COPASAH
GLOBAL SYMPOSIUM 2019
ON
CITIZENSHIP, GOVERNANCE AND ACCOUNTABILITY IN HEALTH

Leaving No One Behind: Strengthening Community Centred Health Systems for Achieving Sustainable Development Goals

OCTOBER 15-18, 2019
NEW DELHI, INDIA

THEME 2:
IMPROVING ACCESS TO QUALITY HEALTH SERVICES FOR THE INDIGENOUS, EXCLUDED, VULNERABLE COMMUNITIES AND THOSE IN FRAGILE CONTEXTS

CONTEXT

The Community of Practitioners on Accountability and Social Action in Health (COPASAH) is a bottom-up learning global network of community practitioners primarily from the global south, working to strengthen the linkages between communities and health systems to provide quality and accountable health care. Health, wellbeing, and dignity for all and the community's claim for the human right to health are at the core of COPASAH's positioning of social accountability. The community of practitioners of COPASAH encompasses various actors ranging from people-oriented community leaders, organic intellectuals, and institutions committed to such an equitable vision of society. (www.coapsah.net)

Building upon the need to bridge up the gap in the top-down and tool led accountability discourse by focusing on bottom-up approach, forefronting citizen voices, and community-centric focus and bringing the most marginalised within the ambit of health systems as active participants, COPASAH organised a Global Symposium on Citizenship, Governance, and Accountability in Health, between 15-18 October 2019 in New Delhi, India.

The Symposium facilitated interactions between nearly 500 delegates from over 40 countries, which included practitioners in health, policymakers, academics, researchers, and other activists on common issues of concern. This Symposium was collectively shaped by the perspectives and inputs provided by the Steering group of COPASAH, the Global and India Organising Committees that included over 100 leading organisations and intellectuals spearheading the community-centred accountability processes. The Symposium organising group included the COPASAH Steering Committee, People's Health Movement (PHM), Accountability Research Centre (ARC) – American University (Washington DC), Global Health Justice and Governance Programme of the Mailman School of Public Health, Columbia University (New York), Institute of Development Studies (Sussex) and Azim Premji University (Bengaluru).

The COPASAH Global Symposium was woven around the issues of Citizenship, Governance, and Accountability in relation to the lives and living conditions of the marginalised communities. It was designed as a conversation and dialogue between grassroots accountability practitioners and community-centred accountability advocates interfacing with public policy spaces, research and academia, and those engaged with policy-making and policy implementation. Such conversations were facilitated through formal and informal spaces. The formal spaces include plenaries, thematic and inter-thematic sessions, accountability praxis, and assemblies endorsing the practitioners' social accountability charter.

KEY THEMATIC AXES FOR THE COPASAH GLOBAL SYMPOSIUM

The key deliberations in the Symposium were premised around five thematic axes which included Theme 1- Community Action in governance and accountability for health systems strengthening; Theme 2- Improving access to quality health services for the indigenous, excluded, vulnerable communities and those in fragile context; Theme 3- Moving forward the agenda for Sexual and Reproductive Health Rights; Theme 4-Setting the framework and agenda for people-centred accountability of private and corporate health care sectors and Theme 5-Forging alliances between the community and the health care workers.

PERSPECTIVE BEHIND KEY THEMES OF THE SYMPOSIUM

The health systems in developing nations include the public health systems as well as a whole array of private health care providers. The public health systems, which are constitutionally mandated to protect and promote the wellbeing of communities, are increasingly rendered fragile, weak, fragmented, and shrunk. Alongside this, the burgeoning private health care system has set itself progressively on the path of commercialisation and corporatisation, resisting

its accountability neither to the constitutional principles nor to patients. Meanwhile, the accountability to the health and wellbeing of citizens and communities has suffered a setback due to the State's evasion of responsibility and the overpowering yet unaccountable presence of the non-state actors in health and health care policy and provisioning. The global and national actors from both the health and non-health sector actors who are operating in this field have contributed to making accountability chains more complex. Such accountability deficits and complexities are created in the upstream and global alignments of private and non-state actors that wield undue influence on global health governance.

