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LOS DERECHOS ECONÓMICOS, SOCIALES Y CULTURALES

Informe presentado por Paul Hunt, Relator Especial sobre el derecho de toda persona al disfrute del más alto nivel posible de salud física y mental

Adición

MISIÓN A UGANDA*

* El resumen del presente informe se distribuye en todos los idiomas oficiales. El informe, que figura en el anexo al resumen, se distribuye únicamente en el idioma en que se presentó.

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Resumen

El Relator Especial sobre el derecho de toda persona al disfrute del más alto nivel posible de salud física y mental ("derecho a la salud") visitó Uganda del 17 al 25 de marzo de 2005 a fin de evaluar la cuestión de las enfermedades desatendidas a través del prisma del derecho a la salud.

Las enfermedades desatendidas son también conocidas como enfermedades "relacionadas con la pobreza" o "tropicales". Cuando no son letales, estas enfermedades causan deformidades y discapacidades graves y permanentes, a casi 1.000 millones de personas de todo el mundo, especialmente entre la población más pobre de los países en desarrollo.

Además del sufrimiento físico y psicológico que causan, las enfermedades desatendidas imponen una pesada carga económica a las comunidades afectadas, entre otros factores, debido a disminución de la productividad. A su vez, ello contribuye a agravar aún más el ciclo de pobreza, la mala salud, la estigmatización y la discriminación que sufren las poblaciones desatendidas.

Aunque existen algunos medicamentos y vacunas para combatir las enfermedades desatendidas, estas intervenciones no siempre llegan a quienes las necesitan, incluso cuando los medicamentos y las vacunas han sido donados. Por otra parte, es necesario aumentar la investigación y el desarrollo en el campo de las enfermedades desatendidas. La experiencia demuestra que cuando la investigación y el desarrollo se rigen solamente por las leyes del mercado, no se presta suficiente atención a esas enfermedades.

En Uganda entre las enfermedades desatendidas figuran las siguientes: la filariasis linfática (elefantismo), la oncocercosis (la ceguera de los ríos), la lepra, la tripanosomiasis africana humana (enfermedad del sueño), los helmintos transmitidos por el suelo y otras enfermedades.

En el informe se describen los principales componentes del planteamiento de esas enfermedades desde el punto de vista del derecho a la salud en el contexto de Uganda: la información y la educación, la participación de la comunidad, la función de los profesionales de la medicina, la forma de solucionar la estigmatización y la discriminación, un sistema de salud integrado, el mejoramiento de la investigación y el desarrollo, el papel de los donantes y de la comunidad internacional, y las actividades de supervisión y rendición de cuentas.

Si bien el presente informe se centra en Uganda, gran parte del análisis tiene una aplicación general a otros países donde están extendidas estas enfermedades.

El Relator Especial expresa su agradecimiento al Gobierno de Uganda por su invitación a visitar el país, que le ha permitido realizar un estudio monográfico sobre las enfermedades desatendidas y el derecho a la salud en el país. También quiere expresar su gratitud a la Organización Mundial de la Salud, con la que el Relator Especial trabajó en estrecha cooperación durante la misión.

Annex

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, ON HIS MISSION TO UGANDA (17-25 MARCH 2005)

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I. INTRODUCTION

1. At the invitation of the Government of Uganda, the Special Rapporteur carried out a mission to Uganda from 17 to 25 March 2005 in order to address the issue of neglected diseases. The mission provided a unique opportunity for the Special Rapporteur to examine in depth one important right-to-health issue - neglected diseases - building on the commendable work being done in this area by health professionals at the national and international levels, in particular through the Ministries for Health in Uganda and the World Health Organization (WHO). The Special Rapporteur expresses his sincere appreciation to the Government for the openness and cooperation extended to him throughout the course of his mission. He is deeply grateful to the WHO offices in Geneva and Kampala, and to the Office of the United Nations High Commissioner for Human Rights (OHCHR), for their indispensable support. In addition to providing the Special Rapporteur with expert advice on neglected diseases, WHO also provided financial support for the mission. In the Special Rapporteur's view, the mission provided a model of how a Government, a specialized agency and human rights independent expert can and should cooperate, with each party respecting the distinctive role of the others.

2. The report of the mission does not purport to address other vital health challenges in Uganda, nor does it analyse in depth the broader issues related to the right to health in the country. Instead, in the context of neglected diseases, the report addresses issues related to: access to health care for marginalized populations in Uganda; underlying determinants of health, such as access to clean drinking water and sanitation; access to drugs and other control mechanisms for neglected diseases; the crucial role of health professionals; and the impact of neglected diseases on the health of people living in poverty, and other marginalized groups, in rural and urban areas. It focuses on key elements of a right-to-health approach to neglected diseases, such as community participation, access to health information and education, non-discrimination, monitoring and accountability, and international cooperation and assistance. The Special Rapporteur hopes that this brief analysis of the right to health in the Ugandan context will contribute to addressing the urgent need, at both the national and international levels, for attention and action to effectively combat neglected diseases and realize the human rights of those affected.

3. The Special Rapporteur consulted with a wide range of actors in Uganda, including representatives of the Government of Uganda, the National Human Rights Commission, international organizations, associations of health professionals, communities and individuals affected by neglected diseases, non-governmental organizations (NGOs), development partners and pharmaceutical companies. He had the honour to be received by the Minister of Gender, Labour and Social Development; the Minister of State for Health (General Duties); the Minister for Internal Affairs; the Minister of State for Northern Uganda Rehabilitation; the Minister for Finance, Planning and Economic Development; and the Minister of Tourism, Trade and Industry. He also held discussions with representatives of United Nations agencies, including the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), UNAIDS, the World Food Programme (WFP) and OHCHR, and with development partners such as the World Bank, the Department for International Development (DFID), Development Cooperation Ireland, and the Danish International Development Agency (DANIDA). He also met with representatives of NGOs, including Médecins sans Frontières, Oxfam, Obalanga Human Rights and Health Association, YMCA and Uganda Youth Development Link. During the mission the Special Rapporteur visited health centres and communities affected by neglected

diseases in Gulu, Lira and Katakwi districts as well as the urban slum areas of Kampala. He visited, inter alia, the Lacor Hospital and Awer camp in Gulu district, Amuria HC-IV and Obalanga camp in Katakwi district and Dokolo HC-IV, Lira district and Kisenyi HC-II in Kampala, and urban slums of Kakaju zone and Irumun Centre. The Special Rapporteur expresses his sincere gratitude to all the people he met.

A. What are neglected diseases?

4. Neglected diseases vary in the extent of the burden they impose, and in the availability and accessibility of appropriate treatments. In general, they fall into two categories:

(a) Endemic, chronic and disabling diseases for which effective treatment or preventive strategies exist, such as leprosy, soil-transmitted helminths, lymphatic filariasis and onchocerciasis; and

(b) The growing epidemic of deadly diseases for which modern effective treatment does not currently exist, or is not safe, such as buruli ulcer, Chagas' disease, leishmaniasis and African trypanosomiasis/sleeping sickness.

5. Low cost and easy to use tools exist for the control and prevention of most neglected diseases, i.e. those that fall into the first category. The tendency for the diseases to be localized assists targeted programme delivery. Also, population-wide interventions such as mass drug administration and vector control are largely free of discrimination and do not further marginalize excluded groups. Several interventions bring rapid physical relief that helps stimulate acceptance and further demand.

