What do we know about marginalised people in the health sector?

Since the publication of the 2004 World Development Report, there has been a growing recognition that decades of investments and action in global health have not led to equitable health gains for all (World Bank, 2003). With the 40th anniversary of the Alma Ata “Health for All by 2000” declaration in 2018, there is renewed interest in strengthening primary health care and the expansion of basic health services as a means of achieving greater health equity. The new Director-General of the World Health Organization (WHO), Tedros Adhanom Ghebreyesus, has made clear his desire for a global movement to push for Universal Health Coverage (UHC) by 2030 (SDG target 3.8). Taking a UHC approach challenges established practices within global health financing, governance, and national-level policy-making processes that have long favoured biomedical and vertically-controlled health interventions.

At its core, a Leave No One Behind approach asks why there has been stagnation, and in some cases decline, in health outcomes for certain groups (Labonté et. al. 2007; Marmot, 2007; Commission on the Social Determinants of Health, 2008; Yazbeck 2009; World Health Organization, 2015a). According to Global Health Observatory data, 35% of children under five from the poorest quintiles experience stunting versus 16% of children in the richest quintiles in 85 countries. In 54 countries, 37% of women with no education have their family planning needs satisfied versus 53% of women with secondary education or higher.
Within health systems, marginalised and vulnerable individuals and groups are caught in a vicious cycle. By definition, to be marginalised is both a cause and an effect of poor health. That is, being in a state of poor health can lead to social exclusion, economic hardship and political marginalisation; while social exclusion, economic hardship and political marginalisation are contributing factors of ill-health. Health systems are highly politicised social systems. Across all levels and activities within a health system, social rules and norms contribute to different levels of exposure to disease, or vulnerability to ill-health, and to different levels of access to promotive, preventive, curative and rehabilitative care. Intersecting patterns of social difference such as economic status, geographic location, gender, religion, ethnicity, race, disability, age, health status, educational status play a substantial role in determining whether individuals and groups can achieve good health and wellbeing, and prevent or treat ill-health.

There is less available data on how experiences of marginalisation and exclusion intersect and further complicate the potential for health and wellbeing (Bates, Hankivsky, Springer, 2009). We know there are big gaps between the poorest and richest households, and between rural and urban areas when it comes to health outcomes (United Nations, 2015). We know that women are more likely to live in poverty than men, and that they are less likely to have a voice in public policy processes that impact on their wellbeing (op. cit). We know that indigenous people experience high rates of ill-health across a range of indicators (Hernandez et. al., 2017). However, these are top-line inequities in health. Patterns of inequity vary from country to country, so a “one size fits all” approach to health systems strengthening is insufficient where an leave no one behind agenda is concerned. In practice, this means that, for example, being female, indigenous and living in a rural area shapes health outcomes in ways that are different from being female, indigenous and living in an urban area; or female, living in a rural area, and from an ethnic majority group. For the purposes of this Working Aid, we have listed generic categories of marginalisation below but when it comes to planning and programming, it is crucial to think carefully about how these categories of marginalisation interact when it comes to accessing health services.

1. Geographic marginalisation
   Access to primary health care services or any higher level of health care depends greatly on where you live. In rural, urban and peri-urban settings, there can be substantial barriers of access due to a lack of sufficient health care infrastructure, lack of transport, lack of a trained and consistently available health workforce, and lack of political will to prioritise resources in marginalised communities, which are marginalised due to political and historical patterns of exclusion, or due to contemporary conflict and violence. Solving one dimension of geographic marginalisation will not resolve the broader issue; for example, building new health clinics without a parallel investment in locally-based health workers to staff the clinics.

2. Gender status and sexual orientation
   The ways that gender and sexuality shape health outcomes is manifest across the whole of the health sector, not just in the field of sexual and reproductive health and rights which is where the issue of gender tends to be siloed (Bates, Hankivsky and Springer, 2009). At the top-level of global health indicators, it is clear that gendered differences in behaviours and risks can contribute to poor health outcomes for both women and men, girls and boys (Hawkes and Buse 2013). It is also the case that the stigmatisation of sexual orientation and gender identities is a factor in shaping health behaviours and risks, as well as contributing to individual and group access to health services. The particularities of how gender norms impact on health varies widely across cultures and contexts, requiring analysis on a case-by-case basis.