Besides, the accountability discourse itself is fret with its challenges and limitations. The discourses of accountability have been delinked from the policy contexts and the experiences of the community. Some of the predominant approaches are overwhelmingly expert-led and instrumental and narrow in their outlook as a tool (ticking a box) or a digital drive for accountability with an overemphasis on efficiency and outcomes simultaneously undermining potential transformative perspectives of equity. It also undermines the centrality of the community and the understanding of the power imbalances that the overarching policy processes create. Such limited, instrumental, and reductionist accountability perspectives have further exacerbated the alienation of communities. They tend to absolve global actors of their influence on the continuing indignities and violations of rights that the communities are confronted with.

COPASAH has positioned health, wellbeing, and dignity for all and the community's claim for the human right to health at the core of social accountability discourse. Such a discourse is also located in the overarching framework of citizenship, governance, and accountability in health. In the same vein, the understanding of health itself is broadened to include wellbeing, dignity, and social justice, within which health care forms a significant part. It is driven by the belief in and engagement with the transformative potential of the community's power in demanding accountability from the state and non-state actors and for realising such a right. Such an understanding of accountability is a process of changing power equations of communities with various actors and national-global policy processes, most importantly the state which is vested with the constitutional obligation to ensure condition for communities be healthy. Realising that such a process of social accountability is only possible in a strong bond of community to global solidarity, the community of practitioners of COPASAH encompasses various actors ranging from people-oriented community leaders, organic intellectuals, and institutions committed to such an equitable vision of society.

CONCEPT AND ORGANISATION OF THE THEMATIC DISCUSSIONS

It is estimated that 370 million indigenous people live in more than 70 countries around the world. Despite the diversity of geography, culture and languages, most indigenous people face a similar history: oppression, marginalisation, poverty and racisms. Also, regardless of whether living in the global north or global south, indigenous population experience worse social and economic indicators than the non-indigenous populations living in the same territories.

In many parts of the world, there are indigenous social movements demanding respect for their ancestral land, a clean and sustainable environment in their territories, the right to maintain their culture and ways of living, among other demands. However, social movements demanding better public services in their territories-including health- is somewhat limited. One possible explanation for this situation is the fact that many indigenous groups maintain their understanding of health and illness and practice their own traditional medicine. However, there is a growing number of groups that recognise that in addition to maintaining their own traditional medicine, there is a need for preventive, curative and emergency health care that is provided by western medicine (i.e. vaccination, antibiotics, surgery and early screening). They have also recognised that the public services available to them are of poorer quality of services available

in non-indigenous areas.

Besides, health and healthcare services are of the essential need for all populations, including those historically marginalised. In the words of an indigenous leader from Guatemala, "All of us are involved in struggles for our ancestral land, fighting extractive industries in our territories or recuperating land taken from us by colonisers. To maintain our struggles we need to be healthy. If we are ill, our struggles will suffer. Hence, improving the public healthcare services that we all use is of utmost importance. Having public services that are responsive to our needs is essential to advance our collective demands".

The indigenous and vulnerable people theme at the COPASAH global symposium explored how health accountability for indigenous populations can help
a) Tackle the situation of poor services in indigenous territories,
b) How accountability is an exercise that allows people to improve their knowledge, skills and strategies about how government and state institutions work,
c) How healthier populations may contribute to advance indigenous people demands.

The discussions on the theme were organized through three sessions of 90 minutes each over a period of three days

- Day 1: Current practices
- Day 2: Cutting across issues
- Day 3: Strategising for the mid and short term

THEMATIC SESSION DAY 1 (OCTOBER 16, 2019): CURRENT PRACTICES

Moderator: Walter Flores of CEGSS, Guatemala

Walter Flores opened the discussion for Theme 2 by outlining the objectives. The participants discussed their current practices though a set of questions including

- What are the most relevant demands or struggles in my community/territory?
- What is our current practice around health accountability and success we have achieved?
- What are our current challenges?