6. The problem in relation to this category of diseases has primarily been one of neglect; for example, exploiting the potential of existing tools against these diseases has not been a priority at either the national or international level.

7. There is no standard global definition of neglected diseases. However, WHO describes them as those diseases that "affect almost exclusively poor and powerless people living in rural parts of low-income countries".[1] The key elements are that these are diseases affecting principally poor people in poor countries, for which health interventions - and research and development - are regarded as inadequate to the need. The Special Rapporteur notes that they are referred to elsewhere in the literature as "tropical" or "poverty-related" diseases. For the purposes of his mission to Uganda, however, he has elected to use the term "neglected diseases".

8. Although neglected diseases are by no means homogeneous, it has been noted that many share the following common characteristics:

(a) They typically affect neglected populations - the poorest in the community, usually the most marginalized and those least able to demand services. These often include women, children and ethnic minorities, displaced people, as well as those living in remote areas with restricted access to services. Neglected diseases are a symptom of poverty and disadvantage;

(b) The introduction of basic public health measures, such as access to education, clean water and sanitation, would significantly reduce the burden of a number of diseases. Improved housing and nutrition would also help in some cases;

(c) Where curative interventions exist, they have generally failed to reach populations early enough to prevent impairment;

(d) Fear and stigma attach to some diseases, and lead to delay in seeking treatment as well as to discrimination against those affected;

(e) Although the eradication of certain diseases can be achieved at low cost per patient, the total cost at the national level can be significant in view of the number of people affected by the diseases;

(f) The development of new tools - new diagnostics, drugs and vaccines - has been underfunded or neglected, largely because there has been little or no market incentive.

B. The global burden of neglected diseases

9. Appendix 1 contains a brief summary of the global burden of neglected diseases. These diseases continue to cause immense suffering and lifelong disabilities among the poorest populations in developing countries, in particular those living in rural areas. According to WHO, "the health impact of these neglected diseases is measured by severe and permanent disabilities and deformities in almost 1 billion people".[2] Globally, nearly 70 per cent of all disability-adjusted years due to neglected diseases occur in children under 14 years.[3] In addition to the physical and psychological suffering they cause, neglected diseases inflict an enormous economic burden on affected communities owing to lost productivity and high costs associated with long-term care, which in turn contributes to the entrenched cycle of poverty, ill health, stigmatization and discrimination experienced by neglected populations.

II. NEGLECTED DISEASES AND THE RIGHT TO HEALTH IN UGANDA

A. Uganda: a brief background

10. Beginning in 1961, under the authoritarian leadership of its first Prime Minister, Milton Obote, Uganda experienced nearly 10 years of multiparty democracy. However civil unrest grew throughout this period owing to tribal, religious and political differences. In February 1966, Prime Minister Obote suspended the Constitution and assumed all government powers. In September 1967, a new Constitution proclaimed Uganda a republic and further concentrated power in the Prime Minister's hands. On 25 January 1971, Idi Amin Dada ousted Obote's Government and seized power in a military coup. His eight years of rule saw a period of massive human rights violations, economic decline and social disintegration. During the 1970s and 1980s the country went through a prolonged period of civil unrest and much of the infrastructure for basic services was destroyed.

11. In 1986, National Resistance Army leader Yoweri Museveni was sworn in as President, bringing stability and the beginnings of an economic renaissance. During the mid-1990s Uganda showed a strong economic performance, following a wide range of economic reform initiatives.

Poverty levels declined from 56 per cent in 1992 to 35 per cent in 2000. However, over the past five years, economic growth and other key macroindicators have been more disappointing. Uganda has a population of 24.7 million people, with a population growth rate of 3.4 per cent and a per capita GDP of US$ 320. Thirty-five per cent of the population continue to live on less than 1 US dollar a day.

12. At the same time, insecurity has persisted in the northern regions of Uganda owing to the ongoing conflict between the Lord's Resistance Army (LRA) rebel group and Government forces. The conflict continues to have a devastating social and economic impact. Since 1986, attacks on civilians by LRA have contributed to internal displacement and forced villagers to seek refuge outside of their homes and communities. In late 1996, the Government ordered the displacement of large numbers of people into "protected villages" in order to protect civilians from further attacks and to undermine civilian support for the rebels.

13. By 2004, an estimated 1.6 million people were displaced and confined to about 200 temporary settlements, with populations ranging from 500 to 60,000 per settlement. These people live without independent means of subsistence, and many live in inadequately protected and serviced camps where they continue to suffer from violent attacks by LRA. Access to clean drinking water, adequate sanitation and basic health services in many of the camps is extremely limited, a situation which has fuelled high levels of morbidity and mortality.[4] Poverty levels in Northern Uganda average between 38 and 67 per cent, compared to other regions with an average of 20 per cent poverty.[5] A recent survey by WHO found that crude mortality rates in Gulu, Kitgum and Pader were above the emergency threshold of 1 death per 10,000 per day,[6] and well above the nationwide rate of 0.46 for Uganda.[7]

14. In the face of these challenges, the Government of Uganda has committed itself to achieving stability, growth and poverty reduction, and to meet development targets within the framework of the Millennium Development Goals (MDGs). In relation to health, the Government has sought to implement its international commitments through the national Poverty Eradication Action Plan (PEAP), the National Health Policy, the Health Sector Strategic Plan (HSSP), the Uganda National Minimum Health Care Package (UNMHCP) and other pro-poor health-related policies. These and other related national policy frameworks are introduced in the sections below.

B. International human rights framework

15. Uganda has ratified a wide range of international and regional human rights instruments which contain important provisions related to the right to health, including the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination against Women and the African Charter on Human and Peoples' Rights. These instruments provide a framework for legislation and policy at the national level. The Government has also committed itself to meeting various health-related goals and targets through its participation in international and regional conferences, including the Millennium Summit of the General Assembly.

16. As a party to international human rights treaties, the Government of Uganda has an obligation to respect, protect and fulfil the right to health for those within its jurisdiction. The international community also has a responsibility to assist Uganda in the fulfilment of its human

rights obligations, including through international assistance and cooperation. NGOs, health professionals, businesses and others also have important responsibilities regarding the right to health in Uganda.

C. National legal and policy frameworks

17. The Constitution of the Republic of Uganda is grounded in basic human rights principles, including non-discrimination and equality for all citizens, with specific provisions to ensure the human rights of women, people with disabilities and children.[8] Preambular paragraph XX provides that the State shall take all practical measures to ensure the provision of basic medical services to the population, while other sections commit the State to promoting access to the underlying determinants of health, such as water, encouraging the production and storage of food, and promoting nutrition through education and other means to support a healthy population. Preambular paragraph XIV (ii) states that all Ugandans shall enjoy rights and opportunities and access to education, health services, clean and safe water, work, decent shelter, adequate clothing, food security and pension and retirement benefits.

18. The Government has sought to implement its obligations regarding the right to health through its national poverty reduction strategies, national health policy and health sector strategic plans. PEAP for 2005-2008 sets out a strategy for poverty eradication based on five pillars: (a) economic management; (b) production, competitiveness and incomes; (c) security, conflict resolution and disaster management; (d) good governance; and (e) human development, including health.

