

Realizing the right to health for minorities and indigenous peoples

By Corinne Lennox and Carolyn Stephens

Introduction

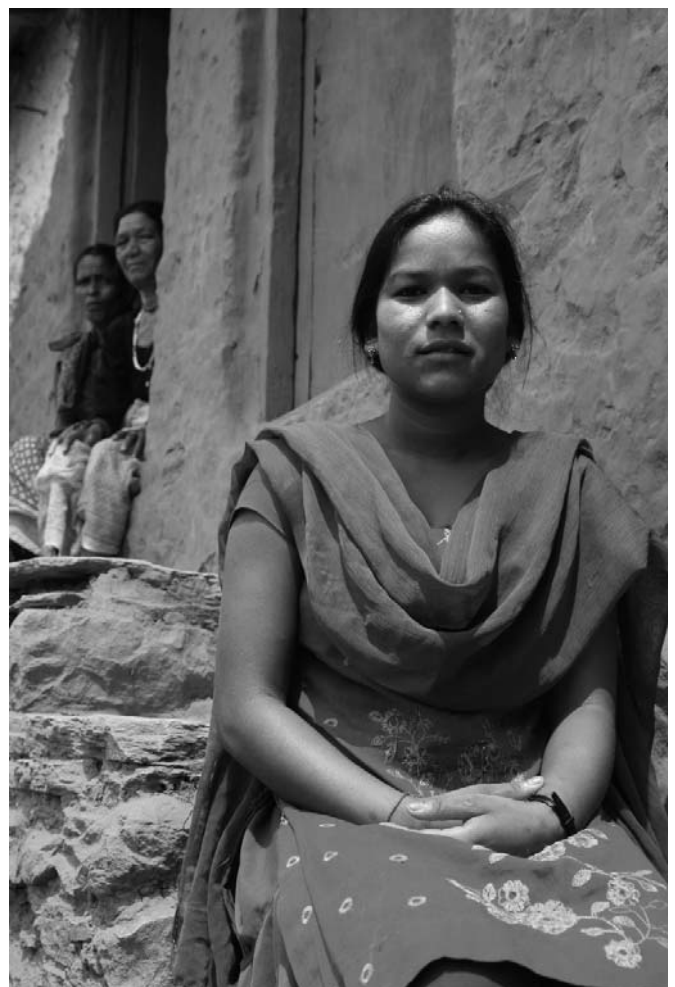
by Carolyn Stephens

'What I think is that well-being is living better, living well. Because ... "well-being" means being well in the family, being well in the home, in good health, not ill, and another thing is eating, or having food in the home – there's beans, corn, food; it means not suffering hunger, not suffering illness, not suffering in your thinking either, because if you're bad in your mind, that means not living well. That's what well-being is about.'
Gaspar Castro Uz, 68 years old, K'iche' Maya indigenous group, Santa Lucia la Reforma Municipality, Totonicapán Department, Guatemala.

Many minority and indigenous groups have a concept of health that is close to the idealized World Health Organization (WHO) description of 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. It is important to realize that for many minorities and indigenous communities, 'health' is a concept linked to the community not the individual, has an important spiritual element and relates strongly to the well-being of the ecosystem and planet.^{1,2} This has important implications for how we measure and treat health in minorities and indigenous peoples. Western medical models treat symptoms of individuals, and measure 'health' with statistics of individual illness and mortality. This is important when we discuss minority and indigenous health as it influences how and what we measure to evaluate the health context of these groups. Critically, the ways in which minorities and indigenous peoples conceptualize health contrast with the ways in which most governments measure health. Their understanding of health also contrasts with the majority of health indicators collected internationally, and with the Millennium Development Goals (MDGs), and their standard indicators

of disease and death rates. But even using these more standard indicators the picture of minority and indigenous health is alarming.

This briefing summarizes MRG's *State of the World's Minorities and Indigenous Peoples 2013* report, which looks at the health situation faced by minorities and indigenous groups worldwide. Improving minorities' and indigenous



A DALIT WOMAN WHO WORKS AS A COMMUNITY PUBLIC HEALTH PROMOTER IN NEPAL. JANE BEESLEY/OXFAM GB.

peoples' health is a critical, but complex, challenge. In some regions, indigenous peoples are unrecognized and uncounted in government data. In every setting, where evidence is available, minority and indigenous health indicators lag behind indicators for the majority and non-indigenous populations. And in almost every setting, this health inequality is rooted in discrimination and marginalization of minority and indigenous groups.

It is important to realize that discrimination against minorities and indigenous peoples has a long history. Policy approaches have to address centuries of prejudice, which in many settings has been accompanied by the ethnically-motivated killing of minorities and indigenous peoples. Five hundred years ago in Latin America, millions of indigenous peoples were displaced or killed, or lost their lives to diseases introduced during the Spanish and Portuguese invasions. In Asia, Africa and the Middle East, the situation of minorities and indigenous peoples is linked to their historical relationship with majority ethnic or religious groups. In India, indigenous groups, known as tribal peoples, are often seen by scientists and policy-makers from the majority culture as backward, and their health problems are blamed on their culture and bad habits.

To an extent, the policy support and attention minorities and indigenous peoples receive in their countries relates to the size of their populations. In some countries, for example Bolivia, indigenous peoples are the majority population, and there is an indigenous president. However, in most countries indigenous peoples are a minority of the population, and often culturally diverse in terms of both the majority population and other minorities, with very different ways of looking at health and their own health systems. For example, according to the 2000 Census, China has 55 different indigenous populations, totalling 104.49 million people, but comprising only 8.1 per cent of the country's total population. Each of these groups has their own language and culture, highly different from each other and from the majority culture.

Different regions and countries have very different approaches to revealing the health situation of their minority and indigenous populations. As we know globally from scientific studies and government reports, indigenous health data is better documented in Australia, North America and New Zealand, where approximately 1.1 per cent of the world's indigenous populations live. The health of minorities and indigenous peoples in lower income regions, including Latin America, South Asia and Africa, has received significantly less scientific and policy attention. Key themes in MRC's *State of the World's Minorities and Indigenous Peoples 2013* report include:

- Lack of data: minority and indigenous identity is not recognized by some national governments, and where it is recognised, data is rarely routinely collected or disaggregated.

