Engaging communities: the key to leaving no one behind in the era of UHC

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Introduction

In the long history of global health efforts, universal health coverage (UHC) holds the promise of reframing the global health agenda by encompassing both the goal of “Health for All” as well as the principle of the right to health, underpinned by the Sustainable Development Goals (SDGs) in which the goal of UHC is firmly located. The right to health means not only equity in access, availability, acceptability and quality of health services but the inclusion of financial protection mechanisms so that households are not impoverished through the act of accessing necessary health care. Equity in access, we argue, includes paying attention to the sexual and reproductive health and rights needs and challenges of marginalised groups which historically have not been adequately met, yet present an opportunity for the most far-reaching and sustainable investments we can make to health in developing countries.1

Domestication of UHC is as much a political process as influenced by economic considerations, with implementation at varying levels across East and Southern Africa (ESA). Amidst the many conversations around how to translate the aspiration of UHC into action in the ESA region, it remains vital to ensure that the operationalisation of the UHC framework at national level aligns with the SDG vision of “leaving no one behind”. This means considering how UHC reforms can contribute to reducing health inequalities within and between countries and how this can be best achieved and sustained. Addressing these questions requires the need to ensure inclusiveness, transparency and accountability in decision-making processes through meaningful, consistent and sustainable engagement of affected communities.

Leaving no one behind

Despite the move to implement UHC at country level, those who are marginalised, who suffer human rights abuses and/or who are vulnerable on the basis of gender and age, amongst other factors, continue to remain at risk of “being left behind”. For UHC to successfully address the pervasive and deepening health inequalities, health systems must focus efforts on reaching disadvantaged groups rather than serving, as historically has been the case, those who are easiest to reach.2 Male, female and transgender sex workers, for example, bear a disproportionate burden of HIV and STIs compared to the general population. However, they face particular challenges in accessing the necessary health care due to stigma and lack of sensitisation and training of health providers over their respective sexual and reproductive health (SRH) needs. In a recent online survey amongst 502 respondents, including people living with HIV, key populations and other young and vulnerable groups, nearly half the respondents (49%) reported that UHC did not cover everyone in their communities in their countries.3 Those who were not being included were primarily sex workers, undocumented migrants or foreigners, refugees, migrants and/or foreigners with a valid
resident permit, and people who were homeless.\textsuperscript{3} Further, young people most often reported that they could not access quality services because they did not have the money to pay for them.\textsuperscript{3}

The notion of including communities in health efforts is not new, with the success of the HIV response providing a clear example of the important role of not only community participation but community engagement. More recently this has been recognised in Agenda 2030 stating that “responsive, inclusive, participatory and representative decision-making at all levels” is critical to the attainment of the SDGs, recognising that enabling more meaningful engagement from community-led and civil society organisations (CSOs) constitutes a key catalyst to achieving the health-related SDG targets and ensuring that no one is left behind.\textsuperscript{4} However, communities still largely lack voice in conversations around UHC and there remains a lack of transparency around how UHC will be realised, particularly for marginalised groups. The political commitment behind UHC offers community organisations more power to demand to sit at the table where decisions around their health needs are being made and to discuss what quality care looks like for the different groups. Ensuring that UHC builds on principles for engagement of key and vulnerable populations, in the well-established pathway of the GIPA\textsuperscript{*} Principles for the HIV response, and a recognition of the rights of key and vulnerable populations, including their right to self-determination and participation in decision-making processes, is an essential step to ensuring no one is left behind.\textsuperscript{5}

Resistance to a rights-based approach to health and sexuality is significant and is a threat to the vision of leaving no one behind, despite global consensus over a progressive development agenda. Harmful social sentiments and norms at the highest level fundamentally shape the health of communities by perpetuating gender inequalities and by creating an environment in which sexual and gender-based violence as well as a limitation of individuals’ rights to bodily autonomy and integrity is the norm. Within contexts such as these, the ability to decide when, how many and if they wish to bear a child is highly constrained for many women and girls, particularly those who are the poorest. Young people lack understanding of their maturing bodies. These inequities extend to the health system in the ESA region, where women and young people continue to face legislative and other discriminatory barriers to accessing health services. Criminalisation of sex work and same-sex relationships and prohibitions and restrictions placed on safe abortion care promote marginalisation and poor health. For example, in Botswana, Malawi, Mozambique, Namibia, Tanzania and Uganda, prisoners are not allowed access to condoms or lubricant because same-sex conduct is criminalised. Even more critical are those uniquely vulnerable sub-groups of young people who are marginal amongst those already marginalised since they are also negatively impacted by age of consent laws. These include young women who sell sex, migrants and refugee girls as well as a number of other not merely young, but particularly adolescent, key populations.

