Leaving no one behind: Health systems that deliver for all

ADVANCING A THEORY OF CHANGE (ToC): POTENTIAL OF SDGs TO TRANSFORM CONTEMPORARY REALITIES OF EXCLUSION TOWARDS REALISATION OF UNIVERSAL HEALTH COVERAGE/CARE

Date: October 12, Friday; 2.00pm-3.30pm,
Place: Liverpool,
Venue: Liverpool Convention Centre, ACC Room 11 A
Executive Summary

Session type: Participatory session

Contributors:

Chair: Lynn Freedman – Mailman School of Public Health, University of Columbia
Panel Discussion Moderator: Abhijit Das, Global Convener - COPASAH (India)
Country case study presenter 1- Latin America: Ariel Frisancho (Peru)
Country case study presenter 2-ESA: Aminu Magashi Garba (Nigeria)
Country case study presenter 3 – East-Southern Europe: Borjan Pavlovski (Macedonia ESE)
Country case study presenter 4 - South Asia: Renu Khanna (India)

Marginalised and disadvantaged communities, including Indigenous and ethnic communities world over have poorer health outcomes and share similar experiences of exclusion in accessing health care. This session, based on COPASAH members’ experiences of working on social accountability processes to challenge power-inequities, will explore possibilities of advancing a ToC towards UHC for adoption by health systems.

Health systems in diverse socio-political contexts of global south reflect the power and hegemonies they are embedded in, as experienced by the indigenous and other marginalized social groups. The indignity and vulnerability experienced in the face of insensitivity and unaccountability of the health care providers further perpetuates the cycle of discrimination and social exclusion in health care, further translating their vulnerability into human rights violations. This seriously impedes achieving the underlying goal of Health for All of Alma Ata Declaration, reflected both in Universal Health Coverage (UHC) and Sustainable Development Goals (SDG).

COPASAH facilitated community centred social accountability processes which include, inter alia, human rights and legal accountability approaches, community based monitoring of health services, and use of information communication technologies, have enhanced the negotiating power of marginalised communities to demand accountability from the health care providers and policy makers. Even as the practitioners across Latin America, East-southern Africa, South-eastern Europe and South Asia, continue to face challenges, they have leveraged their collective power to negotiate as empowered communities for improved access, equitable and affordable access to comprehensive health care.
Introduction

The Chair, Prof. Lynn Freedman, introduced the objectives and design of the session and laid out the key ideas around the issue of social accountability in health. Prof Lynn also laid out the broad context of discussing social accountability in health.

The workshop had a participation of 48 people drawn from various nationalities.

This workshop aimed at stimulating critical thinking of participants drawn from civil society organizations, practitioners, participatory action researchers, policy-makers and funders of accountability projects. All these are significant actors in making and implementing policies for UHC of the marginalized populations. The session aiming at advancing a theory of change that includes negotiating power through ‘community centred’ participatory and bottom-up social accountability processes. It had the following components:

a) The country case studies representing experiences of social accountability processes from four diverse geo-political contexts of indigenous and other marginalised social groups - viz. three from global south, i.e. South Asia (India), East-Southern Africa (Nigeria), and from Latin America (Peru), and one from South-Eastern Europe (Macedonia).

b) Mapping and analyzing contexts, actors, processes/mechanisms/pathways, and outcomes/changes observed in social accountability processes in the health system. The presentations highlighted the following issues:
   - The health policy and rights/entitlement GAPS that are identified and addressed
   - A detailed narrative of the processes and efforts done by the civil society to address such gaps
   - The outcomes, results and learnings from these efforts which are recommended to be adopted as measures towards achieving SDGs and UHC.

c) Facilitating participatory discussion and critical analysis on power asymmetries and negotiating power in health care through theoretical frameworks. This will be done through the group discussion who are formed into groups on the lines of (those who are working with or are) - excluded/marginalized communities; - front line service providers; - programme managers/designers/researchers; and, -policy makers/making

d) Theoretically framing the potentials of collective power of marginalised communities for transformation of their realities of exclusion for equity and dignity.
Panel Discussion

Abhijit Das, the panel moderator, facilitated a discussion around the issues of GAPS, PRACTICE AND LEARNINGS. The following were the panel members:

- **Macedonia**: Borjan Pavlovski, working with Roma People in Macedonia
- **India**: Ms. Renu Khanna, working with young girls and women in India.
- **Nigeria**: Aminu Magashi Garba, working on health budget advocacy in Western Nigeria
- **Peru**: Ariel Frisancho, working with policy issues on health and indigenous people

Copies of the written case-studies were provided to the participant.