19. The Health Sector Strategic Plan II for the period 2005-2010 seeks to reduce morbidity and mortality from major causes of ill health through universal delivery of UNMHCP. The overriding priority of HSSP II will be the fulfilment of the health sector's contribution to meeting the goals of PEAP and MDG, namely reducing fertility, malnutrition, maternal and child mortality, HIV/AIDS, tuberculosis and malaria, as well as disparities in health outcomes. The National Health Policy and Health Sector Strategic Plans have been formulated within the context of the Constitution and the Local Government Act, 1997, which decentralized governance and service delivery. The Government has engaged in a process of health-care decentralization in order to ensure that district leaders are directly involved in, and accountable for, health policies for the communities they represent.[9]

20. The Ugandan health sector is generally underfunded. Only 30 per cent of HSSP I funding requirements were met and, although attempts have been made to mobilize additional funds for the health sector, these have been constrained by macroeconomic concerns and rigid sector ceilings. Although the health sector's share of total expenditure has grown from 6 to 8 per cent of the Government budget, only 3 per cent of GDP is allocated to health. Moreover, the medium-term expenditure framework ceiling reflects fiscal targets for maintaining macroeconomic stability as a condition for accessing International Monetary Fund loans. This requires the Government to control inflation at 5 per cent and reduce its fiscal deficit to 6.5 per cent of its GDP by 2009/2010. Without some flexibility, the Government will be unable to make the health sector investments necessary to meet the poverty reduction objectives reflected in its PEAP.

21. Following on the findings of an inter-ministerial review in 1999 and a participatory poverty assessment, in 2001 the Government abolished user fees for health-care services in public health units. This policy change resulted in a marked increase in the utilization of health services. However, it also led to increased pressure on supplies for health services with drugs frequently out of stock throughout the system. Other problems reportedly include corruption in the form of drug "leakage" into the private sector, as well as requests for informal payments by health personnel in some areas. The second participatory poverty assessment (PPA) report found that although "cost-sharing" has been abolished, community members still often have to make under-the-table payments.[10] The PPA2 notes that people are concerned that drugs "leak" to private facilities, which are largely run by government health workers.[11]

D. Health challenges in Uganda

22. The Government has achieved impressive health successes in some areas. For example, it has achieved the target of halting and beginning to reverse the spread of HIV/AIDS by 2015, by openly addressing and mainstreaming HIV/AIDS prevention and control into different sectors within national policies and programmes, including PEAP.[12] The Government has also committed to the elimination and eradication of other diseases, such as onchocerciasis and polio. It established a strong community-directed treatment with ivermectin for onchocerciasis and a National Disease Control Department to prevent both endemic and epidemic diseases, as well as national programmes to combat schistosomiasis and lymphatic filariasis. It has attained the elimination levels set by WHO in relation to guinea worm and leprosy, achieved 90 per cent coverage in measles immunization and made some progress in the prevention and control of malaria. Overall, the country has seen a steady improvement in health conditions since 1999, including increased coverage of health facilities.

23. However, significant health challenges persist. Access to health-care facilities is limited by poor infrastructure, especially in the rural areas where only 49 per cent of households have access to health care. Communicable diseases such as malaria, parasitic infection, HIV and TB are widespread and contribute to high levels of morbidity and mortality. Poor sanitation and water fuel high rates of cholera, diarrhoea, schistosomiasis and malaria among certain populations. According to reports, recently the Government has shifted away from its comprehensive HIV-prevention policy towards an emphasis on abstinence. In addition, the country has experienced a severe shortage of condoms since late 2004 as a result of problems related to procurement and timely distribution. These factors reportedly have contributed to a recent rise in HIV-infection rates, which have climbed to 7 per cent for men and 9 per cent for women nationally. At the same time, in August 2005 the Global Fund to Fight AIDS, Tuberculosis and Malaria announced the suspension of all its grants to Uganda due to "evidence of serious mismanagement" of the funds.

24. Child mortality rates remain alarmingly high, with a reported increase between 1995 and 2000 from 81 to 88 deaths per 1,000 live births.[13] These deaths are attributable mainly to malaria, diarrhoea, acute respiratory infection, malnutrition, AIDS and maternal conditions such as early pregnancies, lack of access to safe contraception, brief spacing between pregnancies and lack of access to education and information for young women. In addition, 2.2 million people were afflicted with soil-transmitted helminthiasis in 2004 and 16.7 million were exposed to

schistosomiasis, the majority of whom were children. Intestinal parasites in children contribute to anaemia, poor growth and poor cognitive performance - conditions which continue to fuel poverty.[14]

25. Maternal mortality rates in Uganda have stagnated at 505 deaths per 100,000 births.[15] Women also suffer disproportionately from diseases, due to a variety of sociocultural, economic and biological factors, and bear the burden of caring for family members afflicted with illnesses such as HIV/AIDS, malaria and lymphatic filariasis.[16] High rates of domestic violence in Uganda further contribute to the overall burden of ill health for women.[17] The Government has established a Task Force on Infant and Maternal Mortality with responsibility for producing a national strategy to address the problem.[18] However, the MDG targets related to the reduction of child and maternal mortality will not be achieved if serious measures are not adopted through a number of sectors, such as health, education and water.

E. Neglected diseases

26. Neglected diseases in Uganda include lymphatic filariasis (elephantiasis), schistosomiasis (bilharziasis), onchocerciasis (river blindness), trachoma, buruli ulcer, soil-transmitted helminths, leishmaniasis, leprosy and human African trypanosomiasis (sleeping sickness). Most of these diseases are endemic in more than one district or community. Some are life-threatening, while others result in high morbidity and severe disability.

27. In all cases, neglected diseases affect the most marginalized populations in Uganda. Those who have been displaced as a result of the conflict are particularly vulnerable, as they subsist in camps with poor sanitary conditions, overcrowding, inadequate shelter, lack of access to safe and potable water, and limited access to health services.[19] Although medical services are provided in some camps by the district's health system, less than half of the population in Gulu, Kitgum and Pader districts has access to health-care services within 5 km walking distance.

28. Neglected communities in urban areas also are vulnerable to neglected diseases. The Special Rapporteur visited the urban slum areas of Kampala, including Kisenyi, where the lack of an effective system for draining surface water during the rainy season adds to regular flooding in the area and exacerbates unsanitary conditions. Moreover, the slums lack effective sanitation systems and very few public latrines are available to the population.

29. These conditions facilitate the transmission of diseases which persist in conditions of poverty, where they cluster and frequently overlap. Unsafe water and poor sanitation sustain transmission cycles and favour the proliferation of vectors. A lack of access to health-care services, low levels of literacy, inadequate nutrition and poor personal hygiene all help to increase vulnerability to infection and work against prevention and treatment efforts.

30. By way of summary, appendix 2 identifies a selection of neglected diseases in Uganda and signals: the number of cases, the population at risk, the main form of prevention or treatment, their effectiveness and safety, the cost of treatment and a rough estimate of the cost of delivery.

31. Diseases such as HIV/AIDS, tuberculosis and malaria continue to pose massive health and human rights challenges in Uganda. However, in recent years these diseases have attracted

national and international resources and attention and, in certain respects, have met with impressive successes. By contrast, while neglected diseases such as lymphatic filariasis cause immense suffering, they tend to result in lifelong disabilities rather than death, and therefore have not received the attention and funding of high-mortality diseases, like AIDS.[20] For the purposes of the present report, the Special Rapporteur therefore focuses primarily on the diseases listed in appendix 2.

