

TRIPLE JEOPARDY: TACKLING THE DISCRIMINATION FACING GIRLS AND WOMEN WITH LEPROSY

Girls and women affected by leprosy are triply discriminated against because of their gender, the disabilities that can result from the disease and the impact of its stigma. Studies also show that in some countries they are less likely than men to be diagnosed early, and so are at greater risk of developing a lifelong disability. This report shows what can be done to achieve access to treatment and a better outcome.

The wearing of thanaka paste on the face of girls and women is a distinctive feature of the culture of Myanmar [Burma].

Photo: Paul Salmon

If I had been a man I believe I would have been taken for treatment earlier and not abandoned by my family.
Ansu Bibi, West Bengal

As an educated man, I was fortunate to be unaffected by any stigma or discrimination because I was diagnosed, treated and cured very quickly and easily.
Mathias Duck, Paraguay

When I was young I didn't know about the village where I live, but now I do and I can't be happy any more. Wherever I go, I hear people saying things about me and I'm afraid to raise my head because in their eyes we are just like ghosts.
Xiao Yun lives in a leprosy village, China

When I got this disease, the attitude of the family and society changed completely. They deserted me, which made me heartbroken even more and made me think, why is this happening? As I am cured today, I have the opportunity to serve people affected by leprosy. I understand my

rights and I am working to help others and also taking care of my kids. Why cannot others also have this life?
Rachana, Bihar, India



The Triple Jeopardy

Gender, status and education can make a difference to the outcome of a leprosy diagnosis. When Mathias Duck, a pastor at the Leprosy Referral Hospital in Paraguay, felt a tingling in his hands he was rapidly diagnosed with leprosy and cured within six months. Sadly, this was not the case for Ansu Bibi of West Bengal, India. When she felt the same symptoms, her husband did not think that they were serious enough to justify the expense and inconvenience of medical care. After four years of developing symptoms of leprosy, including ulcers and anaesthesia of her foot, she was finally taken for treatment but at this point her husband abandoned her, and she has not seen her children for eight years.



Pastor Mathias Duck

This report warns that the new United Nations Sustainable Development Goals [SDGs], due to be agreed in October 2015, will fail in their aim to 'leave no one behind' if discrimination against girls and women affected by leprosy is not tackled. Such girls and women have all too often become invisible and lost their rights to health, education, employment, and to marry and found a family.

"The biggest jeopardy is not that they are women disabled with leprosy, but that we have ignored them, they are completely invisible: that there are so few research studies about women and leprosy is testament to this."

Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen

Historically, those affected by leprosy were shipped off to leprosy colonies, put on isolated leprosy wards in hospitals or entered leprosy homes away from others. Some of these still exist today. Girls and women are still kept indoors and hidden away to avoid bringing the stigma of leprosy to a family. Their invisibility means that not only do they receive treatment much later than their male

counterparts, but they are often not included in official figures either. Estimates of the proportion of women who contract leprosy in South Sudan, for example, show that over 50% of new cases reported are women (323 out of a total of 576) while in neighbouring Ethiopia, this is around 10% (466 out of 4374). The reasons for this disparity between the two countries is not known but may suggest that in some places women are somehow invisible or deemed unimportant when it comes to data collection.

Key Facts

Leprosy is caused by *mycobacterium leprae* and is of low infectivity.

In 2013, there were 215,656 new cases reported including 79,943 women and 19,796 children.

81% of all new cases come from three countries: India (126,913), Brazil (31,044) and Indonesia (16,856).

Leprosy can be easily treated and cured by multidrug therapy (MDT), a combination of rifampicin, clofazimine and dapsone.

Drug resistance to anti-leprosy treatment, when used as MDT, is extremely rare.

Since the introduction of MDT more than 16 million people with leprosy have been cured. However, many have lifelong impairments due to leprosy.

Drugs for treatment are provided by the World Health Organisation throughout the world and donated by Novartis.

"Women are disproportionately affected by poverty, illiteracy, lack of education, lack of land ownership and lack of political voice and power, which all act as barriers to health-seeking treatment."