**Country Case Studies**

*Country Case study (1) – Macedonia:*

**Social accountability for improved access to health services for Roma community**

Borjan Pavlovski, ESE, Macedonia

Since 2011 *Association for Emancipation, Solidarity and Equality of Women* (ESE), in partnership with local Roma CSOs is engaged with the social accountability work to improve health and access to health care for mothers and children among Roma communities in seven municipalities in Macedonia. In 2014, we also included Roma women’s access to preventive gynecological services. Our work includes Roma communities in four municipalities.

The work was focused on the preventive programs implemented by the Ministry of health. These programs are funded from the state budget and are aimed for vulnerable groups of the population. Our work is focused on the following programs and the respective services under each program: Program for active health care of mothers and children, regarding following services: immunization services, visits from the patronage (outreach) nurses during pregnancy and after the delivery, activities aimed for health promotion and health education; Program for medical check-ups of pupils with emphasis on activities for children out of educational system; Program for cervical cancer screening.

**Strategies and Processes**: Key strategies included (1) Community monitoring, (2) Social audit (community level in Roma communities) and, (3) Budget monitoring and analysis (local and national level).

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1 This is edited version of the document: *ESE’s Approach: Social Accountability*, available at [www.esem.org.mk](http://www.esem.org.mk)
Community monitoring.

- Entitlement awareness: About rights and obligations related to immunization, preventive health services for mothers and children, and cervical cancer screening.
- Mapping communities: Identifying Roma children at immunization age (0-15 years) covering 900 households, women for cervical cancer screening (age group 24–60 years) covering 1500 women in four municipalities.
- Information dissemination and rights awareness on programmes
- Community-based inquiry on utilising health services and about quality of service delivery and report cards by way of score cards.
- Public debates and discussions involving the community, and finding local solutions to issues

Social audit: Objective – To inquire on the delivery of health services by outreach nurses and gynecologists. Findings are shared with managerial staff at the municipal Health Centre in order to indicate to inconsistencies in delivery of services. Significance: There are no mechanisms on performance supervision at public health facilities, hence this fills the gap.

Budget monitoring and analysis: Objective: To examine planning and implementation of funds allocated under preventive health programs. This approach allowed us to establish trends in terms of allocation and spending of funds and to identify all anomalies and changes within the budgeting process, which have an impact on funds allocated and spent. Inadequate planning, inconsistency of anticipated measures, lack of public data, continuous increase of the health budget compared to decrease of budgets under preventive health programs, etc., are just few of identified gaps.

Advocacy: Findings from different levels are cross-checked and use measures aimed to improve health services state-of-affairs at local level (specific issues) and at national level (issues that are common). Every year results of the above strategies are used to develop local advocacy strategies and one joint national advocacy strategy. Local strategies are aimed towards adoption of changes at local and municipal level, while the national strategy aims to promote state-of-affairs at national level. The advocacy process is conducted with active participation of Roma communities.

Outcomes, results and learnings
- Empowerment of Roma community and especially Roma women
- Identifying accountability gaps, health care issues and problems, and articulate them with authorities
- Demanding accountability of decision makers and pressing for action for improving access to health care services
- Continued advocacy before competent state institutions for systemic changes to complement the local efforts at resolving obstacles to access
- Roma organizations, through this approach, have started actively involving communities in promotion of their health rights.
**Results of continued advocacy:** Municipal Health Center obtained vehicle for the patronage nurses, which was one of the identified obstacles for their work. Unfortunately the other obstacle, lack of nurses still remains problem, since national authorities don’t approve employment of nurses.

