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Leprosy

Health reporter, 13th February 2008

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Feature: Leprosy

Leprosy or Hansen's disease is a chronic, infectious disease that can cause nerve damage, muscle weakness and skin lesions. The visual disfigurement and disability caused by leprosy, misguided cultural beliefs, and fear of contagion means that people suffering from the disease have been stigmatised and ostracised from their families and communities throughout history.

Today, leprosy can be easily diagnosed and treated with a combination of three highly effective drugs. In 1991 the World Health Assembly passed a resolution to eliminate leprosy as a public health problem by 2000 whereby less than one per 10,000 people is infected with the disease. This has been achieved in all but four countries: Brazil, the Democratic Republic of Congo, Nepal and Mozambique.

In most endemic countries, governments have integrated leprosy treatment into general health services as part of their elimination campaign. This has shown to help reduce stigma and ensure that treatment is both sustainable and accessible. Efforts to decrease health inequity due to poverty, especially in rural areas where people have limited access to health care, may also help with leprosy control.

Whilst leprosy may have been eliminated as a public health concern in most countries, it is still present in many populations. Persisting stigma prevents people from self reporting leprosy, and lack of knowledge or discrimination by some health workers means that many people receive poor quality care. In addition, leprosy's status as 'eliminated' may deter future funding and research. It is important that the success of this initiative does not lead to complacency in its surveillance and control, and that continued treatment and care is provided for people living with long-term leprosy-related disabilities.

More information:

- LEPROA
www.lepra.org.uk
- id21 Health 'Strengthening the link between research and practice: an Indian leprosy NGO'
www.id21.org/health/h1jp1g2.html

Recommended readings on leprosy

1. Global Leprosy situation, 2007

Publisher: The Weekly Epidemiological Record, 2007

This paper in the Weekly Epidemiological Report, reports on the global burden of leprosy at the beginning of 2007. It finds that the number of new cases detected during the year is stabilising. This is the result of timely detection of new cases and prompt treatment with multidrug therapy which is provided free of charge.

Key findings include:

- at the beginning of 2007, the global registered prevalence of leprosy was 224,717 cases
- the number of new cases detected during 2006 was 259,017
- during 2006, the number of new cases detected fell globally by more than 40,000

- cases when compared with 2005
- only four countries have yet to achieve the goal of eliminating leprosy. These are: Brazil, the Democratic Republic of the Congo, Mozambique and Nepal

The paper concludes that the coverage of leprosy control activities and the quality of services should be maintained and improved to ensure that the disease burden declines in all endemic countries, not only in terms of statistical numbers but also in terms of the reduction of disabilities, cases occurring among children and leprosy-related stigma. In almost all of the highly endemic countries, control activities have been integrated within the general health care system. Referral facilities must also be integrated into the health system so that services are easily accessible to patients, affordable and effective.

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35380&type=Document

2. Current situation of leprosy colonies/leprosjaria and their future in P.R. China

Authors: J. P. Shen; M. Liu; M. Zhou

Publisher: Leprosy Review, 2007

This article in Leprosy Review, reviews the current situation of leprosy colonies and hospitals in China. It is based on a national survey carried out in 2004. At this time China had over 600 leprosy colonies accommodating 18,000 people affected by the disease. A third of these patients had lost the ability to take care of them selves due to serious deformity. The paper finds that the quality of health care in leprosy colonies and hospitals is poor. This is the result of a decrease in health workers and a shortage of medical materials. Furthermore, the majority of leprosy colonies have ceased to provide medical services for patients with serious leprosy reactions and other complications. Most colonies are located in remote and isolated places with difficult transportation, and many buildings were in danger of collapse.

Finally, the paper suggests ways to improve the quality of life and care for people living in colonies. The authors recommend that small, remote and isolated leprosy colonies should be closed. This is because reconstruction to improve the quality of care would neither solve the long-term problems nor reduce stigma towards leprosy and would waste resources. Special hospitals at provincial or national levels should be established to care for patients with leprosy.

