. It also coordinates with the National Health Mission in Ernakulam district. *Mehac* strives for improving mental health literacy and conducts training and capacity building for health workers and volunteers. In collaboration with Banyan, they have initiated a programme called 'home again,' to provide alternative living spaces in urban and rural communities for those living with moderate-to-severe mental disorders and intellectual disability, who otherwise face homelessness or institutionalization. They conduct palliative care programmes in partnership with Pallium India. She concluded her presentation by briefing Mehacs' reach so far- they have been able to reach out to more than 5000 patients, and 40% of them require long-term care. About 1500 ASHAS have been offered training.



## **Structural Drivers of Health Inequities**

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### **Neoliberal globalization and health in India**

The concept of neoliberalism is discussed in two ways. One is as a hegemonic ideological programme. The second is in the context of the relationship between governments and its people and the withdrawal of governments from the various social sectors especially health.

Literature, especially in the 80s and 90s, focused on neoliberal forces and global institutions such as the IMF and the World Bank and the coercion that these institutions employed to impose structural adjustment programmes on many countries. There has been much critical writing on what the neoliberal agenda has done and how it has been furthered by the World Bank and the IMF, in restructuring health services in India. Such an "impositional" perspective does not give agency to the state. A more nuanced reading or understanding of the Indian state is needed. The State in India is not a puppet state. The elite in the Indian state and the medical bureaucracy were in sync with the neo-liberal ideology even before the World Bank came with its ideas for 'Health Sector Reform.' Even though the civil society and academia together resisted the onslaught of World Bank policies, from the late 1970s, neoliberal ideas were already in circulation, and the Indian state was steadily moving towards accepting a neoliberal ideology. An underfunded, weak public sector and an aggressively growing private sector was a favorable ground for neoliberalism to take root in the Indian context. One of the most visible effects of the neoliberal policies is the commercialization of health services. Citing some of the work by Maureen Mackintosh and colleagues, Prof. Baru argued that the health care reforms in public institutions, the introduction of user fees, the division between the public good and the private good and so on, were a result of this.

Thus, the policies of the World Bank in this context found allies within the health bureaucracy. As this progressed, 20 years down the line, we see the consequences of commercialization of services in health regarding the inequities in access to and utilization of health care and increasing out of pocket expenditure. Various rounds of the NSSO health rounds indicate the increase in out-of-pocket expenditures for health, which has brought the issue of universal coverage back to the forefront of the discussions now.

The role of civil society organizations and NGO movements in this process also needs a nuanced reading. We need to recognize that CSOs are not a monolithic group and that there exist ideological differences between civil society organizations. There was a process of engagement of civil society and NGO movements with the neo-liberal programme. One example of this was the World Bank's partnerships with various NGOs for various disease-

control programmes such as HIV, TB, and Malaria. Such partnerships brought about important transformations within the NGO sector. The earlier understanding was that CSOs had played a major role in resisting the neoliberal agenda, but over a period, it became an 'ideologically fractured landscape' of civil society organizations.

The NGO sector itself has experienced commercialization and corporatization. There are some very new players now. Corporations have resurrected themselves. Activities done through NGOs is now sought to be done through foundations set up by Corporates as part of their Corporate Social Responsibility Programmes. Examples of such initiatives are the Coco-Cola Foundation and the Monsanto Foundation. Such foundations now fund well-respected-NGOs of the 70s and 80s. Thus, funding from the sources of ill health has appropriated the spaces that were created to oppose these very forces and are perhaps trying to neutralize opposition. The underlying principle guiding such engagements is not social justice but guided by the neo-liberal ideology of providing access to the market for those without access. These are examples of how NGO collaborations have changed in the recent times. There are now groups within the NGO sector which legitimize the transformative process of modifying the role of the State from one of being an enabler of health to merely being a bystander or regulator of health, leaving markets to determine access and utilization.

Professor Baru concluded her session by stating that it is crucial for young academics to understand the nuances of neoliberalism and the way in which these non-linear, complex transformations are happening.

## **Religious fundamentalisms and Sexual and reproductive health and rights in Asia**

It is not usual to put forth religious fundamentalism as a structural driver of gender inequality, especially about sexual and reproductive rights. The reason is that religion is usually considered as something which influences individual choices and is about the personal realm. Decisions that stem from one's understanding of religion, such as not to undergo a vasectomy or a choice not to perform abortion services, are often considered as individual choices. However, there is a need to consider religion as a factor in making health decisions, especially in contexts where the state itself starts professing a religious identity. While in the past, countries professed secular democracy as the way ahead, currently nations are adopting national religions, for example, the emergence of a Buddhist Sri Lanka, a Buddhist Myanmar, a Hindu India, a Muslim Malaysia or Indonesia or Bangladesh. Religion is now perceived as a critical shaper of national cultural identity. This perspective is very simplistic and denies the diverse composition of religion in each country.

In many countries, the national religion is affiliated with the dominant majority racial-ethnic group. Such an affiliation also means that the majority religion gets a say in all policy-making in the country. When a country adopts a religious identity, matters such as equality of women, or rights of citizens who belong to ethnic and religious minorities or of sexual minorities gets diluted. In Malaysia, Indonesia and Bangladesh there have been efforts to revise the constitution to recognize the nation's religious identity and to ensure that all other articles of the constitution are compatible with this identity. In some countries, governments are specifically charged to recognize and protect the role of religion. Malaysian Constitution states that Islam is the religion of the federation, which means that any article of the Constitution which is not compatible with this tenet, including the rights of the minority to profess and practice religion freely, needs to be made compatible. Similarly, Sri Lankan Constitution says, it shall be the duty of the state to protect and foster Buddhism, so this may be interpreted to mean that all other policies processes and practices should be in line with this religious identity.

There are different views on what religious fundamentalisms implies. Some groups consider it as a return to fundamentals. Most fundamentalists hold the view that men and women are complementary and not equal. It advocates separate work with separate spheres and transgressing these spheres is monitored. She gave an example, where certain states have a curfew law where women must return home before nine in the evening. Otherwise, they will be fined as a sex worker, the justification being, only women who do sex work are out of the house after 9 p.m.

Religion also influences policy discourses and policy-making of states. These discourses usually imply that religion needs to be defended and protected in both personal and political spaces, and the right of culture and religion supersedes over that of the individual's agencies/ choices.

Religious fundamentalism impacts on health equity, especially with regard to reproductive and sexual health, such as:

- Access to safe abortion services- the discourse around access to abortion services prioritizes the religious understanding on when life begins over the life and choices of women and prioritizes the critical social function of women as reproduction above all else.
- Spousal consent for long-acting methods of contraception- this comes from the ideology that women's womb belongs not to themselves but their husbands, in the Muslim majority countries.

- In Malaysia and Indonesia, there is medicalization of female circumcision as a measure to reduce its health risks. Emergency contraception is often seen as an abortive measure, in the Philippines. The Philippines took 12 years to pass a reproductive health law. Religious groups put the barrier asking the department of health to go through a judicial process of certifying every single contraceptive as not being an abortifacient.
- Access to sexual health and reproductive health services for the young couple and unmarried people –this comes from the prevailing view that the purpose of sex is primarily for procreative reasons within the institution of marriage and sex outside of marriage is immoral.
- People with different sexual orientation and gender identity- because their sex is not procreative, it is not within the framework of marriage, and this is again considered an aberration.
- Early age marriage, and its implications- there is lowering of the age of marriage for girls in Iran to thirteen, in Bangladesh marriage below the age of eighteen is done with permission, without mentioning what exactly is the lowest denominator
- Marriage rights- In Myanmar, the government passed a law prohibiting mixed-race marriages. Moreover, in Malaysia, to marry a Muslim, the person has to first convert to Islam.
- Child rights- In some countries, registration of children of mixed unions is not compatible, and children are not able to choose a religion for themselves but are bestowed religious identity upon birth itself. In Malaysia, if a child born to a Muslim couple within six months of marriage, then the child is considered illegitimate. In this case, the national registration department plays the role of moral guardianship.

A concerted effort is required to understand the resurgence of religious identity, ideology, and politics; such fundamentalism is not based on compassion, social justice, equality, and equity, but on power and privilege of few over the others. We need to work together to overcome religious fundamentalisms, although it is seemingly very powerful and very forceful.

### **Philanthrocapitalism and global health**

Understanding health inequities from a critical political economy of health perspective, calls for understanding the crucial factors impeding health justice under the current global order.

These include the role of power, access to resources, and social and political relations –that is, the "rules of the game" that govern society. Current power configurations, including the global financial and trade systems, discriminatory social structures and divisions nationally and internationally, and the uneven distribution of wealth, derived from long historical processes of accumulation and exploitation, processes that accelerated under imperialism and capitalism, and now neoliberal globalization.

Health and humanitarian work that does not address the role of political economy may serve to legitimize the status quo. Such work may contribute to alleviating the responsibility of governments (including current and former imperial powers) and excusing their mismanagement; and their nefarious ties with elite interests. It may also remove attention from governments' failure to avert danger from the other powerful entities in the chain of political and societal determination of health, such as corporate perpetrators of exploitation of people and resources; and international financial actors and their national counterparts, who tolerate or encourage tax evasion, capital flight, deregulation, indebtedness, poverty and inequality, disinvestment in infrastructure, unfair trade rules.