McDonald, M. C. (2011) *Neglected Tropical Diseases (NTDs) and their impact on women's and children's health* <http://www.ncbi.nlm.nih.gov/books/NBK62515/>

The triple disadvantages of gender, disability and stigma further reduce the opportunities for girls and women for education, employment, marriage and participation in society.

- Women and girls already account for six out of 10 of the world's poorest people and two thirds of the world's illiterate people.
- Women affected by leprosy make up some of the world's poorest and most marginalised groups.

Source: *United Nations Development Programmes 2011*

- Women with disabilities are recognised to be multiply disadvantaged, experiencing exclusion on account of both their gender and their disability.
- Women and girls with disabilities are particularly vulnerable to abuse. A small 2004 survey in Odisha, India, found that virtually all of the women and girls with disabilities were beaten at home, 25% of women with intellectual disabilities had been raped and 6% of disabled women had been forcibly sterilised.

Source: www.disabled-world.com/disability/

“For far too long, women and girls with disabilities have been invisible – all too often experiencing double discrimination, due both to their disability and to being female.”

Lakshmi Puri, Deputy Executive Director UN Women

Late detection and diagnosis

Early detection not only enables effective treatment, it also prevents the physical impairments that cause disabilities. Late detection and diagnosis of girls and women is caused by the lack of equal access to information, education and literacy. Early marriage, confinement to the home and the time-consuming domestic tasks required of many, can all reduce access to, and involvement in, the wider world. A very real fear that the stigma of leprosy can lead to rejection by the family and wider community can result in girls and women ignoring or hiding their early symptoms.

“Most women delayed going to hospital, until their husband/guardian felt it was necessary. They had to complete their household chores before setting out for the hospital, and after their return. A considerable amount of time was spent waiting at various service points which conflicted with their domestic work, and lowered their social worth if they were away too long. This demotivated them from visiting hospitals, even for follow-up visits. Medical advice given – such as avoiding prolonged walking and standing, working with hot utensils etc – was not practical.”

Research from Kolkata, Assessment of needs and quality care issues of women with leprosy, A S John et al., Leprosy Review (2010) 81, 34-40



Nafisa from Nigeria

“The results indicate that in this part of Nigeria, female leprosy patients have a much longer period (duration of illness) between first symptoms or signs and presentation for diagnosis, compared with males; on average, the period before diagnosis in women was almost twice as long as that in men. Furthermore, they suffered a higher proportion of disabilities.”

Male-female (sex) differences in leprosy patients in South Eastern Nigeria: females present late for diagnosis and treatment and have higher rates of deformity. E S Peters and A L Eshiet, Leprosy Review 73, 262 - 267



Naw Tan Win, Myanmar. Photo: Paul Salmon

“Early diagnosis is difficult for a number of reasons. One, there is no single test that can diagnose the disease and it requires trained and experienced medical personnel to do so. Two, because of this and the consequences of late diagnosis, there is inevitably fear and this fear leads to stigma and discrimination, which means people either dismiss early symptoms or don't seek treatment. Three, in some cases where leprosy is identified the word leprosy isn't used – again to avoid stigmatisation – but this backfires, because it isn't understood that treatment at this early stage is essential to be effective and avoid subsequent problems.”

Diana Lockwood, Professor of Tropical Medicine at the London School of Hygiene and Tropical Medicine

Disability from leprosy

The disability associated with leprosy arises from physical impairments to the body that the disease can cause. Impairment is a value-free word to describe characteristics of bodily limitations, while disability is the disabling social, environmental and attitudinal barriers that can adversely affect the lives of girls and women affected by leprosy.

CASE STUDY

Mary Nydiang Chuck lived in the Malek leprosy community, near Bor in South Sudan. It is an area significantly affected by intense fighting and because of her disability caused by the effects of leprosy, Mary was unable to flee her home when the village came under attack in February 2014. She was shot in the head and chest and did not recover.



“The real issue is lack of knowledge within communities and populations about the early signs and symptoms of leprosy that helps early diagnosis and treatment, thus avoiding the disabling effects of the disease. Women and girls affected by leprosy are at an increased disadvantage because they are far less likely to receive timely diagnosis or good medical care and the social consequences – isolation, abandonment and profound poverty – make them among the most vulnerable of all women.”