The session was chaired by **Ariel Frisancho** from **Catholic Medical Mission Board (CMMB), Peru,** who provided a short introduction of the theme. He spoke about the need to focus on the indigenous communities across the world. He emphasised that the indigenous communities are

unique, and their total population is 370 million in 70 countries; significantly, they all have a shared history of struggle, oppression and discrimination. He also pointed out that the focus should also be on the marginalised population such as the Dalits in India and the Roma community as they thrive in similar situations although they are from different geographic contexts and therefore have a common issue. It is generally seen that indigenous communities have poor health indicators in comparison to non-indigenous community and indigenous community even in developed countries face similar problems, he outlined, and the levels of exclusion are visible regardless of how rich or poor the countries are. He added that most of the indigenous communities are a neglected population, and there is minimal attention by governments and policymakers. The historical processes and structures of all the indigenous communities are similar. He pointed out that when the UN realised the problems that the indigenous communities encounter, measures for legal corrections of history of exclusion were started. However, as an entry point for accountability, there is a need to correct the situation to create a robust social mobilisation process as only legal measures are not enough; he emphasised. He opined that the ideal approach would be to combine and coordinate various efforts across the globe to ensure accountability in addressing the problems of the indigenous community.

All the participants were divided into groups, and this division was based on the ability to understand common languages- Hindi, English, Spanish. The participants, along with the delegates, shared their experiences of working with the indigenous community in different countries of the world. They specifically shared the problems faced by the indigenous community such as high maternal mortality rate in Nigeria, social exclusion in Brazil, issues of menstrual hygiene among the adolescent girls in India, risky health behaviours such as alcoholism and smoking among the tribal community of South Asia. Along with the problems, the benefits and harm of traditional medicine were also being discussed- such as those of quacks, traditional healers in Nigeria etc. It was also highlighted in the session that traditional medicine is also seen with a bias as compared to modern medicine, and it has been a marginalised healing system. In this light, the importance of setting standards and regulation of the indigenous healers was also discussed.

THEMATIC SESSION DAY 2 (OCTOBER 17, 2019): CUTTING ACROSS ISSUES

The session envisaged a discussion on common issues following a recapitulation of the session on the previous day. It was decided that the participants would discuss cross-cutting issues like traditional birth attendants, culturally appropriate community health services (including health workers), governance of public services and budget in indigenous territories, public budgets, social accountability of health workforce schools etc. These cutting across issues had emerged from the applications submitted by the participants in the Symposium. Furthermore, in the session, the participants worked in small groups to discuss a few questions, which included:

- Is any or several of the issues presented of relevance for my practice or communities?
- Is my organisation already involved in tackling some of those issues? If so, what are our strategies, successes and challenges?
- What other cutting across issues can I identify out of my practice or my community context?

Moderator: Ariel Frisancho, Catholic Medical Mission Board (CMMB), Peru

This session was moderated by **Ariel Frisancho** from **CMMB, Perú**, and facilitated by **Walter, CEGSS, Guatemala.** Rapporteurs from each group presented the key points that emerged out of the group discussions.

- Concerns from the northeastern states of India regarding the use of alcohol and smoking amongst the indigenous communities were highlighted along with the need to strike a balance between traditional drinking habits and abuse. One of the group members shared

experiences of promoting the use of non-plastic sanitary napkins among tribal girls. Concerns and issues regarding maternal health were also discussed. For example, the high maternal mortality rates among the indigenous people in Nigeria was raised, and it was highlighted that it was a serious issue but was not getting enough attention. Overall there was an agreement on the fact that there is a lack of coordination between the state and local levels, and there is no regulation of traditional healers. Further, it was highlighted that in countries like Brazil, exclusion of the indigenous people was common, and information related to their marginalisation was not being captured, and their voices remained unheard.

- Another group shared the common barriers that indigenous people were facing in Mexico, India and Peru in accessing health care services. It was mentioned that most of the time the government functionaries themselves were not aware of the rule and regulations. It was highlighted that the way laws are being implemented is crucial as most of the time it's the laws that hamper people's access to services. Other issues reflected included discrimination of children who are not registered as institutional births. The group members also highlighted that though the government stresses upon institutional (hospital) births, however, the adequate and comfortable facilities are not provided to women in these facilities. One participant in the group shared that earlier, she used to think of health care services as a favour, but now she understood it as a right.