It is in this context that the role of philanthrocapitalism in creating and sustaining global health inequities needs to be understood. The "*philanthro*" preceding capitalism is the ideal accompanying obfuscatory mechanism which enables capitalism to continue business as usual—or even *more business than usual*. When applied to the realm of global health, philanthrocapitalism is cloaked in, and coopts, humanitarian and even social justice-oriented values and language and hoodwinks us all.

Historically, philanthrocapitalism in health may be identified with two capitalist–philanthropists who have pivotally shaped the institutions, ideologies, and practices of international/global health: John D. Rockefeller in the first half of the 20th century and Bill Gates in the 21st. Highly political, both recognize/d the importance of public health to global capitalism *and of philanthropy to their reputations*. They and their powerful eponymous foundations share a belief in narrow, technology-centered, biomedical approaches to health (overlooking social, political, and economic determinants), and extending their colossal empires into education, agriculture, the natural sciences, and development.

However, a critical difference divides them. The Rockefeller Foundation (RF) *historically* supported public health as a government responsibility, also favoring the creation of a single, multilateral coordinating agency for global health (eventually, the World Health Organization, WHO). Moreover, the public was healthily and analytically skeptical of philanthropy and struggled for collective social welfare measures.

By contrast, the Bill and Melinda Gates Foundation's (BMGF's) privatizing venture-philanthropy approach challenges the leadership and public purview of intergovernmental agencies. It undermines WHO's constitutional mandate to promote health as a fundamental

human right, and allows a massive role to Corporate and philanthropic «partners» who influence –and profit from– global health. Today, the public is unhealthily naïve about philanthrocapitalism.

As the world's largest philanthropy, the BMGF's 2016 endowment stood at US\$ 40.3 billion including US\$19.4 billion donated so far by US mega-investor, Warren Buffett, the BMGF's sole non-family trustee. Since charitable donations are tax-deductible, the public underwrites at least a third of this endowment with *no say* in its policies. The foundation spends more on global health than any government except the USA's, some years surpassing WHO's budget.

The BMGF's power far exceeds its 10% share of global health spending, exercised via a range of mechanisms. Not only does it convince other donors and national governments to follow its lead (most eager to be seduced), many grants require counterparts to contribute a significant share of project costs. It also funds the data generation and statistical gymnastics to compile “evidence” for the global health field. It funds major newspaper and other media outlets, garnering attention and plaudits for its short-term, technically-oriented disease control approach. Moreover, since 2007 the H8 (Health 8; akin to the G7/8) comprising WHO, UNICEF, UNFPA, UNAIDS, the World Bank, the BMGF, GAVI and the Global Fund, has enabled the BMGF to leverage its influence over the global health agenda behind closed doors.

BMGF is not alone: Bloomberg, Zuckerberg, and a whole array of “noblesse oblige” actors have co-constructed a good news narrative in which a “royal we” extols the public health success of their generosity.

The BMGF offers a case in point of how venture philanthropy feeds the continuity of the global capitalist order. It appeared on the scene precisely at the apex of neoliberalism—a moment when overall spending for global health was stagnant, suspicion of ODA was at an all-time high. It was also a time when many LMICs were floundering under the multiple burdens of HIV, re-emerging infectious diseases, violence, and soaring chronic ailments (including both undernutrition and obesity), compounded by decades of World Bank and IMF-imposed conditionalities and social expenditure cuts. Today, virtually all key global health actors have received BMGF funding.

Yet, emblematic of elite interests in contemporary society, the BMGF disregards the underlying causes of ill health, overlooks what role the enormous accumulation of wealth in the hands of a few has played therein, and stakes a moral high ground regarding its generosity and narrow technically-oriented savoir-faire, all the while remaining under-scrutinized by scientists and unaccountable to the broader public.

The BMGF has been, mostly uncritically, hailed as a savior of global health, but this assessment excludes the question of what could be achieved through combined social,

political, and public health measures such as investing in peace, improved living and working conditions, creating a fair global system of finance and trade, ensuring food sovereignty, building redistributive welfare states and strong public and universal health care systems, or even abolishing the military.

Philanthrocapitalism is not merely a global health problem but a profound problem of the marked asymmetry of power in the global order—not only in terms of who controls the purse strings and decision-making, but who decides the rules of the game. In addition to the undue influence of private actors *within* the global health field, the corporate sector and its government partners have a crucial *indirect* effect on global health via exploitative trade relations, deregulation of decades of hard-won workplace protections and improvements in social conditions, and the stripping away of already insufficient and inequitable health, education, and other social services, jeopardizing the lives and livelihoods of literally billions of people across the world in LMICs especially, but also in HICs.

Further, as we have seen, philanthrocapitalism conveys a good news narrative and coopts progressive language of reducing global inequities, of empowerment and advocacy, respect, fairness, that all lives have equal value, and even of PHC.

The following is an example from India:

The Mobile Technology for Community Health (Motech) project was launched in Bihar in 2012 with the financial support of the Bill and Melinda Gates Foundation.

Motech's stated goal: Improve Maternal, Newborn and Child Health outcomes in rural areas by combining health information modules (SMS alerts and voice messages) for women and health professionals, and patient data tracking, compilation, and processing.

Motech's aim: to become a global platform used worldwide for different health issues

The reality, according to Marine Al Dahdah's findings, is philanthropy masquerading as liberating primary health care, but remains individual and narrowly technology-based:

Motech

*is limited to the dissemination of health information*

*does not allow dialogue between the health system and its users [that would]. Identify and address structural barriers to healthcare.*

*the empowerment offered by Motech, far from being liberating and political, is instrumental and individualistic. Motech embodies a reductionist view of power relations and domination that offers to compensate gender inequalities by sending unquestionable, centralized and automated information. The top-down structure,*

*lack of feedback and interpersonal communication, the negation of multiple barriers to healthcare, raise major reservations about any empowering effect that mHealth devices like Motech could have on women and health outcomes.<sup>1</sup>*

Conflicts of interest pervade the BMGF. It has been criticized for investing in polluting industries and unhealthy food and beverage TNCs that are the beneficiaries of its health and agricultural initiatives. Despite touting health equity, the BMGF's significant financial interests in Big Pharma (lately through Buffett's holdings rather than directly) tacitly privilege corporate profiteering over access to affordable medicines. Also troubling is the BMGF global health program's 2011 hiring of a Microsoft, patent attorney. To boot, the BMGF's global health leaders hail from Big Pharma and big biotech: current president Dr. Trevor Mundel was previously a senior executive at Novartis, his predecessor came from GlaxoSmithKline, and the BMGF's CEO Susan Desmond Hellmann previously headed product development at Genentech creating gene-targeted cancer therapies.

Perhaps the most significant conflict of interest involves public sector reliance on the BMGF as a leading financier of WHO. It would take just US\$ 2.2 billion (half the budget of New York City's Presbyterian Hospital.) to fully fund the WHO through dues to be paid by the Member States. Instead of resolving its long-standing underfunding crisis, WHO's 2016 reform (FENSA-Framework of Engagement with Non-State Actors) further legitimized BMGF and corporate influence by allowing these actors to apply for «Official Relations» status originally meant for public-interest NGOs that share WHO's primary goals.

However, it is through public-private partnerships (PPPs) that the BMGF exerts its greatest power. PPPs have proliferated since the 1990s as a way of funding and implementing global health initiatives in line with neoliberal prescriptions for solving public problems, typically segmenting markets to ensure market share while exacerbating health inequities. The BMGF launched or funded most major PPPs. GAVI, the Global Vaccine Alliance, promotes new second-order vaccines instead of ensuring universal vaccination using existing effective vaccines, and for underwriting already hugely profitable pharmaceutical corporations in the name of «saving children's lives.

The Global Fund, the largest PPP, offers “business opportunities,” lucrative contracts and decision-making leverage as a prime feature of its work. Sidelining UN agencies, it funds vertical AIDS, TB, and malaria programs in 140 countries, further debilitating health systems, WHO, and any semblance of democratic global health governance. Neither WHO nor UNAIDS has voting rights on the board –nor do most countries –but the private sector, currently represented by Merck and the BMGF, does.

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<sup>1</sup> Marine Al Dahdah (2017) Health at her fingertips: development, gender and empowering mobile technologies, *Gender, Technology and Development*, 21:1-2, 135-151, DOI: [10.1080/09718524.2017.1385701](https://doi.org/10.1080/09718524.2017.1385701)

PPPs allow private interests to frame the public health agenda, justify corporate involvement in the public domain, conflate private and collective objectives, and raise multiple conflicts of interest; most PPPs *channel public money into the private sector, not the other way around.*

The tenet that business models can resolve social problems –and are superior to anti-oppressive, redistributive, collectively deliberated policies developed by democratically elected governments– rests on the belief that the market is best suited to these tasks, despite ample evidence to the contrary. Today the RF behaves just like the BMGF, abandoning its prior support for the *public in public health*.

In the end, philanthrocapitalism is decidedly *not* a Robin Hood endeavor. Instead, its hidden mantra goes thus: To those who profit much, much must be done to justify their riches and ensure the enrichment machine continues. Until and unless philanthropy is on the socially just end of such a transformation, it remains as problematic as its side-boss capitalism, and very much a structural driver of health inequities.

In sum, it is time for governments, United Nations agencies, and their Member States to act in a genuinely moral and politically responsible fashion, pressured by citizens, health activists, and academics, to overturn philanthrocapitalism hold on global health, reject plutocracy, and reclaim democratic, anti-oppressive, accountable, publicly-funded, global public health decision-making.