Even groups dedicated to improving the social and economic status of women and persons with disabilities all too often overlook these women. The UN Convention on the Rights of Persons with Disabilities, which has been ratified by 151 out of 193 countries, exists to promote, protect and ensure the full and equal enjoyment of all human rights by people with disabilities – but the challenge is to implement this in areas where attitudes to leprosy still discriminate. What is required is an ongoing educational approach to combat the misinformation and the fear this generates, much in the same way that was delivered very effectively for the HIV/AIDS epidemic, to help eradicate outdated perceptions.

This is not a one-time effort: it is a process and therefore it is necessary to repeat the message for each new generation, until old prejudices are eliminated. Individuals and organisations working in international development and on women’s economic and social rights, must see women and girls with leprosy as a key group to be reached and served.”

Professor Nora Groce, Director, Leonard Cheshire Disability & Inclusive Development Centre

The stigma of leprosy

The stigma of leprosy continues to be one of its most persistent and damaging features and this can stop those affected coming forward for early and effective treatment. The ongoing ostracism of girls and women affected by the stigma, either directly or indirectly, must be addressed to stop this triple disadvantage. A purposeful and repeated public education programme is needed to stop the stigmatisation because, when stigma is acted upon, it becomes discriminatory.

CASE STUDY

Stigma, and its associated discrimination, isn’t limited just to those who have been diagnosed with leprosy. In Myanmar [Burma] Phyo Kyaw, aged 71, had leprosy as a child but with treatment he was cured. Although he was left with nerve damage to his hands and feet, Phyo has been able to work and marry and he and his wife adopted their daughter, Cho. In 2013, Cho was planning to marry but when her fiancé’s family came to meet Phyo to arrange the wedding they saw

his hands, insisted that the wedding was called off, and the young couple were forced to split up, leaving Cho devastated.



photo: Paul Salmon



Woman in self-help group, Niger



Woman in self-help group, Niger

Girls and women, whose self-worth is often linked to body image and whose social worth is often already at risk, are especially vulnerable to self-stigmatisation, which is an acceptance of prejudiced perceptions held by others. It can lead to a reluctance to seek treatment, excessive reliance on others, social withdrawal, poor self-worth and even to self-harming behaviours.

“When I was first diagnosed with leprosy, I thought I would end up like my aunt, because she had leprosy too and was not doing well. I thought her reality would be mine. There are also the deeper scars of low self-esteem I still struggle with even today, that developed as a result of my ex-husband’s behaviour while I was at the peak of my weight gain, depressed and very ill. I did not realise my worth or the fact that although I had leprosy I never ceased to be me, Nicole.”

Nicole Holmes, IDEA counsellor and support group coordinator, USA

CASE STUDY

For Momina, getting leprosy wasn’t just a physically debilitating illness. It also meant the end of the security of her family life because she lives in the Gaibandha district of Bangladesh, a country where the 1898 Lepers Act, which gave leprosy as grounds for divorce, wasn’t repealed until 2011. Because of the continuing stigma of the disease she was rejected and left homeless and destitute; her husband divorced her and left, taking their son and three daughters with him.

Momina’s late diagnosis has left her with damage to the nerves in her feet, reducing her mobility and at risk of further damage from

ulceration and infection if she walks too far. In spite of this, with the support of a pioneering Food Security for Ultra-Poor Women project, she now has a few animals to care for and provide her with a small income. Equally important, she has the support of other women in the group.



Mother and daughter, Woreda II slum, Addis Ababa, Ethiopia



When Rachana contracted leprosy she was thrown out of her in-laws' house. She now campaigns for the rights of people with leprosy.

Leprosy discrimination

According to an ongoing ILEP study, some 19 countries still have laws which discriminate against people affected by leprosy and their families, and these cover issues of marriage, divorce, residential eligibility and employment.

In recent years, a number of countries have repealed these discriminatory laws. Egypt is currently considering repeal and in India the Law Commission is also reviewing the legislation.