- Some governments actively resist disaggregation of data which might reveal the health effects of political discrimination and marginalization on minorities and indigenous peoples.
- Where data exists, evidence suggests that, in all settings, minority and indigenous peoples suffer extreme ill-health, and many population groups are at risk of demographic extinction.
- Minorities' and indigenous peoples' concepts of health differ from western biomedical models. For example, indigenous peoples see their personal health as intimately linked to that of the wider community and ecosystem in which they live – rarely focusing on individual well-being.
- Socio-political factors linked to marginalization and colonialism, and relationships with land and environment, are seen as fundamental determinants of minority and indigenous health.

In this briefing we outline the ways in which policy-makers can address the health inequalities experienced by minorities and indigenous groups, focusing on the post-2015 framework. These recommendations itself build on years of activism by minorities and indigenous groups, which led to the adoption by the United Nations General Assembly of the UN Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities in 1992 and the Declaration on the Rights of Indigenous Peoples in 2007 (UNDRIP). The two Declarations finally put the rights of minorities and indigenous peoples explicitly onto the agendas of the nation states of the world.

At the time of UNDRIP's adoption, Victoria Tauli-Corpuz, Chair of the UN Permanent Forum on Indigenous Issues, released a statement to the United Nations General Assembly, which outlined that this '*will be remembered as a day when the United Nations and its Member States, together with indigenous peoples, reconciled with past painful histories and decided to march into the future on the path of human rights*'. She went on '*The challenge to ensure the respect, protection and fulfillment of indigenous peoples' rights has just begun. We foresee that there will be great difficulties in implementing this Declaration because of lack of political will on the part of the governments, lack of resources and because of the vested interests of rich and powerful*'.

UNDRIP is particularly detailed when it comes to the right to health; all of the articles of this Declaration have an importance for the health and well-being of indigenous peoples. Box 1 shows specific Articles which refer directly to the indigenous health right. Perhaps one of the most promising ways forward is in the development of inter-cultural health programmes for both minorities and indigenous peoples. This can include programmes where allopathic, or western-trained, medical staff learn about indigenous health practices and remedies; training of

Box 1: Health-related Articles of the UN Declaration on Rights of Indigenous Peoples

Article 24

- 1 Indigenous peoples have the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals. Indigenous individuals also have the right to access, without any discrimination, to all social and health services.
- 2 Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.

Article 31

- 1 Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.
- 2 In conjunction with indigenous peoples, States shall take effective measures to recognize and protect the exercise of these rights.

UN Declaration on the Rights of Indigenous Peoples 2007

indigenous and minority community members in allopathic medicine; incorporation of traditional healers from minority and indigenous communities into allopathic health services; and the incorporation of traditional medicines and practices into health services. There are now many examples of inter-cultural health programmes today – with notable and extensive programmes in Canada, New Zealand and Australia, and new laws and programmes in Bolivia, Ecuador, and Brazil.

It is important to remember Victoria Tauli-Corpuz's words on the difficulty of achieving the right to health for minorities and indigenous peoples. This is a right we still need to call for in the context of the post-2015 development framework, and a right that we will continue to fight for in the years to come.

Addressing health inequalities in the post-2015 development framework³

by Corinne Lennox

In a village in Gujarat, India, most of the Dalits seeking health services have to wait longer for their turn because the dominant caste people are given priority. Only where the doctor is also a Dalit are they given equal priority in appointments. Health workers rarely visit the Dalit quarters of the village. In the health care centre, Dalits do not sit on the benches provided and they drink water from separate vessels kept for them. 'Untouchability' is widely practised in the delivery of health services.⁴ Across India, these realities have meant that Dalits have disproportionately high rates of mortality and diseases compared with most of their fellow citizens.

This is one picture of discrimination in access to health that is faced by minorities and indigenous peoples across the globe. There is wide agreement that tackling inequality needs to be central to the post-2015 development framework that will replace the MDGs in two years' time. Not only is such an approach fair and just, it also makes good development sense. Inequality has been shown to hamper poverty reduction and growth strategies, to create tensions and conflict between communities, and to undermine democratic governance.

This increased focus on inequality has given an important voice to minorities and indigenous peoples, who have long experienced the negative effects of inequality. A major cause of this inequality is the violation of the human rights of minorities and indigenous peoples, and national policies that do not reflect their own priorities or perceptions of development.

This chapter will show how specific attention to human rights for minorities and indigenous peoples, coupled with a human rights-based approach to development, can strengthen any new global development strategy on access to health. As the evidence will suggest, strategies for these groups are needed in both the global North and South.

Assessing the impact of the MDGs

Over the past three years, a major consultation process has been under way to devise a new global development plan for the post-2015 era when the MDGs will conclude. This consultation has involved civil society, states and independent experts, principally guided by UN institutions. In September 2013, the UN General Assembly will meet to discuss the recommendations from this process and to begin planning a new framework to follow the MDGs.

Civil society groups have been involved primarily in a series of thematic consultations organized by the UN. This has been complemented by two other important processes:

the UN High-level Panel on the post-2015 development agenda, co-chaired by Indonesia, Liberia and the UK; and the inter-governmental Open Working Group on sustainable development goals, which is tied to the Rio+20 process. These consultations bring the need for a new development agenda together with the call from the Rio+20 world conference to establish a set of sustainable development goals.

Civil society groups have called for human rights and the principles of equality, non-discrimination and participation to be the basis of the post-2015 framework. The recommendations published in May 2013 by the UN High-level Panel fell short in this regard; while some human rights are mentioned, such as non-discrimination against women, property rights, due-process rights and freedom of expression, there is no systematic integration of human rights in their proposal.

The open working group on sustainable development goals will submit its proposal to the UN General Assembly in September 2013. Notably, the document that came out of the Rio+20 conference makes firm commitments to human rights, including specifically the rights to health, to an adequate standard of living, to food and to non-discrimination.