## **Day II- Plenary 2**

# **'Leaving no one behind': Monitoring health equity at the state level**

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### **North-East Regional Resource Centre (NERRC)**

This presentation focused on the government initiatives in North Eastern states. The most recent national health policy explicitly states that '*Resource allocation aims to correct the existing anomalies in the distribution of health resources across geographical locations and populations and financial protection is planned to be assured through increasing public investment in health.*' The Government now proposes that decentralized, village plan has to be the heart of its health plans, which means that the Government acknowledges that one size does not fit all.

Many government programmes contribute to bridging the health gap across different groups. For example, specific initiatives under NHM such as ASHA, VHSNC, and VHND contribute to health equity. The community makes ASHA's selection, and she is accountable to the community. Women from marginalized sections are given priority in selection so that unheard voices are heard. For example, in Assam, in the tea plantations, because ASHAs from outside the community were not able to interact with the workers due to language barriers, ASHA workers were selected from among the tea plantation workers.

The following are some challenges to equity in health in the NE states of India:

- Retention of staff in remote areas;
- Imparting skills for disaggregated data analysis and interpreting the data;
- Building a robust system for addressing health concerns of most vulnerable groups;
- Improper implementation of various government programs;
- Assuring quality health care to every single household of the community.

### **NHM Orissa**

Orissa has started an initiative called "SAMMPurNA" (Sishuabong Matru Mrutyu Purna Nirakarana Abhijaan"), for accelerated reduction of IMR and MMR. SAMMPurNA programme covers fifteen districts in the state of Orissa including KBK districts and districts with a high proportion of tribal population and districts with a high level of MMR, IMR, and Under-five mortality.

The programme identifies difficult villages not accessible by 102/108 ambulance or any other four-wheel vehicle. Alternative transportation services are arranged for difficult areas.

Mentoring visits by the staff of Medical Colleges help in improving service quality at the periphery, for example in the Nutritional Rehabilitation Centres. There is provisioning of Disposable Delivery Kits (DDK) to ensure safe delivery at home, and exclusive home visits are conducted for high-risk pregnancies. Special provisions have been made for distribution of newborn resuscitation kits.

Another intervention in Keojhar district strives to reach with maternal and child health services those located in difficult to access locations. Special Incentives are being paid as MAMATA incentive @ 1000/- to the mothers of SAM children from the in-accessible pockets of the district for 15 days stay at NRC.

### **SHSRC, Maharashtra**

Studies conducted by SHSRC, Maharashtra, showed that almost 40% of under-five mortality is among SC ST population and 50% of under-five deaths in urban population is reported among urban poor. Similarly, the immunization levels are way below the state average among the poorest sections of the population. A maternal death review conducted in the state found that about 50% deaths are occurring in rural areas. Most maternal deaths in rural areas were due to delay in referral because there was a shortage of staff at the district level. There are 3-4 districts with a higher proportion of the tribal population, and new leprosy cases were reported from these districts. Further analysis showed that these cases occur in only certain villages within the districts. In those areas, the prevalence was more than ten times the district level figures. The rate of disability was also found to be more in these areas. All these point out that there are hidden pockets in the state, where targeted interventions are needed to address inequity.



### **Day III- Plenary 3**

## **Focus on health issues and challenges of selected "socially constructed" vulnerable groups**

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### **Persons living with physical disabilities**

Both in public perspective and policy perspective, disability has been viewed within a charity paradigm. Human right discourse on disability which emerged in the 1970s and 1980s changed this. She highlighted that disability is not to be viewed as a characteristic or a trait of a person, but instead as a condition that over the lifetime, can extend to every person in the population.

Historically, disability has mostly been the domain of NGOs and service delivery. Within the government sector, disability has been more aligned to the social welfare domain rather than the health domain. In the most recent legislation on Persons Living With Disabilities, 21 categories of disabilities have been listed, compared to 7 in the previous legislation of 1995. The addition of new categories of disabled in the Bill was due to India signing the United Nations Convention on the Rights of Persons with Disabilities.

There is still no clarity as to what the demographics of people with disabilities are. Disability figures reported by large-scale surveys may not give the accurate picture, and though the proportion of people with disability may appear to be small, absolute numbers are very high. Large differences are noted in male to female ratio of people with disability, with a male preponderance. The lower incidence of disabilities among girls and women could be due to concealment of women with disability. Also, some disabilities get noticed more than others, for example, visual impairment compared to hearing impairment. It is very difficult to access people with hearing disability. They are invisible but constitute the second largest disability category in India. There is no data available about the morbidity and mortality figures of people with disabilities.

Disability is not just a physical condition, but it is constituted through the interaction of a person with his/her environment. For example, if one has a condition such as Down Syndrome or cerebral palsy, and then the whole domain of socio, cultural, political, economic aspects related to it also become important. One has to take in to account how a disability limits one's activities, roles, opportunities in life, access to services, one's education, and employment, and how disability isolates the person from relationships and limits social interaction, whether it is leisure activities or access to public places. Because they are so embedded in everyday life, they are naturalized. In a disabled-friendly physical

built-space, these limitations would be much fewer, and those with specific disabilities may be able to perform almost all tasks as compared to those without such disabilities.

There are major inequities concerning addressing the healthcare needs of persons living with disabilities. There is a tendency to identify them with their disability. Little attention is paid to their other health concerns. Those with physical disabilities limiting movement, are at higher risk of obesity and non-communicable diseases. Persons living with disabilities may have greater vulnerability to secondary infection, for example, Urinary Tract Infections when one does not have access to a toilet. Another vital issue to consider is age-related conditions: people with disability have the possibility of premature aging. In many healthcare facilities, physical barriers pose a considerable challenge, be it getting access to the hospital or the medical equipment, poor signage's, doorways within clinics and so on. In many hospitals, there is no facility to handle inpatients with disabilities, and many lack basic facilities such as toilets. For women whose mobility is impaired, it is tough to undergo a gynecological examination. Long-term care issues of the disabled are also an important issue that needs to be considered. Persons living with disabilities have to often deal with multiple morbidities, compounded by lack of insurance coverage for them.

The relationship between medicine and disability has always been contentious. Disability has been configured as a medical category, especially in the West. Persons with disabilities have opposed such medicalization and stressed on a focus on social aspects such as creating a social environment that is enabling for persons with disabilities.

Despite the switch to a 'rights' language in the latest legislation on persons living with disabilities, there are major policy gaps in making this a reality. The data gap in examining differences in mortality and morbidity by disabilities needs to be addressed. We need to develop appropriate pedagogy for medicine to enable professionals to deal with people with disabilities, and lastly, we need to evolve standards of care for people with disabilities.

## **LGBTQ communities**

The foundational issue that shapes the discourse on health and mental health of LGBTQ is the widely held idea that everyone is born and dies as a heterosexual. Discussions on health, curriculum planning, training or education of mental health professionals, hospital administration, health service planning, clinical encounter or state policies all tend to suffer from the idea of naturalized heterosexuality.

All policy discussions talk of gender within the binary of neatly divided mutually exclusive, two opposite poles of males and females and this gets translated into every action, from the registration forms in OPD having the column of male and female, to male and female wards and toilets. If a lesbian who visits a gynecologist says she is a sexually active person and has also written in her form that she is unmarried, a well-meaning doctor is likely to proceed

(clinical examination or in the clinical decision making) based on the assumption of a heterosexual relationship. Similarly, a transwoman who presents herself in public health set up, despite her general appearance and her identification as a woman, will most likely be admitted in the male ward and probably stand in the male queue in the OPD. Another example is, trans-people approaching psychiatrists for gender dysphoria certificate so that they can approach an endocrinologist for hormones or surgeons being told that it is unethical practice to operate on healthy body parts. The notion of what is a healthy body, what is essential intervention as opposed to an elective intervention, is a common issue faced by trans-people, as gender dysphoria and affirmative therapies are seen as some preference as opposed to something that is a need.

We need fundamental shifts in our training curriculum, research and practice to improve access to high quality and affordable mental health care for the LGBTQ community. Otherwise, we are likely to (continue to) have an LGBTQ ignorant health care providers or LGBTQ prejudiced service providers and researchers.

For a very long time, homosexuality has been viewed as pathological. It used to be initially classified as sociopathic- personality -disturbance within the DSM1 and 2, and subsequently, as sexual deviance. Transgender was also classified as transsexualism, general dysphoria as disorders of sex development. The range of treatments varied from testicular tissue implants, hypothalamotomy, behavioral interventions like aversion therapy, and hormonal treatments. There are studies on these treatments in India as recent as 2009 to 2012. Later, social and political movements have brought up changes in these classifications. The American Psychiatric Association made these change in 1973 and 1987 and then WHO followed in 1992. However, in India, it was only in 2009 that a Delhi High court judgment decriminalized homosexuality. Much later in 2012, the Indian Journal of Psychiatry carried an editorial stating that homosexuality was a normal variant of healthy sexuality. Even now, some medical professionals believe that general dysphoria and corrective surgeries are just a fad. It should also be noted that not everyone who identified as a trans needs to undergo medical interventions for adjusting their bodies to the gender experience.

