

Final report

CONSULTA SUL-AMERICANA SOBRE DIREITO À SAÚDE

South-American Consultation with the UN Special Rapporteur on the Right to Health, Anand Grover

Sao Paulo, 25 and 26 March, 2009

INTRODUCTION

Anand Grover, UN Special Rapporteur (SR) on the Right to Health, visited Sao Paulo (March 25th and 26th) to participate in the South American Consultation on the Right to Health. The Consultation was organized by Conectas Human Rights, ABIA (the Brazilian Interdisciplinary Association on AIDS), SPW (Sexuality Policy Watch) and the Lawyers Collective.

45 participants from 7 South American countries (Argentina, Brazil, Colombia, Peru, Paraguay, Venezuela, and Uruguay) attended the two-day meeting (see Annex 1, List of Participants). An international organization (Center for Reproductive Rights, US) and observers from Mozambique, Angola and Guinea Bissau also participated in the consultation. The criteria defined by conveners to invite participants was basically that they represent networks with connections in more than one South American country, whose advocacy and research work addresses key areas related to the right to health such as: public health at large, the health impact of conflicts, mental health, HIV/AIDS, sexual and reproductive health and rights, the health-related rights of non-conforming sexual identities, the health status of indigenous people, ethnic and racial differentiations in health indicators and access to health services.

The Consultation sought to:

- Provide the Special Rapporteur with firsthand information about the situation of the right to health in South America in relation to the various domains listed above.
- Inform the concerned communities about the mandate scope and methodology adopted by the SR.

The South American meeting was the first consultation initiated by the SR. Similar consultations will be held in different regions of the world, such as Central America and the Caribbean; North America, Western Europe, Eastern Europe, the Middle East and North Africa, South Asia, Southeast Asia, and East, West, and Southern Africa.

The meeting started with an introductory section during which the SR and his assistants spoke about the mandate and other speakers provided an overview on the right to health in the region. This was followed by presentations and debates on specific topics, when each of the participants provided a synthetic diagnostic of how the right to health is respected or infringed upon in their

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specific area of work, which was followed by questions and comments by all the participants (see Annex 2, Agenda).

All background documents and presentations given during the meeting can be accessed at <http://www.conectas.org/arquivospublicados/anand/anand.htm>

THE RIGHT TO HEALTH MANDATE: SCOPE AND METHODS OF WORK

Anand Grover in his opening remarks strongly emphasized that, in his view, having direct contact with communities affected by the absence of or infringements upon the right to health is crucial to ensure the consistency and quality of his mandate as Special Rapporteur.



After these opening remarks, Dragana Korljan, the liaison between the SR and the Office of the High Commissioner on Human Rights and Diya Uberoi, one of the SR assistants based at the Lawyers Collective (India) gave a detailed presentation about the SR's methodology of work. In particular, they offered substantive information on country visits and the rules that guide direct complaints to the SR, when they highlighted the most common mistakes that applicants make when filing a direct complaint.

THE RIGHT TO HEALTH IN SOUTH AMERICA: AN OVERVIEW

Fernando Aith, National Special Rapporteur on the Right to Health for the Brazilian Platform on Social and Economic Rights¹ presented a general overview of the right to health in the region. He underscored the great difficulties that emerge when we try to analyze the status of the right to health in “all” of South America in light of the quite sharp heterogeneities and inequalities observed across and within countries. While keeping in mind these variations, he briefly identified some common features and trends.

