

Presentation on persons living in vulnerable conditions and their right to sexual and reproductive health

Luz Angela Melo Human Rights Adviser UNFPA

I will briefly address some important issues that should be taken into account in a General Comment on the Right to Sexual and Reproductive Health dealing with some groups which are in general marginalized and victims of discrimination. Although in general terms, persons living in poverty are excluded from accessing services and enjoying human rights, particular groups such as indigenous peoples, persons with disabilities, and older persons share some patterns of vulnerability due to their identities or their conditions in society. In general, those groups live also in poverty. If they are women and girls, then they suffer from triple discrimination: because they are women or girls, live in poverty, and belong to marginalized groups.

1. Persons living with disabilities

Persons with disabilities are not only less likely to receive general information on sexual and reproductive health and are less likely to have access to sexual and reproductive health services, including family planning services, but should they become pregnant, they are also less likely than their non-disabled peers to have access to prenatal, labour and delivery and post-natal services. Physical, attitudinal and information barriers frequently exist. Often, community-level midwifery staff will not treat women with disabilities, arguing that the birthing process needs the help of a specialist or will need a Cesarean section (which is not necessarily the case). Of equal concern is the fact that in many places, women with disabilities are routinely turned away from such services should they seek help, often being told that they should not be pregnant, or scolded because they have decided to have a child.¹

The Convention on the Rights of Persons with Disabilities has two Articles that recognize reproductive rights and sexual and reproductive health of persons with disabilities: According to Article 23, persons with disabilities have the right to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education; and Article 25 requests States parties to provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

¹ Extracted from UNFPA/WHO, Promoting Sexual and Reproductive Health of Persons with Disabilities, WHO/UNFPA Guidance Note, 2010

The Convention is informed by eight fundamental principles as embedded in Article 3: respect for inherent dignity, individual autonomy and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference; equality of opportunity; accessibility; equality between men and women; and respect for the evolving capacity of children with disabilities². These principles must guide the interpretation of the Convention and should also guide the rights and the concomitant obligations, regarding sexual and reproductive health of persons with disabilities.

For instance, respect for inherent dignity, individual autonomy, and independence of persons includes various types of rights fundamental to the right to sexual and reproductive health: the right to self-determination, self-direction, the right to informed consent for any kind of decision, including any kind of treatment, such as voluntary contraception and voluntary sterilization, right to refuse a treatment, right to parent, right to marry and engage in consensual sexual relationships, and the right to information about one's own rights. In addition, these principles should be applied to all individuals with disabilities, regardless of their race, sex, disability, sexual orientation, religion or national and ethnic origin.³

In that regard, those individuals who are cared for by another person have the right to expect that their caregiver acts according to their will. The individual has the right to dismiss a caregiver who is acting against their wishes and needs, even without any stated cause.

One primary obligation is that the Convention requires States Parties to incorporate disability-sensitive measures into mainstream service delivery, and to provide disability-specific services that are necessary to support the inclusion and participation of persons with disabilities⁴: this applies to sexual and reproductive health services.

There are many challenges. First, legal and policy reform must be undertaken in a concerted manner with organizations representing persons with disabilities and persons with disabilities themselves. A General Comment should address the need of the State to adopt and implement laws, policies and programmes that are in compliance with the Convention on the Rights of Persons with Disabilities, including laws that provide persons with disabilities with equal rights to marriage, family, parenthood and relationships, on an equal basis with persons without disabilities. In addition, these laws should allow persons with disabilities to choose freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education and sexual and reproductive health services.

Gender-neutral laws are not enough. To ensure that women with disabilities are at a level playing field with women and men without disabilities, states should adopt laws and policies that are aimed at ensuring that they can enjoy *de facto* equality, including temporary measures such as affirmative action. Similarly, there is a lack of information and data on persons with

² UNDG guidelines at http://www.un.org/disabilities/documents/iasg/undg_guidance_note.pdf

³ Disability Rights California (2007). Personal Autonomy Principles. Retrieved from http://www.disabilityrightsca.org/legislature/Principles/102401.htm

⁴ UNDG guidelines, op. cit.

disabilities - and more particularly on women with disabilities- which hampers interventions in their favour. Lack of data means invisibility. Invisibility is precisely what the Convention is trying to redress. It is imperative that all efforts be made to ensure that there is enough information on persons with disabilities disaggregated at least by sex, age, ethnicity, and rural/urban in order to reveal multiple discriminations and adopt laws and policies accordingly.

2. Indigenous peoples

It has been noticed that indigenous peoples lack access to health care not only because of their physical isolation, but also because their concerns are not taken into consideration in national priorities and frameworks.⁵

Despite some advances during the last years on international human rights standards, including the landmark adoption of the Declaration on the Rights of Indigenous Peoples, and increased, albeit uneven, participation of indigenous peoples in global, regional and national political processes - indigenous peoples' lives, health, cultures, values and traditions are still under threat. According to PAHO, indigenous populations have suffered from disproportionately high rates of maternal and infant mortality, malnutrition, and infectious diseases.⁶

A General Comment on the Right to Sexual and Reproductive Health should request States to adopt laws, policies and programmes in order for indigenous persons to have the right to enjoy the same human rights as non indigenous persons. A note of caution is needed: This should not mean absorption into the mainstream but rather ensuring that respecting, protecting and fulfilling the human rights of indigenous peoples also takes into consideration those elements that are unique to their identity, and which are recognized in the UN Declaration on the Rights of Indigenous Peoples.