One component of the UN global civil society consultation process focused on addressing inequalities, which offered minorities and indigenous peoples an important opportunity to participate in the creation of the post-2015 agenda. No equivalent opportunity was available when the MDGs were drafted.

The MDG framework had many deficiencies for minorities and indigenous peoples. The reliance on aggregate results and the lack of disaggregated data collection meant that very few measurements were made on the progress of these groups towards the goals. Stretched resources and pressure to achieve the targets has prompted governments to focus on the populations that are easiest to reach and those whose levels of inequality were least costly to address. Linguistic barriers or differences in cultural or religious practices were often not taken into account when formulating national strategies on the MDGs. Thus, minorities and indigenous peoples now find themselves, in many cases, further from achieving the targets of the goals than other populations that have benefited from these interventions.

These trends are evident in some statistics regarding the health MDGs. In India, child malnutrition is about 14–20 per cent higher for Scheduled Castes and Scheduled Tribes and has been declining at a slower rate than for the rest of the population over the MDG period.⁵ In Tanzania, the goal on reduction of HIV/AIDS was hampered for pastoralists in part because the national HIV/AIDS prevention campaigns were issued only in the dominant language of Swahili and anti-retrovirals, although free, were not easily accessible in several districts where pastoralists predominantly live.⁶ In Pakistan, UNICEF reports that the maternal mortality ratio for Baluchistan – largely inhabited

by the Baluchi minority – stands at 758 per 100,000 live births, nearly three times the national average of 276 per 100,000, and a long way off the MDG target of 140 per 100,000. The prevalence of malaria is very low in large parts of Bangladesh but is especially high in the Chittagong Hill Tracts, where the indigenous Jumma peoples reside, and largely attributable to less investment in adequate living standards and health services in this high-risk area. Chronic malnutrition among indigenous children in Guatemala is nearly twice the rate of non-indigenous children.

While governments may cite resource limitations or remote locations to explain these inequalities, they cannot be justified from the perspective of human rights.

The right to health: some key international standards and principles

Minorities, indigenous peoples and civil society organizations have all called for a human rights foundation to the post-2015 agenda. It is therefore important to discuss the scope of the human right to the highest attainable standard of physical and mental health (International Covenant on Economic, Social and Cultural Rights [ICESCR], Article 12). According to the General Comment No. 14 of the UN Committee on Economic, Social and Cultural Rights, which oversees the core treaty that recognizes the right to health, this right:

'is the right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health... [The right includes both] timely and appropriate health care ... [and] the underlying determinants of health, including access to safe and potable water, and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.'

Thus, although the state cannot protect people against ill health, the state can provide services and an environment that enables people to achieve the highest possible standards of health.

Regarding underlying determinants of health, the ICESCR also recognizes rights to an adequate standard of living (Article 11), adequate housing (Article 11), food (Article 11), education (Article 13), and just and favourable conditions of work (Article 7). The treaty also requires states to take steps for 'the improvement of all aspects of environmental and industrial hygiene' (Article 12.2 (b)); 'the prevention, treatment and control of epidemic, endemic, occupational and other diseases' (Article 12.2 (c)); and the 'creation of conditions which would assure to all medical service and medical attention in the event of sickness' (Article 12.2 (d)).

Reproductive health rights for women are also firmly recognized: ICESCR holds that states should make ‘provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child’ (Article 12.2 (a)), through measures such as access to reproductive and sexual health services, emergency obstetrics, information and resources to access these services. The Convention on the Elimination of all forms of Discrimination Against Women (CEDAW) has further provisions: states ‘shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation’ (Article 12.2).

Specific rights to health for children are detailed in Article 24 of the Convention on the Rights of the Child. These include the obligation of states ‘to ensure that no child is deprived of his or her right of access to ... health care services’ (Article 24.1); to reduce infant and child mortality (Article 24.2 (a)), to provide adequate nutrition and access to water and a clean environment (Article 24.2 (c)), and to ‘develop preventive health care’ (Article 24.2 (f)). Health rights and special measures are also noted for children with disabilities (Article 23).

The right to health for minorities and indigenous peoples

Against the backdrop of these general human rights provisions on the right to health we can sketch a framework that focuses on rights of particular concern to minorities and indigenous peoples: the right to non-discrimination, the right to participation and the right to protection of identity.

The right to non-discrimination

Everyone has the right to access health facilities, goods and services without discrimination (ICESCR and International Convention on the Elimination of all forms of Racial Discrimination [ICERD], Article 5.e.iv). This means non-discrimination both in access to health care and in enjoyment of the underlying determinants of health. States have obligations to prevent discrimination both by state actors in the public sphere and by non-state actors in the private sphere, including by private corporations. Crucially, even where resources are scarce, states cannot discriminate in the allocation of access to adequate health in the progressive realization of this right (ICESCR, Article 2).

Non-discrimination in access to the right to health encompasses both positive and negative obligations of state actors. This requires more than the mere refraining from discrimination in providing access to and within health facilities, goods and services, but also taking positive measures, including through allocation of resources, legislative change or policy reform to ensure the fulfilment of this right.

Discrimination can be both direct and indirect. Direct discrimination results when a person is treated less favourably than another person in a similar situation based on prohibited grounds of discrimination. Indirect discrimination refers to practices that may appear neutral but nevertheless have the effect of discriminating on prohibited grounds. States have obligations to prevent both kinds of discrimination in access to health.

The right to participate

Fulfilling the right to participate will be essential for the post-2015 framework. The Committee on Economic, Social and Cultural Rights holds ‘the participation of the population in all health-related decision-making at the community, national and international levels’ to be an important dimension of the right to health.

Minorities have the right ‘to participate effectively in decisions on the national and, where appropriate, regional level concerning the minority to which they belong or the regions in which they live’ (UN Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities [UNDM], Article 2.3). Moreover, ‘national policies and programmes shall be planned and implemented with due regard for the legitimate interests of persons belonging to minorities’ (UNDM, Article 5.1).

Similarly, indigenous peoples enjoy the right to self-determination, including ‘the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions’ (UN Declaration on the Rights of Indigenous Peoples [UNDRIP], Article 23). Furthermore, states should obtain from indigenous peoples their ‘free, prior and informed consent before adopting and implementing legislative or administrative measures that may affect them’ (UNDRIP, Article 19).