In countries across the world, from Italy to Japan to India and Brazil, there used to be a policy of isolating people affected by leprosy because of the stigma of the disease. And even when anti-discriminatory laws have been repealed, this can still happen informally, leaving not only those directly affected unable to access education and healthcare provision, but also their families and, again, girls and women in particular are disproportionately affected.

CASE STUDY

For Xiao Yun, born in rural China in 2000, the stigma and discrimination of leprosy are a day-to-day reality that prevent her from attending the official local primary school. Although she has not had the disease, Xiao Yun has family members who have been affected and they live in a designated leprosy village, Dahuodi, where no official schooling is provided. The only teaching the children have had since 2004 is from one teacher, teaching every subject to all levels of students.

In March 2014, the local government approved the intake of children from Dahuodi to the official Shisun Hope Primary School, but this

news was poorly received by the parents of the children already there, who mistakenly feared that their children would be at risk, so much so that more than 80 students transferred to another school. Teachers refused to teach the children from Dahuodi, too, except for the headmaster and one other teacher. The children were ostracised or taunted with the insult 'laizi', meaning leper, while on one occasion excrement was left in their classroom. Parents, including those affected by leprosy, nearly always push harder for their boys to receive an education, especially in the country where they have limited resources.

What needs to be done

Many global and national policies recognise the effect of gender on the prospects of girls and women with disability, including that caused by leprosy. But without practical action the health systems will continue to fail girls and women living in poverty, by failing to detect leprosy early enough to prevent disability, so reinforcing barriers to their inclusion in society.

Stopping transmission of leprosy

The World Health Organisation (WHO) should

- Continue to disaggregate all data into female and male, children and adults and extend this for data on disability.
- Promote active contact tracing of each person diagnosed with leprosy, so women and girls as well as men and boys are detected early and treated.
- Develop a target to ensure timely reporting for women – Grade 2 (visible) disability rates in women should be no higher than in men and should decline at a similar rate.
- Regionally audit and share analysis of delays in detection among women and girls in different countries to share good practice.
- Develop gender-sensitive policies and language.

The United Nations (UN) should

- Have specific targets on access to health care for girls and boys, women and men with disabilities and those at risk of leprosy and other neglected tropical diseases when developing Sustainable Development Goals (SDGs).
- UN Women should share expertise on gender and disability with national leprosy programmes.
- UNICEF should prioritise gender-sensitive approaches to Neglected Tropical Diseases such as leprosy in its health programmes.

National health programmes should

- Identify the barriers to early detection in women, implement strategies to ensure early reporting and report all data gender-disaggregated at national level.
- Disaggregate Grade 2 disability rates in new cases into four groups: men, women, boys and girls.
- Work with maternal and child health programmes and women-focused community structures to raise awareness of leprosy among women and girls.

Researchers should

- Investigate overcoming barriers to reporting by women e.g. using mobile detection devices and culturally appropriate health education and services.

Non-governmental Organisations (NGOs) should

- Ensure that their leprosy programmes are gender-sensitive and engage girls and women affected by leprosy in all aspects of their work including health education, service delivery, advocacy, monitoring and evaluation.

Preventing disability caused by leprosy

- Globally: WHO should monitor and publish the scale and nature of leprosy-related residual morbidity by age and sex.
- Nationally: Health Ministries should ensure that services are accessible to girls and women as well as men and boys, map unmet needs of girls and women, men and boys suffering residual disabilities from leprosy and integrate gender-sensitive leprosy rehabilitation and prevention of disability programmes into broader, community-based rehabilitation programmes.

Breaking barriers to inclusion

- The UN Commissioner on Human Rights should report on the implementation of the principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members in relation to girls and women.
- Governments should repeal laws that discriminate against people affected by leprosy – some of which, e.g. annulment of marriage – have particular consequences for girls and women.
- NGOs should help to build the capacity of groups of girls and women with disabilities, including those affected by leprosy, to advocate for their rights.

“The main barrier to diagnosis and treatment is not just lack of healthcare provision, but also the lack of awareness of early symptoms of the disease, and this is a particular problem for girls and women because they are economically dependent on their families and spend most of their time in the home.