There are two significant moments in the history of LGBTQ movement in India. One is the HIV Bill, which brought some visibility and some kind of legitimacy to sex outside marriage – i.e., monogamous, procreative heterosexual sex. With the advent of HIV, many studies were conducted, and new terminologies were coined, such as MSM (Men who have Sex with Men) as opposed to the old terminology of gay. At the same time, MSM, gay men, and transwomen were being highlighted as high-risk groups within the HIV discourse from late 90s early 2000s, and a disproportional number of research studies focused only on sexual risks, HIV and STI. There seems to be an assumption that gay men or transpeople's health issues are all related to their sexual health. The advent of HIV brought back pathologization of transgender people, not as deviant but in a more medicalized way, as 'risk population' or

vulnerable population. Also, this period witnessed movements for granting citizenship rights to transgender persons. Later, research also focused on links between experiences, structural violence, stigma and discrimination faced by transgender persons and how that impacts their physical and mental health.

Health and mental health issues among LGBTQ include premature deaths and self-harm. Suicide among young trans-persons has been very high, and the data on this is not conclusive. In her own experience, the speaker had encountered a high number suicide cases, and many were young. While issues of some groups such as MSM, gay men, and transwomen, hijras have been highlighted, concerns of lesbian and bisexual women and all transpersons assigned female at birth, i.e., transmen have been ignored. A recent study reported of violence at home, correction of their gender, not-fitting into an educational institution, coercion to "normalize" their behavior, dropping out of education, running away from home and issues of livelihood and housing, to mention just a few.

Besides the HIV Bill, the second essential development in the history of transgender health is the Transgender Rights Bill of 2016. Currently, several states have a transgender policy. The famous supreme court judgment gave transgender persons the right to opt for gender identity. However, in the current version of the Bill, there is an expert committee to certify the person's gender when s/he applies for gender reassignment. There are many apprehensions, as to the kind of test they may do, whether it would be a physical test, and so on. This Bill vests massive power in the hands of medical professionals; currently there is no clarity on how this is going to be tackled.

A recent study from Kolkata reported in the journal of endocrinology, point to unregulated private practice while dealing with transgender interventions. There are vast differences in the cost of surgeries. Severe postoperative complications are reported. Denial of services is also pervasive, not just gender-affirmative therapies, but all kind of services. It ranges from refusing to physically examine the person in the clinic to all misgendering practices, such as sending them to the male (female) queue, male (female) ward which makes access difficult.

There is a need for some very fundamental shift in the way teaching and research is conducted and in curriculum design, to be able to address the health and equity issues of LGBTQ persons.

### **Persons living with psycho-social disabilities and mental health conditions**

There is a debate as to whether mental health should feature in public health discourse or belongs within the development discourse or the disability discourse. According to Ms. Davar, mental health belongs more within the realm of disability and inclusive development. She highlighted that there is still a debate as to whether mental illness is a real disease or whether it is socially constructed. The convention on United Nations Convention on the

Rights of Persons with Disabilities (CRPD) looked at social barriers as definitive of the experience of disability. Equality is a cross-cutting principle, a core principle in the CRPD along with non-discrimination, equality of opportunity, gender equality, accessibility, legal capacity, respect for human diversity and autonomy. The convention underlines that being symptom-free is not the desired outcome. Instead, it is social inclusion, especially for highly marginalized, excluded groups. While inclusion involves living in the community, even the Constitution does not talk of it as a human right or as a fundamental right and freedom.

"Sehar" is a program implemented by the Bapu Trust, an NGO founded by Dr. Davar, based on this principle. The program worked based on the CRPD principle of community living. Sehar was started in 2004, and it was a slow and steady transition from being a mental health service to a CRPD-compliant, inclusion-based service. Before the CRPD, the vision was to provide mental health support and reduce the burden of the disorder. After CRPD, the focus was to create care-giving communities and stress on inclusion as the outcome. This



was a major shift, because, after CRPD, *Sehar* started working with communities with whom there was little direct engagement before.

*Sehar* mainly plays the role of facilitator, enabler, and capacity-builder. The work is not just limited to medical intervention or targeted psycho-social interventions. It is more

of targeted inclusion intervention, and the work is intersectional. The focus is on structural barriers that impact on mental health such as poverty, lack of civic amenities, violence, hunger and starvation, age, work and employment, housing issues, migration, general health, and nutrition.

There are five community-wellness centers with three full-fledged services. Population outreach covers around 3 lakh people across 20 slums, PHC, small community centers, and Anganwadis in the area. Other stakeholders include Urban community development department of the municipal corporation. The program directly serves about 350 people with low or high support needs. A big part of the program is making people link up with available development services. Support and assistance are provided for people and communities facing human rights violation to access social justice systems. Many patients are found from beggar's home in Pune.

*Sehar* uses mental health as a gateway for providing access to general health care for a large number of people. Almost 75 to 80% of the clients go through general health check-up, and they get treatment, particularly for malnutrition, anemia, tuberculosis-HIV and sometimes

for other chronic diseases. Every third household would have someone with a psycho-social need, depression or anxiety. There are many cultural-linguistic expressions of emotional distress, for example, '*dhaddhad, badbad*', many of these expressions signify that there is a psychosocial issue involved. People with high support psychosocial needs and people with active symptoms are the highest number of people registered in *Sehar*, and they stay on longer. People with low support needs move on. For the *Sehar* program, prevention of involuntary institutionalization of persons with mental health conditions is an important strategy, by working with neighborhoods to support the person and to set up a circle of care for the person.

#### **Day III- Plenary 4**

### **Dissemination of research studies on Health Inequities and the health of Adivasi/ Tribal communities in three regions of India**

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This session was meant to disseminate the significant findings from a collaborative research project on Health inequities and the health of Adivasi/ tribal communities, undertaken in three regions of India as part of the '*Closing the Gap*' project. Four speakers made presentations on their respective studies.

#### **Health inequities in a conflict area- An in-depth qualitative study in Assam**

Conflict ranks among the top ten causes of death and ill health in the world today. There are many health effects of conflicts. Conflicts destroy livelihoods, impairs nutrition, and damages health infrastructure, and cause displacement. There are many studies which show that women, children, aged populations and people with special needs get disproportionately affected by conflicts. However, violence and conflict have not received enough attention from public health research and policy community. There are not many studies talking about the long-term impacts of conflict, especially in the North Eastern states of India. The fact that India does not recognize conflict within its boundaries makes such studies somewhat challenging to undertake.

The study by Jennifer and her team focused on the differential health consequences of conflict across and within different ethnic groups. It was conducted in six villages of Chirag district on the border between Bhutan and India. Only one of the six villages was a revenue village, and the other five were 'encroached villages' in forestry officials' parlance. The fact that the villages are located on forest-encroachments then makes it possible for the Government to not be responsible for these five villages and therefore not accountable.

The study population included Adivasis and Tribals – the former are from other states of India who do not hold ST status in Assam, while the latter is from Assam and have ST status. This study, which had elements of an ethnography was carried out by the ANT, an institution which had the trust of the local communities and that is why we could locate the study there. We used existing records, observations, photographs and about 8-10 life histories. The research was a participatory process.

The study found that there was a functioning health system till the 1990s, but the system got 'worn out' with years of militancy and repeated bouts of ethnic conflicts. Private players – e.g., NGOs/ traditional healers/ non-qualified 'pharmacists' - filled the health services gap during the years when public health services were absent. Physical infrastructure improved with NRHM but getting qualified health personnel was a challenge till date because of negative perceptions among health professionals about lawlessness and insecurity. A case history of a dispensary collected as part of the study showed that there is an apparent correlation between conflict and decline in services provided.

Key findings on health and wellbeing of conflict-affected communities were that the poor and the marginalized in a conflict area are pushed to the edge after an episode of conflict, resulting in impoverishment, ill-health, and deaths. People experience a complex web of losses at multiple levels - physical, economic, social, psychological and ecological. Risk factors for ill-health persist long after the episode of violence is over. Vulnerable populations of women, young girls and children were affected disproportionately. Importantly, health and well-being of host populations also disrupted by conflict.

In the absence of a functional public health system, dependence on informal health care providers is very high. Faith healers, informal practitioners, and private pharmacies are the first point-of-contact. All communities in the study area, Bodo, Adivasi, and Nepalis use a mix of treatment services. The choice depends on affordability and level of affluence. Adivasis delay seeking modern allopathic treatment for most illnesses because of poverty. Catastrophic health expenditures were a common experience.

There is a need to consider conflict as a public health issue, and conflict response has to be much more systematic. There needs to be multi-agency, multi-layered, and long-term strategies to deal with conflicts. Health services need to be beyond relief camps. Innovative strategies such as mobile and door-step health services need to be developed. The Government needs to acknowledge the presence of conflict-displaced populations and work to reduce their vulnerabilities in the long-term. Health centers and health personnel working in fragile and conflict-affected areas must receive more support.

## **Exploring Health Inequities amongst Particularly Vulnerable Tribal Groups: Case Study of Baigas in Chhattisgarh and Sabars in Jharkhand**

This study looked at the health and nutrition of two Particularly Vulnerable Tribal Groups in Chhattisgarh and Jharkhand, respectively, and analyzed the barriers to wellbeing. It documented the community's perception of the health system. The study used both quantitative and qualitative methods. They collected data through household survey, anthropometry, individual and group interviews with PVTG and non-PVTG, community health workers, traditional healer, and health service providers.

The *Baigas* of Chhattisgarh consider themselves as 'kings of the jungle.' They are also known for their knowledge of traditional medicine. *Sabars* were initially classified as criminal tribes by the British and are now denotified. They do not have any experience in agriculture. The traditionally forest-dwelling *Sabars* rely on forests for their livelihood. Very little information exists on the *Sabars* as compared to *Baigas*. *Sabars* are known for their skills as Dais. Malnutrition is very common among both the tribal groups, but it was higher among *Sabars* than *Baigas*. Both these groups live in 'kaccha' houses made with leaves, mud and they do not have any structure. Landlessness was more common among *Sabars* as compared to *Baigas*. *Baigas* with land also face issues with documentation and ownership. Forced displacement and migration are found to be very common.