These collections of circumstance make it even more critical to ensure community engagement. Addressing legal and policy barriers, as well as harmful social, traditional and cultural norms that prevent groups of people from receiving health services, is a necessary step that needs to be at the heart of UHC reform. Marginalised groups have first-hand experience of the impact of these violations and are therefore central to identifying gaps between their health needs and services and leading the way in addressing the health challenges facing themselves and their peers. Engaging communities, including health care providers who both live in and serve the community, is key to start breaking through some of the silences around the SRH needs and rights of young people and to better understand broader community-level health challenges and needs. In addition to drawing on their lived experience to influence policy, programme design and implementation, affected communities play a key role in holding governments and health-related organisations accountable for ambitious SDG3 + commitments.\textsuperscript{4} They also ensure social accountability and foster transparency by serving as watchdogs and independent monitors to ensure the availability, accessibility, acceptability and quality of services. For example, a project supported by ARASA in Malawi between 2012 and 2014 ensured social

*Greater involvement of people living with HIV and AIDS.
accountability through support to a cohort of 25 Community Health Advocates (CHAs) from the affected communities who were linked to local clinics to monitor access to services and commodities as well as human rights violations. Amongst others, the CHAs discovered and resolved supply chain challenges and corruption to restore the uninterrupted supply of antiretroviral treatment in Karonga district in the Northern part of Malawi.

Lastly, service provision must be strengthened. Despite the well-established SRH needs and recognition of their significance to development in the ESA region, these interventions are not necessarily being prioritised in UHC reforms. Inclusion of essential SRH interventions into UHC can be one of the most far-reaching, and sustainable investments to be made to health and development. Not only are SRH interventions health-promotive, preventive, inexpensive and, in the long run, cost-effective, but these interventions also contribute towards achieving UHC’s broad health and development goals through being inclusive of the rights of key and vulnerable populations. In addition, the integration of SRH into UHC reforms can arguably assist governments in ESA to maximise health outcomes without alienating any of their larger constituencies or compromising management of other urgent health issues. That is, the UHC umbrella affords Africa’s Health Ministers opportunity to make provisions under the “health” rubric in places where SRH encounters cultural and societal normative resistance.

Addressing gaps in coverage of key SRH interventions, especially for population groups who are marginalised and disadvantaged and for services that are stigmatised, is crucial to realising rights and attaining equity, as well as to reducing preventable mortality and morbidity and minimising the health, financial and economic burden on families, communities and nations. In the region, Rwanda serves as an example, having included interventions across most of the nine essential SRHR categories in their health insurance benefits package.

The role of civil society

In order to contribute to increased access to health services for all under UHC, civil society and community voices need to be increasingly involved in the broader UHC planning, implementation and monitoring processes. This includes being engaged in some of the more technical discussions around how health services are delivered and financed, as this is where the broad political UHC strokes are operationalised into specific services and interventions and where trade-offs are being made. More specifically, civil society must be involved in the country processes for defining the UHC package of services to ensure that SRHR interventions are prioritised according to equity-adjusted cost effectiveness analyses and that principles of quality of care, equity in access to services and accountability are considered. This is critical to ensure that the most effective interventions are provided to the entire population. Financial and capacity investment in the next generation civil society and community-based organisations will be crucial to this process to ensure that community representatives are able to participate fully and knowledgeably in UHC discussions. Key, marginalised and vulnerable populations must have the right to organise, mobilise and be legally recognised and protected to ensure that their communities are represented in key decision-making platforms and processes. Civil society organisations are challenged to go beyond merely including the “usual suspects” in national and regional stakeholder consultations and to consider innovative ways for including those often left out because they are hard to reach as well as those community members who bear influence within their communities.

As we increase efforts to tackle inequity in health care, creating a more permissive environment and strengthening service provision, civil society and communities are well-positioned to hold their governments accountable for matching political commitment with mobilisation of resources. They are also well placed to remind Nation States and their implementers of the vision of the SDGs, thereby drawing attention to groups at the extreme edges of vulnerability and ensuring that the principles underlying the prioritisation of services support equity, human rights and gender equality. The global health crisis in the form of COVID-19 has cast into sharp relief existing health inequities and poor health outcomes amongst disadvantaged or marginalised groups of people and compels us to think critically about how to address these inequities through
the achievement of UHC. After all, UHC is about equity, dignity and human lives.

Disclosure statement
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