In addition, many people in Ethiopia still think that leprosy is inherited and a curse from God, and marriage between a person affected by leprosy and someone that isn't is very difficult if not impossible and, when leprosy occurs in a woman, divorce is considered acceptable for this reason.

We would like to see an aggressive education and awareness programme about leprosy and also a strong self-care and physical rehabilitation programme, because the disability that can arise from the disease fuels further stigmatisation and discrimination.”

Tadesse Tesfaye, Ethiopian National Association of Persons Affected by Leprosy (ENAPAL)

The triple jeopardy facing women and girls with leprosy leads to a downward spiral where they are discriminated against on grounds of gender, disability and leprosy stigma leading to late detection of leprosy, leading to disability, leading to more discrimination and reduced job and marriage prospects, leading to poverty and exclusion and potential abuse.

“We work hard for our place in society. Together we can work for equal rights and justice. All over the world we have the right to be equal citizens.”

Zilda Borges, Brazil, Coordinator, IDEA Women’s Opportunity Program



“Individuals and organisations working in international development and on women’s economic and social rights, must see women and girls with leprosy as a key group to be reached and served.”

Professor Nora Groce, Director, Leonard Cheshire Disability & Inclusive Development Centre



“I think doctors who were not familiar with my illness treated me more like a specimen than a human being.”

Nicole Holmes, IDEA counsellor and support group coordinator, USA

“Women are less likely to be diagnosed with leprosy as a result of being disadvantaged when it comes to education, early marriage and access to the wider world. This leaves them at far greater risk of developing a lifelong disability.”

Jan van Berkel, President of ILEP

ILEP The International Federation of Anti-Leprosy Associations

- **Leprosy is curable** and ILEP is working for a world free from leprosy.
- We are a Federation of 14 international non-governmental organisations. We support a Technical Commission of world experts on leprosy. Members co-ordinate their work in 63 countries, where they spend some \$60 million on 700 projects and over \$2.5 million per year on leprosy research.
- Together we are stopping leprosy. Every two minutes one more person is diagnosed and starts treatment for leprosy.
- Together we are preventing disability due to leprosy. Millions of people around the world are still disabled by leprosy, which left untreated causes nerve damage and disfigurement of the face and limbs; lack of sensation can lead to injury and blindness.
- Together we are fighting the stigma of leprosy, which can cause people affected and their families to be shunned and excluded from everyday life, their rights ignored.
- Members work with half a million girls and boys, women, and men affected by leprosy, with Ministries of Health and the World Health Organization; with Novartis, which is providing anti-leprosy drugs for free; The Nippon Foundation and other philanthropic trusts; with NGOs and governments and with the support of some 500k individual donors.

ILEP was founded in 1966. Its Members are: American Leprosy Missions (USA) <http://www.leprosy.org/>, Associazione Italiana Amici di Raoul Follereau (Italy) <http://english.aifo.it/>, Austrian Leprosy Relief Association (Austria) <http://www.aussaetzigen-hilfswerk.at/>, Damien Foundation Belgium (Belgium) <http://www.damienfoundation.org/>, Deutsche Lepra-und Tuberkulosehilfe (Germany) <http://www.dahw.de/>, FAIRMED (Switzerland) <http://www.fairmed.ch/>, Fondation Raoul Follereau (France) <http://www.raoul-follereau.org/>, Fontilles (Spain) <http://www.fontilles.org/>, Lepra (UK) <http://www.lepra.org.uk/>, Mãos Unidas P. Damião – Portugal (Portugal) <http://www.maos-unidas.pt/>, Netherlands Leprosy Relief (Netherlands) <http://www.leprastichting.nl/>, Sasakawa Memorial Health Foundation (Japan) <http://www.smhf.or.jp/e/>, Secours aux Lépreux – Leprosy Relief Canada (Canada) <http://www.slc-lr.ca/en/> and The Leprosy Mission International (UK) <http://www.leprosymission.org/>.

IDEA The International Association for Integration, Dignity and Economic Advancement

IDEA is the first international advocacy organisation whose leadership is primarily made up of individuals who have personally faced the challenges of leprosy, also called

Hansen’s disease. IDEA has 20,000 members in 30 different countries, spanning five continents.

www.idealeprosydignity.org

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