- A group comprising of members from Chile, India, Mozambique and Peru shared discussions about the changing role of advocacy while working with the indigenous communities. They highlighted the significance and the need to enhance the visibility of indigenous people's issues and their needs. The importance of people's right to health and ensuring these rights are an entry point for accountability was suggested. The overarching opinion of the group was that law doesn't work for indigenous people. It is suggested that practitioners should play a mediating role to further the communication between the indigenous people and health care providers. The group members also suggested the significance of training indigenous communities in the use of social media to further their advocacy work.

Following the presentation of discussion pointers of the groups, selected panellists deliberated on the cross-cutting issues of indigenous people.

PANELISTS

Claudia Lema from **Salud Sin Limites, Peru** shared about the Peruvian experiences of culturally appropriate services in the realm of maternal health. She highlighted that the number of births in

the health facility was low in Peru, but the number of women coming for antenatal care (ANC) check-ups was relatively high. She lamented that the clinical guidelines were globally common and didn't recognise the differences and are based on the notion that all bodies are similar. She opined that there was a need to acknowledge and involve the indigenous health practices and practitioners, for example, involve Traditional Birth Attendants (TBA) in the birthing process; use of traditional wooden furniture for delivery, give women the choices of their delivery position etc. She emphasised that knowledge of the Traditional Birth Attendants (TBA) is valuable and cross-learning should happen interchangeably, i.e. doctors can learn from Traditional Birth Attendants, and Traditional Birth Attendants can learn from doctors.

Sharing her experiences from India, **Vandana Prasad** from **Public Health Resource Network (PHRN), India** spoke about her experiences from tribal areas and the indigenous communities. She pointed out that the accountability framework did not replace the rights framework and stressed that the starting point should be on rights. She emphasised that community mobilisation and collectivisation are critical for accountability, and the social determinants should be the key to understanding health and nutrition. She opined that representation at all levels is needed, however currently there is less representation from the tribal community, which can only be achieved through decentralisation of governance. There is the hegemony of biomedical sciences in health-specific issues which need to be broken down she opined. She highlighted that the ratio of community health workers to population was skewed in India, and there was a need for high labour intensity along with capacity building for the frontline workers. She pointed out the critical element of the lack of activism among the ASHAs in India. She also emphasised the need for collaborating with men to ensure accountability in health.

Luz Estrada from **ForoSalud, Perú** shared about the problems faced by the traditional birth attendants in Peru. She outlined that the TBAs were not recognised by health officials, though in the Andean world they were being considered as empirical. The law makes no space for them to assist home delivery as they are not seen as empiric or scientific she said. She pointed out that though a change has been observed since 1995-2000s, the TBAs were getting trained and registered and were given delivery kits, but they still lacked in using the kits. It is mandated that the TBAs who were working under contracts would be terminated if they delivered at home and children delivered at home do not get birth certificates and other benefits from the government. Since the year 2000, researchers started exploring why women in the Andean world prefer to give birth at home rather than at the health facility. The research reflected that women trusted the expertise and knowledge of the TBAs as compared to medical doctors. TBAs also used local herbs such as coca leaves for facilitating labour during childbirth. She explained that the culture of the indigenous people is not respected- for example the placenta is thrown by the health care workers in the medical facilities and not handed over to the woman/family for ritual purposes, as is a practice in the indigenous culture. She stressed the need for ensuring a homely environment in the health facilities.

Jasminka Frishchikj from **Association for Emancipation, Solidarity and Equality of Women (ESE), Macedonia** stressed on the need for budgets and funds. She shared experiences of working with the Roma community. She pointed out the need of the community knowing about health budgets. She opined that there was no transparency in how donor aids were being utilised. She highlighted that with the advocacy efforts in Macedonia, the government and the Ministry of Health were becoming transparent by making data available on the health budgets.