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35290&type=Document

3. The stigmatization of leprosy in India and its impact on future approaches to elimination and control

Authors: J. T. Jacob; C. Franco-Paredes

Publisher: Public Library of Science Medicine , 2008

This article in PLoS Neglected Tropical Diseases presents a historical review of leprosy in India and highlights future challenges in control the disease. The paper shows that people suffering from leprosy have been marginalised for several reasons including its chronic, potentially disfiguring nature; its association with sin; and fear of contagion. More recently, the government has launched campaigns to detect, treat and eliminate leprosy. These campaigns have focused on integrating leprosy care into general health systems, and implementing family counselling and community outreach programmes to reduce stigma.

The future of leprosy control and elimination offers several challenges with both structural and cultural dimensions. Efforts to decrease health inequity due to poverty, especially in rural areas with limited access to health care, may help with leprosy control. However, if cultural beliefs are not addressed, increased availability may not translate into an appropriate increase in utilisation. The paper concludes that sustaining the gains made so far and further reducing the disease burden in India requires an innovative, holistic approach that includes ongoing education, efforts to identify interventions to dispel stigma, and the inclusion of traditional practitioners in disease control programmes.

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35379&type=Document

4. Leprosy: too complex a disease for a simple elimination paradigm

Authors: D. N. Lockwood; S. Suneetha

Publisher: Bulletin of the World Health Organization : the International Journal of Public Health, 2005

Can leprosy be eliminated? This paper considers the question against the background of the World Health Organization programme to eliminate leprosy. In 1991 the World Health Assembly set a target of eliminating leprosy as a public health problem by 2000 where prevalence is less than one case per 10,000 people. The paper finds that whilst the elimination programmes has been successful in delivering highly effective antibiotic therapy worldwide, new-case detection rates remain stable in countries with the highest rates of endemic leprosy such as Brazil and India. This suggests that infection has not been adequately controlled by antibiotics alone.

The paper suggests that leprosy is perhaps more appropriately classed as a chronic disease than as an acute infectious disease responsive to elimination strategies. In many countries activities to control and treat leprosy causes long-term immunological complications, disability and deformity. The health care activities of treating and preventing disabilities need to be provided in an integrated setting. It concludes that detecting new cases and monitoring disability caused by leprosy will be a challenge. One solution is to implement long-term surveillance in selected countries with the highest rates of endemic disease so that an accurate estimate of the burden of leprosy can be

determined. [adapted from authors]

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35291&type=Document

5. Sustainable leprosy related disability care within integrated general health services: findings from Salem District, India

Authors: K. Madhavan, P. Vihayakumaran, L. Ramachandran; et al
Publisher: Leprosy Review, 2007

This paper, published in Leprosy Review examines the effectiveness of a self-care programme for people living with leprosy-related disabilities in a district of south India. The programme involves self-care training, guidance and monitoring by general health staff and facilitated by a non-governmental leprosy centre operating in the area. The programme identified 1,232 people with leprosy-related disabilities who were trained in self-care. Follow-up assessments indicated that 86 per cent were found to be practising self-care regularly, and all the general health workers were actively involved. At the one year follow up 70 per cent of patients reported healing of ulcers on the soles of their feet.

The paper concludes that the prevention of disability with the focus on educating patients to take care of their disabilities with guidance from their families and health workers can be implemented in an integrated set-up. Good leadership, effective coordination, systematic field-based training and simplified operational procedures with back-up supervisory and referral support are necessary. Whilst this model can easily be adapted to different situations there should be clear guidelines for sustaining effective collaboration among all the stake holders.

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35386&type=Document

Latest additions from the Health resource guide

1. State of urban health in Delhi

Authors: S. Agarwal; A. Srivastava; B. Choudhary; S. Kaushik
Publisher: Urban Health Resource Centre , 2007

This report from the Urban Health Resource Centre focuses on the health of the urban poor in Delhi. Due to rapid urbanisation, the city has a large and growing population of slum dwellers. Factors such as undernutrition, lack of piped water and chronic overcrowding encourage the spread of communicable diseases including tuberculosis and malaria. Prevalence of both diseases is much higher than among the urban rich. Reproductive and child health (RCH) services are also inadequate, with low attendance at antenatal check-ups and low rates of skilled care at birth. Rates of immunisation are

similarly low, while poor urban children are three times more likely to be undernourished than children in rich urban families. All these factors contribute to high rates of neonatal, infant and under-5 mortality. Meanwhile, lack of co-ordination between programmes and departments has meant that policies targeting the urban poor have had little impact.