Both groups had much higher proportions of children underweight and stunted than the state average. The nutritional status of adults was also found to be much poorer when compared to the state average, with *Sabars* worse off than *Baigas*. Both groups have high morbidity rates. *Baiga* women had more hospitalization when compared to *Baiga* men. Loss of children and infants and occurrence of maternal deaths are widespread.

The intersection of social determinants and their implications for ill health are evident. The politics of development in these resource-rich regions where mining for bauxite and uranium is done, resulting in dispossessing them and alienating them from their lands. 'Development' renders them landless in their land and intruders in their places and loss of traditional livelihoods without the means to choose alternatives. The dislocation also forces changes in diets, from millets and forest produce to less nutritious options, which resulted in malnutrition. Displacement is not a one-off process, it is continuous, and relocations to new settlements continues. The discrimination and stigma also continue, especially for *Sabar* groups.

Concerning gender, women are excluded from holding any influential positions, do not have ownership of economic resources, and wages are not equal. Women face domestic violence and 'witch hunting.' There are higher stigma and discrimination towards *Sabars*. There is a push towards 'assimilation' and homogenizing by Government Institutions. Very few government workers, including even village level service providers (like ASHA, Anganwadi

worker, helper, ANM) were from the PVTG community. An added problem was government order against sterilization to prevent pregnancy, as a means to address their dwindling population. Although reversible methods of contraception are exempt from this ban, front-line health workers appear to have interpreted the order to mean that all contraceptives are banned for PVTGs. Women bear the burden of frequent pregnancies and childbearing.

The present study had helped to draw the attention of policymakers in the state to the health inequities suffered by two of the PVTG groups in the Central Indian tribal belt. An action plan was being developed to address the situation.

### **Utilization of MCH services among Kerala's tribal population**

The tribal population of Kerala faces health inequities despite various government initiative. The key objectives of HAP's study were to explore utilization of maternal and child health services among the tribal population of Kerala as compared to the non-tribal population and to identify reasons underlying any health inequities. The study was conducted in Wayanad, Palakkad, Idukki, Thiruvananthapuram, and Kannur. The study population comprised of Tribal and Non-tribal residents of the selected Panchayats.

The quantitative study found that there were only minor differences in utilization of MCH services between tribal and non-tribal populations. For example, effective antenatal care ( $\geq 4$  ANC visit) was not received by 6 % of tribal mothers, as compared to none among non-tribal mothers. The only area of difference was in coverage by schemes like the conditional-cash-transfer *Janani Suraksha Yojana* (JSY), which was below 50% among tribal population.

Case studies were carried out of vulnerable tribal groups. It was found that the lack of adequate road access and transport facilities led to health workers spending less time in geographically interior locations as compared to the rest of their assigned field areas. Difficulties in making house-visits to tribal settlements were further aggravated by the less than an optimal number of healthcare personnel including ASHAs deployed in such areas. The dearth of personnel did seem to hinder addressing the inequity in health care services available and in turn, responsiveness.

It was found that there was a lack of trust in the health system, which also influenced the utilization of healthcare facilities. Another striking finding was discrimination of tribal people by non-tribals. Further, welfare programmes often treated tribals as a homogenous group and often overlooked specific characteristics of each tribal group. Non-recognition of tribal heterogeneity led to the lack of effectiveness of many programmes.

Policies and programmes were needed which factored-in the specific needs of different tribal groups; included front-line workers from within the specific tribal communities; and

educating and empowering healthcare personnel to be culturally sensitive to the problems and values of the tribal populations.

### **Geospatial mapping of health inequity among tribals in Noolpuzha Panchayat**

Noolpuzha Panchayat in Wayanad is a very remote area that includes the Muthanga forests. The study aimed to undertake participatory mapping to study physical access to health facilities among tribal and non-tribal people and to create digital spatial health infrastructure for Noolpuzha Grama Panchayat using free and open source resources. Study methods included a compilation of secondary data, mapping of health care, facilities, mapping of habituation patterns, geospatial analysis, thematic maps, proximity analysis and network analysis and participatory training of health workers, panchayat members, community volunteers. His was work-in-progress, and he shared some of the maps created using GIS, which helped identify the physical distribution of health and social welfare infrastructure.



#### **Day IV- Plenary 5**

### **Policy and Program Interventions for Health Equity**

#### **Financing UHC**

Many countries have been striving to make progress towards Universal Health Care, and Thailand is counted as one country which has made considerable progress in this direction.

In Thailand, there has been a progressive realization of UHC over the past twenty years. Per capita Public expenditure on health increased very significantly during the past ten years or so. Out of pocket expenditure reduced to 12% from 33%. The proportion experiencing

catastrophic health expenditure had also significantly declined, with the most recent figure at 2% of the population.

One of the significant steps towards UHC in Thailand was to expand the availability of health services. Thailand's policy is to have a functioning primary health care center for a population of 5000 people. There are about 10,000 districts, and more than 11,000 health centers including primary health centers have helped translate policy into an actual good outcome. Rural recruitment of students from ethnic minorities and Muslim communities for health-professional-training and hometown placement has been implemented from 1972 until today, to ensure that an adequate number of highly qualified workforce is available at the field level. The key policy message is to fix the supply side promptly. If the health system is not responsive, fix the supply side and gradually fix the financial risk protection to prevent catastrophe. There is no absenteeism in the Thai Health system, another component of fixing the supply side. A key message is that LMICs will never achieve UHC if they depended on premiums from the informal sectors. The way to go is to use tax as an income equalizer for financing health services and providing health security for all citizens.

It is important not only to have a broad population coverage but a broad-enough benefits package. In China, 1.3 billion people are covered by one of three insurance schemes, but the benefits package is too shallow, and consequently, the out of pocket expenditure (OOP) is high. Thailand has a comprehensive benefits package including curative, personal-preventive and promotive and rehabilitative services. Drugs are included in the benefits package, with 849 medicines included in the 2017 list.

What has UHC achieved in Thailand? Some of the achievements include:

- A shift towards pro-poor utilization and benefit incidence
- Significant reduction of Out of pocket payment, and low level of catastrophic health expenditure and impoverishment
- Low level of unmet healthcare needs, on a par with OECD average
- A steady decline of all-cause mortality between 2001 and 2014, and reduction in the inequality of adult mortality across geographical areas

It is noteworthy that a decade and a half of political turbulence has not derailed the UHC policy. Between 2001 and 2015, UHC survived eight rival governments, six elections, two coup d'états and thirteen health ministers. Overwhelming popular support for the program and commitment of the bureaucracy may have ensured continued political support for UHC despite the many changes in government.

## **Planning for Integrating Gender and equity Concerns in health programmes: An example from Orissa**

This presentation showcased an attempt by the Government of Orissa to integrate gender and equity concerns in all its health programmes.

There are gender disparity, high infant mortality rate and falling child sex ratio in the poorer districts of Orissa, known as the KBK (Koraput, Bolangir, and Kalahandi) districts. Subsequently, Malkangiri, Navrangpur, Rayagada, Gajapati, Noapara, Kandhamal and Boudh districts have been added to this group, which now go by the name *KBK plus* districts. These districts have higher poverty, lower literacy, higher infant mortality, more Malaria, more malnutrition compared to the rest of the state.

The health department of Orissa initiated policy changes to reduce health inequities. The first change was a geographical focus: instead of dividing the budget into 30 districts, more budget allocation was given to the KBK plus districts and districts which had poorer health indicators. A system of classification of villages was adopted based on the inaccessibility and distance from the sub-center, the characteristics of a service area such as mountainous, whether there is connectivity or not, and assessment of conflict- which is the left wing extremism which interferes with the provision of services. This assessment of risk is done by the ANM herself, and by the *Rogi Kalyan Samiti* which is the patient welfare committee consisting of both Medical and non- medical personnel at the block and district levels. Scores were allotted based on the assessment, and vulnerable villages were identified.

The enabling environment in the state was a stable political environment, committed to improving the conditions of disadvantaged communities in various sectors including in health. The state increased the health budget, and there was also flexible funding from bilateral donors. Construction and renovation of health facilities were undertaken on a large scale. Malaria management was done by providing mosquito nets to everyone in the KBK districts, especially for all pregnant women. ASHAs were trained in these districts for the use of rapid diagnostic kit and treatment at the village level. Many of these areas are chloroquine resistant, and so they were given the Artemisinin combination drugs. Capacity building of the ASHAs focused not only on malaria management but dealing with other primary health care issues and maternal and child care and improving women's access to health services.

Labor rooms were improved with screens for more privacy, and separate toilets were constructed for women. Earlier, there were no separate toilets for women in any institutions including in the government secretariat. Conditional cash transfer for institutional delivery also helped in improving the access. Mobile health units which were equipped with doctors, lab technicians, pharmacists, and nurses, were beneficial in KBK districts. Regarding human resources for health, there was compulsory posting for three

years for doctors in KBK plus districts, and an effective system in place, of monitoring postings and rotation of doctors to these districts. Besides, financial incentives were provided to doctors in government service and contractual doctors, nurses, ANMs and ASHA workers working in difficult areas.