Josslyn Tully from **Torres and Cape Hospital and Health Service, Australia** shared her experience of working with the Aboriginals or Torres Strait Islander origin. She highlighted the challenges of childbirth of the indigenous women. She pointed out that women were travelling long distances for childbirth due to lack of health care facilities in their villages. The doctors were only available for a few hours and getting quality health care remained a challenge for

pregnant women amongst the aboriginals. She opined that it is a difficult task to bridge the gap between global and national unless the aboriginal people are empowered. **"Fixing our people our way"** was the need of the hour, she opined.

Stephanie Topp from **James Cook University, Australia** shared challenges faced by the health workers. She shared reflections of 60 interviews conducted with health care providers on what the law means to them. She shared the reflections from the interviews. The health care providers opined that law is complex and cannot be easily defined; it differs from culture to culture; clinical services provided also differs from clinic to clinic. The state health system is profoundly biomedical oriented, and due to this biomedical orientation, there is risk aversion in which whatever happens outside the clinic is considered as inappropriate, or any intervention is considered wrong. The primacy of the clinic makes all other interventions invisible. In the social and cultural process, the health workers working with the Aboriginals or Torres Strait Islander are in a highly isolated setting in New Queensland although it is a big state the population is much less, as a result of which houses are located far away from each other, and this poses a challenge. She also expressed that the health service is not involved in trauma counselling; however the community health workers play a specific role in counselling, and they can manage their complex role, but the authorities do not realise their potential in the health system.

DISCUSSION AND REFLECTIONS

After the presentations, the participants were invited to comment on their concerns and opinions.

- The participants reflected that it was significant to analyse the reality and support for the community health workers as a key strategy towards for ensuring accountability.
- One of the participants raised a question regarding the regulation of traditional healers, to which one of the panellists responded that the TBAs are not hired, and there is no contract; therefore they cannot be told what to do and what not to do. But there is always a tendency of pushing them away from the birthing process.
- A participant opined that conceptualisation of quality in terms of access to care was more appropriate than its infrastructural meaning.
- A representative from WHO expressed that the concepts of indigenous people were undervalued. The process of childbirth followed by the indigenous people are not cost intensive models; still, they remain undervalued. The representative expressed **"I am struggling to understand why institutions such as mine do not value this concept."**
- It was highlighted that gaps wouldn't be bridged if the indigenous people themselves do not run the services. The more broad agreement was that indigenous people are excluded from policy designing. It was also stressed that there was a need to empower the community health workers as they were the ones who understand their health problems. The broader reflection was that there was a need to unlearn everything and learn everything from the community.

THEMATIC SESSION DAY 3 (OCTOBER 18, 2019): STRATEGISING FOR THE SHORT AND MIDTERM

The session on the third day discussed the international and national frameworks aimed specifically for indigenous populations (UN convention, World Bank safeguards, and national laws) and current global initiatives and goals (SDGs UHC) and how they can be used strategically to advance indigenous peoples' demands. This session also presented specific strategies such as appropriate litigation and legal empowerment and the modality of short and participatory interventions.

After the presentations, participants worked in small groups to reflect on a few questions:

- How can my organisation use the international and national legal framework and global initiatives to advance our practice and struggles?
- What kinds of support do my organisation and I need to develop concrete strategies for the

short and mid-term?

- Am I interested in continuing this reflection and being part of an action group for indigenous populations and accountability at the local, regional and global level?

Moderator: Walter Flores, CEGSS Guatemala

The session was opened by **Walter Flores** from **CEGSS, Guatemala** with a summary of the two days sessions and provided an introduction on global initiatives that counter World Bank Projects. He laid out the expected outcomes of the session. He said that the key objective of the session was to form an action group with indigenous representatives from all the different regions of the world. As a follow-up to the symposium, the action group would be expected to develop a plan to advance health accountability for indigenous populations at local, regional and global levels.