The right to protection of identity

Identity factors, such as cultural or religious life, can impact on the right to health for minorities and indigenous peoples. Beliefs about health and well-being, both individual and community, can be deeply rooted in cultural practices or religious beliefs that shape communities’ response to mainstream and strictly biomedical approaches to health care and health.

Minorities have the right to practise and to enjoy their own culture, to practise their own religion, and to use their own language, in private and in public, freely and without interference or any form of discrimination (UNDM, Article 2.1; International Covenant on Civil and Political Rights [ICCPR], Article 27). Indigenous peoples have the right to exercise self-determination over their cultural development (UNDRIP, Articles 3 and 11), to practise their traditional religions (UNDRIP, Article 12), and not to be subjected forced assimilation or destruction of their culture (UNDRIP, Article 8.1). Protection of indigenous

land and resource rights is interdependent with these rights (UNDRIP, Article 26).

Regarding traditional forms of medicine, Article 24.1 of the UNDRIP states that ‘Indigenous peoples have the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals.’

Cultural and religious practices can also be harmful to health and some provisions have been made to overcome such harms; in the CRC, for example, states are to take measures for ‘abolishing traditional practices prejudicial to the health of children’ (Article 24.3), which could include both community practice or entrenched and systemic forms of discrimination coming from outside. More generally, CEDAW Article 5(a) calls upon states to eliminate customary and other practices based on assumptions of female superiority or inferiority, some of which can impact on health.

It is essential, however, that potential impact on health from traditional harmful practices not be used as a justification to prohibit outright the cultural and religious beliefs of minorities and indigenous peoples. Often what is needed is informed dialogue on how to reform certain specific practices without restricting or denigrating a culture or religion as a whole.

Understanding inequalities and inequity in health

The poor MDG results for minorities and indigenous peoples can be attributed to state failures to fulfil their obligations to these groups. More than mere inequality, minorities and indigenous peoples also face inequity – distinguishable by the unfair and avoidable nature of the inequality witnessed. Inequity is therefore a better term to describe the unjust situation of minorities and indigenous peoples and the unwillingness of states to remedy this situation.

Discrimination

Discrimination is one key cause of health inequity. Discrimination can manifest in the access to health facilities, in the delivery of health services and in exhibited inequalities in the underlying (social) determinants of health like access to safe water, sanitation, adequate housing and nutrition, having higher rates of illiteracy, or working in more hazardous types of employment.

Direct discrimination occurs, for example, when health practitioners give less quality care to those discriminated against, evidenced by longer waiting times, inadequate diagnosis, the provision of less quality medication, patient segregation, or neglect in patient hygiene or nutrition. Indirect discrimination can manifest, for example, when access to information on health services and preventive practice is typically provided only in dominant languages or in accordance with dominant cultural practices.

Delivering the right to health

The UN Committee on Economic, Social and Cultural Rights has developed a framework to define many of the minimum standards for delivering on the right to health in *goods, facilities and services*, including the underlying determinants of health. This consists of: Availability, Accessibility, Acceptability and Quality.

Availability. Health services should be readily available to all without discrimination. This includes sufficient provision of hospitals, clinics, trained health professionals and essential medicines. Services relating to the underlying determinants of health, such as safe drinking water, sanitation facilities, adequate housing and public education on health, must also be provided to an adequate level for all.

Accessibility. Health services must be accessible to all without discrimination. Services must be made affordable to all and must be located within safe and reasonable reach of everyone. Accessibility also includes the right to seek, receive and impart information on health, with due respect for confidentiality.

Acceptability. Health services must be provided in a manner that is compatible with cultural and linguistic rights, for example, by providing services in local languages and sensitive to different cultural practices. Health service delivery must also be responsive to gender and age differences. Medical ethics must be adhered to in the delivery of health services.

Quality. Health services must be culturally acceptable, scientifically and medically appropriate and of good quality. The provision of skilled medical personnel, quality drugs, safe water and good sanitation are among the minimum expected standards of quality.

Minorities and indigenous peoples are often also poorer than other groups, making fee-based health services much harder for them to use. Both direct and indirect discrimination can be compounding factors: in India, for example, although only about 1 per cent of disabled persons receive help from the government for education, the percentage of beneficiaries among Dalits and Scheduled Tribes is about half that of the dominant caste group. This is likely attributable both to direct discrimination and ‘untouchability’ practices but also to higher rates of poverty among these groups.⁷

Culture and identity

A second key factor is the different priorities and perceptions of health that minorities and indigenous peoples often hold. This can stem from traditional cultural or religious beliefs about health and well-being, different

customary practices around health care, or living in distinct locations with unique health challenges. In order to achieve better equity in health outcomes, these different viewpoints must be taken into consideration in policy development and service delivery.

Women's reproductive rights

Reproductive health rights warrant special attention here. There is evidence from around the world to show that women from marginalized minorities and indigenous peoples have disproportionately high rates of maternal mortality and often have less access to reproductive health services. In some severe cases, minority women can be coerced or intimidated into making involuntary decisions regarding their sexual and reproductive health, such as sterilization or (for or against) abortion.⁸ Both culturally based preferences and discrimination play a role in these outcomes.

Poverty and social exclusion

The underlying determinants of health can also be experienced differently by minorities and indigenous peoples. Disproportionately high rates of poverty and low rates of employment (or underemployment) affect these groups. They are typically pushed into jobs with higher occupational health risks as a result. Poverty contributes also to inadequate housing and less food security. All of these factors also contribute to higher rates of many non-communicable and some communicable diseases for minorities and indigenous peoples. In Pakistan, UNICEF reports that rates of polio are highest among the minority Pashtun population, comprising 77 per cent of cases. In Alaska, the Non-Communicable Diseases Alliance reports that indigenous Alaskans have twice the mortality rate from rheumatic heart disease than non-indigenous Alaskans.

