Remarks for UN Briefing on Ageing based on Participation and the Right to Health:

Lessons from Indonesia

Sam F. Halabi, J.D., M.Phil.
O'Neill Institute for National and Global Health Law
Georgetown University Law Center

Thank you so much. My name is Sam Halabi and I am a Fellow and Adjunct Professor at the O'Neill Institute for National and Global Health Law located at Georgetown University Law Center. I am grateful for the opportunity to participate in these briefings.

My presentation today is broadly on the topic of participation as a component of the obligation that states have to provide for their citizens the highest attainable standard of physical and mental health. That formulation is specific to countries that have ratified the International Covenant on Economic, Social and Cultural Rights – so it would not apply as a legal matter, for example, to the United States – but it forms the basic framework by which health and human rights scholars think about the underlying determinants of health and that scholarship has universal applicability.

There is not agreement, however, on what we mean by participation or why it is important for health. I argue that there are two different types, if you will, of participation and that in general we have focused on one to the detriment of the other although they are certainly not mutually exclusive. The first is what we traditionally think of as political participation – the right to have a say in how decisions that affect our lives are made but simply applied in the context of health and health care. Most often, health rights scholars and public health practitioners use participation as shorthand for the ability of citizens to have a say at every level, from where resources are allocated to logistical planning. In order to realize participation in this meaning, governments and communities would organize national and regional conferences, hold permanent and temporary citizen forums that include providers, patients and decision-makers. It is true that in many countries, both developing and developed, democratic institutions like these – health care specific institutions -- are lacking.

But that conception – robust democratic process applied to the field of health – is too narrow. General Comment No. 14 from the UN Committee on Economic, Social and Cultural Rights lists participation along with food, nutrition, environmental and occupational safety and housing as underlying determinants of health. That is, there is a conception of participation as a component of the right to health that envisions patients and community members all contributing to the improved health of individuals and the community as a whole. Democratic forums would not be enough. Individuals would contribute time and material resources to public and community health projects, participate in prevention and awareness campaigns and make contributions toward measurable individual and community health outcomes.

That these two types of participation are different is not inherently problematic. What is worrying is that decision-makers and even health professionals have shown a tendency to believe that only one type of participation – the political participation articulated above – is enough and neglect other aspects of participation altogether. I believe that the distinction between these two types of participation is demonstrated by the case of decentralization of health care decision making and financing in Indonesia over the last 10 years. The driving idea behind decentralization is that it allows smaller political units to experiment with participation and financing in a way that achieves efficiencies over centralized planning. Individuals feel they have more of a stake at the local level and therefore participation should increase.

Between 1978 and 1999, Indonesia embarked on a massive effort to improve health outcomes. It did so through extensive resort to training local volunteers. As Indonesia's Ministry of Health understood participation, its core function was to expand available resources under a national development strategy that aimed at local access to an "essential health care package" that would raise the national standard of living, particularly that of the rural poor who faced higher levels of social and economic exclusion. Mutual burden sharing activities included providing expanded access to toilets, maintaining common gathering places, and cleaning the floors of houses. These basic sanitation schemes brought about reductions in mortality at low cost. The central government also trained teams of villagers in preventive strategies dedicated to nutrition, family planning, and immunization. By 1996, approximately 1.25 million volunteers, mostly women, were involved in these initiatives. The proportion of births attended by skilled health personnel increased from 40% in 1992 to 68% in 2002. These participatory strategies complemented Suharto's program to establish community health centers throughout the country in the 1970s and 1980s. The program realized full national health care coverage by the late 1980s, and encompassed 900 general hospitals and 7000 community health centers by 1998. These centers charged low user fees with the intention of thus ensuring access to basic health care. A requirement for physicians to provide public service increased access to health care providers through an incentive scheme: more remote assignments required less public service time. The results were gains in health outcomes, such as declining infant mortality and incidence of communicable diseases like polio. Between 1980 and 1997, child mortality for children under the age of five dropped 30–40%. For the period 1990–1996, infant mortality rates improved in each of Indonesia's 26 regions by about 20%. Between 1985 and 1997, vaccination coverage increased from 28% to 70%. Like food, water, and sanitation, participation was viewed as an underlying component of improving the basic health profile of communities.

Driven by the financial pressures of the 1997 financial crisis and the demands of international lenders, the Indonesian Ministry of Health modified this view of participation as burden sharing to instead emphasize community consensus and planning as a way for regions to "implement development…in the health sector, to accelerate even distribution and justice according to local problems, potential, and diversity." Indonesian government, with the support of international lenders and Western aid agencies, reshaped the state's role in health care provision under three interrelated objectives: 1) advocacy; 2) health promotion/demand generation; and 3) community participation. Instead of mobilizing community resources toward the common objectives of basic health care access and enhanced community health, "community participation" in the new idiom could be defined as: village-based certification program[s] [in which] local stakeholders agree on a limited number of priority health issues, develop standards for those selected issues, and then publicly recognize and reward families that achieve and maintain those standards. These families act as models for other families to adopt new health behaviors. These NGOs held workshops and training sessions aimed at encouraging the formation of participatory bodies and setting common agendas – democratic forums. Preliminary results from these sessions showed little success. Few medical personnel or community members knew of the NGOs activities; that when they did know of them, community members showed indifference; and that suggested preventive practices were already commonplace. While these forums proliferated, the quality of the available health care deteriorated, particularly for Indonesia's poor. Instead of playing a major role in setting standards, providing personnel and funding, and monitoring outcomes, the national Ministry of Health established minimal standards for services and public health provision with inadequate corresponding ability to secure or implement them. Rather than viewing health care as a public good, administrations in regions and subdistricts viewed health care as a private good that was accessible on the basis of affordability. The number of private hospitals steadily grew under the decentralized regime, while doctors increasingly used their position in community health centers to "attract patients to their own private and more expensive services." Increased local outlays on health care providers corresponded with a reduction in spending for environmental or preventive measures. District parliaments, empowered to set user fees, focused on the more profitable curative approach to health. Following these changes, preventable diseases that were in abatement — like leprosy and tuberculosis — reemerged. Between 1995 and 2005, childhood immunization rates fell from 70% to 60% before climbing again. Between 2000 and 2006, the number of births in Indonesia that were attended by skilled health personnel averaged 66% even as the number of village midwives serving poor Indonesians was decreasing. The picture that emerges is one of community residents no longer participating in building community health centers or maintaining water and sanitation schemes because 1) the community health centers could not provide necessary care, and 2) the alternatives were prohibitively expensive.

The two interpretations of participation as a political right and as a determinant of health are not mutually exclusive. Indonesia's central government could have retained its centralized financing structure, albeit perhaps not at pre-1997 levels, together with its commitment to providing health care as a public good while at the same time establishing local, regional, and national participatory forums.

With respect to the topic we are here to discuss today, these lessons are applicable as societies increasing confront the challenges and opportunities presented by longevity. First, access to health care is and must be a public good from which no one should be excluded as a matter of right. Second, it will not be enough to create and sustain democratic forums to discuss longevity. Social inclusion will require thinking in terms of both public and private citizen groups: religious groups, schools, civic organizations and government offices as entire societies age. Solutions will definitely vary with availability of resources, but these principles – especially a unified view of participation – provide a useful framework with which to consider policy options.