Orissa set up a public health cadre of doctors. A nursing directorate was established so that nurses who are in the hospitals, clinical nurses, peripheral nurses and ANMs are all under one umbrella for their continuing education, their promotion, and career path. Nursing students from Southern Orissa were encouraged to join a school where admission criteria were lower, where scholarships were given, and extra coaching was provided so that candidates were able to catch up with the actual nursing course. Once they completed the course, they were posted in their home districts. Retention of such staff has been excellent, and there has been a gradual increase in the number of posts of health personnel. There is always a tussle with the finance department as to how they will be able to find the resources for this.

In Orissa, more than 50% of the hospitalization costs and under 50% of outpatient costs are met by families by taking loan or mortgage or sale of assets. The Orissa Government increased the budget for additional staff and programmes from the National Health Mission (NHM) budget. The state budget for health increased substantially from about 6.8 Million dollars in 2010 to 40 Million dollars in 2016-17. Differential budgeting was introduced, and in the four years between 2008 and 2012, the average annual growth of health expenditure in the KBK Plus districts was 45% as against 28% in the other districts. Besides, in every district 70% was allotted to the blocks and not to the district hospital, the allocation was according to the proportion of Scheduled Castes and Scheduled Tribes in the Block population. The National Health Insurance RSBY gives coverage of 30000 INR per year for a family. The State Government's Insurance Scheme tops this up, up to a total of one lakh. There is also Orissa State Treatment Fund of severe illnesses which is at the discretion of the chief medical officer at the district level.

The Government of Orissa has improved the systems for gathering information related to health, nutrition and water sanitation. It includes disaggregation of data by gender, caste, socioeconomic status and rural-urban residence, at the least. There is close coordination with the departments of Women and Child Development, Rural Development and Panchayati Raj institutions. An interdepartmental action plan was developed for the Particularly Vulnerable Tribal Groups (PVTGs), which spells out how each department could complement others' work.

A Gender and Equity cell was set up in the Directorate of Health, which looks at all the data and breaks it down by various axes. The Cell has enabled tracking of gaps between Scheduled Tribes, Scheduled Castes and Other castes and action to bridge the gaps.

Significant improvements are noted in institutional delivery, among SC and ST and the lower income population. Percentage of deliveries attended by skilled birth attendants too has improved. However, nutritional indicators in the last ten years have not shown much of a difference.

The main challenges in the programme are:

- Financial protection is still very inadequate, and coverage is not universal. There is still some out of pocket spending for delivery in public health facilities.
- There is poor visibility of women doctors at the sub-district level. Women doctors are mostly posted in the district hospital and large sub-district hospitals but not below that, so while trying to be more gender sensitive to the doctors the access of women to health facilities in the periphery has remained quite weak.
- The focus has been only on reproductive issues of women but not on other health issues. The District and Sub District capacity for planning and monitoring still needs strengthening.
- State outlay for noncommunicable diseases is very low. The central budget is inadequate, and the state has not yet put enough money into the non-communicable disease issue.
- There is still prejudice among many health workers towards the poor and scheduled tribe patients.
- There are problems of vacancy rates of doctors and absenteeism. In a few hard to reach areas, due to security reasons, ambulance refuses to go there after 5 p.m. So women going into labor after 5 p.m have no way to reach the hospital.

### **Reflecting on increasing access to comprehensive reproductive health services in early post-apartheid South Africa**

In this presentation we heard of the experiences of a non-governmental organization – Women's Health Project – at a particular historical moment. Women's Health Project was not a typical NGO but was located in the Centre for Health Policy in the University of the Witwatersrand, as an interlocutor between the community and the State.

The organization's focus was to increase access to comprehensive reproductive health and to advocate for policy changes that would make this possible. Three fundamental principles drove their process. One was capturing the voice of the people who are affected and working with experts who share the same values. The second was the commitment to

evidence-based policy-making. The third was the understanding that health systems strengthening was crucial for improving access to SRH services because the whole system has to work to be able to make any change.

Consultation with people helped in understanding people's perspectives on health issues. Grassroots consultation and education helped to reach thousands of people. WHP also worked with people's organizations and trade unions, to get their perspectives on health issues affecting them. It used innovative approaches to sensitize people on health issues as well as explored remedial measures. She gave an example of working with a trade union which demanded annual cervical cancer screening. WHP managed to convince the unions that screening could be done more infrequently, with minimal adverse consequences. The change in Unions' position was achieved through a process of engagement and capacity-building, through which trade unions learned how to assess the cost-effectiveness of health interventions so that scarce resources would be used most appropriately.

WHP's constant engagement with the state resulted in 13 new policies, many of which later became national government policy, and a few others were made into laws. As a part of the advocacy process, stakeholders working in the field of women's health were taken on a study tour to Bangladesh to understand the services provided by the Bangladesh Women's Health Coalition. The trip was a success as people were taken to a resource-poor environment and it gave some insights to program managers as to how to run programs even with limited resources. It was also the first time that the health managers saw how data was used for monitoring and evaluation.

There were quite many learnings as well as challenges. For example, the team pushed for a department of Primary Health Care in the government but ended up with a department of maternal and child health, which was merely a child health and immunization initiative rather than a maternal and child health department. Another issue was that although social determinants were one of the focus areas, the programme could not adequately address issues of sanitation, water, and transportation. Some interventions faced resistance from within the department itself, for example, providing abortion services. Also, certain viewpoints affected the implementation, views such as doctors alone should provide abortions, which then resulted in reduced access.

Similarly, some of the policy initiatives did not succeed, because of poor engagement with the service providers during the policy development process. For example in Mandela's initiative for free maternal and child health services, service providers were unprepared and, and they were resentful. Another key learning was that one had to influence the Ministry of Finance, to be able to bring about any change in health services.

Policymaking towards promoting equity was a long-term project and an ongoing struggle. What enables equity-oriented policies is the building of long-term systems, processes, and organizations that are accountable to the people.

## Plenary 6

# The role of social movements and CSOs in equity in health and in social determinants of health

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### The Right to Food Movement

What is the role of social movements in moving towards equity in health? We need movements and campaigns because health is a matter of politics and health inequity is a matter of power differentials maintained by politics. Movements give a platform to **defend** and retain the valid space of social determinants in health, to demedicalise and demystify health. They help us find the 'right' perspective through learning from each other, getting to the 'truth,' arriving at the 'right' strategy and stand. Movements provide a platform to foreground issues of the most vulnerable sections of society. Movements allow us to retain the notion of 'rights' rather than 'benefits' and 'rights-holders' rather than 'beneficiaries.' They help us defend the space for human rights in health and upholds the values of privacy, consent, agency: freedom and democracy. Movements use community- based approaches and foster the principles of democracy.

Through movements that share the above perspective, we are enabled to create conceptual models, develop programme models, generate evidence, as well as engage in action through lawsuits, pressure groups and so on, for effective social policy and action. The Right to Food movement had participants from various backgrounds- activists, economists, academics, media and so on. All were also members of the Jan Swasthya Abhiyan (JSA - People's Health Movement, India). JSA acknowledges Right to Food as a central social determinant of health but does not duplicate the work of the Right to Food Movement. The issue of undernutrition and stunting among children gave birth to the Right to Food movement. A working group for children under six was formed drawing from JSA and Right to Food movements, to tackle child undernutrition. This led to advocacy, capacity building, research and evidence-building, mobilization, and publications. The campaign had to focus on many related aspects as well, such as labor rights, maternity entitlements, agricultural crisis, public distribution system- the absence of daycare or creches, protecting and enhancing midday meals, scaling up of ICDS and supplementary nutrition, almost all of which are political.

The Working Group worked very closely with the former Central Government, the Planning Commission, and other policy groups and succeeded in the enactment of the Right to Food Act. It was no longer active, but its members have gone on to engage in other activities in the Campaign.

The work of the Right to Food Campaign may be best illustrated through an example of how it has challenged the “Community Management of Acute Malnutrition” (CMAM) programme of the WHO and UNICEF, which advocated the use of factory-manufactured ‘Ready-to-Use-Therapeutic-Food’ (RUTF) over locally-prepared food for the malnourished children.

The Campaign challenged the definition of the programme, in which the community had in fact been allowed no role except that of sending their children to the programme. Alternative community-based programme models were developed and implemented to show how the community could be centrally involved and how this could make a significant impact on child undernutrition. Research and evaluation helped create evidence on the comparative efficacy of both models, proving the superiority of the alternative model developed by the Campaign. The results were published in mainstream and academic journals, which helped bring policy attention to the limitations of CMAM. Thus, evidence was used to fight RUTF. The Campaign has defended people's right to choose their food, against the imposition of vegetarianism in ICDS centers. It has fought for the Right to Food in courts of law, and most important of all, the movement has led to the creation of an informed mass of affected people who will stand up for their rights.

### **Challenging caste-based discrimination**

Examining health issues and access to health from a human rights framework will show that *Dalits* in India are excluded and face discrimination. In most parts of the country, *Dalit* homes are located in the peripheries of the village, while the health centers are usually in the center of the villages, and so it is difficult for *Dalits* to access health services. *Dalits* often face discrimination and have a fear of being rejected by the health practitioner. They fear being asked about their caste status. The age-old discrimination based on the nature of work done by *Dalits* persists. *Dalits*, particularly women from groups known as Valmiki still remove human excreta with bare hands. People who are forced into such jobs do not even have access to the necessary basic support, including minimum wages and access to health.