At national level, action was taken towards benefitting Roma women under the Program for Active Health Protection of Mothers and Children for 2018. Based on our demands in the last years, the program’s budget is increased to 17 million MKD in 2018 compared to 10.5 million MKD in 2017.

In the Program for Cervical Cancer Screening, through our advocacy work since 2016, Ministry of Health in 2018 introduced a series of measures to improve quality in screening performance and monitoring. For the first time Roma women are enlisted as vulnerable group in the Program for 2018. Budget for this Program was increased to 10.5 million MKD in 2018, compared to 6.7 million MKD in 2017.

**Learning and adapting newer strategic approaches:** After having perceived the need for integrated work, in 2015 ESE has started integrating the approaches of social accountability and legal empowerment strategy in order to maximize impact on the rights of Roma communities.

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**Country Case Study (2): India**

**Social Accountability for Adolescents’ Rights and Citizenship**

*Renu Khanna on behalf of SAHAJ Team, Vadodara, Gujarat, India*

**Manisha – an adivasi girl from Mahisagar District**

I am Manisha Parsing living in village Dotawada Village, Santrampur Taluka, District Mahisagar. I am 17 years old, and have passed Class 10.

Before the Kishori Group (Adolescent Girls’ Group around which the SABLA programme is organised) started in our village, we did not get our Take Home Ration, nor iron tablets regularly. After the group was formed - we are only ten girls in our group - we started having regular meetings in the anganwadi. SAHAJ arranged a leadership training for us. I have attended all the training workshops after I joined as a peer leader. After learning about Body Mass Index (BMI), I started measuring heights and weights of girls in our group. The anganwadi worker found it difficult to calculate BMI, so we decided to do it ourselves.

The nurse was not giving us Iron tablets regularly, we talked to her over the phone and now she gives us the tablets regularly. We started getting our Iron (Haemoglobin) levels checked. Kishori Divas (Adolescent Girls’ Day) was organised by us in our anganwadi.

I feel a lot of change in myself. Initially I used to feel scared to talk to anyone, especially in front of a group. But now I can talk anywhere, in front of any one!
Manisha is one of the 100 peer leaders nurtured by a collaborative project ‘Adolescents as Citizens and Change Agents for Social Accountability’ being implemented by SAHAJ and partners in four backward districts of Gujarat in western India.

The goal of the project is to create a model of leadership and citizenship amongst adolescent girls and boys (11 to 18 years) based on a gender and rights perspective.

Main activities of the project are to: increase awareness about gender, sexuality, and rights; promote collective action by local groups of girls and boys; and, advocate with stakeholders – like parents, government functionaries, and village leaders - on adolescent rights. The project is anchored on entitlements related to three government programmes – SABLA (adolescent girls’ empowerment and nutrition programme implemented through the anganwadi centres and the Department of Women and Child Development), ARSH (Adolescent Reproductive and Sexual Health Programmes implemented by the Health Department) and NYKS (Nehru Yuvak Kendra Scheme implemented by the Youth Department).

**Some Outcomes**
- Relevance for building citizenship and rights awareness among the adolescents and Marked increase in awareness among the adolescents about their entitlements (As reported in Review)
- The skills imparted equipped them to claim these entitlements.
- Successful mobilisation of other youth and member of the community to get new school building, improvements in the anganwadi centres, regular water supply, bus service to their remote villages, computer classes for the youth in the villages and so on, also using the instrument of RTI.
- Increased self-expression and ‘voice’ amongst the girls and boys.
- They have been able to negotiate for their rights and freedoms within their families, represented their collective issues in public fora like the Jan Samvaads (Public Dialogues).
- As part of Yuva Manch (Youth Platform), they have gone to the state level to ask why the programmes are not working well in their districts. Participation of the young people in public affairs is also beginning to increase going beyond the three select programmes.