Presentations from the panellists followed the opening remarks. **Ariel Frisancho** from **CMMB, Perú** shared his views on Universal Health Coverage. He said that the concept of Universal Health Coverage is mainly understood in terms of financial access, and the package of curative care drives it. He opined that the indigenous health workforce function in isolation; they do not receive any support from the government. He reflected that there is a big gap between the norms and the law and the laws don't get implemented. He stressed on the need of generating political will and creating capacity on both sides- the government and the community. He reflected that indigenous people are ignored as they are not politically relevant. He opined that it was significant to reflect on the systematic discrimination in the current landscape and work towards the initiatives required to address the marginalisation as we assimilate lessons learnt from the past.

PANELISTS

Jonathan Fox from **Accountability Research Centre (ARC), USA,** highlighted successful stories of countering World Bank projects which were impinging on the community rights. He outlined the history of social movements from the 1970s-80s in the Philippines and of Narmada Bachao Andolan from India. He said that there are ongoing struggles where people have shed their blood and tears and have got little outputs, but these struggles have led to significant policy changes. The grassroots level protests in the early 90s led to the creation of possible sets of reforms in terms of inclusion and gender equity, he said. The advocacy campaign in Uganda has led to policy shifts in the prevention of gender-based discrimination. He opined that citizen engagement is crucial for creating the possible sets of reforms that enhance the creation of grievance redressal mechanisms which are very much required. He expressed that the biggest challenge was connecting the dots between the different layers of government. He said that it is important to identify the pressure points, for example, the World Bank- which part of it is vulnerable to pressure. He emphasised that the main aim is to get inside the black box of these big institutions and understand where practitioners can play a role.

Ofelia Conceicao from **Namati, Mozambique,** shared experiences of efforts of legal empowerment of community by the civil society in Mozambique. She outlined that the community was being supported and trained in policies, and simultaneously the civil society supported the Ministry of Health in Mozambique. She said that though Mozambique has progressive laws and policies, these were not being implemented effectively. With Namati's efforts, slow change has progressed since March 2013. The approach used by Namati helps builds the gap between policy and processes. Namati is working in collaboration with Centro de Colaboração em Saude (CCS) through health advocates, who work towards increasing awareness on health policy. She added that the focus was also on strengthening the capacities of the village health workers as these were the people working with the most marginalised- such as those suffering

from HIV/AIDS, disabled etc. She closed her presentation with the success stories of the Namati's interventions like improvement in the infrastructure of the health facilities, drug availability, provider performance and availability of human resources etc.

DISCUSSION AND REFLECTIONS

- Inclusion of the LGBTQ community and the situation of the World Bank , working with the issues of the LGBTQ community? It was reflected that SOGI a body of the World Bank works with the LGBTQ community but who monitors this body, remains unknown. It was reflected that it would be significant for the World Bank to pursue appropriate projects that do not violate the rights of the indigenous community.
- The participants appreciated that the ability of the civil society to work together with the Ministry of Health in Mozambique and lauded that aspect of both the government and civil society pursuing the same goals.

The participants engaged in a small group discussion on the questions

- What do you think should be the priority of the COPASAH group?
- How do we address the cutting across issues?

The key points that emerged from the group discussion as further steps of action include:

- To reflect on global policies that are not in line with the local priorities, for example, increasing institutional delivery and ignoring the Traditional Birth Attendants and reflect on the need for legal empowerment of Traditional Birth Attendants
- Prioritise dialogue and reflect upon the question who is driving the agenda and taking violating rights
- Encourage the exchange of experiences among member from different countries as a step forward with COPASAH as the platform for practitioners coming together
- The strategy should be from the grassroots to the top level as the indigenous people live and understand their realities.
- Recognise the significance of the role of paralegal volunteers in making the community aware of their rights
- Use ICT like short films, videos and social media at the local level to promote advocacy work
- Identify common problems and organise international campaigns to defy the denial of rights of people

CONCLUSION

Overall the discussions in this theme were incredibly enriching as the cross-cutting issues were understood and the commonalities of problems of indigenous, marginalised and vulnerable people came to fore. Practitioners expressed a strong bond of solidarity as they resolved to solve their issues and challenges together through COPASAH.