When one talks about caste-based issues in the context of health, there is a need to go beyond physical health and to consider psychosocial aspects too. For example, mid-day meals are provided for children in schools, and children from *Dalit* or other lower castes often utilize this scheme. In many schools, *Dalit* children are made to sit separately. One has to consider the impact of such discrimination on the child. Such practices extend to other spheres such as workplaces, or healthcare facilities.

There have been instances where *Dalits* are falsely accused of crimes, refused treatment in government health facilities and so on. This raises a serious question as to what can be done when formal structures of the government turn against a particular group of people. Another key issue is that many a time, the community is not even aware that its rights are violated. The laws and regulations concerning *Dalits* are implemented very poorly, and often

the general perception is to look down upon the *Dalits* as people who are just trying to exploit such a provision of the law. When multiple disadvantages come together, the consequences are much worse: for example, an elderly *Dalit* woman living in poverty.

There is an urgent need for more research on the health issues of *Dalit* populations and especially of the health consequences of social exclusion and discrimination.

### **Civil society and CBO engagement with maternal-neonatal health and safe abortion**

'CommonHealth,' a coalition for maternal-neonatal health and safe abortion, has more than 200 members from across 22 states. The members come from different kinds of backgrounds and include healthcare providers, public health researchers, members of non-governmental organizations, advocacy, research and service delivery organizations, human rights lawyers, grassroots activists, public sector programme managers.

The strategies of the coalition are two-pronged:

- a) an 'Agenda-shaping' or 'discourse-influencing' role through engagement with policymakers, research, concept papers, media engagement and
- b) mobilizing and enhancing the capacity of a new generation of advocates for maternal-neonatal health and safe abortion.

The specific initiatives to address health equity and social determinants in the past have included:

- Documenting maternal deaths across ten states (The "*Dead Women Talking*" Initiative)
- Monitoring of quality of maternal health care services in Gujarat
- The "*Creating Common Ground*" initiative to bring together advocates against sex-determination and advocates for access to safe abortion services

The Coalition views maternal and reproductive health as a right and acknowledges the role of social determinants. It recognizes gender as a critical determinant of reproductive health, and so believes in making women's voices heard through community participation and community mobilization.

The 'Dead Women Talking' initiative of the coalition was a combined effort of more than twenty organizations, which documented maternal deaths across specific geographic areas

of 10 states over two years. 'Social Autopsies' were conducted, where the focus was on gender and social issues as well as health system factors that contributed to maternal deaths. The social audit involved community representatives and was done democratically.

The maternal deaths were analyzed across four domains

- Technical (Science) factors
- Health system factors
- Social factors
- Human rights

Social determinants were given particular attention. Issues of marginalization and exclusion included caste, poverty, religion, geography, gender, and nutrition. The Initiative examined how these affected maternal health and health care. Health system issues focused on complex pathways that led to the death and did not just limit to the linear model of the three delays framework. The Dead Women Talking process captured women's "lived experiences," and paid attention to inter-sectoral issues such as migration, livelihoods, roads, and transportation.

After this was done, the information gathered was fed back to the community and the health system at different levels, using women's groups, community-based organizations, and local government -Gram Sabha. She reflected that the human rights perspective helped them to move beyond the bio-medical issues, and to see maternal health and health care as a fundamental human right.

The 'Creating Common Ground' initiative has sought to build capacities of grassroots advocates, the media, healthcare providers and officials of MTP and PCPNDT Committees at the district level to understand that prevention of sex-determination and selection, and promotion of access to safe abortion were both informed by a concern for gender equity and equality; and further, to ensure that the two Campaigns did not work against each other's interests (for example, through unintended antiabortion messages in the Campaign against sex-selection).

Dr. Subhasri highlighted that there is a need to work closely with community and the health system to improve maternal health care. One had to give visibility to the lived experiences of women and to frame maternal health as a 'rights' issue. Access to information from the health system and inherent power hierarchies between communities and the health staff posed major challenges to such bottom-up and rights-based approaches.

## Closing Session

## Towards transformative research for health equity: Dr. T. Sundararaman, Tata Institute of Social Sciences, Mumbai

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It is indeed a challenge to be talking about transformative research at the end of four days where every speaker has engaged with this subject.

One of the big questions faced by public health researchers is how to do 'meaningful' research. How to ensure that the research they do serves some immediate purpose – for example, have utility in terms of informing action on the ground or policies or programmes. However, meaningful research is not only about the motivation of the individual researcher – his or her activist impetus.

There is another way of looking at meaningful, transformative research. Research is not something external to health systems. Health systems are dynamic and evolving, and research provides an integral feedback loop into the way health systems are shaped and grow. So research needs to be integrated into each of the components of building blocks of health systems (an expanded version of WHO's well-known framework, which has some elements missing - for example, the community).

A researcher is not someone who sits as judge and jury or an evaluator, outside the health system, it is not just a matter of the researcher holding the health system accountable, but of the researcher sharing in the accountability for health systems' performance. Thus, transformative research is integral to the working of health systems.

The second big question reflected in many articles is whether the recommendations they make from their research is taken on board in policy-making or programme-planning. While talking about evidence-based policy, one has to understand that evidence is not the only basis of policymaking. A policy is the result of an interplay between the interests of different stakeholders and is driven by a play of power and institution. At the same time, evidence brings its powers, it gives the negotiating power and can be leveraged by different people for different purposes.

*"Social scientific research will always be tentative and imperfect. It does not claim to transform the domain into an exact science. But patiently searching for factors and patterns, and calmly analyzing the economic, social and political mechanisms that might explain them, it can inform democratic debate and focus attention on the right question. It can help redefine the terms of the debate, unmask certain preconceived or fraudulent notions, subject all positions to constant critical scrutiny".<sup>2</sup>*

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<sup>2</sup> Thomas Piketty. Introduction in *Capital in the Twenty-first century*. Cambridge, Harvard University Press, 2014. Page 3.

In this understanding, transformative research is much more of a basis for dialogue rather than a basis for defining policy. In the contested terrain of policy-making, research is a force which can potentially enable the shaping of the discourse or ask some fundamental questions about it.

Using evidence in policy-making is not passive play. Researchers need to understand that stakeholders also leverage evidence consciously, some studies are deliberately picked up by policymakers; some evidence gets amplified by power structures, while some are attenuated and marginalized by them.

It is not only that researchers bring power to the policy negotiating table. But if they are conscious, they can use the evidence generated with other groups and stakeholders who can use the evidence as a basis for a more democratic dialogue with policymakers. For example, courts and Human Rights Commissions have been commissioning research and using the evidence inform judgments, laws, and policies. Politicians, especially pre and post-election time, are an influential audience to reach out with research findings. The media is another major consumer of research. Civil society actors and especially activists not only produce a lot of research but also have to be kept informed of the research that is going on. All these various groups may be considered to constitute the ‘policy community’ – heterogeneous in composition and at times, cutting across political positions– but having a shared vision for change. It is the policy community that maintains continuity across different political regimes in taking a particular agenda forward.

Having talked about evidence-based policy, it is important to acknowledge that in policy-making, attribution is often difficult. A specific idea may get picked up, and the source of the idea may never be acknowledged. For example, many of the policy innovations of 2005-2009 were based on groundwork done by various civil society movements and academics during 1999-2004. Some examples are the Forest Rights Bill, National Rural Health Mission, Right To Information and the Right to Education. All these policy ideas were incubated within the policy community and when at a particular juncture when there was a change in government, became policy.

Although policy is made by the dominant, in the interest of the dominant, in a democracy the dominant have to course-correct to manufacture consent for their dominance. This provides us – the policy community – with the space to make changes. These changes are incomplete and by no means revolutionary. However, they are nevertheless, essential.

What must researchers do? One key issue is getting the research questions right. Descriptive papers are useful for those who are being introduced to a field, but they have limited use in policy-making. Often, even the solutions proposed tend to be well known. One need not reinvent the wheel, but try and find out what worked and why, and if something did not work, why it did not work. That is the kind of information that is useful from a policy angle.

Most speakers in this Conference began with saying "we created a framework of analysis to do that." Creating original frameworks is unusual. Often, researchers tend to become constrained and caught-up within frameworks rather than critically examining and adapting them or even creating new frameworks. The same applies to methods – the complex

research questions that we are required to address may not fit neatly into the "quantitative" and "qualitative" methods boxes. We need to be able to innovate – but do so without compromising on rigor. Research has to have credibility if it is to make someone sit up and take notice of it, and even change his or her mind about an issue. The need for rigor is even more if the findings



of the study are counter-intuitive

Finally, there is the issue of reaching the decision-maker. We have learned to use "policy-briefs" and media stories for this purpose. However, by far, peer-reviewed publications have a much longer half-life and much more credibility than all other forms. However, one has to acknowledge that authors from low and middle-income country face many challenges in publishing in prestigious journals, which may require playing by a set of rules that we are not comfortable or agree.

We have talked extensively about what researchers can do for policy. There is something that policy must do for researchers, and that is to fund research. Much of public health research in India is dependent on funding from international organizations, many of them, private players. The National Health Mission and the Indian Council for Medical Research, to a more modest extent, have allocated budgets for health and medical research. However, much of this budget does not get spent. Systems and modalities are not in place to operationalize research-funding on a large scale, and that is one of the big challenges.

In conclusion – many of us are seized of the need for carrying out meaningful research; and yet, we may feel powerless as researchers in making the research transformative. One of our key contributions is to bring to the policy table the voices of the marginalized.