**Challenges faced**
- It was especially difficult to involve school going adolescents in the community based programme.
- Initially it was difficult for the girls to get permission from their families to attend the group meetings.
- It took repeated visits and discussions and trust building by the NGO field staff before the girls were allowed to come for the project activities.
- It was difficult to have a continued intervention with the adolescent due to seasonal migration.
- Confrontation with the duty bearers after the rights and entitlement awareness, followed by threats and intimidation.
• Reluctance amongst the ICDS officers to admit the need for external monitoring of the SABLA scheme.
• The poor implementation of NYKS scheme and the ARSH programme resulted in non-response towards peer leaders’ efforts to claim entitlements – led to frustration among children.

Lessons learnt:
The adolescents as a group are effective change makers. The impact of inputs given to this group gets amplified once they acquire the necessary skills and information to claim their rights. However, there is also a need to take a differential approach considering the age group, educational levels, and socio economic and cultural contexts of the children.

Where adolescents are central actors in programme implementation, it is necessary that the parents and community members - such as local elected representatives or members of the Village Health and Development Committees- also be involved. This lends greater seriousness – and credibility - to the adolescents’ efforts to demand accountability of service providers. Since adolescents are a vulnerable group, there is a need to undertake additional measures to safeguard them from a backlash.

Country Case Study (3)- Nigeria

Social Accountability leading to the enactment and the implementation of the National Health Act in Nigeria; the role of Civil Society Coalitions

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BRIEF BACKGROUND

In Nigeria, the Government’s commitments to Universal Health Coverage resulted in the passage of the National Health Bill and its signature into law in 2014. Throughout the development and adoption processes, the civil society, professional bodies and media as well as the Health Sector Reform Coalition (HSRC) have been unceasingly advocating for the passage of the bill in to law.

This case study focuses on the advocacy efforts, prior to and after the passage in to law of the National Health Act (NHA). To carry out this case study, key informants have been interviewed as well as review of documents and secondary analysis.

The Health Sector Reform Coalition (HSRC) was established in 2011, explicitly in order to promote the passage of the National Health Act. Prior to that, numerous voices had taken a stand in favour of UHC but there was a need for harmonization. Therefore, the platform’s advocacy goal was very
clear since the start. It has about 35 organisations and has representatives of almost all states of the federation.

**ACTIONS**

*Advocacy activities for the passage of the National Health Bill/Act*

Advocacy activities have been undertaken at both national and federal levels. They first aimed at pushing for the passage of the National Health Bill, then for the assent and the gazetting of the Act. More recently, activities moved towards ensuring the fulfilment of the government’s commitments through the implementation of the Basic Health Care Provision Fund which the Act provided the legal framework for its implementation via the commitment of at least 1% of the government total consolidates revenue yearly from its annula budget.

Various advocacy actions have been undertaken, ranging from influencing individuals, organising public meetings and public hearings, directly protesting and using the media (publications in newspapers). Different target audience were influenced to pass the bill: first key members of the senate and the House of Representatives, then more broadly all Nigerian health and civil society stakeholders (in particular traditional and religious leaders), and finally policy makers, including the Presidency. Internationally acclaimed leaders, but also national “Champions” were also mobilised for the cause.

*Coordination with other platforms*

The HSRC collaborated with “Accountability for MNCH in Nigeria”, by convening meetings and seminars as well as mobilizing peaceful rallies to the national assembly to push for the final passage of the NHA. This collaboration was valued as it brought together two complementary platforms with different constituencies. The Coalition is the convener of the Nigeria Civil Society Working Group for the Global Financing Facility (GFF) which is now working with National Advocates for Health advocating for the Basic Health Care Provision Fund implementation.

The National Advocates for Health (NA4H) established in 2017, is a 26- member policy and advocacy think-tank comprising of distinguished individuals from diverse professional backgrounds committed to influencing national and state level health financing policies and programes. The Advocates lead high level advocacy to ensure adequate budgetary allocation for health, timely disbursement and spending of health budget in an efficient, transparent and accountable manner. The group has a seat representing Civil Society Organizations in the National Steering Committee of the Basic Health Care Provision Fund (BHCPF), its highest decision-making body with the Minister of Health as the chair.