3. Health and/or disability status
   In spite of legal frameworks and global commitments that enshrine access to basic health services for all citizens in a given national context, the reality is that stigmatisation of a wide range of physical and mental health issues can limit access to health services and to health literacy (see below). How stigmatisation plays out will vary widely by socio-cultural context and the politicisation of certain health issues. Disability status can impact on access to health information (e.g. not produced or delivered in a form that is accessible); access to health service infrastructure, and access to health entitlements, where there are weak or absent accountability mechanisms.
4. Ethnicity, race, religion and origin

Ethnicity, race, religion and origin are markers of social difference. Depending on the context of a given health intervention, there may be particular groups that are excluded from the benefits of the public health system, either wholly or partially, due to discriminatory practices, as well as patterns of exclusion that shape health institutions over time. For example, in countries where indigenous populations or religious minorities have been the direct targets of state-sponsored violence, there can be substantial barriers of trust between these communities and representatives of the public health system including doctors, nurses, auxiliary nurses, community-based health workers. Another marker of exclusion relates to origin, which often affects migrants whose access to health services may be limited due to structural, economic, social or cultural factors and whose exclusion may be particularly exacerbated when in an irregular status.

5. Education and health literacy

Health markets – that is the buying and selling of medical knowledge, services and supplies – are, by their nature, defined by “information asymmetries” (Bloom and Standing, 2008). The patient, or consumer, is at a disadvantage in the exchange because of the highly specialised nature of medical knowledge and practice. Therefore, across countries and cultures, it is the case that the less powerful members of society face the greatest difficulties in navigating the health system to meet their needs. This is even more the case when there are substantial disparities in educational status between the health service provider and the individual or group on the receiving end of health services.

How to make a good diagnosis of marginalisation in the health sector?

The challenge, then, is to make a diagnosis that sufficiently accounts for overlapping and intersecting patterns of exclusion that impact on health outcomes. In addition, it is crucial that this diagnosis takes into account the ways in which marginalisation operates at multiple levels within a health system, for example, at the level of access to basic health services, at the level of resource allocation and prioritisation at the regional level; and at the level of legal protection and policy action at national and transnational level. There is no perfect tool that will enable this type of diagnosis, as intersectional analyses of marginalisation in health systems are a developing area of research (see Waldman, Morgan and Theobald, 2018). However, a combination of the four tools and approaches suggested below will generate a more accurate understanding of the patterns of exclusion and barriers to positive health outcomes and enable programmatic action to implement the Leave No One Behind principle.

1. Disaggregated data collection

The first step towards a better understanding of the scope and nature of marginalisation is to begin to build in disaggregated data collection at both the planning and implementation stages of a given project. The WHO is building up a health inequalities monitoring database on a country-by-country basis, which can allow for a broad understanding of patterns of marginalisation in health systems (WHO, 2017c). However, these data are not of sufficient detail when it comes to intersecting patterns of marginalisation and exclusion at sub-national, regional or local level. It will not be feasible to address the whole range of possible social identifiers of difference, but depending on the nature of the intervention, a good place to start is to pick at least two or three categories of marginalisation relevant to programmatic action and track change over time across these categories. In practice, this might mean instead of simply tracking how many men and how many women participate in project activities, you might develop sub-categories that break down participation further by age, ethnicity, religion and health status. This type of data collection will begin to generate a clearer picture of who is benefiting and who is not within the context of SDC programming.
2. Gender and intersectionality analysis
The starting point of a gender and intersectionality analysis is to understand that health systems are not gender neutral and that they are structured by unequal power relationships. Therefore any action aimed at making health systems more equitable necessarily requires a gendered and intersectionality approach. Here we take gender to mean “the socially constructed roles, behaviours, activities and attributes that a given society considers appropriate for males, females and other genders” that impact on how people “live, work, and relate to each other at all levels, including in relation to the health system” (Morgan et. al, 2016; p. 1069). Gender analysis, and the related endeavour of intersectionality analysis, can be incorporated into health programming content, process and outcomes (Morgan et. al., 2016). At the level of content, the sex-based disaggregation of data (mentioned above) and gender analysis frameworks and questions, can help to steer programme design and decision-making towards greater gender equity. In terms of process, gender analysis enables critical reflection on relationships of power and how they may shape the ways in which questions are asked, analysis is made and strategies determined. Finally, in terms of outcomes, a gender and intersectionality approach can build an understanding of how to transform power relations within health systems in ways that can help to meet the commitment to leave no one behind (see also, Larson et al., 2016).

3. Stakeholder analysis and accountability mapping
Accountability is increasingly being instrumentalised as an intervention to improve health systems performance and health outcomes. As with the politics of evidence (Pankhurst, 2017) and or the politics of gender and other forms of social exclusion in health systems, accountability is also concerned with relationships of power as these are mediated at multiple levels of health service delivery and decision-making. To understand how relationships of power can constrain or open up pathways to change in health systems, it is necessary to map out the key stakeholders of a given health intervention and the relationships of accountability that structure their interactions (Hernandez et. al., 2017). For example, one common approach to improving health system performance at the local level is the use of a "community scorecard" to identify, track and remedy issues of poor or inadequate service provision at the local level. Such an approach, however, can mistakenly put increased pressure on the least powerful actors within a health system such as front-line community health workers or auxiliary nurses, who cannot control the resources they are allocated (medical supplies, medicines) or the support they are given (training, supervision) to perform their roles. A stakeholder and accountability mapping approach, using the Brinkerhoff matrix as a starting point (Brinkerhoff, 2004), can help to begin to identify how relationships of power play out within a given set of health systems actors in ways that may promote or inhibit the marginalisation and exclusion of certain groups.