III. KEY FEATURES OF A RIGHT-TO-HEALTH APPROACH TO NEGLECTED DISEASES

32. In this section, the Special Rapporteur identifies key interrelated features of a right-to-health approach to neglected diseases. The analysis is introductory, not exhaustive.

A. Access to health information and education

33. Access to health-related information and education is a crucial aspect of the right to health. Individuals are entitled to a full range of health information that bears upon them and their communities. This includes information on preventive and health-promoting behaviour, as well as how to access health services. The Government should be commended for ensuring that public information campaigns form a key part in various health initiatives, such as on HIV/AIDS and measles, and for its commitment to health promotion as reflected in its Health Policy Statement 2004/2005.

34. While the Government has a legal duty to disseminate accessible educational information on neglected diseases to all the population, especially to marginal groups, the Special Rapporteur found relatively little public information about most neglected diseases. Moreover, harmful misconceptions about neglected diseases are widespread. For example, some people believe that traditional curses or dark spiritual forces cause lymphatic filariasis. As a result, they are likely to first seek help from traditional medicines until the disease has reached an advanced stage. Public information campaigns, such as on transmission and prevention, would help reduce the rate of morbidity and mortality caused by neglected diseases.

35. **More can and should be done to dispel damaging myths and misinformation about neglected diseases. The Special Rapporteur recommends that the Government adopt public information campaigns targeting disadvantaged rural and urban communities, including internally displaced persons camps, which should utilize the mass media, village health teams, health professionals, church and other faith networks, schools, trade unions, and so on so as to raise awareness of neglected diseases and to promote non-discriminatory behaviour towards afflicted persons. Information should always be available in local languages.**

B. Community participation

36. An integral feature of the right to health is the active and informed participation of individuals and communities in health decision-making that affects them. Those living in poverty are entitled to participate in the identification of priorities and targets that guide the technical deliberations underlying policy formulation. In most cases, a local community will

have a very keen sense of its health priorities. A participatory approach can help to avoid some of the top-down, technocratic tendencies often associated with old-style development plans.[21]

37. To its credit, Uganda actively encourages participation in health decision-making. For example, the Constitution underlines the importance of "active participation of all citizens at all levels"[22] and civil society organizations have been involved in the preparation of Uganda's PRSP/PEAP.[23]

38. Crucially, Uganda has a new policy of decentralization in the health sector. Within district health systems, there are four levels of organization and administration, the lowest being Village Health Teams, also known as Village Health Committees (Health Centre I).[24] From the right-to-health perspective, these Village Health Teams have a pivotal role to play in providing grass-roots community participation in the health sector.

39. Although considerable progress has already been made to roll out the four-tier decentralized structure within health districts, the entire structure is not yet in place. The Government has tended to give priority to establishing the higher levels; however, the lower tiers (Health Centres I and II) are beginning to attract the attention they deserve. For example, in some districts the appointment and training of Village Health Teams has begun. HSSP II confirms that priority will now be given to accelerating the operationalization of the health sub-districts, including Village Health Teams.[25]

40. Effective Village Health Teams can help to dispel the neglect that characterizes the diseases and populations that are the focus of the present report. They can help to ensure that local needs are clearly identified, understood and addressed. Moreover, the Teams can provide the crucial grass-roots delivery mechanisms for community interventions in relation to neglected diseases, and health protection generally.

41. **Community participation has a vital role to play in the struggle against neglected diseases. Vehicles for community participation, in particular Village Health Teams, are already an integral feature of Uganda's decentralized health structure. However, it is imperative that the authorities give serious attention to the urgent development of Village Health Teams. The teams must be provided with adequate resources, training and support. They should be both listened to and used strategically as delivery mechanisms in relation to neglected diseases. Also, there must be smooth and effective coordination, cooperation and collaboration between the local political structure and Health Centres I-IV.**

C. Health professionals

42. Health professionals have an indispensable role to play in the realization of the right to health. Presently, Uganda employs and retains too few health professionals to deliver a basic level of health services and protection to the entire population. Between 1990 and 2002, there were five doctors per 100,000 people.[26] Qualified staff fills only 42 per cent of approved posts.[27] In 2000, only 40 per cent of health units had trained staff. Each year, only about 60 to 120 doctors graduate from medical school, and only some 10 to 20 per cent of them are assimilated.

43. To its credit, the Ministry of Health recognizes that there are not enough trained health workers to implement HSSP and that they are unevenly distributed with most going to the urban areas and well-placed districts.[28] PEAP 2004/5-2007/8 includes amongst its health priorities the recruitment and deployment of health workers, including pay reform on general wages and hardship allowances.[29]

44. The Special Rapporteur notes that he was informed by some NGOs that in some cases health professionals engage in corrupt practices, such as siphoning public drugs to the private sector or referring patients to their personal private clinics.

45. **In Uganda, human resources in the health sector constitute a major, urgent issue that demands a report of its own. The issue has multiple dimensions: inadequate health budget allocation that precludes the appointment of a sufficient number of health professionals; the application of a rigid ceiling on the health budget; the "skills drain" from Uganda to income-rich countries, as well as rural-to-urban migration within Uganda; poor terms and conditions; human rights training for health professionals; the corrupt practices of some health professionals; and so on. The Special Rapporteur was informed that in recent years the Ministry of Health has returned recruitment funds to the treasury. Because of space constraints, the Special Rapporteur here confines himself to only two aspects of this crucial topic.**

46. **First, in cooperation with development partners, the Government must urgently re-examine this issue and devise a coherent strategy, and costed plan of action, for human resources in the health sector. The maintenance of the status quo is incompatible with Uganda's right-to-health obligations.**

47. **Second, neglected diseases give rise to special human resource issues that require distinctive policies. Most of the disadvantaged communities afflicted by neglected diseases are located in remote rural areas far from modern amenities. When visiting health facilities in Gulu, Lira and Katakwi, the Special Rapporteur was informed that it was difficult to hire and retain health professionals in these rural districts.**

48. **Firm measures must be taken to break this cycle of deprivation. Two specific proposals should be given urgent consideration. First, compelling incentives should be introduced to attract health professionals to, and retain them in, isolated disadvantaged communities. Second, on qualifying, all health professionals might be required to work for a certain period in an isolated disadvantaged community.**

D. Tackling stigmatization and discrimination

49. Stigmatization and discrimination are two major impediments to the enjoyment of the right to health. Often, stigmatization is based on myths, misconceptions and fears - including, for example, misconceptions related to certain diseases or other health conditions. Fear of stigmatization can lead people living with neglected diseases to avoid diagnosis, delay seeking treatment and hide the diseases from family, employers and the community at large. Discrimination involves acts or omissions which may be directed towards stigmatized individuals.

50. The socio-economic consequences of stigmatization and discrimination associated with neglected diseases can have devastating consequences for individuals and groups that are already marginalized. For example, stigma related to tuberculosis can be greater for women: it may lead, inter alia, to ostracism, rejection and abandonment by family and friends, as well as loss of social and economic support.[30] Social and behavioural research on stigma and neglected diseases suggests that women also may experience more social disadvantages than men, in particular from physically disfiguring conditions like lymphatic filariasis.[31]

51. In northern Uganda, the Special Rapporteur heard testimonies from children, men and women who had experienced ostracism and discrimination as a result of conditions related to lymphatic filariasis. Their experiences highlighted the devastating impact this disease can have for those affected, not only on their health, but also on their rights to work, education, housing and food. In Obalanga, the Special Rapporteur was told stories of the myths and misconceptions surrounding lymphatic filariasis. Some individuals continued to believe that individuals afflicted with hydrocele had contracted it by riding a bicycle, while others referred to the widespread and persistent belief in their community that hydrocele was indicative of male virility. The Special Rapporteur was impressed by the initiative of one community-based organization, the Obalanga Health and Human Rights Centre, which provides support to people affected by lymphatic filariasis, advocates for accessible and affordable treatment, and endeavours to combat stigma and discrimination.