The National Advocates for Health has developed, validated and shared the 2018 Basic Health Care Provision Fund and GFF Performance Scorecard. The bi-annual scorecard supports in-country civil society organizations, relevant stakeholders and interested members of the National Steering Committee of the Basic Health Care Provision Fund (BHCPF) to regularly monitor the performance
of the BHCPF and GFF. It also provides useful information for feedback, remedial actions and accountability.

The Basic Health Care Provision Fund (BHCPF), aims to extend Primary Health Care (PHC) to all Nigerians by substantially increasing the level of financial resources to PHC services. The Act provides that at least 1% of the federal consolidated revenue should be allocated to BHCPF. In 2018 the 1% is equivalent to N55.15b (USD 160m) allocated as a Health Capital Expenditure not a statutory transfer as the Act proposed.

IMPACT

Passage and assent of the National Health Bill in 2014
Building a momentum for the development of the operational guideline for the implementation of the BHCPF
Development of the accountability framework via annual performance scorecard that measures progress and gaps.

CHALLENGES

Limited funding for advocacy and promoting accountability and transparency.
Another challenge is the difficulty to raise and maintain members’ interest and commitment.

KEY RECOMMENDATIONS

- Continuously engaging with the Government at both policy making and accountability levels
- Coordinate with other initiatives such as the GFF

Country Case Study (4) PERU

Improving State Responsiveness to Accountability & Social Action in Health

Ariel Frisancho (Peru)

I. Citizen Monitoring to Promote Accountability on Health Services Quality and Rights’ Respect

- In the Puno Region in Peru, Quechua and Aymara women community leaders engaged with ForoSalud, CARE Peru and regional office of the Human-Rights Ombudsman to monitor women’s health rights, particularly the right to good quality, appropriate and culturally respectful maternal health services. Four key components make this initiative unique within Peru: taylor-made capacity building; citizen monitors’ visits to health facilities in pairs 2 to 3 times per week, discussing issues with female patients in their native language
about how they were treated, how long they had to wait to be attended, whether personnel complied with working schedules and whether they were provided with information in their own language; monitors documentation of findings and reports production and monthly analysis of findings with the regional Ombudsman's office, CARE Peru, the Departmental Officer for Integral Health Insurance (ODESIS) and ForoSalud members to generate a “dialogue agenda” for a meeting (audiencia) with the directors of health micro-networks, provincial hospitals, the head of the health establishments and their teams. In these meetings the monitors express their concerns and issues that need to be addressed locally. Monitoring and evaluation is conducted based on the minutes signed by the authorities present in the consultation meetings.

II. Summary of main findings

- On the basis of direct inter-action with rural women who use the services and individual and collective empowerment processes, women leaders are well positioned to demand information and changes in health services through dialogue spaces with local and regional authorities.
- The initiative has contributed with greater transparency, respect, cultural sensitivity in service delivery and increased demand of health services by rural women and children.
- It has helped to identify and detect bad practices that prevent rural women from seeking care (i.e., health services that are closed at times of peak demand, long waiting times, poor care, ignorance of standards that promote culturally appropriate vertical delivery and improper charges for services and medicines that should be free)
- It has installed, for the first time, systematic spaces for dialogue and local consultation between health care providers and rural women, in which they express what they expect from health care services and the strengths and weaknesses of existing health care.
- It contributes with the agreement of commitments for the improvement of health care (opportunity, treatment, information, language, culture)
- The initiative has contributed to create conditions for the empowerment of women and to address unjust power relations between health providers and rural women
- The initiative has contributed to better understanding of the rights of health care services’ users
- Health care providers and authorities are accountable for their successes and shortcomings with respect to the needs of the population

II. Qualitative & Quantitative studies’ findings on the initiative’s impact

- Both monitors and health care authorities and personnel report that monitoring has started to change practices in some local health care facilities.
- However, there is still a long way to go before doctors and other health care professionals recognize the problems faced by health care users: some providers do not recognize issues of discrimination and mistreatment and instead focus on issues related to organization and service management – i.e., lack of drugs -, arguing that it is outside of their responsibilities.
Some attempt to justify problems such as user mistreatment by referring to their own poor working conditions – low salaries, inadequate infrastructure and equipment, and understaffing.