Displacement and land rights

Displacement from land is a major underlying cause: groups can be displaced from their land (to urban areas or to less fertile land), reducing access to traditional food sources and production. Achievement of the MDGs has been used to justify such displacement, usually with net negative outcomes for communities. In Mexico, for example, an MDG 'Sustainable Rural City' in Chiapas displaced indigenous communities into prefab settlements with the aim of improving access to health and other services. However, in the new houses, they could no longer grow their own food for consumption and income, nor cook their food staple, maize, thus putting pressure on incomes and food security; and while they were closer to health services, residents reported that the quality of such services was poor.⁹ The polluting effects of many extractive industries encroaching on traditional lands have also severely harmed health outcomes for these groups. In the Ahwazi-Arab minority region of Khuzestan in Iran, from where 90 per cent of the country's oil revenues originate,

minority communities suffer ill health from the industry pollution of the Karoon River on which they rely.

These and other factors need to be taken into consideration when shaping the post-2015 agenda if the aim of health equity is to be achieved.

Post-2015 reforms: 'Leave no one behind'

The High-level Panel's final report published in May sketches out a vision for post-2015 reforms. While this vision does not fulfil a human rights-based approach, there has been some important recognition of discrimination and exclusion as barriers to sustainable development. The panel calls first and foremost to 'leave no one behind' in the post-2015 framework:

*'We should ensure that no person – regardless of ethnicity, gender, geography, disability, race or other status – is denied universal human rights and basic economic opportunities. We should design goals that focus on reaching excluded groups.'*¹⁰

To achieve this, the panel recommends that states build 'accountable public institutions' and enable 'inclusive growth', and that indicators of new goals be disaggregated by variables such as gender and ethnicity. The panel acknowledges that the 'cost of delivering services in remote areas may be only 15 to 20 per cent higher than average', and judges this to be 'reasonable and affordable' and 'the right thing to do'.

These suggestions can help to meet the rights of minorities and indigenous peoples. Furthermore, the Rio+20 outcome document emphasizes that policies for sustainable development and poverty eradication should: 'enhance the welfare of indigenous peoples and their communities, other local and traditional communities, and ethnic minorities, recognizing and supporting their identity, culture and interests and avoid endangering their cultural heritage, practices and traditional knowledge'.

In order to 'leave no one behind', states should adopt specific targets that will ensure minorities and indigenous peoples achieve the right to health through the new global development framework. A key tool for this is a national action plan to eliminate health inequity, including for minorities and indigenous peoples. National action plans, including the process by which they are devised, are considered by the UN Committee on Economic, Social and Cultural Rights to be a core obligation of ICESCR. National action plans should be elaborated with the full and effective participation of minorities and indigenous peoples, in accordance with their rights as outlined above. They should include clear indicators and benchmarks and be regularly monitored. National action plans must take a comprehensive approach to health inequity, rather than relying on isolated projects that cannot tackle underlying determinants of health. The new guidance note of the UN

Secretary-General on Racial Discrimination and Protection of Minorities (2013) also offers some useful baseline recommendations for UN country teams to support these efforts.

Several states have taken positive steps in this direction. In the **USA**, the Department of Health and Human Services has recently outlined its action plan to reduce racial and ethnic disparities. This plan is being implemented in collaboration with existing Offices for Minority Health, which have been established in all 50 states and work to educate, monitor disparities, create community partnerships and develop targeted policies and programmes on racial and ethnic health inequalities.

In **Ireland**, the Traveller Health Strategy has involved members of the Traveller communities in reviewing national and regional health strategies to ensure that their interests and needs are reflected. The government has also launched an All-Ireland Study of Travellers' Health Status and Health Needs, an extensive census-style examination of all Travellers in Ireland and Northern Ireland.

In **New Zealand**, a Māori Health Strategy and action plan have been adopted. This is supported by the Māori Health Business Unit, which provides evidence-based research on health strategies, and by Māori health providers who give on-the-ground service delivery. This strategy also includes an innovation fund, which supports positive Māori approaches that improve Māori health outcomes. In all three examples, there is a strong emphasis on target groups taking the lead in delivering these national strategies.

An alternative approach is to mainstream attention to minorities and indigenous peoples into general action plans on specific health sectors. In **Brazil**, for example, the National Pact to Reduce Maternal Mortality included specific objectives for 'the inclusion of gender, race and ethnicity considerations in all strategies and measures', and 'the consideration of social inequalities in decision-making processes'. Brazil also has a specific Sub-System for Indigenous Health, which runs alongside the national health service system and is specifically designed for the indigenous population.

Health targets can also be featured in any national anti-racism action plans (mandated under the UN Durban Declaration and Programme of Action from the 2001 World Conference Against Racism). This was pursued in **Ecuador**, where both indigenous peoples and people of African descent were targeted for culturally sensitive inclusion in health programmes. This was achieved through capacity-building and infrastructure development to ensure that medical services were culturally appropriate to these communities. The programme was linked to MDG targets and included a specific project on culturally relevant childbirth preferences.

There are several key areas these national action plans could address.

Non-discrimination in health access and service delivery

Many practitioners have called for universal health coverage in the post-2015 aims but this cannot be achieved without specific targets for minorities and indigenous peoples and positive measures to tackle discrimination.

Collecting evidence

Disaggregating mortality and morbidity data by ethnic and minority groups is a first step to identify their needs. Mapping access to health services by minorities and indigenous peoples is a useful baseline that can help to determine relevant national targets. This should include an assessment of resource allocation to services in regions where these groups mainly live. Key quantitative and disaggregated indicators could include:

- Disaggregated health data on mortality and morbidity to help identify health inequalities between minority and indigenous groups and the rest of the population;
- information on health of the minority and indigenous population, including prevalence of diseases, mortality rates and access to reproductive health;
- data related to health determinants, such as access to clean water, sanitation, health services, secure land rights and adequate housing;
- information on health facilities by location, such as the number and type of hospitals and clinics and their user rates, including disaggregated data on users;
- details on the health service workforce, including by location, and points such as patient–health worker ratios, and disaggregated data on staff recruitment and promotion levels;
- information on health levels of the population, including prevalence of diseases, mortality rates and access to reproductive health;
- inventories on the equipment, types of facilities and quality and affordability of drugs at health services by location; and
- information on traditional practices and medicines, and inter-cultural health initiatives where they exist.