52. The International Covenant on Economic, Social and Cultural Rights proscribes any discrimination in access to health care and underlying determinants of health, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health, on a number of grounds. The guarantee of non-discrimination and equal treatment in relation to the right to health under international law is an obligation of immediate effect. Uganda's Constitution guarantees non-discrimination and equality to all citizens, and provides for the protection of the human rights of particular vulnerable groups, such as people with disabilities and women. The Government has taken a number of measures to implement these national and international obligations, such as identifying gender issues as a national priority in PEAP and establishing a ministry with specific responsibility for addressing gender issues. In addition, the mandate of the Uganda Human Rights Commission includes the promotion and protection of non-discrimination and equality.

53. **Wide-ranging measures are required to combat all forms of discrimination and stigma associated with neglected diseases in Uganda, including through the implementation of health-related laws and policies which confront discrimination in the public and private sectors. As referred to in section A above, public information campaigns should be developed to raise awareness of neglected diseases and to promote non-discriminatory behaviour towards afflicted persons. In addition, human rights training for health professionals should be integrated into the curricula of medical schools in Uganda.**

54. **The Government is encouraged to take measures to ensure that health policies and practices promote equal access to health services, and to integrate a gender perspective throughout its policies and programmes.[32] The Government, development partners and other actors should support and foster vital community-based initiatives such as the Obalanga Centre.**

E. An integrated health system responsive to local priorities

55. The right to health gives rise to an obligation to establish a system of health protection which provides equality of opportunity for all people to enjoy the highest attainable standard of health. It requires the State, and all other actors in a position to assist, to establish a health system that gives a high priority to the control and elimination of neglected diseases that are experienced by disadvantaged populations.

56. In international human rights law, the State has an obligation to use its maximum available resources to establish an effective health system.[33] For example, if a State already has a mass drug administration (MDA) in relation to one disease and, at minimal extra cost, another drug for another disease could be safely administered with it, the State has a responsibility to organize such co-administration.

57. In Uganda, many districts experience several neglected diseases which all require MDA. However, the delivery mechanisms for MDA are different for each disease. Conceivably, interventions for neglected diseases could be integrated into Ugandan Child Health Days, which use health facilities and outreach services as distribution channels, but this possibility requires further careful examination. Indeed, generally speaking, the possible alignment of MDA delivery mechanisms needs additional urgent consideration.

58. The Special Rapporteur is pleased to note that during HSSP II the vertical interventions that tended to characterize the Government's approach to neglected diseases will be reconsidered with a view to implementing a more integrated approach.[34]

59. **From the perspective of the right to health, a key objective must be an *integrated* health system that is responsive to local priorities. In this context, "integrated" has two meanings. First, so far as possible, an intervention for one disease should be designed in such a way that it can also be used as a vehicle for one or more interventions in relation to one or more other diseases. Second, so far as possible, all interventions should form part of the regular health system. In no circumstances may any intervention undermine or jeopardize progress towards the long-term goal of an effective, inclusive health system of good quality for all.**

60. **The Ministry of Health, and other relevant actors, should urgently examine the possible alignment of various mass drug administration delivery mechanisms. Further research is urgently needed regarding the possible co-administration of some drugs, such as Albendazole, Ivermectin, Praziquantel and Azithromycin.**

61. **All relevant actors should urgently consider whether or not the national and international programmes in relation to HIV/AIDS, tuberculosis and malaria could also enhance interventions for other diseases that are health priorities in particular localities. At the international, national and district levels, there must be closer and more effective coordination among the various global initiatives.**

F. Research and development

62. The right to health encompasses an obligation to engage in research and development that addresses the health needs of the entire population, including disadvantaged groups. In all countries there is a large number of compelling - and competing - research and development needs. Space does not permit the present report to explore how prioritization of research and development can take place in a manner that is respectful of the right to health. However, an essential point is that the prioritization process must take into account the health needs of those living in poverty, as well as other disadvantaged groups. The record shows that this rarely happens.

63. Currently, only 10 per cent of global funding for research and development goes towards diseases that affect 90 per cent of the world's population. Of the 1,393 new drugs approved between 1975 and 1999, only 1 per cent (16 drugs) was for tropical diseases and tuberculosis.[35] To give a more specific example from the Ugandan context, only one drug for sleeping sickness is less than 40 years old (eflornithine),[36] and the first-line treatment for second-stage cases is a toxic drug (melarsoprol) that has been in use since 1949.[37] Moreover, studies in Arua District report that 15 per cent of patients are not responding to eflornithine, as well as there being 30 per cent resistance to melarsoprol. In short, while the specific requirements vary, there is an urgent need for more research and development in relation to neglected diseases.

64. Low-income countries like Uganda have limited technical capacity in the field of research and development. They also lack the economic capacity to provide substantial incentives to influence research and compensate for market failures. In recognition of these difficulties, a number of global private-public partnerships have been established to enhance research and development into neglected diseases, and to improve drug accessibility through price reductions and cash/product donations. More, however, needs to be done.

65. Research and development is understood to encompass classic medical research and development into drugs, vaccines and diagnostics, as well as operational or implementation research into, for example, the social, economic, political and policy issues that determine access to health care and protection. As already noted, classic research and development is needed in the Ugandan context. So far as the second element is concerned, this is also urgently needed with a view to tackling societal obstacles to health technologies.

66. **While more research and development is urgently needed in relation to neglected diseases in Uganda (and beyond), this must not obscure the fact that a number of relevant drugs and vaccines already exist but they are not reaching all those who need them. Thus, a central challenge is to enhance access to what already exists, while also engaging in research and development that will lead to more effective medical interventions.**

67. **The Doha Declaration confirms that the TRIPS Agreement should be implemented in a manner supportive of WTO members' right to protect public health and promote access to medicines for all. The TRIPS Agreement contains "flexibilities" which a country may utilize to design a national patent law that protects public health. The Doha Declaration allows least developed countries not to provide patent protection for pharmaceuticals up to 2016. The Ugandan Patent Act of 1993, enacted two years before TRIPS, is not reflective**

of the TRIPS "flexibilities". Thus, the legislation should be revised to take full advantage of the TRIPS "flexibilities", as reaffirmed by the Doha Declaration.