It is important for States Parties to the Covenant on Economic, Social and Cultural Rights to recognize that indigenous peoples' traditional knowledge is essential for the realization of the right to sexual and reproductive health. This should be a priority wherever indigenous or ethnic minorities or other distinct groups continue to retain such traditional knowledge and cultural expressions provided that those do not constitute human rights violations. As the UN Declaration asserts, "respect for indigenous knowledge, cultures and traditional practices contributes to sustainable and equitable development and proper management of the environment." Moreover, Article 31 of the Declaration affirms that 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 medicines, and that States shall take "effective measures to recognize and protect the exercise of these rights."

Such a recognition and protection should be effective, grounded on realities, and translated into effective policies and sustainable programmes aimed at preserving their cultural heritage, traditional knowledge and traditional cultural expressions.

⁶ Ibid, para. 3.

⁵ Ibid.

⁷ United Nations Declaration on the Rights of Indigenous Peoples, Preamble

As for non indigenous peoples, for indigenous peoples - including those living in hard-to-reach remote areas - health services, including sexual and reproductive health services, should then be available, accessible, of good quality and culturally acceptable.

The notion of cultural acceptability deserves, however, a particular focus in the case of indigenous peoples because of the fact that they have their own customs and practices. For instance, in the Latin America region, indigenous peoples have developed a system of beliefs and practices about the human body "and how to live in harmony with other human beings, nature and the spiritual world. The strength and survival of indigenous peoples is significantly linked to the efficiency of their traditional health systems, whose main conceptual axis or view of the world is based on equilibrium, harmony and a holistic approach." Practice has shown us that this applies to other indigenous groups all over the world.

Intercultural human rights approaches to sexual and reproductive health respond to the need of ensuring that indigenous peoples have their right to sexual and reproductive health respected, protected and fulfilled by preserving their notions of disease, associated with their worldviews, traditional knowledge, cultures and traditional practices while guaranteeing that the principles of availability, accessibility, good quality, and of course, acceptability, are met. As PAHO says about the intercultural approach to health "[it] involves the recognition of human and therapeutic resources, together with strategies that reach beyond conventional health systems paradigms." In his last annual report to the Human Rights Council, the first appointed Rapporteur on the right of everyone to the enjoyment of the highest standard of physical and mental health stated that a "health system must be respectful of cultural difference. Health workers, for example, should be sensitive to issues of ethnicity and culture. Also, a health system is required to take into account traditional preventive care, healing practices and medicines. Strategies should be in place to encourage and facilitate indigenous peoples, for example, to study medicine and public health. Moreover, training in some traditional medical practices should also be encouraged. Of course, cultural respect is right as a matter of principle. But, additionally, it makes sense as a matter of practice." In that respect, intercultural human rights approaches to sexual and reproductive health require not only health systems that recognize different ways of conceptualizing sickness and treating it, but also States that include indigenous peoples' traditions and knowledge in their policies and programmes.

Providing effective health services, including sexual and reproductive health services, especially preventive care, to indigenous peoples, often depends on the ability of medical and social services to accommodate cultural understandings, perceptions and practices. But it is more than that. It acknowledges that the ways in which indigenous peoples understand the world are essential to their identity, and development policies should therefore reflect and reinforce them. Indigenous peoples have much to contribute to development and as more emphasis is given to citizen and community participation and people-centered approaches, applying a

⁸ Pan American Health Organization, *Health of the Indigenous Peoples of the Americas: Concepts, Strategies, Practices and Challenges*, p. 16.

⁹ Ibid., p. 39

¹⁰ Human Rights Council, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt A/HRC/7/11, 2008 Para.44

cultural perspective includes acknowledging, appreciating and working with the social capital that exists among indigenous and ethnic minority communities.¹¹

3. Older Persons

Older persons are consistently among the poorest in all societies. The majority of the older poor in developing countries live in rural areas and are typically engaged in agriculture until they can no longer work in the fields. Whether rural or urban, poverty among older people is linked to low levels of literacy, low standards of health, lack of access to information, social exclusion and isolation, and to minimal participation in political and administrative decision-making.

Ageing populations present a major challenge to systems of health and long-term care. Despite the relatively good health of many older people, there is a heavy concentration of health problems and long-term care costs among the aged, particularly the very elderly. In most developing countries, governments provide only limited health services or medical care, so the needs of older people, especially the poor, whether preventive, curative, restorative or rehabilitative, remain largely unmet.¹²

There is a general assumption that older persons are not or should not be active sexually, which not only contributes to stereotyping and stigma but also to prevent them from accessing services and information. Older persons are fully entitled to have access to preventive and curative care, including rehabilitation care and sexual and reproductive health information and services.

It is important for health systems to integrate sexual and reproductive health needs for older persons, including requiring medical and para medical personnel to be sensitive and respectful of the needs and dignity of older persons. As latterly, evidence has shown that older persons are at higher risk of contracting HIV and AIDS and other STIs as they are less likely to have protected sex, information campaigns and programmes should also target order persons.

¹¹ United Nations Population Fund, Report submitted to the UN Permanent Forum on Indigenous Issues, 8th Session, E/C.19/2009/3 2009, Para. 4.

 $^{^{12}}$ From UNFPA, Population Ageing and Development, Operation Challenges in Developing Countries, 2002, at

 $http://www.unfpa.org/webdav/site/global/shared/documents/publications/2002/population_ageing.pdf$