4. Participatory research and planning approaches
A vital way to steering programme activity, policy action or advocacy work in the direction of greater health equity, is to directly involve the least powerful and most marginalised groups in the process. There are a wide range of participatory and socially-inclusive approaches on offer many of which are already in use within SDC's Health programmes. When recruiting participants to be involved in the diagnostic process, it is important to avoid drawing upon the “usual suspects”, by which we mean community leaders, religious leaders or other local gatekeepers with substantial informal and formal power at the local level. Once a basic level of diagnosis of marginalisation is achieved using the previous three steps, the goal of participatory research should be to continue to test and refine the assumptions on which the health action is premised (Belle-Isle, Benoit, and Pauly, 2014). Without consistently including the perspectives of those at whom the intervention is targeted, there is still a risk that the project or programme will inadvertently reinforce the very hierarchies of power it seeks to disrupt.
Entry points to leave no one behind in the health sector

There are no simple answers when it comes to addressing marginalisation and exclusion in health systems and in the global health sector. It is important to recognise that patterns of marginalisation and exclusion change over time, and therefore, an adaptive learning approach is a prerequisite for any attempt to address health inequities. It is crucial to embed a learning process within the design of a health programme, one that involves participatory engagement with key populations and intersectoral action, so as to continually revisit the question of “who isn’t benefitting and why?”

There is already a substantial body of knowledge within the SDC and partner organisations on a range of strategies and tools that can be used to design and implement pro-equity health programmes (see SDC Strategic Framework 2015-2019, Global Programme Health, the WHO’s Innov8 technical handbook and facilitator’s handbook, and the WHO’s National Health Inequality Monitoring Manual, all cited below).

Between 2015 and 2016, IDS and SDC conducted a learning trajectory on the topic of equity and inclusion in health. Through this learning trajectory, the group identified the following entry points to Leave No One Behind in the health sector:

- Support multidisciplinary studies to document patterns/drivers of marginalisation and exclusion and their impacts on health outcomes for vulnerable groups;
- Strengthen policy analysis and strategic planning to address barriers of equity;
- Strengthen capacity for monitoring and enforcement of existing regulations and established health entitlements;
- Strengthen the capacity of stakeholders to gather information and influence change.4

In addition to emerging protocols and strategies within SDC related to Leave No One Behind in the health sector, the WHO has also developed the ‘Innov8 approach’, with the explicit objective of supporting country programmes in the attainment of SDG3 (WHO, living document version 2016). The Innov8 manual outlines concrete steps to diagnose and address health inequities at a national level. It is limited in that it targets country-level health managers and staff, and thus national level health decision-making processes (rather than dealing with the nuances of exclusion and marginalisation as they play out at local and sub-regional levels). However, it is helpful in that it highlights the importance of challenging and revising programmatic theories of change and programme design as part of a multi-step process.

Fig 1. The “Innov8 approach for reviewing national health programmes to leave no one behind”, World Health Organization (2016), p. 10. Reproduced with kind permission from the World Health Organisation (WHO)
References


Endnotes

1 Health inequity here refers to “those inequalities that are deemed to be unfair or stemming from some form of social injustice” (Kawachi, Subramanian, Almeida-Filho, op. cit.), as well as those health differences that are “avoidable” and preventable when viewed from the standpoint of the human right to health (Whitehead and Dalgren, 2006; WHO, 2015a; Braveman and Gruskin, 2003; Farrer et. al., 2015). Thus, all action targeting the reduction of health inequities first demands a moral judgement on what is “right, fair or acceptable” in a given society (WHO, 2015a, p. 5).

2 Up-to-date Global Health Observatory data can be found here: http://www.who.int/gho/health_equity/en/

3 Health inequity here refers to “those inequalities that are deemed to be unfair or stemming from some form of social injustice” (Kawachi, Subramanian, Almeida-Filho, op. cit.), as well as those health differences that are “avoidable” and preventable when viewed from the standpoint of the human right to health (Whitehead and Dalgren, 2006; WHO, 2015a; Braveman and Gruskin, 2003; Farrer et. al., 2015). Thus, all action targeting the reduction of health inequities first demands a moral judgement on what is “right, fair or acceptable” in a given society (WHO, 2015a, p. 5).

4 Adapted from meeting notes Tirana F2F September, 2016 and Erika Placella, presentation at SDC headquarters, October 2017

Imprint

Editor:
Swiss Federal Department of Foreign Affairs FDFA
Swiss Agency for Development and Cooperation (SDC)
3003 Bern
www.fdfa.admin.ch/sdc

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Zoi Environment Network, Geneva/Switzerland

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