68. **The Special Rapporteur understands that the Government is establishing the Uganda National Health Research Organization to promote and strengthen national health research. He urges the Government to ensure that the Organization: engages in both classic research and development, and operational or implementation research; gives high priority to neglected diseases; advises on the most strategic use of governmental incentives to encourage research and development on neglected diseases; receives adequate national funding; and is established as a matter of priority.**

69. **Apart from the Government, others have major responsibilities in relation to research and neglected diseases in Uganda. These are very briefly discussed in the next section.**

G. Donors and the international community

70. The primary obligation for implementing the right to health falls upon the State. However, States have the obligation to take steps individually and *through international assistance and cooperation* towards the full realization of various rights, including the right to health. The responsibility of those States that are in a position to assist, to engage in international assistance and cooperation towards the enjoyment of economic, social and cultural rights, is recognized in the Charter of the United Nations, the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child and elsewhere.[38]

71. Uganda very much depends on aid. In 2001 the amount of official development assistance received was US$ 782 million. Donors have played a very significant role in Uganda, particularly in the health sector. The Health Policy Statement 2003/2004 estimates that donors contributed 81 per cent of the 2003/2004 development health budget. The donor support is largely managed through a sectorwide approach (SWAp).

72. DFID is the largest bilateral donor. The central focus of its policy is a commitment to nationally agreed targets, including basic health care and universal primary education. It supports SWAp and a number of health initiatives such as the Family Health Projects and the AIDS Service Organization (TASO). The assistance provided by the United States Agency for International Development (USAID) focuses on improving collaboration between TB and HIV VCT services. Other donors assisting the Government in the areas of health, development and poverty reduction include Sweden, Denmark, Germany, Italy, Ireland, UNICEF, the African Development Bank, the World Bank and the European Union. Some donors are project-specific, for example, USAID, Germany and Spain.

73. At the global level, pharmaceutical companies, including Novartis, GSK, Merck, Aventis, Bayer and Bristol Myers Squibb, donate drugs for neglected diseases. Uganda is among the beneficiaries of these donations. Most of the drug donation programmes have nationwide coverage of the endemic areas; however this is subject to problems of insecurity in some

districts. While some donations are given for as long as needed, others are time-limited, thereby causing a lack of sustainability of programmes and compounding the funding challenges facing the health sector.

74. **A number of Uganda's development partners deserve credit for making considerable financial contributions towards the country's health sector. Also, the management of donor contributions by way of a sectorwide approach and budget support is to be warmly welcomed. However, despite existing donor support, there remains a wide gap between the cost of a national minimum health-care package in Uganda and the funds that are currently made available for this purpose. For example, according to HSSP, US$ 28 per person per year is needed to finance Uganda's national minimum health-care package. WHO *Report of the Commission on Macroeconomics and Health* estimates that for a low-income country the minimum financing needed to cover essential health inventions is around US$ 30 to 40 per person per year.[39] Yet in Uganda the public expenditure - from both the national Government and donors - is only US$ 9 per person per year, in addition to US$ 7 per person per year from households and employers. In short, as a United Nations report recently put it: "Uganda is a basket case in chronic underfinancing of the health sector."[40] Thus, the Special Rapporteur recommends that development partners increase their sustainable and predictable contributions to the health sector in Uganda.**

75. **While recognizing the serious security issues, the Special Rapporteur has formed the view that most donors have paid insufficient attention to the health problems in northern Uganda, where individuals and communities are among the most vulnerable and disadvantaged on the continent.**

76. **The United Nations is commended for recently strengthening its engagement in the north. To give just one example, WHO has recently opened a sub-office in Gulu, and OHCHR has set up a human rights presence to undertake human rights monitoring and training, and to work on a protection strategy in cooperation with the National Human Rights Commission and the United Nations Country Team. However, on the whole, it appears to the Special Rapporteur that the United Nations was slow to recognize the severity of the humanitarian crisis in northern Uganda. For many years the acute needs of the local population did not receive the international attention and support it desperately needed. To this day, adequate and well-coordinated international assistance does not reach the people of northern Uganda. Thus, as a matter of urgency, the international community and all donors should devote more attention to, and invest more health and other resources in, northern Uganda.**

77. **Budget ceilings: In recent years, there has been much controversy in Uganda about macroeconomic policies, the application of inflexible ceilings to the health budget, and the absorption of foreign funds that are available to the health sector.**

78. **From the perspective of the right to health, the following points must be kept in mind when considering this important issue. First, the Government is obliged to take into account its binding national and international right-to-health obligations to all those within its jurisdiction**.

79. **Second, if the Government declines health resources from overseas, prima facie this would be inconsistent with its international obligation to use the maximum resources available for the implementation of the right to health. However, if there were objective and rational grounds for declining such foreign funds, the Government would not be in breach of its international right-to-health obligations. In such a situation, the Government has the burden of proving that the resources have been declined on objective and rational grounds that are consistent with all of its national and international human rights obligations. When evaluating the grounds for any decision to decline foreign funds, special regard must be given to the impact of the decision on Uganda's most vulnerable individuals and communities, including those living in poverty.**

80. **Third, development partners may not apply any pressure on the Government to impose inflexible budget ceilings that would or may have the effect of restricting the flow of available funds into the health sector.**

81. **"A global epidemic of global initiatives": Uganda benefits from a large number of global initiatives for different diseases, such as the Global Alliance for Leprosy Elimination, the Global Alliance for the Elimination of Lymphatic Filariasis, and the National Onchocerciasis Control Programme. These global programmes translate into a range of national initiatives. Although these initiatives bring significant benefits, they also place a very considerable administrative burden on the Ugandan authorities. As argued elsewhere in the present report, much greater integration among interventions and initiatives is needed at the district, national and international levels, so as to make the most effective use of scarce resources (see section on "An integrated health system responsive to local priorities"). Donors and the international community have a particular responsibility to better coordinate their activities, working in close cooperation with the Ministry of Health**.

82. **WHO: The Special Rapporteur urges WHO to more proactively assume a coordinating role among the myriad health partners working throughout Uganda. For example, WHO could provide a regular forum for information exchange and discussion across a very wide range of health actors. WHO is also encouraged to collect more - and better quality - health information from the local level, with a view to enhancing local, national and international policy-making. Further, it is urged to invest more resources in neglected diseases and neglected populations.**

83. **Research and development: Donors and the international community should give a higher priority to health research and development in Uganda. They should actively seek new funding mechanisms for research and development in relation to neglected diseases. They may need to increase direct funding for public research and enhance private sector incentives, such as tax credits. Intellectual property regimes must not be allowed to constrain access to essential medicines. So far as necessary, new intellectual property frameworks for neglected diseases and essential medicines should be explored. The fruits of research and development in relation to neglected diseases must be translated into specific drugs, vaccines and diagnostics that are accessible to the afflicted populations. Donors and the international community should help Uganda enhance its economic and technological capacity so it can determine its own research and development agenda and priorities in relation to neglected diseases.**

84. **Pharmaceutical companies: A number of pharmaceutical companies deserve credit for initiatives that enhance access to essential medicines and medical care. However, they should be encouraged to improve their coordination amongst themselves, as well as with other actors working in the health sector. While on mission, the Special Rapporteur was informed that the pharmaceutical companies were invisible outside the major urban areas, other than when organizing seminars to promote their products. Accordingly, they should be encouraged to regularly visit disadvantaged communities, urban and rural, including the internally displaced persons camps, to learn at first hand about the health realities of those living in poverty. Regular visits of this type should be reported to the companies' national and international headquarters with a view to informing policies and finding ways in which the companies can assist in the implementation of the right to health for all.**

85. **The international and regional human rights systems: Whenever possible, the international and regional human rights machinery should draw attention to the issue of neglected diseases and neglected populations. For example, when Uganda submits its periodic reports to the Committee on Economic, Social and Cultural Rights and the African Commission on Human and Peoples' Rights, among others, the Government's reports and the human rights bodies should give careful attention to the issue of neglected diseases and neglected populations.**

H. Monitoring and accountability

86. A right-to-health accountability mechanism establishes which health policies and institutions are working and which are not, and why, with the objective of improving the realization of the right to health for all. Such an accountability device has to be effective, transparent and accessible.