The report's recommendations include identifying and targeting the most vulnerable slum communities, strengthening links with community groups, aligning health facilities managed by different agencies to improve co-ordination, and setting up a city-wide taskforce to improve co-ordination between the health, water, sanitation and related sectors. When planning for RCH services, policymakers must also consider trends in migrant labour and the resulting slum communities.

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35282&type=Document

2. The state of the worlds children 2008: child survival

Publisher: United Nations [UN] Children's Fund , 2008

The State of the World's Children 2008 provides a wide-ranging assessment of the current state of child survival and primary health care for mothers, newborns and children. The report argues that these issues serve as sensitive barometers of a country's development and wellbeing and as evidence of its priorities and values, and states that investing in the health of children and their mothers is a human rights imperative and one of the surest ways for a country to set its course towards a better future.

The report is divided into five chapters:

- Child survival: where we stand: examines the state of child survival and primary health care for children, with a strong emphasis on trends in child mortality
- Lessons learned from evolving health-care systems and practices: appraises lessons from failures and successes in child survival over the past century
- Community partnerships in primary health care for mothers, newborns and children: examines the role and importance of community partnerships in providing health care to mothers, newborns and children
- Strengthening community partnerships, the continuum of care, and health systems: looks at several of the most promising approaches - community partnerships, the continuum of care framework and health-system strengthening for outcomes - to reach those mothers, newborns and children who are currently excluded from essential interventions
- Uniting for child survival: provides recommendations for action.

The report identifies six pivotal actions at the macro level that urgently require unified engagement to intensify efforts for maternal, newborn and child survival and fulfil the right of women and children to health and well-being. These are:

- work towards creating a supportive environment for maternal, newborn and child survival and health
- develop and strengthen the continuum of care across time and location
- scale up packages of essential services by strengthening health systems and community partnerships
- expand the data, research and evidence base
- leverage resources for mothers, newborns and children
- make maternal, newborn and child survival a global imperative.

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35217&type=Document

3. Euthanasia in legal limbo in Colombia

Authors: M. Ceaser

Publisher: The Lancet, 2008

Euthanasia has been practised informally by some doctors in Colombia for over 10 years, but proponents say that the practice still needs to be regulated to reduce opportunities for abuse. Euthanasia was illegal in Colombia until 1997, when the high court ruled that ending a life was not a crime when a patient suffered from a terminal illness, had requested death, and no medical treatments existed. This ruling threw the practice into legal limbo - no longer prohibited, but not explicitly legal, either. Since then, euthanasia's opponents have tried to ban the practice, while some supporters want to create regulations for a practice which doctors now undertake as they see fit.

This report looks at the specific example of a doctor who advocates and practices euthanasia and who has spoken publicly about the practice, and gives the opposing opinions of another doctor who regards euthanasia as a criminal act. The author of this article explains that:

- supporters of the practice may see euthanasia as more justified in a developing nation such as Colombia than in a high-income nation, because of the lack of provision of palliative care
- other doctors hold the opposite position, arguing that in a developing nation such as Colombia, where corruption is common, euthanasia is more subject to abuse. In a wealthy nation every possibility for treating a patient will probably be tried, whereas in Colombia ill people could be euthanised even while possibilities for treating them remained
- those opposing also argue that some severely ill Colombians may request euthanasia only because there are few palliative-care specialists, because other doctors shy away from treating terminally ill patients, and because of a fear prescribing morphine, but when a satisfactory system for the control of symptoms is in place, those thoughts of euthanasia actually subside

Please note: online registration with the Lancet (free of charge) is required in order to access this article.