The first common characteristic across South American countries is the impact of poverty on the access and implementation on the right to health, which has as its main consequences:

- Lack of access to health public services
- Lack of access to medicines
- Lack of information/education related to health issues
- Huge problems regarding basic sanitation
- Poor housing conditions
- Poor nutrition

¹ Mirroring the UN Special Mechanisms, the *Plataforma Brasileira de Direitos Econômicos, Sociais e Ambientais* (a Brazilian Network of NGOs) created a national system of Special Rapporteurs. See http://www.dhescbrasil.org.br/_plataforma/menu.php?id=707&site=http://www.dhescbrasil.org.br/_plataforma&cd_sit e=30

A second common feature mentioned by Fernando Aith was the impact of religious dogma on the design and implementation of health policies, which particularly affects the areas broadly defined as “sexual and reproductive health and rights”. Lastly he noted as another commonality the contexts of vulnerability that impact the health status of particular groups, especially afro-descendent and indigenous peoples. He highlighted the lack of access to specialized services or even, in many cases, access to basic health services for these populations.

George Liendo, from the Observatorio de los Grupos Antiderechos (Peru)² complemented Aith’s overview, particularly in relation to the impact of religious dogmatic visions on the right to health. The research developed by the Observatorio shows that dogmatic religious forces are extremely well-organized within and across countries and that it is their aim to oppose and hinder the protection of reproductive and sexual rights, particular in relation to the access to safe and legal abortion. The research also shows that these forces presently make use of existing democratic mechanisms in the domain of political participation, the electoral process and legislative work to oppose pro-choice policies.

INDIGENOUS PEOPLES’ RIGHT TO HEALTH

Fernando Antonio de Carvalho Dantas, professor at the Universidade do Estado do Amazonas (Brazil), introduced the debate on the situation of indigenous peoples in the region, with a more detailed focus on the Brazilian situation. He highlighted the importance of the 1988 Brazilian Constitution concerning the special rights guaranteed to indigenous groups. He also mentioned the complementary, but also often contradictory, responsibilities of several state institutions responsible for the protection of indigenous people’s right to health, such as the National Sub-System of Indigenous Health, the Special Indigenous Peoples Health Districts and Agents of Indigenous Peoples Health.

Pablo Kamaiura, an indigenous leader from the Xingu area (Brazil), complemented Fernando Carvalho’s presentation by sharing his personal experience. Pablo started by reminding the audience that while the Brazilian state views “health” as fundamentally relating to “disease”, in the perspective of his own community health means a preserved environment, clean water, food, happiness and being able to engage with parties. But in reality what prevails, he reported, are very poor health conditions of indigenous peoples in Brazil and difficulties in identifying professionals who are able to respond to the problems of indigenous peoples on their own terms. He also mentioned that the Brazilian indigenous health system as it exists today is plagued by “politicization” and corruption. In particular, he strongly called for the importance of forming indigenous peoples’ doctors to be responsible for health management and services.

RACIAL INEQUALITY AND HEALTH

Jose Marmo da Silva, from the Rede Afro Saúde (Brazil)³ emphasized that the access to the right to health is not the same for white and black people in Brazil. In Brazil both researchers and activists consider “black” the summing up of those who self-classified themselves as black and brown in National Census that comprises roughly 50 percent of the population. Today more than

² The Observatorio is a Project of PROMSEX, Peru, <http://www.promsex.org/>

³ Visit: <http://religrafosauade.blogspot.com/>

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80 percent of the black population defined as such fully depends on the public health system which is universal and free of charge but very uneven in quality across the country and particularly problematic in the poorest areas. Within this population, black women are the most underprivileged group in Brazil.

Marmo gave a concrete example of the unequal access to medical care with respect to pregnancy and deliveries. The results of a survey performed by Fiocruz in 2004 revealed that in Rio de Janeiro black pregnant women receive less medical guidance during pre-natal care and that doctors use less anesthesia during deliveries. Additionally, although a protocol exists ensuring that partners and relatives are allowed to be present during deliveries, this rule is not usually followed in the case of black women. Other Brazilian researchers that have examined the subject have also detected that some illnesses that affect black women in particular, creating a greater risk of death during the delivery, are not correctly treated. This is the case, for example, of blood hypertension. As a result, Marmo highlighted, while the life expectancy for white Brazilians is 71 years, for black Brazilians it is 66.