87. Monitoring is a precondition for accountability. While it is commonplace for the impact of health policies to be monitored, it is less common (a) for a health policy to be assessed against a right-to-health standard and (b) for those responsible for the policy to be held to account for the discharge of their duties arising from the right to health. This, however, is what the right to health requires, with a view to enhancing enjoyment of the right to health for all, including those living in poverty.

88. The Ministry of Health monitors the impact of health policies in Uganda. Also, these policies are subject to general mechanisms of accountability. For example, parliamentarians hold the Minister of Health to account in relation to the discharge of his responsibilities. However, it is not clear whether these general mechanisms provide adequate accountability in relation to neglected diseases and the right to health. In addition to general mechanisms of accountability, a right-to-health approach also requires one or more mechanisms that provide accountability in relation to specific right-to-health standards.

89. In Uganda, there appear to be two main mechanisms of human rights accountability: first, by way of the Constitution and the courts, and second via the Uganda Human Rights Commission. Both have a role to play in relation to the right to health. While the Constitution enshrines elements of the right to health, it is doubtful that the Ugandan judicial process provides the most appropriate mechanism for holding national and international policymakers to account in relation to neglected diseases.

90. The Uganda Human Rights Commission provides more promising possibilities. The Commission is a constitutional body established to promote and protect human rights in Uganda. As an independent institution, it reports annually to Parliament. It has a wide range of functions and powers. As its annual report (2003) reveals, the Commission's work encompasses poverty eradication and human rights, as well as the right to health. Indeed, the Commission has produced at least two publications specifically on the right to health.

91. **A right-to-health approach to neglected diseases and populations requires accessible, transparent and effective human rights mechanisms of monitoring and accountability. The existing mechanisms need to be enhanced. It is recommended that, for an experimental period of three years, the Uganda Human Rights Commission establish a right-to-health unit that is responsible for monitoring those policies, programmes and projects relating to neglected diseases. For example, relying on existing data, the unit should track the incidence of neglected diseases and the initiatives taken to address them.**

92. **Further, the right-to-health unit should go beyond monitoring and hold all actors to account in relation to neglected diseases and the right to health. For example, adopting an evidence-based approach, the unit would endeavour to assess which initiatives are working and which are not - and if not, why not. In its monitoring and accountability functions, the unit should consider the acts and omissions of all actors bearing on neglected diseases in Uganda. Significantly, the unit should monitor and hold to account national and international actors in the public and private sectors.**

93. **The unit should consist of a health professional and a human rights expert. They should submit a public annual report to Parliament which would indicate where successful initiatives have led to positive health outcomes, as well as highlight where there are concerns. Whenever possible, realistic and practical recommendations should be identified for all actors. At all times, the unit's yardstick should be the national and international right-to-health standards to which the Government of Uganda has agreed to be bound.**

IV. CONCLUSION

94. **Throughout section III, the Special Rapporteur identifies a number of conclusions and recommendations and he will not repeat them here.**

95. **The present report considers neglected diseases in Uganda through the prism of the right to health, with a view to identifying what needs attention if these diseases are to be tackled in a manner that reflects the Government's national and international right-to-health obligations. It does not attempt to set out a right to health *programme* for neglected diseases; that would require further discussions with a range of actors, as well as more space than is available in the present report. However, the report identifies the key interrelated features that such a programme should encompass.**

96. **Although the report focuses on Uganda, many of the points have general application to other countries where neglected diseases are prevalent. The Special Rapporteur will be very pleased to discuss the issues raised in the present report with the Government of Uganda, as well as other interested parties**

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Notes

[1] *Global Defence against the Infectious Disease Threat*, (WHO, 2002), p. 96.

[2] Ibid., p. iv.

[3] Intensified Control on Neglected Diseases (Berlin, 2003), p. 14.

[4] Heath and Mortality Survey among Internally Displaced Persons in Gulu, Kitgum and Pader Districts, Preliminary Draft, July 2005, pp. 31 and 40.

[5] HSSP II; UNHCR 2003, p. 56.

[6] WHO Health and Mortality Survey, p. 21.

[7] Uganda Bureau of Statistics, National Demographic and Health Survey (1995 to 2000-2001).

[8] See arts. 21, 33, 34 and 35 of the Constitution of the Federal Republic of Uganda, 1995.

[9] Health Sector Strategic Plan II 2005/06-2009/10, Final Draft, July 2005, pp. viii-ix, and National Health Policy 1995, p. 6.

[10] Second Participatory Poverty Assessment Report, p. 113.

[11] PPA2 p. 118.

[12] UNAIDS, 2004 Report on the Global AIDS Epidemic.

[13] Millennium Development Goals Report, 2003, p. 13.

[14] *Global Defence against the Infectious Disease Threat*, WHO, 2003, p. 124.

[15] UDHS 2000/2001.

[16] The Revised National Strategic Framework for HIV/AIDS Activities in Uganda, 2000/04-2005/06, p. 12.

[17] Office of the United Nations High Commissioner for Refugees, 2003, p. 103.

[18] Millennium Development Goals Report, 2003, p. 13.

[19] WHO, March 2005.

[20] *Global Defence against the Infectious Disease Threat,* (WHO, 2002), p. 96.

[21] Participation is not confined to the two stages signalled here, i.e. making policy choices and implementation. It also applies, for example, to monitoring and accountability.

[22] Preamble, art. II (i).

[23] See PEAP 2000, summary and objectives, pp. 6 and 12, *PRSP, Resource Allocation to the Health Sector in Uganda*, paper No. 7, 2004, p. 16.

[24] In addition to the four levels within the health districts, there are also levels V (General Hospital), VI (Regional Referral Hospital), and VII (National Referral Hospital). In this report, the focus is on levels I-IV because of their special relevance to community participation.

[25] Health Sector Strategic Plan II, 2005/6-2009/10, July 2005, p. x.

[26] Human Development Indicators, 2003, www.undp.orghdr2003/indicators/cty_f_UGA.html, 20/02/05.

[27] IPPH, pp. 8-11.

[28] Health Sector Review Paper, Ministry of Health, 2003, p. 44.

[29] Ibid., p. 167.

[30] World Health Organization, *A Human Rights Approach to Tuberculosis*, 2001, p. 12.

[31] Coreil J., Mayard G., Addiss D., *Support Groups for Women with Lymphatic Filariasis in Haiti*, Report Series No. 2, Social, Economic and Behavioural Research, TDR, 2003, p. 42.

[32] General comment No. 14, para. 20.

[33] See, for example, article 2 of the International Covenant on Economic, Social and Cultural Rights.

[34] Health Sector Strategic Plan II, 2005-2005/6-2009/10, July 2005.

[35] Trouiller P., Olliaro P., Torreele E., Orbinski J., Laing R., Ford N., "Drug development for neglected diseases: a deficient market and a public-health policy failure", *The Lancet*, vol. 359, 22 June 2002, p. 2189.

[36] Stich A., Abel P. and Krishna S., "Clinical review of human African trympanosomiasis", *BMJ*, vol. 325, 27 July 2002.