Baseline mapping needs to be accompanied by regular monitoring. Global datasets, health status statistics and access to universal health coverage should integrate disaggregated data on variables such as ethnicity, religion, language-use, region and intersect with data on sex, sexual orientation, gender identity, disability, age and other information relevant to marginalized groups. The UN Commission on Information and Accountability for Women's and Children's Health is one initiative that has recognized the need for such data on a global scale. Monitoring should focus both on access to health services and inequalities in the underlying determinants of health.

Data collection should be supplemented by qualitative, participatory approaches. Service user groups can be

established to gather information from minority and indigenous groups on their experience of using health services. This can help to pinpoint particular problem areas, whether it be direct or indirect discrimination, lack of cultural understanding or poor outreach to affected communities. In British Columbia, **Canada**, an Aboriginal Maternal Health Forum was convened to invite First Nations women, particularly those living in under-served rural areas, to provide inputs on their perinatal health support needs. As part of this initiative, 26 First Nations women were trained from two rural communities as *doulas* (midwives).

Improving data collection capacities needs to be built into the post-2015 framework. In the **UK**, the London Health Observatory's Ethnic Health Intelligence Overview provides an ethnic health database and data collection guidelines for health institutions across the city and nationally. Among the resources they have developed is a toolkit to help the National Health Service analyse ethnic differences in health and health care.¹¹ Listserves on specific topics in minority and ethnic health have also been established for practitioners to share data, research findings and good practices.

Targeted measures to tackle discrimination

Targeted measures for especially excluded groups can also help tackle discrimination. Such needs can be identified through mapping and developed in national action plans.

- In **Serbia**, the Women's Association in Kovil provides weekly workshops for young Roma women who are wary of mainstream health services, and provides them with access to a paediatrician, pregnancy counsellor and other health information.
- In the **UK**, the Black and Minority Ethnic Health Forum has devised a targeted maternity health programme. The programme works with community-based organizations to reach out to minority women and provide them with information on maternal health services and how to raise their concerns with service providers and other relevant institutions. The programme also supports network building among minority women, who tend to be under-represented in mainstream maternal health networks.
- In **Australia**, an Indigenous Youth Health Service has been established to target vulnerable Aboriginal and Torres Strait Islander youth who are experiencing or at risk of homelessness, substance abuse and unequal access to sexual and reproductive health care, providing both clinical and non-clinical services.

Access to justice

Tackling discrimination also requires access to justice and knowledge of rights. Health Ombudspersons and other complaints mechanisms should be established and take a role in monitoring for non-discrimination in access to

health services. Patients should be instructed on their rights in relation to health services and have support to access remedies in cases of violations of those rights. In **South Africa**, a patients' rights charter was developed to give expression to the constitutional right to health. The charter is implemented through a number of complementary complaints systems mandated by the 2003 South African National Health Act 61, with support from the South African Human Rights Commission.

Such targeted measures have been recommended by UN treaty bodies. In the case of *Alyne da Silva Pimentel v. Brazil* (Communication No. 17/2008), the CEDAW Committee found that Ms da Silva Pimental, an Afro-Brazilian, faced discrimination on the basis of her sex, her status as a woman of African descent and her socio-economic background in access to emergency obstetrics services, resulting in her death. Moreover, the committee found that her family faced undue delay in access to justice when seeking accountability for her death. The committee called upon Brazil to 'ensure access to effective remedies in cases where women's reproductive health rights have been violated and provide training for the judiciary and for law enforcement personnel'. The establishment of maternal mortality committees at the local level was also recommended to monitor and investigate such incidents. These committees can be charged with reviewing medical but also non-medical and system-related factors that may have impacted on mortality rates, including differences across ethnic or other identity groups.

Training health professionals

Training and recruitment strategies need to be reviewed to deliver on health equity post-2015. All staff responsible for delivering both public and private health services need to be trained on non-discrimination standards and expected practices.¹² This includes understanding and reforming their own prejudices and discriminatory behaviours, as well as understanding wider societal inequalities and injustice along these lines and their interaction with health. Recruitment should aim for a proportionate level of staff from minority or indigenous communities, especially in regions where the population of these groups is high. Targeted training programmes or scholarships for health-related studies can be offered; **Hungary**, for example, has created pre-training programmes for Roma for health care careers. Given that language can be a significant barrier for members of minority and indigenous communities seeking medical assistance, staff should be recruited who speak relevant local languages, or should be trained to speak local languages.

Inter-cultural health services

Cultural and religious variables were ignored in the one-size-fits-all approach of the MDGs but must figure in the post-2015 agenda for it to be effective. The health-related

agenda needs to be adapted to the cultures, religious beliefs and lifestyles of minority and indigenous communities. Specific targets for the establishment of inter-cultural health schemes can be adopted.

Health services designed to meet the post-2015 aims should include specific provisions for minorities and indigenous peoples. For example, this could mean making public health campaigns available in minority languages and media outlets. Those same campaigns could be adapted to reflect different cultural practices or religious beliefs related to health issues, to ensure that information is better understood and responded to. At another level, minorities and indigenous peoples may require distinct health policies that depart from the mainstream post-2015 framework. Such group-specific policies would respond to significant differences that groups can express in terms of their worldview on health and well-being.

In **Ethiopia**, for example, Health Poverty Action has been working with pastoralist communities to create traditional birthing huts where pastoralist women can give birth safely and in accordance with customary beliefs but also be referred to equipped health facilities if complications arise.¹³ In **Panama**, the government has created an 'Office of Traditional Medicine' under the Medical Bureau and a medical commission for the purpose of 'harmonizing and fusing western with traditional medicine'.¹⁴

More research is needed into culturally specific practices and beliefs related to health. This should include analysis of both positive and negative impacts on health of such practices and beliefs. In the **UK**, numerous studies have been done to highlight inequalities by ethnicity in access to health services under the auspices of the Better Health initiative. Better Health has produced a briefing collection, providing studies to help practitioners understand how minorities have differing experiences of health care in areas like mental health, maternal health, certain diseases such as cancer or diabetes, or people with learning disabilities.