THE HEALTH IMPACT OF ARMED CONFLICTS: THE COLOMBIAN CASE

Carlos Iván Pacheco, from the Centro de Investigaciones en Sociedad, Salud y Cultura (CISSC) de la Asociación Tumerqué (Colombia) spoke about the impact of the armed conflict on the access to health in Colombia. He starting by recalling that in 1993 Colombia reformed its health system introducing a policy of “state subsidy for health care demand” (instead of state subsidy for full coverage of services/universal access). Consequently since then individuals and families must negotiate health insurance premiums with private insurance schemes, a model also adopted in other countries of the region, which combines subsidized universal basic packages (mainly for maternal and child health care) and the establishment of users fees in the case of health interventions of higher complexity.⁴

He also emphasized that access to health care is extremely limited for people living in the rural areas (40 percent of the total population) due to the lack of means of transportation for them to reach health centers where services are provided. Most principally he underlined that access to health care is practically inexistent for the population living in areas of conflict, due to the growing violence against the civil population as armed groups also impede the dislocation of persons in search of clinics and hospitals, but also affect the work of medical missions that try to reach out to people living in the conflict areas.

Lastly he spoke about the absence of the full fruition of the right to health in the case of indigenous peoples, people living with HIV, or afro-descendants, as the access of these particular groups to health services is constrained not just by structural problems – as the distortions of health reform or the impact of conflict -- but also by discrimination and stigma experienced by these groups.

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⁴ The same model is also implemented in Chile, Argentina and Mexico and directly derives from the so called World Bank “reformed health reform prescriptions” that were adopted in the region after 1993.

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Lilian Abracinskas, from *Mujer y Salud* (Uruguay)⁵ also stressed that it is not possible to make any generalizations about women's social and economic conditions and their right to health across South American countries because of great heterogeneity and patterns of inequality that characterize the sub-regional scenario. But at the same time, she reminded that some common cultural and socio-economic features can be identified across countries in respect to gender, such as the sexual division of labor among men and women and the imprint of patriarchal cultural norms on political, economic, social and religious institutions. One clear illustration is that in all relevant social and economic institutions positions of power remain predominantly in the hands of men. This long standing gender bias in politics has, among other consequences, the dominant cultural perception that women's main social identity is to fulfill their roles as "mothers". When this construct is translated into health policies the result is that programs being implemented still prioritize mother and child health care interventions. Those behaviors and demands that do not comply with this deep rooted "ideal notion of motherhood" tend to be socially sanctioned or even criminalized as in the case of abortion.

SEXUAL ORIENTATION, GENDER IDENTITY AND SEXUAL RIGHTS

Marcelo Ferreira from ILGA (Argentina)⁶, Mauro Cabral from Mulabi (Argentina)⁷ and Marcela Romero from RED LACTRANS (Argentina)⁸ made complementary presentations on the social and health policy factors that affect the exercise of the right to health in the case of persons and groups whose sexuality does not conform with the dominant heterosexual norms.

Marcela Romero presented the results of a first survey recently performed by RED LACTRANS about the situation of trans people in the region. Due to lack of education, trans persons tend to work almost exclusively as sex workers, suffering the effect of remaining rules that criminalize commercial sex. She also reported on the high rate of suicide among trans persons and the high incidence of homicides that result from stigma and discrimination (*transphobia*). She also highlighted the negative impact on the right to health of the juridical restrictions in respect to the change of name (civil identity) in personal documents. And, in particular, she spoke about the discrimination and "confusion" experienced by trans persons in health services, in particular hospitals, because the spatial organization of services is fully based on a binary conception of gender that separates men and women and is not prepared to treat those whose bodies and sexual identities do not fall into these categories. She also mentioned the high rates of HIV among trans persons (35 percent) and persistent difficulties in terms of access to adequate AIDS treatment. All these biases and limitations reflect life expectancy that is one key health and social economic indicator, which is of approximately 33 years in the case of trans persons in contrast to the 70 years of life expectancy registered in South America for the population as a whole.