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35307&type=Document

4. Grand challenges in chronic non-communicable diseases

Authors: A. S. Daar

Publisher: Oxford Health Alliance, 2007

This briefing paper from Oxford Health Alliance identifies 20 policy and research priorities, or 'grand challenges', for chronic non-communicable diseases (CNCDs). Agreed by a panel drawn from 50 countries, these challenges focus on heart disease, stroke, chronic respiratory disease, type 2 diabetes and certain forms of cancer, which together make up the largest burden of disease worldwide. The main risk factors for these diseases are poor diet, physical inactivity and tobacco smoking.

Key policy goals in the paper include improving public education about healthy lifestyle choices, developing trade agreements and regulations to discourage consumption of alcohol, tobacco and unhealthy foods, and developing and monitoring codes of responsible conduct with the food, drink and restaurant industries. The paper also recommends moving health training and practice towards prevention and health promotion, increasing the number and skills of professionals working on CNCDs, and increasing access to medications for preventing complications of CNCDs. The authors stress the need for long-term financing and interdisciplinary research, for example to explore how behaviour, environment and genetics influence disease. With co-ordinated action by countries and multiple funding agencies, they argue that it is possible to prevent at least 36 million premature deaths by 2015.

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35109&type=Document

5. Neglected patients with a neglected disease? a qualitative study of lymphatic filariasis

Authors: M. Perera

Publisher: Public Library of Science Medicine , 2007

This research article from PLoS Neglected Tropical Diseases aims to find more effective ways to help people with lymphatic filariasis (LF). Also known as elephantiasis, this neglected tropical disease causes extreme swelling of the limbs and male genitals, resulting in long-term disability. A survey of LF patients in Sri Lanka showed that they suffered social stigma, leading to isolation and emotional distress as well as delaying diagnosis and treatment. Some avoided free government clinics for fear of drawing attention to their condition. All households reported loss of income while the poorest

were almost destitute. Those from low-income households also had problems accessing distant clinics and their living and working conditions made treatment difficult.

The article highlights an estimated 40 million people worldwide with LF symptoms requiring long-term care, many of whom have been neglected or forgotten by governments and donors. It calls for a comprehensive survey of LF patients, followed by expansion of mass drug treatment programmes and better surgical care. It also recommends special measures to identify, reach and care for patients in advanced stages of the disease, and specific poverty reduction policies targeting the poorest affected households.

Available online at: www.eldis.org/go/topics/resource-guides/health&id=35107&type=Document

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Announcements

Announcement: IDS Health and Development Information Team at the Global Forum on Human Resources for Health

The IDS Health & Development Information Team will be attending the first Global Forum on Human Resources for Health in Kampala, Uganda from 2nd to 7th March 2008 . Please come and meet members of the Team and learn more about our services in the Forum's marketplace. A range of HDI resources and other materials will be available at the booth.

Conference: Global Health: Current Issues, Future Trends and Foreign Policy, 29 April 2008, Royal College of Physicians, London

This conference will explore the growing UK debate on global health, with updates on communicable and chronic disease. Coming after the publication in 2007 of Lord Crisp's 'Global health partnerships' and Sir Liam Donaldson's 'Health is global: proposals for a government-wide strategy' this conference will discuss their impact and the latest Government initiatives. Drawing together experts from the clinical and policy worlds, the conference will examine the role the UK has to play through the prism of its foreign policy. It will afford an opportunity for people from different fields to interact in lively and informative debate.

More information: www.eldis.org/go/topics/resource-guides/health/health-events-and-announcements&id=35366&type=Item

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- Health Resource Guide - <http://www.eldis.org/health/index.htm>
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- HIV and AIDS Resource Guide - <http://www.eldis.org/go/topics/resource-guides/hiv-and-aids>

The HRC provides access to technical assistance and information for the Department for International Development (DFID UK), and its partners, in support of pro-poor health policies as well as health systems, service delivery and public health topics and programmes.

Eldis currently includes descriptions and links to over 4,500 organisations and over 22,000 full-text online documents covering development and environmental issues. It can be searched or browsed free over the Internet.

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Contact details:

Rebecca Wolfe
IDS Health Development Information Team
Institute of Development Studies, Sussex
Brighton BN1 9RE, UK

Email: r.wolfe@ids.ac.uk

Tel: 44 1273 877 540

Fax: 44 1273 621202