For many indigenous communities, access to traditional medicine can supplement services from mainstream health facilities. The Ba'Aka in **Cameroon** have poor access to health services but have used their traditional medicine skills to use forest resources to support their health; where they are displaced from access to such resources, health levels decline. Specific rituals and taboos associated with childbirth also greatly impact on uptake of mainstream services. For example, in **Bolivia**, a micronutrients programme is failing to reach many pregnant women because it does not take into account the traditional diet of indigenous groups, including taboos related to certain foods during pregnancy.¹⁵

Training for all health services staff is needed on cultural impacts on health and use of health services. Specialized staff with expertise in communities that experience discrimination can help to ensure better access

to health services. This strategy has been adopted in **New Zealand** with the creation of Māori Health Providers.

In at least six countries in Central and Eastern Europe (**Bulgaria, Romania, Slovakia, Serbia, Ukraine** and **Macedonia**), there has been a similar widespread programme of Roma Health Mediators. They provide various services, including referring clients to the appropriate health services, assisting in outreach with public health campaigns, and making legal referrals in cases of discrimination or abuse, as necessary. The mediators have had success in increasing vaccination rates among Roma, in enabling them to acquire necessary identification and insurance documents, and have educated communities on health and improved health care provider knowledge and attitudes about Roma.¹⁶ Notably, some of the weaknesses of the programmes have been insufficient resource allocation, poor institutional support for the mediators and continuing neglect of many underlying determinants of health for Roma by governments. The report recommends addressing these problems and also taking steps to ensure mediators are better integrated into the health system, are collecting more detailed data on outcomes of interventions, and that there are more opportunities for health and social policy officials to learn from mediator experiences.¹⁷

Addressing underlying determinants of health

Many agree that the World Health Organization's major review of social determinants of health concluded in 2008 needs to figure centrally in the post-2015 agenda. This is crucial for addressing health inequities of minorities and indigenous peoples, which often stem from differences in social determinants. The drive towards a 'Health in All' approach to mainstreaming health considerations across multi-sectoral public policies similarly can help to create a more comprehensive approach to improving health in the post-2015 development sectors.

Poverty

Poverty reduction strategies targeted at minorities and indigenous peoples would tackle a key underlying determinant of their health. Specific targets on poverty reduction for minorities and indigenous peoples need to be adopted. As noted above, disproportionately high levels of poverty for these groups are in evidence across the globe, suggesting that poverty reduction efforts are not benefiting them equally. For example, cash transfer schemes have been shown to be effective for many poor people but may be less effective for minorities who can face discrimination in access to services, including in health. Poverty may also increase other social problems in communities, such as abuse of alcohol or drugs, that impact greatly on health. Poverty also pushes groups into more hazardous forms of employment, which can be better regulated through safety

measures and other monitoring and legal protections. The post-2015 health agenda needs to take account of these distinct forms and effects of exclusion.

Land and natural resources

Land is a critical determinant of health, and minorities and indigenous peoples typically have less legal protection for their land rights and less access to quality land. They may also be more vulnerable to 'land grabbing' or involuntary displacement from their land. The net effect is that minorities and indigenous peoples often lose livelihoods, food security, traditional forms of housing and access to spiritual practices, increasing poverty and exposing them to lower physical and mental health outcomes.

The post-2015 framework needs to approach land rights and displacement differently, including by developing targets on access to land. Repeated cases show that forcibly displacing people to increase access to health services has actually had negative impacts on health for the reasons outlined. Investment in local health services for communities living more remotely is a more sustainable and cost-effective approach.

Making land security a top priority post-2015 will have a strong multiplier effect on health outcomes, underpinning key issues like poverty reduction, employment and food security. Any targets on nutrition will have to consider the link to land displacement. Where large-scale development of land is pursued, communities should give their consent to such processes and legally enforced benefit-sharing agreements, and/or just and equitable compensation for land and resources, should be secured. In **Cambodia**, some indigenous communities are receiving UN funding to map their ancestral lands in an effort to secure communal land tenure; this will hopefully

help safeguard traditional ownership of land from encroachment by companies entering indigenous territories.

Protection of the environment will figure prominently in the post-2015 framework. Rio+20 recognized that the right to health is an essential component of sustainable development. Many minorities and indigenous groups use natural resources sustainably and responsibly, but they also face the polluting effects of industry on their land and the harsh impact of climate change on their local environment.

Access to justice and legal aid for marginalized groups to hold actors to account for environmental harms should be one dimension of post-2015 environmental reforms. Cooperation with minorities and indigenous peoples in developing locally owned natural resources management schemes can also help deliver the Rio aims in a way that does not force people off land, away from their resources and further into poverty.

Participation

Lack of political participation is another determinant of health. The inability of minorities and indigenous peoples to secure the fair allocation of resources in national budgets is but one dimension. Targets for minorities and indigenous peoples on greater representation in political institutions at different levels can be developed. Health Poverty Action has been working with indigenous women in Peru to build their advocacy capacities to engage local and regional government in dialogue on their failure to deliver adequate nutrition programmes. The programme has also included institutional capacity building for women's organizations, for example on budgeting, as well as integrating men into discussions on traditionally gender-based domains of work, thus helping to tackle gender inequality.

Conclusion

The bold experiment of the MDGs has yielded mixed results but it has taken the world closer to the realization of human rights for all. For the post-2015 framework, we need to be bolder and also smarter in how we tackle inequality. Adopting specific and concrete targets and building capacities to include minorities and indigenous peoples in the new global agenda is a key piece of the puzzle for achieving sustainable development for the 21st century in both the global North and South.

'Health in All' policy approaches are needed for a new cross-cutting strategy post-2015. The case of minorities and indigenous peoples illustrates well how underlying determinants of health across many sectors, from land development to education and employment and environmental protection, impact on access to adequate health. The more holistic cultural and religious view of health and well-being held by many minority and indigenous communities can also inform the mainstream

approach to health care, moving us all beyond narrow biomedical prescriptions.