- Diverse studies show a variety of positive changes in the health care services where citizen health monitoring was implemented, as improved progress in health care indicators (positive differences observed in a) the opportunity of the control of the pregnant mother (early control), b) the coverage of pre-natal control, c) care during institutional delivery, and d) access to laboratory tests provided by the Integral Health Insurance (SIS). Quantitative data showed increased access to culturally appropriate birth delivery - vertical birth delivery - from 194 in 2008 to 437 in 2009 in Azangaro Province.

- Discriminatory and abusive behavior has diminished, as have incidents of illegal charges and culturally insensitive care. This may have translated into greater usage of local health facilities.

- In health centres where social monitoring was introduced there was four times higher awareness of complaint mechanisms. Equally, where social monitoring was introduced, the percentage of users with complaints was twice as high. This has driven both a rise in expectations and an improvement in the quality of services, but not at the same rhythm that expectations have increased.

- Citizen monitors report significant positive changes to their ability to play a public role. They state that their involvement in monitoring has increased their leadership ability, their confidence in dealing with officials, and their capacity to act effectively in the public sphere.

- Participation in monitoring is a volunteer activity that entails significant costs for monitors in terms of time and resources. However, monitors clearly value their involvement in the initiative, and even inactive monitors interviewed indicated their intention to return to monitoring when their circumstances would permit it.

- Building on the citizen monitoring model in Puno, political advocacy led to launching in 2011 of National Policy Guidelines for the Promotion of Citizen Monitoring of Health, institutionalizing, for the first time, citizen monitoring as part of Peru’s national health policy. to dialogue for other civil society organizations as well.

- The experience has also been hailed as an example of best practice at international level. The first report produced by the UN Commission and the World Health Organisation for Information and Accountability regarding the health of women and children - Independent Expert Review Group (iERG) for Information and Accountability for Women’s and Children’s Health – in September 2012 included eight examples globally of how to promote citizen participation and accountability. CARE Peru and ForoSalud’s initiative with social monitoring in Melgar and Azángaro was one of the case studies.
Group Discussion

The Chair then, quickly briefed on the methodology of the discussion. Keeping in mind the nature of the participants, instead of the work in four small groups, it was decided to have a generic discussion. The group discussion aimed at eliciting the experiences of social exclusion, strategies practiced in facilitating community analysis and negotiations and the components of context-actors-mechanisms/processes and outcomes. The following questions guided the discussion:

- What are the main gaps that you feel that marginalized communities have to face?
- Are these gaps and issues specific to particular communities/locations or is it generic as applicable to larger sections of marginalized communities?
- What are the additional efforts/interventions needed to address such gaps and to fulfill SDGs?

Synthesis:

The chair synthesized the points of discussion. The key points contributing to Theory of Change on social accountability included the following:

- The social accountability cannot be limited only to a few tools or events such as score cards or discussions.
- Social accountability centres around the power of citizens and communities to act.
- In more than one ways the power of citizens is expressed as power to demand, power to question, power to dissent and power to engage.
- Most of the health related programmes designing itself is top-down and non-participatory. The power to demand participation itself is a huge gain the process.
- Evidence, emerging the engaging the communities, has a great potential of validating demands and leveraging citizenship.
- Social accountability in terms of galvanizing citizenship is a continuous process of engaging citizens with these issues, augmenting citizen and community voices.
- The various country studies demonstrated the need for innovative methodologies, occupying and capturing of spaces for making these voices heard.

. S/he also invited volunteers from participants to collaborate in the further work of developing a brief. An announcement on the advancement of this theme through the global symposium was made.

E. Premdas Pinto, the Symposium coordinator, introduced the global symposium and its theme of Citizenship, Governance and Accountability. He informed that the theme no. 1 of the symposium is a
generic theme on social accountability provided an opportunity to further fine tune the ideas emerging from this workshop.

Conclusion

*The Chair closed* the session by thanking everyone for their participation and contribution.
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