Marcelo Ferreira called attention to a main regional feature regarding gays and lesbians access to health care in the Latin America and Caribbean region as whole: the big differential across countries in terms of legal frames. For example, while most countries in the Caribbean still criminalize same-sex relations, in Spanish-speaking countries and Brazil "sodomy laws" have been abolished (most recently in 2008), in Ecuador the new constitution grants full rights, including the right to health, to persons with diverse sexualities and in many countries anti-discrimination laws have been adopted (at least at state/province or local levels). However anti-

⁵ Visit <http://www.mysu.org.uy/>

⁶ Visit <http://www.ilga.org>

⁷ Visit <http://www.mulabi.org/>

⁸ Visit <http://www.redlactrans.org/portal03/>

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discrimination legislation coexists with other norms that criminalize conduct considered “homosexual behavior”, such as cross-dressing and same-sex relations among members of the armed forces. Another recent and rather worrying trend to be mentioned is the proliferation of private clinics in Ecuador and Brazil, for instance, devoted to the “cure of homosexuality.” These clinics are predominantly managed by religious institutions. Finally, Marcelo noted that despite improvements in terms of HIV/AIDS policies a clear absence of specialized health services sensitive to the needs of the LGBT population is quite evident across countries.

Mauro Cabral’s presentation focused on the experience of intersex persons. He provided detailed information about the consequences of mutilating surgeries, aimed at “fixing” intersex bodies for them to become culturally “acceptable”. These widely implemented surgeries openly violate human rights because they are performed on infants at an early age and do not imply informed consent. Their detrimental impact is also extremely problematic as the surgeries determine not only the legal gender status of these persons but also the shape of their bodies and the sensitivity of their sexual organs⁹. Genital mutilation of intersex children damages genital sensitivity in irreversible ways; it causes post-surgical trauma and the internalization of brutal prejudices by denying or stigmatizing the diversity of sexuality that, in fact exists, in all human bodies. He concluded by saying that medical “treatment” of intersexuality as it is currently applied implies extreme levels of discrimination, exclusion and stigma¹⁰.

HIV AND ACCESS TO MEDICINES

Lorenzo Vargas, from LACCASO (Argentina)¹¹ analyzed the South American context in relation to HIV/AIDS as characterized by discrimination, lack of information, fear and permanent violation of fundamental rights of people living with HIV. He highlighted how the pandemic has mostly affected groups surrounded by conditions of vulnerability, as in the case of gay men, trans people, sex workers, drug users and women. He mentioned that while the legal recognition of the right to health policies for access to medicines exists in most countries, in reality they are not being implemented as required.

In LACCASO’s view one of the main obstacles hindering the exercise of the right to health is the absence or limitations of HIV/AIDS prevention policies. The conservative religious lobby, in particular on the part of the Catholic Church, is one main factor explaining this gap. Regarding access to ARV treatment he recalled that even today no reliable information is available about the total number of people living with HIV. Another key factor to be considered is the trend towards privatization of health care services, which particularly hurt the poorest sector of the population. Lastly, access to treatment is impaired, as elsewhere, by cost and restrictions deriving from intellectual property rights/patents and the powerful lobby of the pharmaceutical industry.

Renata Reis from ABIA (Brazil)¹², complemented the analysis on the impact of intellectual property rights (IPR) on the access to medicines. She especially called the attention of the SR to some questions affecting the South American region that need further research and analysis such as:

⁹ See 2004 UN NGO Statement by Mauro Cabral, available at:

http://www.ilga.org/news_results.asp?LanguageID=1&FileCategory=44&FileID=61

¹⁰ See 2004 UN NGO Statement by Mauro Cabral, available at:

http://www.ilga.org/news_results.asp?LanguageID=1&FileCategory=44&FileID=61

¹¹ Visit <http://www.laccaso.org/>

¹² Visit: <http://www.abiaids.org.br/>

- The impact of IPR legislation on the access to medicines;
- The incorporation or not of TRIPS flexibilities in national IPR legislation and the verification if in those countries where flexibilities have been incorporated they are or not being effectively used;
- The abuses perpetrated by big pharmaceutical companies regarding the pricing of drugs;
- The state of art in relation to clinical testing being performed in the region, in particular because medicines that are increasingly being tested in South America, but when the drug is approved later it is not made available in the countries where trial have taken place.
- Lack of transparency of trade negotiations that have direct impact on the access to medicines, as well the need to ensure the participation of civil society organizations in the processes leading to these negotiations;
- A mapping of new free trade agreements which include TRIPS Plus regulations and of their impacts.

SEX WORKERS' RIGHT TO HEALTH

Maria Lucila Esquivel, from Unidas en la Esperanza (Paraguay), reminded that in several countries of the region prostitution is still criminalized. Even when not enshrined in penal codes' definitions criminalizing measures are implemented through local ordinances and other regulations. The lack of health policies that focused on the special needs of sex workers, combined with discriminatory conduct in most of the public hospitals, are the main obstacles to the access to health of this population. In her opinion, better designed and more effective HIV prevention policies and programs are also needed to respond to the needs of sex workers.

MENTAL HEALTH

According to Elsa Bustamante, from Aprodeh (Peru)¹³, psychosocial problems associated with poverty, unemployment, impunity and the erosion of public policies are the main causes of the increasing numbers of mental health problems in the region. Other signs of mental illness are the growing levels of stress and depression.

In terms of access and quality of care one persistent problem is that even today mental health patients are perceived as "passive" recipients of treatment whose opinions and decisions are not taken into account by health systems. In South American societies, persons with mental disabilities generally suffer discrimination, stigma and isolation. Though in some countries psychiatric health care reforms have occurred, this is not the case everywhere. In Peru, 40 percent of persons with mental disabilities still live in psychiatric hospitals and are, in many cases, subject to cruel and inhuman treatment. In Peru, at least 3 hospitals continue to use electroshock therapy without informed consent.

CHILDREN & HEALTH

¹³ Visit <http://www.aprodeh.org.pe/>

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Luciano Macedo, from Organización Movimiento Nacional Gustavo Volpe (Uruguay), listed as the main problems affecting children's right to health in the region:

- Lack of health care centers and hospitals equipped with adequate human and material resources
 - Poor coverage of pre-natal care and growing rates of adolescent pregnancy
 - High concentration of health care resources in urban areas
 - Child labor
 - Malnutrition
 - HIV vertical transmission
 - The conditions experienced by adolescents in juvenile criminal systems, whose health facilities are extremely precarious.
 - Degraded environmental conditions
 - The extreme vulnerability of homeless children

Macedo also addressed a specific problem, which has not yet achieved much visibility in the health and human rights regional debates: the growing use of methylphenidate (Ritalin) for the treatment of children's and teenagers "conduct disorders". He informed that in Uruguay, for example, while in 2001, 900 grams of Ritalin were imported, in 2007 this amount increased to 17 kilograms. In his opinion, similar trends are observed in other countries. This reflects a trend towards high levels of medication administered to children and adolescents as a means of altering behavior. This phenomenon today mainly affects the middle and upper-class, but already constitutes a public health problem and should be examined more closely by those committed to the right to health.

COMMENTS BY PARTICIPANTS

After each presentation, participants complemented the analyses with additional information and other angles through which the problems presented could be interpreted. These debates allowed for a very rich cross-cutting exchange among the different areas and groups represented in the consultation. The SR also requested clarifications whenever necessary.

CLOSURE - ANAND GROVER

The consultation was closed by Anand Grover's final remarks. He thanked the participants for their presence and contributions. He also requested the group to continue sending him information about the situation of the right to health in South America. In particular he called for complementary information regarding the situation of indigenous peoples and the afro-descendent population.