Strategies for building the capacity of minorities and indigenous peoples to claim their right to health, and for governments to respect, protect and fulfil this right, should be included in post-2015 plans. Human rights-based approaches to health rooted in non-discrimination, participation and accountability are needed. A key component of this is putting in place adequate monitoring and accessible accountability mechanisms to counter discrimination. Such mechanisms should be sensitive to and respectful of the differing cultural and religious views of groups that influence their priorities and activities in development. Ensuring the participation and leadership of minority and indigenous groups in the elaboration of policy and programme responses is also essential for creating interventions that will work better in reaching our common goals for sustainable development.

Recommendations

To ensure the right to health for minorities and indigenous communities in the post-2015 framework, MRG calls on international decision-makers to:

1. Ensure the participation and leadership of minority and indigenous groups in the development and implementation of policy and programme responses to the global health situation.
2. Adopt specific and concrete targets that include minorities and indigenous peoples in the new global agenda.
3. Ensure that the post-2015 health goals are based on a human rights framework.
4. Put in place adequate monitoring and accessible accountability mechanisms to counter discrimination with regard to health outcomes. These mechanisms should be respectful of the differing cultural and religious views of groups that influence their priorities and activities in development.

International organizations and all levels of government must:

1. Incorporate indigenous and minority peoples' voices, values and ideas into policy-making and programmes for addressing health inequalities.
2. Collect data disaggregated by ethnicity, gender, religion and language to target health initiatives toward the most vulnerable groups.
3. Acknowledge and remedy inequalities in access to health care, including the multiple forms of discrimination faced by indigenous and minority women, through the establishment of complaints and disciplinary mechanisms and training of staff.
4. Support grassroots initiatives that address the needs of minority and indigenous communities.
5. Develop culturally appropriate health information material to raise awareness about disease-prevention and other health issues in minority languages that is gender sensitive where relevant.
6. Prioritize education and training for indigenous and minority health care workers, fostering full participation in health care administration and policy development.

Notes

- 1 Nettleton, C., Napolitano, D. and Stephens, C., *An Overview of Current Knowledge of the Social Determinants of Indigenous Health*, Geneva, World Health Organisation (Commission on Social Determinants of Health), 2007.
- 2 Nettleton, C., Stephens, C. and Bristow, F., 'Utz Wachil: A study of indigenous perceptions of health and environment in five countries', *Ecohealth*, vol. 4, no. 4, 2007, pp. 461-772.
- 3 Parts of this section have been reproduced with permission of the Indian Institute of Dalit Studies from a working paper prepared by the author on *Good Practice in Combating Discrimination in Access to Education and Health: International Norms and Local Strategies* (July 2012).
- 4 Excerpt taken from Acharya, S.S., *Access to Health Care and Patterns of Discrimination: A Study of Dalit Children in Selected Villages of Gujarat and Rajasthan*, Working Papers Series, New Delhi, Indian Institute of Dalit Studies and UNICEF, 2010, p. 26.
- 5 Thorat, S. and Sabharwal, N.S., 'Addressing the unequal burden of malnutrition', *India Health Beat*, vol. 5, no. 5, June 2011, p. 1.
- 6 Sikar, N.K. and Hodgson, D.L., 'In the shadow of the MDGs: Pastoralist women and children in Tanzania', *Indigenous Affairs*, vol. 1 (2006), pp. 34-6.
- 7 Pal, G.C., *Dalits with Disabilities: The Neglected Dimension of Social Exclusion*, Working Paper Series, New Delhi, Indian Institute of Dalit Studies, 2010, p. 20.
- 8 See, for example, Downing, R.A. *et al.*, 'Intersections of ethnicity and social class in provider advice regarding reproductive health', *American Journal of Public Health*, vol. 97, no. 10, October 2007, 1803-7; Maternity Alliance, *Experiences of Maternity Services: Muslim Women's Perspectives*, London, The Maternity Alliance, November 2004.
- 9 SIPAZ, 'Sustainable rural cities – "Violated rights, campesinos forcibly urbanized"', *SIPAZ Report*, vol. 17, no. 2, May 2012, retrieved July 2013, <http://www.sipaz.org/en/reports/107-informe-sipaz-vol-xvii-no-2-mayo-de-2012.html>
- 10 United Nations, *A New Global Partnership: Eradicate Poverty and Transform Economies through Sustainable Development; The Report of the High Level Panel of Eminent Persons on the Post-2015 Sustainable Development Agenda*, New York, United Nations, 2013, Executive Summary.
- 11 Aspinall, P.J. and Jacobson, B., *How to Analyse Ethnic Differences in Health, Health Care and the Workforce: A Toolkit for the NHS*, London, London Health Observatory, 2006, retrieved July 2013, <http://www.lho.org.uk/viewResource.aspx?id=10625>.
- 12 For some useful strategies on staff training, see Physicians for Human Rights, *Ensuring Equality: A Guide to Addressing and Eliminating Stigma and Discrimination in the Health Sector*, Cambridge, MA, Physicians for Human Rights, January 2011.
- 13 See Health Poverty Action, 'Improving health services for South Omo and Dollo Ado pastoralists', retrieved July 2013, <http://www.healthpovertyaction.org/where-we-work/africa/ethiopia/health-services-in-south-omo-and-dollo-ado>
- 14 Vasquez, J., *Human Rights and Health: Indigenous Peoples*, Pan American Health Organization, 2008, retrieved July 2013, http://www.who.int/hhr/activities/indigenous_peoples/IndigPeople_10069.pdf, p. 7.
- 15 Vinding, D. (ed.), *Indigenous Peoples and the Millennium Development Goals: Perspectives from Communities in Bolivia, Cambodia, Cameroon, Guatemala and Nepal*, Geneva, International Labour Organization, 2006, p. 11.
- 16 Schaaf, M., *Roma Health Mediators: Successes and Challenges*, New York, Roma Health Project, Open Society Public Health Program, Open Society Foundations, October 2011.
- 17 *Ibid*, pp. 59-64.

working to secure the rights of minorities and indigenous peoples

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Realizing the right to health for minorities and indigenous peoples

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