[37] Legros et al, "Treatment of human African trympanosomiasis - present situation and needs for research and development", *The Lancet*, vol. 2, July 2002, p. 437.

[38] See, for example, article 2 of the International Covenant on Economic, Social and Cultural Rights and article 4 of the Convention on the Rights of the Child as well as general comment No. 14 (para. 13), of the Committee on Economic, Social and Cultural Rights and CRC/GC/2003/3, paras. 14 and 42.

[39] WHO, 2001, p. 16.

[40] Office of the United Nations Resident Coordinator, *Uganda: Promise, Performance and Challenges: for Attaining the PEAP and MDGs*, 2003, p. 50.

Appendix 1

GLOBAL BURDEN OF SELECTED NEGLECTED DISEASES

		Total	Africa	Americas	Middle East	Europe	South-East Asia	Western Pacific
Buruli ulcer	Incidence*	3 154	2 515	24	568	Not endemic	No recent information	47
	Prevalence							
	YLL							
	YLD							
	DALYs							
Dengue	Incidence	71 000	4 000		7 000		51 000	9 000
	Prevalence							
	YLL	646 944	6 018	89 562	84 479		355 764	111 121
	YLD	6 180	360		599		4 456	765
	DALYs	653 125	6 378	89 562	85 078		360 221	111 886
Leishmaniasis	Incidence	2 000 000						
	Prevalence	12 000 000						
	YLL	1 848 930	277 091	27 428	201 699	370	1 321 840	20 503
	YLD	507 679	125 070	32 071	76 286	5 366	264 388	4 497
	DALYs	2 356 609	402 161	59 498	277 986	5 737	1 586 228	24 999
Leprosy	Incidence	174 000	21 000	17 000	17 000		112 000	7 000
	Prevalence	897 000	109 000	89 000	84 000	1 000	580 000	35 000
	YLL	64 140	3 011	6 880	4 768	274	47 176	2 032
	YLD	112 443	12 947	11 466	11 182	36	72 238	4 574
	DALYs	176 583	15 957	18 347	15 949	310	119 414	6 606
Lymphatic filariasis	Incidence							
	Prevalence	120 000 000	40 800 000	36 000 000	36 000 000		58 800 000	19 200 000
	YLL	3 035	27	52	550	745	1 576	86
	YLD	5 641 087	1 933 394	9 612	488 505	1 431	2 800 658	407 487
	DALYs	5 644 122	1 933 421	9 663	489 055	2 176	2 802 234	407 573

GLOBAL BURDEN OF SELECTED NEGLECTED DISEASES (*continued*)

		Total	Africa	Americas	Middle East	Europe	South-East Asia	Western Pacific
Rabies	Incidence							
	Prevalence							
	Persons treated for exposure		413 450	299 190		40 452	891 289	9
	YLL							
	YLD							
	DALYs							
Schistosomiasis	Incidence							
	Prevalence	193 000 000	165 000 000	7 000 000	19 000 000	600	420	2 000 000
	YLL	235 072	115 249	14 253	67 395	408		37 767
	YLD	1 524 486	1 305 333	69 169	134 240		2 484	13 260
	DALYs	1 759 558	1 420 583	83 422	201 636	408	2 484	51 026
Soil-transmitted Helminths	Incidence							
	Prevalence (estimate)	2 billion						
	YLL	342 745	88 853	26 357	18 847	733	164 084	43 871
	YLD	4 363 181	585 332	597 409	248 278	7 462	1 386 179	1 538 520
	DALYs	4 705 926	674 185	623 766	267 126	8 195	1 550 263	1 582 392
Trachoma	Incidence							
	Prev. (active Trachoma)	81 000 000	21 700 000	1 060 000	9 300 000		20 700 000	28 500 000
	Prev. (Trachomatous Trichiasis)	7 600 000	2 220 000	27 000	1 700 000		330 000	3 260 000
	Prev. (blindness due to Trachoma)	1 900 000						
	YLL	1 774		44	281	8	1 395	47
	YLD	3 995 702	1 526 084		602 379		246 597	1 620 642
	DALYs	3 997 477	1 526 084	44	602 660	8	247 992	1 620 689

GLOBAL BURDEN OF SELECTED NEGLECTED DISEASES (*continued*)

		Total	Africa	Americas	Middle East	Europe	South-East Asia	Western Pacific
Trypanosomiasis	Incidence							
	Prevalence							
	YLL	1 504 194	1 469 579	50	34 282	40	225	18
	YLD	93 410	87 810		5 599			0
	DALYs	1 597 603	1 557 390	50	39 881	40	225	18

Source: *Consequences of Neglected Diseases and Tools to Fight Them*, WHO working paper prepared for the International Workshop on Intensified Control of Neglected Diseases, Berlin, 10-12 December 2003. The Special Rapporteur has modified some presentational aspects of the original document.

* Annual new cases.

YLL - Years of life lost due to premature mortality.

YLD - Years of life lived with disability due to the disease.

DALYs - Disability-adjusted life years.

Appendix 2

SELECTED NEGLECTED DISEASES IN UGANDA

(Prepared by the Ministry of Health, Uganda and WHO, April 2005)

Disease	Number of cases	Population at risk	Main prevention/treatment	Effectiveness/safety	Cost of treatment (US$)	Cost of delivery (US$)	Remarks
Buruli ulcer	7	227 809	Early detection and surgical treatment	Effective			
Trypanosomiasis	558*	8 484 957	Early case detection and prevention, vector control	Drugs quite toxic	Donated	50 per treatment	Outbreak in 3 districts in 2004
Leishmaniasis	Data not available at national level	172 456	Early detection and treatment	Drugs quite toxic	40	50 per treatment	Endemic in only one district
Leprosy	753	2 659 556	Early detection and treatment	Safe and effective treatment	Donated	20 per treatment	Endemic in 5 districts
Lymphatic filariasis	Data not available at national level	10 203 944	Mass chemotherapy with ivermectin and albendazole	Safe and effective treatment	Donated	0.13 per treatment	Endemic in 20 districts, MDA** reached 4.2m people in 2004
Schistosomiasis	Data not available at national level	16 700 000	Mass chemotherapy with praziquantel	Safe and effective treatment	0.2	0.15 per treatment	Endemic in 38 districts, MDA reached 1.5m people in 20 districts
Soil-transmitted Helminths	2 250 195	14 000 000	Mass chemotherapy with albendazole	Safe and effective treatment	0.03	0.10 per treatment	Endemic in all districts, especially in school-age children, MDA reached 7m in 2004
Onchocerciasis	Data not available at national level	1.8 million	Mass chemotherapy with ivermectin, targeted vector control	Safe and effective treatment	Donated	1	Endemic in 21 districts, MDA reached 1.3m people in 2004
Trachoma	No data	No data	Mass chemotherapy with azithromycin	Safe and effective treatment	Donated	0.2	Baseline survey not yet conducted

* Data for only 6 months of 2004.

** MDA: Mass drug administration.

Number of cases: Data that are not captured through the Health Management Information System (HMIS) are not available at the national level. They are only available at health facility level. Due to vertical implementation, neglected diseases have not been fully integrated into HMIS. Thus, in some instances, data on the number of cases are unavailable.

Cost of delivery: Except in relation to lymphatic filariasis (where WHO is the main funder and it is possible to be more certain), these are estimates based on expert opinion.