He also announced that his first report to the Human Rights Council (June 2009) will focus on the relationship between the right to the highest attainable standard of physical and mental health, specifically in regard to access to medicines, and intellectual property rights. It will also discuss TRIPS and TRIPS flexibilities and the effect of TRIPS-plus requirements on access to medicines. But he also mentioned he may explore the possibility of focusing one of his future reports on the notion of "**consent**" regarding access to health care and the right to information, as in his view this lens is a sharp tool to examine the detrimental effect of forced health treatments. Another area he may explore is the consequences on the right to health of long-standing or novel rules of **criminalization** of different conduct such as:

- the use of drugs,

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- sex work and
- the transmission of HIV.

He finally listed as another potential area of study the impact on health of **violence** against sexual minorities and women. Last but not least, he reiterated his openness and willingness to keep in close contact with the affected communities, and reiterated his commitment to quickly respond to any complaints or requests for information he receives.

To provide input or to bring issues and complaints to the Special Rapporteur's attention, Anand Grover can be contacted under srhealth@ohchr.org, specialrapporteurhealth@lawyerscollective.org or by fax under +41 22 917 90 06.

EXPENSES

All the expenses of the participants were covered by the organizers, including:

- Transportation (flights and local transportation from and to the airport)
- Hotel
- Per-diem
- Health insurance

The expenses were covered with a donation of US\$25.000 from the Lawyers Collective. Oxfam Brazil also donated 10.000 Reais for local costs (hotel).

São Paulo, 12 May 2009.

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South-American Consultation on the Right to Health
Sao Paulo, 25 and 26 March, 2009¹⁴

CONSULTA SUL-AMERICANA SOBRE DIREITO À SAÚDE

Com Anand Grover, Relator Especial da ONU para o Direito à Saúde

25 e 26 de março, 2009 – São Paulo, Brasil

Wednesday 25 March

9.00 – 9.30	Registration and materials
9.30 – 10.00	Welcome Conectas, Abia and SPW
10.00 – 10.30	Opening Remarks – Anand Grover
10.30 – 11.00	General presentation on UN Special Procedures – Dragana Korljan and Diya Uberoi
11.00 – 11.30	Break
11.30 – 12.00	Overview on the situation of the Right to Health in LA – F. Aith, Brazil Q&A
12.00 – 12.30	The impact of religion on the right to health in LA -George Liendo, Peru Q&A
12.30 – 14.00:	Lunch
14.00 – 14.45	Environment and Health - Carolina Fairstein, Argentina Q&A
14.45 – 15.30	Indigenous Peoples - Fernando Antonio de Carvalho Dantas, Brasil Q&A
15.30 – 16.15	Race and Health - José Marmo Silva, Brazil Q&A

¹⁴ Two representation originally scheduled were not finally done: Environment and Health (Carolina Fairstein, Argentina) and Tuberculosis (Aurea Abbade, Brasil).

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16.15 -17.00 Armed Conflict, Carlos Ivan Pacheco Sanchez, Colombia
Q&A

Thursday 26 March

9.00 - 9.45: Women & Health - Lilian Abracinskas, Uruguay
Q&A

9.45 – 10.30: Sexual orientation and sexual rights - Marcelo Ferreira & Mauro Cabral,
Argentina
Q&A

10.30 – 11.00: Break

11.00 – 11.45: HIV and access to medicines – Lorenzo Vargas, Argentina
Q&A

11.45 – 12.30: TB – Áurea Abbade, Brasil
Q&A

12.30 – 14.00: Lunch

14.00 – 14.45: Sex Workers, Maria Lucila Esquivel, Paraguay
Q&A

14.45 – 15.30: Mental Health - Elsa Bustamante, Peru
Q&A

15.30 - 16.15: Children & Health – Luciano Macedo, Uruguay
Q&A

16.15 – 17.00: Closing – Anand Grover

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