## A Health Equity Research Agenda for India

One of the key activities under the "Closing the gap: Health equity research initiative in India" project was to identify and build an agenda towards relevant health equity research in India. The agenda was to be based on a consultative process and participatory identification of medium-term and immediate priorities.

For this, the team had to go through a systematic process of synthesizing the available literature on health equity and identifying the gaps. The research gaps were presented to more than 60 participants in a national seminar held in 2015, who generated a list of broad areas, themes, and questions based on the gaps. There was an online consultation through the health inequities web portal, to consult diverse constituencies. In 2017, all the themes generated were organized and consolidated. There were still major gaps in specific areas:

- Issues related to persons living with disabilities and mental health problems
- Problems of the elderly
- Issues of LGBTQI communities
- Issues faced by the migrant population

For each of these areas, specific persons were identified, and research questions/themes elicited in consultation with them.

The last round of iteration was done during this conference, where a group of experts identified immediate priorities for research.

The whole exercise was completed within three years, a total of about 200 persons were contacted for this purpose at various points. The participants included young and intermediate career researchers, senior public health experts, civil society actors representing various constituencies, and (a few) policymakers. The exercises resulted in an extensive list of research questions identified as priority questions ranging from exploratory questions on various health inequities to dealing with interventions addressing inequities.

The key areas of research can be divided into four major categories:

- I. Descriptive research that answers the "what," "where" and "when" questions on the extent and nature and time trends of health inequities

- II. Explanatory research that answers the “why” and “how” questions, on the pathways through which health inequities are created, and the political/ policy environment that facilitates the process
- III. Explanatory research that answers “how” health systems create or facilitate inequities in accessibility, affordability, acceptability, and quality
- IV. Intervention research which answers the “so what can be done, what has worked where and why”? questions

## I. Descriptive research

### **IMMEDIATE PRIORITIES FOR DESCRIPTIVE STUDIES**

- Focus on persons living with physical or psychosocial disabilities; health conditions such as sexual and reproductive health; within-group variations by marital status, caste / tribal status/religion/ location/ combinations of these (e.g., the health of women living with disabilities in tribal communities)
- Focus on North-East
- Focus on marginalized within Dalit and Adivasi populations: e.g., Valmikis, Nomadic Tribal groups.
- Focus on LGBTQI: Desk Review on policy and law, and overall health status across states of India
- Focus on morbidity; on health conditions beyond MCH;
- An examination of how curriculum/pedagogy addresses sexuality and gender in medical and allied health professions.
- Structural determinants of access to health care by workers in the informal sector (by gender, caste, age, geographic location)
- Mental health of people who have experienced violence (both interpersonal and social/ communal / conflict-related) across gender and age

### ***Least-studied population groups to include in descriptive studies***

- Muslims and other religious minorities
- Nomadic tribes
- Urban homeless
- Migrants
- ‘Left behind’ households of migrants
- Adolescents
- Elderly
- Single (never married/ widowed / separated)
- Persons living with physical /psychosocial disabilities
- LGBTQI communities

- PLHA (beyond HIV)

***Areas to study under descriptive studies include***

- Looking at stratification within the group of Dalits/ Adivasis/ Muslims/ persons living with disabilities
- Intersections of multiple vulnerabilities: e.g., elderly by class and gender, or rural-urban location and age, or any other such relevant combinations
- Changes over time and differences across geographic locations of inequities by caste / economic position/gender etc.
- Comparing relative position in the social gradient of different marginalized groups (for example, Dalits versus Adivasis versus Muslims)

***The health outcomes to consider include***

**Health needs**

- Overall health needs of specific populations
- Specific health conditions about which there is limited information (e.g., cervical cancer); Specific health conditions in specific population groups (e.g., TB in elderly or internal migrants;)
- Ignored health needs of specific populations, e.g., beyond SRH for adolescents; beyond HIV for PLHA
- Nutritional status
- Quality of life, perceived psychological and physical wellbeing

**Health behavior**

- Health literacy/ awareness of healthy behaviors and symptoms of health problems
- Care-seeking behavior (from whom, after how many days, for which conditions)
- Access and utilization, unmet need for health care/ treatment compliance/treatment completion and barriers to these
- Experience with healthcare providers/ in healthcare facilities

**II Explanatory research: 'Why' and 'how' questions related to social mechanisms and processes**

**IMMEDIATE PRIORITIES FOR EXPLANATORY STUDIES RELATED TO SOCIAL MECHANISMS AND PROCESSES**

**In the immediate future, the focus needs to be on building the theoretical, conceptual and methodological tools that will make possible such research**

- A conceptualization of processes of inclusion, exclusion, discrimination, stigmatization, marginalization – how does (what are the processes through which) social position result in unequal access to social determinants

***Groups to be included in explanatory studies: Those population groups whose health disadvantages have been noted by study after study, but we do not understand why this is the case:*** e.g.

- Dalit
- Adivasi
- Low-income groups
- Women in specific settings
- Residents of rural areas/ urban slums / “backward” districts or states
- Comparison of groups - for example, Dalits as compared to Adivasis?
- The adoption of an intersectional lens, e.g., looking at the intersections of more than one axis of vulnerability: e.g., low-income *Dalit* women as against low-income *Dalit* men (i.e., explore whether the mechanisms and processes underlying inequities differ for them?)

***Social processes and mechanisms (pathways) to be studied***

- The macro-level situation which includes the structural / socio-economic-political determinants/drivers – which create the environment or conditions that widen or narrow social stratification (Cuts in public spending on the social sector; informalisation of labor; corporate control over natural resources)
- Social processes that translate a specific social location into disadvantages in terms of access to resources and power (e.g., social exclusion; discrimination; stigma)

***Outcomes to be studied:***

- The influence of these mechanisms on health outcomes (mortality, morbidity, wellbeing –general or w.r.t. specific health conditions; quality of life).
- The social and economic consequences of the unequal outcomes

### **III. Explanatory research: ‘Why’ and ‘how’ questions related to the role of the health system**

#### **IMMEDIATE PRIORITIES FOR EXPLANATORY RESEARCH RELATED TO THE HEALTH SYSTEM**

- What has been the impact of the growing presence of corporate private sector on access, availability, quality, and affordability of healthcare?
- What has been the impact of philanthrocapitalism on global and national health governance? With what consequences? Note here the impact also of the corporate private sector.
- How does match bottoms-up planning, top-down financing, and choice of technology (strategy and design)? Does the tension between the three remain the same for groups across the social gradient?
- Districts with similar levels of social determinants perform differently at levels of health system performance. What features of governance make the difference? Can they be replicated?
- What is the perception of different levels of the health system on the scope of community involvement across the levels of the health system?
- What are the processes to follow to attract and retain workers to serve in marginalized areas?

***Groups to be included in explanatory studies: Those population groups whose health disadvantages have been noted by study after study, but we do not understand why this is the case:*** e.g.

- Dalit
- Adivasi
- Low-income groups
- Women in specific settings
- Residents of rural areas/ urban slums / “backward” districts or states
- Comparison of groups - for example, Dalits as compared to Adivasis?
- The adoption of an intersectional lens, e.g., looking at the intersections of more than one axis of vulnerability: e.g., low-income *Dalit* women as against low-income *Dalit*

men (i.e., explore whether the mechanisms and processes underlying inequities differ for them?)

#### ***Processes and mechanisms (pathways) to be studied***

- Macro-level factors influencing the structure and functioning of the health system (e.g., government policies on the privatization of health care; WTO intervention to alter the pharmaceutical scenario; employment opportunities abroad for nurses)
- Health system structure (public / private mix, levels of care; the extent of decentralization; financing); design of service delivery; distribution of human and financial resources; decision-making

#### ***Outcomes to be studied***

- How both the above mechanisms influence/ impact on inequities in terms of Accessibility; Acceptability; Affordability and Quality
- The social and economic consequences of the unequal access, acceptability/ affordability, and quality

#### **IV. Intervention research: “what works in addressing health inequities, in which context, and why?”**

##### **IMMEDIATE PRIORITIES FOR INTERVENTION RESEARCH**

- Documentation of successful pilots, projects, innovations that have broken the barriers to equity and worked with the marginalized populations to see how some of them can be upscaled and integrated into the health system?
- What kind of interventions have worked or not worked for healthcare providers/ health system to become responsive to specific needs of vulnerable groups (e.g., LGBTQ, migrants, PWD, Sex workers)
- What interventions have worked to increase accountability to and participation by vulnerable groups?
- What has been the implementation and impact of Maternal Death Review for different population (e.g., increased maternal death reporting; increased action taken over deaths reported; has it led to better identification of ‘high-risk’ groups).
- What are the best practices of convergence models that have brought out better health and nutrition outcomes especially of vulnerable groups?

### ***A broad typology of interventions***

- Those aimed at improving health outcomes (reducing fertility, MMR, IMR, severe malnutrition)
- Those aimed at specific population groups (e.g., children, elderly, tribal) or locations (e.g., high priority districts)
- Those aimed at improving knowledge, changing behaviour, and so on.
- Those improving access to determinants of health (e.g., food, housing, credit, livelihoods, education)

### ***Areas to be studied***

- Descriptive: What are the health inequities addressed by interventions? By whom (government/ private sector/ civil society)? What strategies have they used? What is their theory of change? Is there room for flexibility to adapt to different contexts?
- What have been the challenges in / barriers to implementing the interventions? (from a user and provider perspective)
- What has been the impact of different interventions? Which outcomes have changed, which have not? Why? Has equity improved? Are there variations across different settings in the impact of the intervention? What makes them work or not work?

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